

Chronic Fatigue Syndrome, time perspective and the self

First submission: January 2002

In a study aimed at establishing a greater understanding of the subjective experience of sufferers from Chronic Fatigue Syndrome (CFS), time perspective was identified as one of the most affected dimensions of the self. It was found that the chronic and unpredictable nature of CFS affected both the past and the future of participants. As both of these dimensions reside within the present, the present was marked by a sense of anxiety and uncertainty. Participants showed, however, that they were able to countermand this anxiety by focusing on the extended present. In this dimension they had the power to consciously shape a perspective from which to (re-)interpret events and (re-)appraise the self.

Kroniese moegheidsindroom, tydsperspektief en die self

In 'n studie gerig op die ontwikkeling van 'n grondige begrip van die subjektiewe siekweeservaring van diegene wat ly aan Kroniese Moegheidsindroom (KMS), is tydsperspektief geïdentifiseer as een van die dimensies van self wat die meeste deur KMS geraak word. Daar is vasgestel dat die kroniese en wisselvallige aard van KMS die deelnemers se persepsie van beide die verlede en die toekoms beïnvloed het. Aangesien beide hierdie dimensies ook deel vorm van die hede, is die belewing van laasgenoemde dikwels gekenmerk deur vrees en onsekerheid. Tog het deelnemers getoon dat sodanige vrees teëgewerk kan word deur doelbewus te fokus op die uitgebreide hede. In hierdie dimensie het lyers die vermoë geopenbaar om bewustelik 'n perspektief daar te stel waardeur hulle verlede en toekoms kon (her-)interpreteer en die self kon (her-)waardeer.

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Chronic Fatigue Syndrome (CFS) is an illness that, despite its broad incidence, is very little understood, easily misconceived, and severely stigmatised. What is more, it is a chronic illness, inflicting serious incapacity and grave disability that appears largely unresponsive to medical treatment (Goldstein 1990: 150-6). Given both the heated controversy and the severe suffering associated with this illness, this study set out to develop a greater understanding of the distinctly subjective experience of the illness.

During research interviews, participants were strongly encouraged to tell us their experience of having CFS in terms of their situations, their relationships, and their actions, as well as the meaning they make of living their lives with CFS. As participants so constructed their experience of illness and suffering, we became aware of the intimately interconnected dimensions which constitute the personhood of the sufferer. And we discovered that each of these dimensions is not only profoundly affected by illness, but also very often left injured or disabled in the wake of illness.

In accordance with Cassell's (1991: 38-43) discussion, one of the most important dimensions of the complex personhood of the sufferer directly affected by chronic illness is his or her time perspective. This may be regarded as an intricate expression of one's past, the lived history that has occurred over time, in many places, involving countless others; one's present, the here-and-now of immediate, in-this-moment happenings, each transformed by a past and projected into a future; and one's perceived future, the life of expectations, hopes and dreams, forever exerting an influence in the present. For each sufferer, the personal meaning and experience of a chronic illness arise from all three levels: the lived past, the here-and-now present, and the anticipated future. Bearing this in mind, a fuller exploration of the dimension of time could not but constitute an integral element of our pursuit of a better understanding of the subjective experience of CFS.

By means of an exploration of participants' experience of time, we were able to develop a particular understanding of this important dimension of the illness experience. Before proceeding to explicate this understanding we need to clarify the focus of our study, our methodological strategy, and our approach to interpretation.

1. Chronic Fatigue Syndrome (CFS)

As indicated above, we focused our research efforts on the experience of sufferers from Chronic Fatigue Syndrome (CFS). The most recent and most refined working case definition of this illness was developed by Dr Fukuda and others (Fukuda *et al* 1994: 953-9).

To meet this definition, a patient must suffer from unexplained, persistent or relapsing chronic fatigue which is of new or definite onset (not lifelong), not due to ongoing exertion, and not substantially alleviated by rest. This fatigue results in a substantial reduction in occupational, educational, social and/or personal activities. Yet, CFS is not limited (and certainly not identical) to chronic fatigue. For in addition to fatigue, the patient must also suffer from four or more of the following minor symptoms:

- self-reported impairment in short-term memory or concentration severe enough to cause a substantial reduction in occupational, educational, social and/or personal activities;
- sore throat;
- tender lymph nodes;
- muscle pain;
- multi-joint pain without joint swelling or redness;
- headaches of a new type, pattern or severity;
- unrefreshing sleep, and/or
- post-exertional malaise lasting more than 24 hours.

Each minor symptom must have persisted or recurred for six or more consecutive months of illness. Symptoms must not have predated the fatigue. Very often, it is also possible to note an unpredictable variation in the nature and severity of symptoms from week to week, day to day, even hour to hour (Macintyre 1998: 7). According to Hyde *et al* (1992: 26), such variable expression of the above symptom pattern can be explained by injury to different functional areas of the central nervous system. This variability in symptoms is quite comprehensible if one realises that CFS, very much like paralytic poliomyelitis, can injure certain areas of the central nervous system while sparing others.

As suggested above, the majority of symptoms and symptom patterns associated with the clinical presentation of CFS point strongly towards the central nervous system as the primary system involved in this disease. This is confirmed by Chabursky *et al's* (1992: 19-20) argument that CFS represents a major acquired central nervous system dysfunction in which brain function undergoes a metabolic alteration. This persisting multi-level central nervous system dysfunction defines the nature of the disease and the disease process.

The process is explained more clearly by Hyde & Jain (1992: 38-9), who state that CFS represents an acutely acquired, chronic change in the ability of the central nervous system to process, with any dependability, the functions of reception, interpretation, storage and recovery of information and to programme dependable, normal, smooth end-organ responses. Depending upon the patient, a physiological encephalopathy exists in at least one, but usually several of the cortical areas responsible for motor, sensory, cognitive and emotional function. The deeper levels of the central nervous system function responsible for the co-ordination of motor, sensory, cognitive, emotional and hormonal functions, and at times for rational value judgement, may also be physiologically injured.

According to Hyde & Jain (1992: 63), the dysfunction of the central nervous system outlined above may result from a chronic viral infection. Such an infection may, as Hyde (1992a: xi) explains, provoke reactive changes in neuropeptide messengers which, in turn, stimulate compensatory immune reactions to rid the body of the infectious stressor and return it to normal homeostasis. By definition, however, chronic infections have managed to escape these initial compensatory immune mechanisms. Yet the neurochemical homeostatic events continue to be employed uselessly and to the detriment of the organism.

Treatment is extremely difficult, both because the exact clinical pathology and aetiology underlying the condition are as yet little understood, and because of the great variability inherent in the clinical presentation and course of CFS. These factors also serve to explain why there is as yet no specific treatment protocol for CFS. Professional assistance is largely directed at relieving symptoms, managing the

disease, and reintegrating the patient into society at a level consistent with his or her illness (Vorster 1996: 19-20).

2. Methodology

2.1 The participants

At the outset of the study, it was envisaged that a limited number of CFS sufferers would be selected for participation. In order to restrict the number of confounding variables, it was decided to select participants of similar demographics with regard to gender, age, medical status, and location. We therefore specifically sought to select only female participants in the age group 20-50. This cohort represents the population apparently most directly targeted by CFS (cf Hyde *et al* 1992: 29; Levine 1992: 203). We also selected only subjects who had been medically diagnosed as suffering from CFS. We do, however, recognise that case definitions used recently in the medical profession to diagnose CFS are beset by severe problems (cf Jason *et al* 1997). This regrettable state of affairs may have introduced into our study a certain degree of bias (in the form of either excluding legitimate cases or including illegitimate ones). Finally, for practical reasons, it was necessary to limit our pool of potential participants to those residing in the Western Cape at the time of the study (October 1999-May 2000).

In addition, following the recommendation of Rubin & Rubin (1995: 66), we selected participants who were particularly knowledgeable about the proposed research question, or who were, in Spradley's (1979: 47-9) terms both thoroughly encultured and currently involved. Participants therefore had to be fully acquainted with the experience of CFS and in the position of using this knowledge to guide their actions on a regular basis. Furthermore, selected participants had to be willing to participate openly in the proposed research enterprise by sharing their experience of CFS. According to Rubin & Rubin's (1995: 66-7) discussion, this criterion would directly assist us in avoiding idealised or fictionalised answers. Finally, research participants had to be able to offer sufficient time (and energy) to engage in the proposed study (Spradley 1979: 51-2).

Following the example of Martin & Dean (1993: 86), we adopted a combination of recruitment strategies to secure the participation of eligible CFS sufferers. The rationale behind this approach was that recruitment from a variety of sources would help ensure. In the process, we employed the assistance of the medical profession (physician referrals), made use of existing lists of CFS sufferers in the country, placed advertisements in selected media, used personal referrals and, to a limited extent, developed a network sample.

Yet our efforts to locate and recruit potentially suitable participants were often frustrated. The difficulties encountered probably relate to the fact that the CFS community, in Biernacki & Waldorf's (1981: 144) terms, constitutes a target population with "low social visibility". This community is, in other words, surrounded by and enmeshed within the moral, legal, social and medical dilemmas and sensitivities evoked by the illness. The community has been stigmatised and isolated, and may well be wary of yet another (possibly derogatory) study which may prove to be nothing but a waste of time and energy. What is more, the members of the Western Cape CFS community clearly do not necessarily know one another. This may have something to do with the fact that support groups within the region were operative for a very short time during the late 1980s and early 1990s, and were even then scattered. CFS sufferers in the area thus did not have any organised opportunity to meet with other sufferers. Hence our struggle to make use of any type of referral.

In summary, then, to develop an intimate understanding of the illness experience of CFS, four sufferers who complied with the specified criteria were selected by means of a combination of recruitment strategies. Every element of this process testified to the necessity for extreme care when carrying out a study on a sensitive topic and a highly sensitive population (cf Lee & Renzetti 1993: 30).

2.2 The in-depth interview

Authors such as Lee (1993: 104), as well as Rubin & Rubin (1995: 51-2), contend that the in-depth or qualitative research interview is an exceptionally sensitive and well-suited means of developing an intimate understanding of experiences best communicated through rich narratives and detailed examples. In addition, the in-depth in-

terview is strongly “inter-active” in nature. According to Kvale (1996: 183), the researcher is not concerned simply with passively collecting the participant’s statements like gathering pebbles on a beach. The researcher is much more directly involved as he or she actively steers and co-determines the course and nature of the interview. Consequently, the knowledge constructed in the interview cannot be accepted as an independent given, let alone as a direct representation of an underlying (“really real”) reality. Rather, this knowledge is a socially co-constructed creation. It is, in Kvale’s (1996: 124-5) words, “created inter the points of view of the interviewer and the interviewee”. In this sense, the research interview is a specific form of human interaction through which knowledge is interactively produced.

An understanding of the interactive, interrelational construction of knowledge within the interview forces us to consider the power relationship between the researcher and the researched. The researcher has the ability to control not only the interaction, but also the interpretation thereof (Brannen 1988: 554-7). The researcher may thus attribute meaning to the descriptions of participants. For Kvale (1996: 227-8), the danger of “expertification” arises, where the “expert” researcher expropriates meaning from participants’ descriptions and reifies it into “the real meaning” of their experiences so as to give expression to some “more basic” reality. In the process, participants may be rendered vulnerable, individually and collectively, as they have very little control over the interpretation of their stories by either the researcher or anyone else (cf Finch 1984: 85). In the in-depth interview, according to Kvale, there is no question of some “more basic reality”. The stories told by participants within the dynamic (power-laden) research relationship is a product of and, therefore, directly contingent on this very relationship (cf Cunningham-Burley 1985: 76). It is not a given. It is not to be worked through or given an extra “expert” meaning. For there is no more “really real” reality, no more “basic” knowledge, than that constituted by and through participants’ descriptions.

In view of its well-established reputation, as well as the opportunity it provides to co-construct with participants an understanding of their reality as they experience it, the in-depth research interview was incorporated into the methodological design of the present stu-

dy. A double set of in-depth interviews was conducted with participants. These interviews, which usually took place at participants' residences, lasted from two to nine hours. Each interview was conducted, recorded and transcribed by the first author. In the process, almost 30 hours of recorded data was collected, which required approximately 250 hours of transcription and yielded close on 1500 pages of interview transcripts.

2.3 The autobiographical sketch

For Daly (Plummer 1983: 82), "a man's life is to him the most obvious and overwhelming of all realities". A full exploration of this "reality of all realities" calls for a method that can expose an individual's intensely subjective experience of being. To this end, we opted to incorporate the autobiographical sketch into the methodological design of the present study.

Within this context, the autobiographical sketch was considered akin to Redfield's (Plummer 1983: 14) conception of a "human document". It constitutes a document

[...] in which the human and personal characteristics of somebody who is in some sense the author of the document find expression, so that through its means the reader of the document comes to know the author and his views of events with which the document is concerned.

In this sense, the central thrust of the autobiographical sketch is to enable the voices of participants to be heard on their own terms. The uniquely subjective perspective attained through the use of the autobiographical sketch allowed us not only to consider, but also to become intimately familiar with participants' concrete lived experiences (Plummer 1983: 65 & 72). As we were thus able to ground our understanding firmly in the empirical world under consideration, we could avoid the risk of unfounded speculation, the risk of simply being wrong.

In addition to showing the path into the subjective, the autobiographical sketch contains a clear emphasis on process and history. Hence, it stands to offer incisive insight into the ever-changing nature of human experience (Plummer 1983: 68).

Process is, in fact, a particularly difficult quality to capture in research as all research — qualitative research included — invariably has to “amputate”, select and organise materials. This is done from a particular point of view or perspective. For Plummer (1983: 68-9), the perspective which governs the use of the autobiographical sketch is one of totality: “the totality of experience”. This is a totality which necessarily weaves between biological bodily needs, immediate social groups, personal definitions of the situation, and historical change (both in the participant’s own life and in the outside world). The autobiographical sketch allows the researcher to achieve some sense of this totality of a life, admittedly not as an undiminished whole, but at least to the extent that it is concerned with the field of study in question.

The perspective of totality that distinguishes the autobiographical sketch paves the way, thus, for a consideration of process and of history. As Bogdan (Plummer 1983: 69) explains, such a perspective does, after all, stand to offer

a fuller understanding of the stages and critical periods in the process of development. It enables us to look at subjects as if they have a past with successes as well as failures, and a future with hopes and fears. It also allows us to see an individual in relation to the history of his time, and how he is influenced by the various currents present in his world. It permits us to view the intersection of the life history of men with the history of their society, thereby enabling us to understand better the choices, contingencies and options open to the individual.

Thus the autobiographical sketch endorsed the hope of greater insight into the changing meaning of participants’ lives as they progressed not only through history in general, but also through the history of their own illness.

The use of the autobiographical sketch significantly enhanced the appropriateness of the methodological approach employed. It offered the promise of access to what Plummer (1983: 67) calls the “human coefficient”. That is, it stood to illuminate the ways in which participants constructed and gave meaning to their own lived experiences.

Thus, at the end of our first interview session, participants were requested to compose an autobiographical sketch concerning their own experience of CFS. To assist them in doing so, we offered a brief

guide consisting of a number of questions to which they could respond in whatever way seemed meaningful to them. The sketches were to reach us before our next meeting. It was foreseen that, in combination with the material developed in the first interview, the autobiographical sketches produced by participants would provide a powerful foundation for the second and final round of in-depth interviews. This expectation, indeed, reveals a further benefit of the autobiographical sketch: its rich potential to complement other methods within a sensibly designed methodological approach.

2.4 A note on transcription

Kvale (1996: 129) asserts that the lived interview situation, involving participants' voices as well as the facial and bodily expressions which accompany their every statement, provides a much richer access to the meaning they construct than the transcribed text alone. The transcript cannot be identical to the conversational interaction of the interviews. In fact, unlike the interviews, transcripts can never comprise the "rock-bottom" data of research. And they are certainly not copies or representations of some more "original reality". On the contrary, transcripts are, as Kvale (1996: 167) puts it, only "decontextualized conversations", artificially constructed for the purposes of communication. They are "abstractions, as topographical maps are abstractions from the original landscape from which they are derived" (Kvale 1996: 165). Thus, while transcripts attempt to describe interview situations and their content, they can never fully represent what had transpired in actuality.

Still, it is necessary to recognise that without transcripts, frozen as they may be in all dimensions, there would be little opportunity of repeated inspection. This does not mean that transcripts must be regarded as "the fundamental verbal data". Instead, it simply means that transcripts can be accepted as a means of evoking and reviving for the researcher the personal interaction of the interview itself. They are not the basis of all future analysis, but they can undoubtedly aid and support it. Moreover, without transforming the interpersonal interaction of the interview situation into a written transcript, we would be severely limited in communicating our participants' stories to potential readers.

2.5 The presentation of transcription

For the interview excerpts presented below we made such modifications as we believed would make them easier to follow, but without affecting the participants' meaning. We permitted ourselves to eliminate words, sentences, and paragraphs (and often our own questions) in order to achieve a more compact statement. However, we never changed or added words. We also made every effort to preserve participants' phrasing and characteristic mode of expression.

Furthermore, although aware of advice to researchers to omit "nonsensical" noises such as "mmm" from quoted text (Weiss 1994: 196-7), we did not follow this practice blindly. Very often, such "distractive" utterances and phrases serve a distinct purpose within communication. In the present study, it was, for instance, important to indicate when participants were struggling to express their experiences, either because of insufficient vocabulary to express their experiences or as a result of the cognitive difficulties which set in with increasing fatigue. The only way to do this was by including participants' interjections. Thus, far from being simply unnecessary distractions, such interjections help to clarify meaning and assist in understanding the text. In addition, they often also help to establish a sense of speech as a co-constructed product of contextualised interaction. We therefore opted to retain such information, provided that it did not pose a major obstacle to the intelligibility of the text in question.

2.6 Analysis

The data gathered in the course of the research process formed an almost seamless aggregation of material. To arrange and so assess its meaning, we embarked upon a conceptual process of classification that involved two related activities. We not only cut our data puzzle into bits and pieces; we also assigned these to different categories and eventually to different concepts. So, all the pieces "belonging" to a particular category were brought together and united under one concept. As the process became more focused, we were able to discriminate more clearly between the criteria according to which material was allocated to one concept or another. The boundaries between concepts became more precisely defined, and new concepts were crea-

ted. Some older concepts were subdivided, and others were subsumed under more abstract concepts. Each concept was firmly grounded upon the participants' descriptions of their world and, in combination, geared to reflect an intimate understanding thereof (Dey 1993: 45; Rubin & Rubin 1995: 226).

Yet, as Dey (1993: 40) notes, the only point to taking the aggregation of data apart in this way is, of course, to find a way of putting it together again. In other words, taking apart and organising our data puzzle into concepts did not constitute an end in itself. It served an overriding purpose: to produce a picture. Thus, while classification had provided the basic concepts, these concepts now had to be meaningfully connected to produce a new picture. In order to establish such meaningful connections, we looked to Dey (1993: 47) and Rubin & Rubin (1995: 226-7) for advice. They suggest that while working through the classified data, the researcher should be sensitive to regularities, variations, and singularities, as these are very often indicative of larger associations. By studying such relationships, we were able to weave various concepts into distinctive themes. These themes, which appeared to explain or give insight into related issues, constituted the basis of our emerging understanding.

So the different parts of our data puzzle again came together. For us, as for Dey (1993: 40), the emerging picture represented a very important step towards defining our findings. It reflected an understanding infinitely clearer and more complex than any initial impression of the data might have given. In this sense, analysis involved much more than simply fitting the various pieces of the data puzzle together; it involved the conception of something new.

2.7 Interpretation

We were explicitly concerned with a relational unfolding of meanings — meanings which construct unique social realities, which tell us about participants' worlds, as co-produced by means of our interaction. Thus, whatever is presented in and through our description does not represent a revelation of some pre-existing meaning, but merely supports those meanings developed during the course of an interactive research process. In this sense, description is not a question of simply re-stating our "findings". Indeed, as Dey (1993: 242)

very importantly notes, the term “findings” can be “grossly misleading, with its implication that we have only “found” what were already in the data simply waiting to be discovered”. If this were the case, qualitative work would be “as straightforward as collecting rubbish. And if we were to adopt this approach, rubbish is all we might be able to produce!” Far from garbage collection, the description we produced was very much the product of the conceptual tools that we had used in its creation.

One very important set of conceptual tools derived from the literary tradition of story telling. As we were describing the research process and the human experiences it had studied, we were making use of the particular writing style and techniques involved in telling a good story (cf Dey 1993: 39). We summarised events, focused on key episodes, selected and developed themes, delineated roles and characters, and even set out a chronological sequence, using the techniques of story-telling to construct an illuminating narrative. In this way, we set out to produce a meaningful description of the interactively produced realities of participants.

For Dey (1993: 239), such a description, if it is really a good story, is very much like a journey. It is a journey that allows readers to travel with the characters of the story through the intricacies of the plot, eventually reaching its final twist in the form of a conclusion. To enable others to “travel” with our participants and us it was, as Dey (1993: 239) recognises, imperative that we should be able to reconstruct the journey that had led to the final conclusion. Once we were able to do so, we were in a position to mark out our path for those who wished to follow and arrive at the same conclusion. This emphasis on the importance of revealing the journey taken in the description of the social world under study implies that another researcher should be able to consider the same data and arrive at the same interpretation. Of course, as Giorgi (Kvale 1996: 209) recognises, there is also the possibility that a different researcher could consider the data, ask different questions, adopt a different perspective, and thus arrive at an entirely different interpretation. The point here, however, is not so much whether a different interpretation of the research material can be developed — this we take for granted. The issue is much rather whether a reader, following the journey

articulated by us, can also see what we saw, regardless of whether or not he or she is able to agree with us. For Giorgi, this is the key criterion of good qualitative research.

3. Time perspective

In Nuttin's (1985: 16) view, "time perspective" consists of a "mental perception", at a certain moment, "of events that, in reality, happen in temporal succession and with longer or shorter time intervals between them". These "events" — which Nuttin (1985: 17) refers to as "temporal signs" — serve as personal or social "points of reference" to which less important objects are anchored. In each individual life, there are certain key events that function as digits on a personal or social clock. They help the individual in the relative temporal localisation of other events. Such "reference marks" create "the temporal background against which earlier experiences or projections of future events take shape" (Nuttin 1985: 19). This means that at a given moment, an individual's time perspective is not limited to the object that he or she has in mind, but includes a configuration of temporally localised objects residing within both the past and the future contexts of that moment (Nuttin 1985: 21). This notion closely corresponds to Cottle's (1976: 85) "spatial conceptualisation of time flow" as marked by an awareness of the relatedness of present, past and future. By means of this relatedness, the past (through recollection) and the future (through expectation) are contained and reside within the present (Cottle 1976: 86).

When we regard "time perspective" in this way as filled with events, objects and contexts from the present, past and future, it is clear that such perspective is not a pre-existing "empty space". That is, unlike the very abstract notion of time, the temporal perspective cannot be conceived independently of its content. Content is, indeed, "an essential element of time perspective" (Nuttin 1985: 23). And while open to the influence of the anticipation or memory of someone else's action and its outcomes, the most important contribution to the content of a person's time perspective is made by the objects of personal experiences and tendencies (Nuttin 1985: 27).

Thus, a person has a unique time perspective which consists of a configuration of temporally localised objects residing in the present, past and future and distinguished by its highly personal content. In our study, the content of participants' time perspectives appeared strikingly moulded by the distinctive nature and impact of their illness. Hence, we now turn to explore the particular influence of CFS on the time perspective of our participants.

4. Where illness and anxiety go hand-in-hand

CFS is a chronic illness spanning time. Enduring. Lasting. This chronicity appeared to exert the most significant influence on sufferers' time perspectives and hence on their experience of illness and the self.

Natalie's¹ account offered substantial insight into a CFS sufferer's experience of chronicity:

'n Groot probleem by my bly maar... die tyd. Die chroniese aard van die siekte en die feit dat ek reeds byna my hele jongmenslewe hieraan spandeer het, laat my soms vir kort rukkies 'n bietjie moedeloos... veral met die tydperk van my studies en nou meer onlangs waar ek begin sien wat ander mense om my vermag... dan sien ek ook wat ek nie regkry nie... Ek... ek kan myself... mmm... beter ondersoek en sien hoe siek ek regtig is en dit laat 'n mens ook moedeloos... Ek het nooit daai groeiproses gehad tot daar nie... mmm... daar is 'n groot deel van my jongmenslewe... dis net... dit is net weg, dit het nooit gebeur nie, ek het nie matriekafskied toe gegaan nie, ek het nie 'n ou gehad nie... So daai deel is... is nie daar nie... die groeiproses waardeur hulle al is wat ek nog nie gedoen het nie, ek... en ek weet nie wanneer ek dit gaan doen nie. So, dit is ook iets wat my affekteer... Ek weet wat ek gemis het, ek weet... So, dis... dis maar net... dis maar net nou vir my moeilik... dit is... daar is definitief 'n verloop van tyd... ek bedoel... jy sien net soveel dinge wat jy misgeloop het en dan voel jy maar jy het nie al die beheer wat jy wil hê nie.²

- 1 We have used pseudonyms to protect the identities of our research participants.
- 2 A large problem for me remains ... time. The chronic nature of the illness and the fact that I have already devoted almost my entire youth to it, leaves me at times a little despondent ... especially while I was studying and now more recently when I can see how much others around me are able to accomplish ... then I see what I am not able to achieve ... I ... I can ... hmm ... examine myself more closely and realise how ill I really am and this also lets one feel despondent ... I have never experienced that process of growth to that point ... hmm ... there is a large part of my youth ... it's just ... it is just gone, it never happened,

Natalie's recollection clearly reveals that the chronic nature of her illness and, in particular, the fact that she has devoted almost her entire youth to it, at times leaves her feeling utterly despondent. She cannot but acknowledge the enormity of everything she did not experience, of the personal development, growth and experience of a young adolescent life, which she never enjoyed. While this is lost to her forever, Natalie's account shows that the memory of that time is still vivid and is still able to play a strong (and at this stage unsettling) role in her present. That is, by recapturing her past experiences and relocating them in the present moment, Natalie's account clearly reveals that the past (along with its deeply personal content of chronicity) can indeed reside in the present and exert a powerful influence on experience in the here-and-now. Thus, for Natalie, the memory of the past represents an integral basis for perceiving time and for experiencing illness in the present (Cottle 1976: 13).

The connection between the experience of time in the presence of a chronic illness was even more pronounced in Cheryl's case. Speaking after almost ten years of illness, she candidly revealed:

I'm really, really, really... not excited about what I'm learning about the connection between cancer and ME... long-term ME... because your body has suffered for such a long time, your immune system has been battered and... you yourself have been under par for so long... So, there are worrying things... worrying things ahead for people whose ME has lingered for so long... So, if I had to be very honest with you now, the thought of being... maybe... mmm... you know, ten or fifteen years away from... from... dying of cancer... is pretty hair-raising... And... I have confronted the fact that I might have ME for the rest of my life. And I can't pretend the thought... excites me at all. I would... very much... like to think that there were a cure around the corner, but after all I've learned and experienced... I don't think there's a cure. I honestly don't think there's a cure... I've remained... hopeful that I am going to get better... I've only, in the last... mmm... two or three weeks that I've felt so very ill, become... for the first time ever, I

I didn't go to the matric farewell, I didn't have a boyfriend ... So that part is ... isn't there ... the process of growth that they have experienced, which I haven't yet done, I ... and I don't know when I will do it. So, this is also something that affects me I know what I have missed, I know ... So, this ... this is just ... this is just very difficulty for me now ... it is ... there is definitely a progression of time ... I mean ... you see so many things you have missed and then you feel that you don't have all the control you would like to have.

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can honestly say to you, become... disheartened to the point that I wonder if I'm going to get better. It's happened a few times now... that I've wondered if I'm going to get better... So at the moment I don't see the future... rosily... I'm actually deep down starting to get a little bit frightened that I'm not going to get well, for the first time... I haven't... mmm... feared for the future before these last two or three weeks... but I've just been so ill... that I actually... mmm... started thinking sad thoughts...

For Cheryl, the chronicity of CFS has at times instilled a fear that a body battered by severe illness for such a long time may be exposed to worse affliction. What if she is bound to be ill forever? What if a chronic illness becomes a terminal illness? Indeed, while Cheryl has generally remained hopeful of recovering, times of acute suffering have confronted her with a grave despondency, when the hope of recovery deserts her and the fear of permanent illness takes its place. At such times, the dread of attenuated illness violates the sufferer's perspective on the future. Yet the future is "the primary meaning of existentiality". It gives meaning and purpose; it is filled with intention and possibility. Moreover, as Cassell (1991: 42-3) reminds us, it is the dimension of existence in which hope dwells. When the future is lost to anxiety and extreme uncertainty, intense sadness results, for "no one has ever questioned the suffering that attends the loss of hope" (Cassell 1991: 43). Thus, when Cheryl defines her future as filled with dread and anxiety, it affects her perspective on the here-and-now as well as her experience of illness and the self.

In accordance with our participants' experiences, the content of their time perspectives was not distinguished solely by the chronicity of their illness. It was also very strongly affected by the fact that CFS is inherently unpredictable. It is variable, unstable, uncertain, even erratic.

Denise's account clearly reveals the relationship between unpredictability and time perspective in the life of a CFS sufferer:

Die toekomst is vir my... dis moeilik om nie rêrig te kan planne maak nie... mmm... want dit... dit is nie vir my realisties op hierdie oomblik nie... Jy kan niks beplan nie... nie kort of langtermyn nie want jy weet nie of jy dit sal kan bybring nie... Jou aksies en aktiwiteite word rondom jou energievlakke beplan... wat kan wissel van oomblik tot oomblik... So, jy kan nie jou lewe rêrig organiseer soos wat jy graag sou wou nie... En ook, ek dink 'n mens... mens leer om teleurstelling te hanteer, want daar is dinge waarna jy

uitsien en dan ewe skielik is jy siek en jy kan nie daarby uitkom nie... Dit... dit maak jou half skepties in terme van langtermyn-doelwitte... mens sou graag wil weet jy... jy werk na iets toe... wat 'n mens op hierdie stadi... wat ek op hierdie stadium nie het nie, jy weet, op hierdie stadium gaan ek nou maar net aan... Ek dink inherent e..ervaar meeste mense dit, ek dink net met ME is dit... is dit vir jou 'n baie meer konkrete komponent... van... gaan jy fisies in staat wees om dit te doen? Dit maak dit soms moeilik... jy weet, dis half sleg, 'n mens wil... mens wil weet, maar jy weet nie...³

For Denise it is obviously extremely difficult to make any definite plans. It is simply not a realistic exercise. Her activities are, after all, determined by her physical energy and as this fluctuates without warning, so too does her ability to carry out whatever plans have been set. The resultant inability to map out and bargain on implementing either short- or long-term plans has rendered her dourly sceptical about the potential of constructive planning and goal-setting in her own life. Even worse, when Denise found herself unable to plan, unable to cherish a future, she no longer felt in control. The future is, after all, as Nuttin (1985: 40) confirms, "an essential dimension of a person's behavioural world and his motivated purposive action". Indeed, "the ability to construct far-distant personal goals and to work toward their realization" is an important characteristic of simply being human (Nuttin 1985: 9). However, when a person's future time perspective is severely limited by the impact of an unpredictable illness, the ability to set goals, make plans, and, in effect, feel in control, be-

- 3 For me the future is ... it's difficult to really make any plans ... hmm ... because it ... it is not very realistic for me at this stage ... You cannot plan anything ... not short or long term, because you don't know if you'll be able to make it ... Your reactions and activities are planned around your energy levels ... which can vary from one moment to the next ... So, you can never really organise your life as you would like to ... And also, I think one ... one learns to deal with disappointment, because there are things that you look forward to and then suddenly you are ill and you cannot make it ... It ... it makes you somewhat sceptical in terms of long-term objectives ... you would want to know that you ... you are working towards something ... something that one at this stage ... that I at this stage don't have, you know, at this stage I simply carry on ... I think inherently all people experience this, I think it's just that with ME it is ... it is a much more concrete component ... of ... are you physically going to be able to do this? This makes it difficult at times ... you know, it's rather bad, one wants ... one wants to know, but you don't know.

comes jeopardized. This sensation is strongly reflected in Denise's awareness of simply drifting from one moment to the next, without clear direction or purpose, without being able to locate herself on the trajectory of her illness, and without being able to anticipate what may follow (cf Bury 1997: 114; Strauss & Glaser 1975: 47-9).

Like Denise's experience, Natalie's account reveals a stark perspective on time, and specifically on the future, as disrupted by illness:

So, as 'n mens praat oor die toekoms dan is dit 'n langtermyn-ding... en dis waar my probleem lê... Die toekoms is moeilik, want die... die langdurigheid daarvan, die feit dat dit... dat dit nie in 'n moment geskied nie... dis moeilik... Ek dink nie... ek dink nie 'n mens... enige iemand is eintlik... hulle... hulle is nooit rêrig seker nie, so ek... verbly my nou daarin dat ek nie die enigste een is wat so rigtingloos voel nie... Ek het net nooit gedink ek sal so rigtingloos wees nie, ek was nog nooit... my hele lewe lank was dit net... my pad, ek het geweet waar lê my pad... en... ja, nou's dit... mmm... ek sien soms... mmm... ek loop myself vas, ek weet nie waarheen nou nie... omdat my lewe so... moeilik is om vooruit te beplan en vooruit te kyk.⁴

The sense of future possibility is, as Cottle (1976: 161) explains, first encountered through the very act of planning or intending. So, "in working out these plans, following them, and having them realised, one learns that, to a certain degree, the future can be shaped by one's own efforts". For Natalie, however, the variable intrusion of illness left hardly any room for definite planning. And where planning was uncertain, the future was equally unclear. For the future perspective is shaped not only by our specific plans for today and tomorrow, but also by those we conceive for our life as whole (Barrett in Cottle 1976: 161). In this way, the unpredictability of her illness directly affected Natalie's deepest sense of self and being.

4 So, when one talks about the future then it is a long-term thing ... and that is where the problem lies ... The future is difficult, because it ... the long-term nature of it, the fact that it ... that it doesn't happen in a instant ... that is difficult ... I don't think ... I don't think one ... anyone is truly ... they ... they are never really sure, so I ... find comfort in that I am not the only one who feels so directionless ... I never thought that I would be so directionless, I was never ... my whole life was just ... my path, I knew where my path was ... and ... yes, now it is ... hmm ... I sometimes see ... hmm ... I get stuck, I don't know where to go now ... because my life is so ... difficult to plan ahead and look ahead.

The utter unpredictability of CFS that so deeply touched Natalie's sense of self also invaded her life of dreams and hopes:

... dan kyk jy in die toekoms en dan sien jy soos byvoorbeeld... goed soos om 'n verhouding te hê met 'n man. Dit is moeilik vir my, want... omdat ek so wisselvallig is... mmm... is dit moeilik om van iemand anders te verwag, van enige iemand te verwag om saam met jou... mmm... 'n leefstyl... in jou leefstyl in te gaan, want hulle... mmm... dit verskil net baie van gesonde mense... Ek sien nie... wel, ek... ek... ja, ek... ek is baie bang om in 'n verhouding in te gaan en soveel van die persoon te verwag... Ek wil nie iemand se lewe half van hom wegneem nie, ek wil nie uitgaan met 'n ou en as hy vanaand iets wil doen vir hom sê, nee, hoor hierso, ek kan nie... en dit is al die tiende aand in 'n ry wat ek vir hom so sê nie, dit sal baie onregverdig wees teenoor hom... Maar... dit is vir my... mmm... ek is baie... ek dink ek is baie skepties daar... daaroor.⁵

Every person has a secret life, a life of dreams, fantasies, wishes, hopes, and desires with a real existence known to only a few close friends (Cassell 1991: 42). In Natalie's world, one of her dreams is to be involved in an intimate relationship with a partner. But CFS precludes this: whenever Natalie dares to think of entering such a relationship, she immediately confronts uncertainty. Indeed, the utter unpredictability of CFS has changed her life so radically that she can no longer conceive of someone who would be willing to accommodate such persistent change and disruption within a relationship. Hence, CFS has filled Natalie with the fear of expecting too much and left her unable to tie the present to the future by means of hopeful expectations (Cottle 1976: 149). Indeed, Natalie's illness has impaired her vision, her perspective on the future — the very “building

- 5 then you look in the future and then you see for example ... things like a relationship with a man. It is difficult for me, because ... because I am so variable ... hmm ... it is difficult for me to expect from someone, to expect from anyone to share with you ... hmm ... a lifestyle ... your lifestyle, because they ... hmm ... it is just so different from the lifestyle of healthy people ... I don't see ... well, I ... I ... yes, I ... I am afraid to enter into a relationship and to expect so much from a person ... I don't want to take away a person's life from him in some way, I don't want to be in a relationship and when he asks if we could do something tonight, I have to say no, I can't ... and then it is already the tenth time in a row that I say so, this will be very unfair to him ... But ... it is for me ... hmm ... I am very ... I think I am very sceptical about ... about this.

site of constructive behaviour and human progress” (Nuttin 1985: 40) — clouding it with fear and anxiety.

Thus, participants’ experiences of their illness revealed that, through perception, they were aware of the present. But their time perspective was not limited to the here-and-now. On the contrary, memory allowed them to recall and reconstruct their experiential past, while their future came into existence on the level of representation, expectation, and imagination. While this clearly shows that for our participants both their past and their future reside within their present, this was not necessarily ideal. Their past was filled with the dread of attenuated illness, their future with the anxiety that accompanies severe uncertainty and a sense of diminishing control.

5. To countermand anxiety while ill

From the interpretation above, it appears as though the suffering participants’ experience springs from both the past and the future. The past is a history of lived hurts, of repeated distress. The future is landscaped by dread in anticipation of such (iterated) distress. Yet, participants’ experiences also showed that they had not wholly surrendered to the powers of a chronic, unpredictable illness. Cheryl offered us our first insight into an alternative powerful enough to countermand the disruption and anxiety of severe illness:

This is... this is a strange thing... I... I think of it, of a relapse, as an academic possibility... and, in fact, after ten years, if I were to [be] put on the spot, I would know it were a surety. I mean, I’m not... I know I’m not... I’m not cured. Symptoms are building up rapidly as we speak... today is not a good day... But... but... that is an amazing thing! The optimism is... completely unfounded (laugh)! Completely unfounded (laugh)! Not based on fact or past experience... I don’t live in fear of a... of a relapse... at all... which is totally, as I say, it’s... it’s totally abnormal (laugh)... based on past experience (laugh)!

Cheryl’s approach suggests that an alternative to the severe experience of anxiety and dread lies in her present. In her mind, in this moment, a relapse was only an academic possibility. To be sure, based on past experience, she would probably have had to concede that it was far more likely to happen than not. Still, Cheryl did not dwell on this knowledge. Instead, she maintained the self wholly located in

the present moment of here-and-now. The relapse was not considered a reality and it was not feared. Thus, to countermand anxiety, Cheryl deliberately chose no longer to linger in the past of had-beens and could-have-beens. In like manner, she saw no use in dreading a future that had not yet come to pass. Instead, Cheryl maintained the self entirely in the present moment, in the here-and-now.

According to Cottle's (1976: 173) discussion, this does not mean that Cheryl was perceiving her present from the point of view of an "observer of action", for this would imply that the present exists for her only on a moment-to-moment basis. This would render "the observer" powerless to change or influence it. Instead of such an instantaneous perception of time, Cheryl's account suggests that she perceives the present as "extended". That is, she is an "agent of action"; she can control the present. In this way, Cheryl had discovered and embraced the present as that dimension of existence most likely to be affected by personal choice and control (cf Cassell 1991: 58-9).

Denise's experiences reveal another dimension: to maintain the self entirely in the present liberates the sufferer not only from past hurt and impeding dread, but also from the rush of interpretations which such memories and prospects are likely to evoke:

... dis aanvanklik baie negatief, maar jy... elke negatief het sy positief, so jy... dis 'n negatiewe oms... situasie, maar jou belewenis daarvan, jou hantering daarvan kan dit omskep in 'n positiewe situasie... Kyk, jy kan half net die negatiewe kant daarvan raaksien en in 'n hoekie gaan sit en jou aan die slaap huil, maar dit... dit gaan niks daaraan verander nie. So, jy vat die positiewe saam... saam met die negatiewe... en ek dink ook 'n mens... mens leer om die negatiewe te erken. Jy... mens word half groot met die... e... met die konsep van dat as iets negatief is, dan ignoreer jy dit... terwyl uit die negatiewe kom daar wel ook die positiewe, so jy het nodig om die negatiewe te erken... mmm... maar jy... jy het nie nodig om dit te koester nie.⁶

- 6 initially it is very negative, but you ... every negative has its positive, so you ... it's a negative circ ... situation, but your experience of it, your handling of it can transform it into a positive situation ... Look, you can only notice the negative side of it and go and sit in a corner and cry yourself to sleep, but that ... that is not going to change anything. So, you take the positive along with ... along with the negative ... and I also think one ... one learns to recognise the negative. You ... one grows up with the ... eh ... concept that if something is negative then you ignore it ... while out of the negative the positive can also come, so you need to recognise the negative ... hmm ... but you ... you do not need to embrace it.

Denise's account suggests that while certain adverse qualities may undeniably be present within a particular experience, there is no need to cherish such qualities. There is neither any use nor any need to reflect on their counterparts in the past or on their potential influence on the future. Instead, a different focus can be deliberately adopted, one that may permit a more benign experience and interpretation of the present situation, in the present moment.

This approach reminds us of Schutz's concept of "attention to life". This is the basic regulative principle of the self's conscious life, which both defines the realm relevant to the self and determines the attention directed by the self to the given experiences. The self's "attention to life", however, is not a static entity. It is very much open to modification and capable of all sorts of nuances: from actually comprehending to merely noting to hardly noticing to ignoring completely (Schutz 1967: 73-4). For the self, every moment in time — every here-and-now — is constituted by such attentional modifications. Consequently, the interpretation (or meaning) which the self imputes to experiences depends on the attentional modifications marking the very moment of interpretation, that is, the actual here-and-now from which the self is observing.

If we follow Denise's approach, it would appear that we should remain consciously aware of the attentional modifications marking the moment of interpretation. In other words, when a sufferer holds her personal time still for a moment of perspective, she becomes aware of these modifications, and so also able to determine the interpretation of actual events. She is, in fact, able to choose an interpretation, a perspective, from which to view the particular instant, as well as subsequent events. Cassell (1991: 59) agrees that "the person's choice of interpretation is central to how that person experiences the events — it is the interpretation that determines whether suffering or merely distress is experienced". Events are, in other words, not necessarily inherently positive or negative, good or bad. Instead, the nature of events — as they are experienced — is determined by a personal choice of interpretation.

When participants held their personal time still, when they lived entirely in the present moment, their distress was relieved, not only because they were able to (re-)interpret the nature of experienced

events, but also because they were able to (re-)appraise the self. Helen's conclusion to her autobiographical sketch was a powerful statement of this:

I coped with an illness that has no foreseeable end to it, by trying to stay positive and by trying to concentrate on the invaluable experiences and lessons I could learn from it... It [was] a time of suffering that I would not wish onto anyone else, but at the same time, [was] a period in my life I would never wish away either... it brought with it much pain and heartache, but left me with a much richer and deeper understanding of myself that I will cherish forever.

While Helen's illness clearly represented a time of great suffering, it was also a period in her life that she will not discard, since it afforded her a much deeper understanding of her self and of the power residing within her. Indeed, for Helen, suffering was mitigated by a distinctly revised appraisal of the self in the present moment. It was an appraisal of the self as not powerlessly dictated to by illness, but powerfully supportive of the self despite illness (cf Collinge 1993: 77-8). In the very act of reflecting on the self, a new context of meaning is created, to which experiences may be referred for interpretation in the extended present. This process of referral in effect reflects the chosen content of the sufferer's time perspective, through and from which the self's interpretative glance operates (cf Schutz 1967: 78-84).

For participants, it became imperative to refrain from reliving past hurts as well as from continually tumbling into the future of the coming moment. They had to live entirely in the present, in the moment — not in the capacity of an observer, but as an agent actively taking responsibility for the self. In this sense, the extended present represents that expanse of time that they believe they have shaped or will still shape (Cottle 1976: 173). An essential part of this "shaping" is to take control over their own interpretation of events. Thus, by positioning the self as an active agent in the extended present, as an agent who has the sovereign power to choose an interpretation, participants were able to assume greater responsibility for their experience of both illness and the self.

6. Conclusion

We hesitate to claim full knowledge in the area of severe illness, time perspective and self for two important reasons. Firstly, our study was complicated by the fact that the perception we wish to understand — time perspective — is constantly changing because our participants continue to live it. In chronological terms, the present becomes the past and the future becomes the present; with each second our perceptions of the past, present and future are altered and modified. People — our participants included — are, after all, perpetually in motion. And that very motion is part of the horizon of time we wished to explore with our participants.

Secondly, we did not draw a comprehensive sample of all CFS sufferers in the country, or even in the specified region. We are well aware that this fact and its implications means that we cannot proclaim our interpretations to be representative of all CFS sufferers. Still, we believe that the particular selection of participants allowed us to develop a well-balanced and in-depth understanding of the CFS illness experience (cf Rubin & Rubin 1995: 69-70).

Even given these qualifications, it remains clear that our participants experienced profound changes at the onset and during the progress of their illness. The character and consequences of these changes are particularly pronounced in the case of an illness as notoriously lengthy and variable as CFS. The subjective experience of such an illness can be desperately disempowering. Where a past filled with insecurity and a future brooding with anxiety reside within the present, the ill person suffers. In a sense, the content of the person's time perspective — the temporal signs — which governs the interpretation of new events is sculpted by the sufferer's experience of severe illness.

Yet, our participants had the option to choose to direct their "attention of life" to the extended present. There, the sufferer has the power to choose a perspective from which to view events and appraise the self. There, she can make a decision, can consciously choose an interpretation of actual happenings that is supportive of the self in the moment. In the extended present the sufferer assumes responsibility for the self and its suffering.

While this approach may appear deceptively simple, it is not. It is not merely a matter of liberating the experience of time in this moment of past and future dimensions. In fact, this cannot be done. For to experience the present, we must have the memory of the past and the expectation of the future. Time perspective is never an empty space. The extended present, therefore, includes both past and future, but only that portion of past time for which the sufferer feels responsible and only that portion of future time that she believes she can shape and control.

At this point, the experience of illness and the self has become a matter of personal responsibility. In fact, it is now an act of utter irresponsibility to dwell on a past-gone-by or cast an anxious glance towards the future-to-come. It is irresponsible precisely because it diverts the person's focus from the new locus of the gist of personal responsibility: the extended present. It is, after all, in the extended present that the sufferer must be wholly supportive of the self-of-now who confronts the challenges of illness. In this context, personal responsibility is, more distinctly than anywhere else, defined and lived in the present tense.

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