

**THE EVERYDAY LIVED EXPERIENCES OF PEOPLE
WITH CERVICAL DYSTONIA:
A QUALITATIVE APPROACH**

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ABSTRACT

Cervical dystonia (CD) is a chronic neurologic disease which has been extensively studied in terms of diagnosis and treatment and treatment outcomes. The resulting psychological manifestations of chronic diseases is well-documented. The majority of the studies on CD take a post-positivist quantitative approach therefore there is a lack of rich descriptive research done in this area from the perspective of the person living with this disorder. The aim of this study is to add to the body of literature on CD by providing a description of the impact that CD has had on the lived experience of people with CD. This was accomplished by performing two open-ended long interviews with people with CD. The data was transcribed verbatim and analyzed using thematic analysis looking for key themes relating to the impact of CD on lived experience in their daily lives. It was found that CD greatly impacted the participants' daily lives in terms of limitation of activities because of social embarrassment, pain and physical limitations. Those with more severe CD were most impeded in their activities of daily living but over time were able to make adjustments in their lifestyle to accommodate their disease and find deeper meaning in everyday experiences.

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CHAPTER 1

INTRODUCTION

Cervical dystonia (CD), also referred to as spasmodic torticollis, is a chronic neurologic disease for which there is no cure (Dystonia Medical Research Foundation, N.D). CD is the commonest of the focal dystonias (Nutt, Meunter, Aronson, Kurland, Melton, 1988) and also one of the most under recognized movement disorders (Fahn, 1984). It is believed that abnormal functioning of the basal ganglia, which assists in initiating and regulating movement, causes CD but how and why it is functioning abnormally is not yet known (Dystonia Medical Research Foundation, N.D.). The result is that it causes the neck muscles to contract involuntarily, pulling the head into an abnormal posture with mild to severe spasms causing jerky head movements (Consky, Lang, 1994). The incidence of pain in CD is remarkably high (over two-thirds) and this significantly impacts on activities of daily living (Jankovic, Leder, Warner, Schwartz, 1991). As well, stress, fatigue and other motor activities such as walking or repetitive use of the arms exacerbates this disease often significantly impeding activities of daily living (Tolosa Marti, 1997). People with CD are often embarrassed by their head deviation and/or shaking and therefore restrict their social activities (Gundel, Wolf, Xidara, Busch, Ceballos-Baumann, 2001). The combination of abnormal appearance, pain and physical limitation warrants separate research from other medical conditions.

Interaction with people with CD, while working as a medical secretary for a movement disorder specialist, has lead me to notice that their ability to adjust

to living with this disease varies significantly and that their quality of life is not necessarily dependant on the severity of their condition. My assumption is that people with CD can lead fulfilling lives. As well, while the disease itself can be debilitating there are also socially imposed obstacles that may lead to increased personal difficulties. Individual issues such as self-consciousness, loneliness, depression, relationship problems, low self-esteem and poor self-confidence are often exacerbated by broader structural issues. These may include negative attributions on the basis of appearance because of culturally defined aesthetic norms and assumptions regarding the cause and nature of the condition with frequent misinterpretation and misunderstanding. Many people with CD have impairment of usual work performance and some may in fact be unable to engage in voluntary or gainful employment. Other people with CD may be confronted by negative expectations regarding their ability to perform at the usual level of their occupation by co-workers or employers who may assume inability despite the lack of true disability. Negative assumptions based on appearance may also significantly impact recreational and social activities. Participation in the social life of their community or cultural group and the ability and opportunity to maintain community relationships may be impaired, not only by the physical limitations imposed by the disease, but also by social embarrassment of the person with CD and lack of understanding and acceptance by others. Using an unstructured methodology to gather information about CD may provide new information and richness of data that otherwise may not be expressed.

The research question that I am exploring is, how does CD affect the every day lived experience of people with this disease?

CHAPTER 2

REVIEW OF THE LITERATURE

2.1 Overview

The medical community in terms of clinical features, treatment options and treatment outcomes has extensively researched CD. CD is a chronic neurologic disease with the following subtypes: rotational torticollis (turning), laterocollis (tilting), anterocollis (forward flexion) and retrocollis (extension) (Consky, et.al., 1994). Several other characteristic clinical features are generally present, such as the use of *geste antagonistes* (sensory tricks such as touching the side of the face or resting the head on the back of a chair) to provide transient correction of head position, morning benefit (temporary morning remission lasting a few minutes to a few hours), common exacerbating factors (stress, fatigue, repetitive use of the arms, walking), neck pain, tenderness on palpation and muscle hypertrophy (Consky et.al., 1994, Kedlaya, Reynolds, Scott, Strum, Waldman, 1999). Onset of adult CD usually occurs between the fourth and sixth decades, with women affected 1.5 to 1.9 times more often than men (Epidemiological Study of Dystonia in Europe Collaborative Group, 1999, Jankovic, et.al, 1991). Symptoms tend to worsen for three to five years and then may mildly improve before stabilizing (Lowenstein, Aminoff, 1988). CD does not become generalized dystonia (Dauer, Burke, Greene Fahn 1998) but Jankovic et.al. (1991) found in a study of 72 patients that one-third of

participants experienced spread beyond the neck to another focal area such as the arm, hand or oral mandibular region. Complete or partial remission unrelated to medication occurs at a rate of approximately 20% usually within the first few years (Jahanshahi et. al., 1990). "A younger age at onset is the only consistent clinical characteristic that appears to predict remission, and remissions tend to be sustained only if they occur after the first 2 years of onset. However, nearly all patients relapse within 5 years, and a cycle of remission and relapse may occur, although rarely more than three times" (Duane in Dauer et.al., 1998, p. 549).

2.2 Treatment

Treatment goals are symptom relief, improvement of quality of life and prevention of secondary complications such as cervical spondylosis (arthritis) (Dauer et.al., 1998). Treatment options include local injections and drug therapy. On rare occasions patients may require complex surgical interventions such as selective peripheral denervation (Bertrand, Molina-Negro, 1988) and deep brain stimulation (Krauss, Pohle, Weber, Ozdoba, Burgunder, 1999).

Botulinum toxin injections of the affected overactive cervical muscles is the treatment of choice for CD (Kedlaya et.al., 1999). These injections provide temporary relief of symptoms (reduction of head deviation and pain) and need to be repeated every three to six months (Consky, et.al., 1994). Approximately 75% of patients improve within the first week of receiving injections. Five to ten per cent of patients may develop neutralizing antibodies relating to dosage and

interval between injections. (Dauer, et.al., 1998). Although, since the formulation of Botox changed in 1998 Jankovic, Vuong, and Ahsan (2003) reported that they found no evidence for immunoresistance on consecutive CD patients treated with the current formulation of Botox.

If the response to botulinum toxin injections is not adequate other medications such as anticholinergics, benzodiazepines, and antispasticity agents are used. Surgical therapies are only used when conservative treatments are inadequate (Dauer et.al, 1998). Treatment outcomes of CD are most prevalently reported on in terms of neck deviation, relief of pain and effect on quality of life.

2.3 Measurement of Quality of Life

There are many scales that measure quality of life. "Quality of life refers to the perception of an individual's physical and emotional health. It is a highly personal assessment, since a person measures their quality of life in relation to their value system and their desired activities" (Shulman, 2004). The Sickness Impact Profile (SIP) is an example of a tool which measures perceived health status in activities of daily living including, sleep and rest, eating, work, home management, recreation and pastimes, ambulation, mobility, body care and movement, social interaction, alertness behaviour, emotional behaviour, and communication (Bergner, Bobbitt, Carter, Gilson, 1981).

A study by Hilker, Schischniaschvili, Ghaemi and Jacobs, Rudolf (2001) compared the health related quality of life of CD patients before and after

treatment with botulinum toxin type A using the SF-36 Health Related Quality of Life (HRQoL) scale. This scale measures physical and social function, physical and emotional limitation of role, mental health, vitality, pain and general health. This study found that CD has a negative impact on HRQoL compared to the general population and that after injections there were significant improvements in mental health and amount of pain. These improvements were found to be temporary with no significant differences between the baseline HRQoL scores at the beginning of the study and HRQoL scores before the next set of injections were due.

Jahanshahi and Marsden (1992) studied 67 people with CD and found symptomatic improvement and significant reduction of depression and disability following botulinum toxin injections with 85 % of patients. Interestingly, there was not a significant improvement in body concept and self-esteem. It is thought that depression and disability are consequences of the postural abnormality of the head. Self-depreciation, disability, degree of control over head position, extent of satisfaction with available social support, and maladaptive coping accounted for 75% of the variance in depression.

These findings are substantiated in an Amsterdam study which investigated the long-term effect of botulinum toxin type A on impairment and functional health in terms of disability, handicap, and quality of life in 54 patients with CD. This study showed improvement in these areas after one year of treatment and, contrary to other studies, it suggested a cumulative clinical effect of botulinum toxin injections (Brans, Lindeboom, Aramidch, Speelman, 1998).

Camfield, Ben-Shlomo, Warner (2002) studied the effect of cervical dystonia on quality of life comparing it with that of the general population and three other better-known neurological condition, multiple sclerosis (MS), Parkinson's disease (PD) and stroke. A postal questionnaire was sent to 289 patients in seven European countries. The questionnaire was translated and back-translated for accuracy. The response rate was 75% with 101 men and 188 women. The mean age was 52.8 and 56.7 years for men and women respectively. Patients on average waited 4.6 years from onset of disease to correct diagnosis. It was found that CD has a detrimental effect on health status comparable to progressive diseases, specifically MS, PD and stroke. Yet, these diseases are generally clinically perceived to be of greater severity. There was age-related decline in physical levels which were more marked than that seen in the general population. As well, women and patients of lower educational level consistently reported worse quality of life. The study also found that patients with CD had relatively low mental health and emotional role limitation scores which may result from anxiety, depression, and isolation due to a lack of recognition, understanding, and support for this disease.

A rating scale for measuring the health impact of CD with the aim of capturing patients' perceptions of disease impact has been developed by Cano, Warner, Linacre, Bhatia, Thompson, Fitzpatrick, Hobart (2004). This study used a postal questionnaire sent to 650 English-speaking patients over the age of 18 with questions generated from semi-structured interviews with 25 CD patients, literature review and expert opinion. The principal components included

symptoms, activity limitation, and psychological and social consequences. The scale was found to be a reliable and valid patient-based rating scale but specific findings of the impact of CD on patients was not discussed.

Muller, Wissel, Kemmler, Voller, Bodner, Schneider, Wenning, Poewe and the Austrian Botulinum Toxin and Dystonia Study Group (2004) collaborated to develop a rating scale called the CDQ-24. It is based on five subscales: stigma, emotional wellbeing, pain, activities of daily living and social/family life. It was found to be valid and reliability in assessment of 231 consecutive patients with CD and blepharospasm (forced eyelid closure) following preliminary questionnaires which were given to 203 consecutive patients. It was found that that the CDQ-24 score significantly improved following Botulinum toxin injections. The largest effect was in the stigma subscale. Stigma was found to severely affect social, private and working lives.

Green in Jankovic, et. al. (1994, p. 286) provides objective, subjective and indirect factors which negatively contribute to quality of life in people with CD as follows:

A: Factors measured objectively

1. Degree of head deviation.
2. Direction of head deviation: anterocollis or retrocollis are more disabling than rotation for the same degree of deviation; rotation away from the dominant arm is more disabling than rotation toward the dominant arm.
3. Tremor or jerky movements: often produce more disability for the same degree of head deviation.

4. Presence of "sensory tricks": ability to straighten the head by gently touching the cheek, neck or back of head, raising the arms in the air, etc. may allow relatively normal function even in the presence of extreme head deviation. These tricks are often lost as the disease progresses.
5. Dystonia at other sites.

B: Subjective factors

1. Difficulty in overcoming head deviation: small degrees of deviation may be disabling if the head cannot be rotated in the opposite direction.
2. Pain: even mild pain may be disabling if unremitting.
3. Muscle tension: patients who do not complain of pain may have a constant sensation of pulling, which is distracting and enervating.
4. Presence of painful spasms.

C. Factors indirectly related to torticollis

1. Depression (may actually be part of the underlying disease, or a reaction to the disease).
2. Insomnia because of pain, spasms, or depression.
3. Radiculopathy: may be more likely in the presence of torticollis.
4. Dysphagia: related to extreme head deviation or dystonia in pharyngeal structures.
5. Disequilibrium.
6. Compression neuropathy at the elbow from the use of sensory tricks.
7. Skin abrasion at the chin from rotation of the head into the shoulder, or occasionally from sensory tricks.

2.4 Psychological Manifestations

Negative body image was found to be a prominent component of depression in CD and this also leads to social avoidance (Jahanshahi, Marsden, 1988, 1990). In a study by Gundel et.al. (2001) social phobia and perceived stigma were also found to be prevalent in people with CD. Social phobia was exhibited in more than 50% of 116 patients with CD treated with Botulinum toxin. They found no correlation with the severity of the CD but found that depressive coping behaviour was a predictor of social phobia. Social phobia was measured using DSM-IV criteria A-G suspending the criterion that prohibits the diagnosis when applied to a patient with a physical disability.

While most researchers studying CD use a quantitative methodology, in a study of perceived stigma in CD Papathanasiou, MacDonald, Whurr, and Jahanshahi (2001) use both a qualitative and quantitative methodology. They interviewed ten patients to identify the effect of their condition on their social interaction. Perceived stigma was defined as:

- avoidance of others
- avoidance by others
- self-consciousness
- feeling unattractive
- feeling apologetic
- feeling different from others

An open-ended interview was used to explore patient's perspectives and to gain information about the specific dimensions of stigma and the situations in which stigma was found. The data was analyzed using content analysis to identify key themes. The study patients were approached in an outpatient department of the medical facility. The questions asked were not identified and it is uncertain who administered the interviews. The second stage of the study involved a questionnaire that was mailed to patients at the same medical facility. Of 100 questionnaires sent out, 73 were entered into the study. Both samples showed that the majority of people with CD felt mild to severe stigma and that it was focused mainly on physical appearance and attractiveness relating to the deviation of the head.

Ben-Shlomo, et.al. (2004) designed a study to evaluate determinants of quality of life in people with CD. Patients in seven European countries were recruited from movement disorder specialists. Data on quality of life, measures of coping and intrinsic, extrinsic, and disease related factors were collected by a self completed postal questionnaire. Of 289 completed questionnaires it was found that physical and mental quality of life scores were predicted by:

- self esteem and self depreciation
- educational level
- employment status
- social support
- response to botulinum toxin
- disease severity

- social participation
- stigma
- acceptance of illness
- anxiety
- depression

The study concluded that care for patients with CD must not only focus on reducing the severity of the dystonia but also on the psychological well-being of the patient. Interventions aimed at treating depression or anxiety may have a large impact on improving quality of life. It was thought that the marked effect on mental well-being may reflect the stigmatizing effect of living with such a visible disorder. Severity of the condition and responsive to treatment related to quality of life, as well as intrinsic personality features and educational status, which modified the patients' ability to cope. Findings revealed that people who had CD for a longer duration often had a better quality of life which was likely related to their ability to develop successful coping strategies. Limitations of the study included:

1. response rate, which although was high may not have included people severely depressed
2. recruitment only from movement disorder specialists, resulting in other CD populations not being represented
3. a questionnaire that may not have accurately measured the variables that they were trying to test.

2.5 Qualitative Research

Since there is a lack of qualitative studies on the psychological and psychosocial manifestations of CD, studies on other non-life threatening chronic disorders of adults with physical rather than psychiatric disorders were examined.

Kelley (1997) studied people with fibromyalgia. Fibromyalgia is a condition which results in chronic pain, and often disrupts employment, family life and overall social functioning leading to depression and withdrawal from activities. Kelley's standpoint is that "chronic pain may bring about a sick role identity (Gaston-Johansson et al., 1990), but that externalizing the illness so that it "afflicts but does not constitute" the individual (Wynne, Shields, & Sirkin, 1992) is an important one." The aim of this study was to provide information to social workers working with people with fibromyalgia and their families to improve social functioning. Kelley felt that this knowledge is best found by listening to the participants' experiences with illness. The participants were given eight questions which were planned to help them tell their stories to feel understood; to look at other aspects of their lives and assess where they were already coping, assess what helped them to cope and to rediscover what other aspects of themselves may have been pushed aside by focusing on their illness. These questions were given as part of a treatment program in eight two-hour group sessions over a 16-week period. Participants were also asked to keep a journal on these questions. Kelley acknowledged the necessity of trust to produce richer and more accurate data. To this end the group facilitator also assumed

the role of co-investigator. The data from the group sessions and journals was analyzed by two investigators, one graduate student, and by Ethnograph (qualitative data analysis software). The validity of the study was increased because common themes were noted by three different people and were presented back to the participants for feedback. The general themes were described in the results, and were illustrated with a few key quotes. People felt loss of their previous self, loss of activities and often loss of relationships. Feeling understood was very important to respondents, as well as validation by family members, friends, health care professionals and employers. Depression was common among respondents and this too was tied to loss of health, independence, employment and relationships. The participants had specific needs: to be understood, get rest and exercise and have expectations of them reduced. Other participants discussed more concrete needs such as help with housework and other chores, and financial support. Self-esteem was affected positively as participants learned to externalize the condition as something afflicting them, not as intrinsic to them and they found new strengths. Self-esteem was also affected negatively because of the loss of independence and lack of validation.

CD like fibromyalgia is often associated with chronic pain. Unlike fibromyalgia, people with CD have the additional physical head deviation. People with fibromyalgia are often misdiagnosed and validity was seen as an important need. Similarly CD patients are often sent to chiropractors,

orthopaedic surgeons, physiotherapists and psychiatrists before a correct diagnosis is made a neurologist and treatment is administered.

A qualitative study by Kleinschmidt (1999) explored older adults' perspectives on their successful adjustment to vision loss and results were used to plan and implement interventions and services for the newly legally blind. Kleinschmidt comes from the position that there are explanations for successful adjustment to vision loss and that these explanations can be more fully understood through those who have accomplished it. The participants were either identified at an eye examination or through a support group for the visually impaired with a diagnosis of age-related macular degeneration (ARMD). Participants qualified for the study based on their subjective opinion and the researcher's subjective opinion that they had made good adjustment to being visually impaired and based on normal ranges on standardized questionnaires measuring depression and trait anxiety. Kleinschmidt therefore combines subjective and objective criteria for inclusion in the study. She used a long-interview methodology, one to one and a half hours in length, in-home open-ended questionnaires consisting of three questions that were established before the study began and did not change during the course of the research. These interviews were audio-taped and transcribed but not read back to the participants for changes to be made. There was no interaction between the participants. Interpretation of the data were not made with the help of the participants, nor was the analysis shared for feedback. As well, the author presents the data using the "impersonal language of the third person singular"

(Maguire, 1987, 18), which distanced her from the participants and is more typical of dominant paradigms. Good adjustment was defined by participants having both a positive view of their own ability to function and a positive attitude or outlook. Results showed that the initial reaction to vision loss was frustration, discouragement, fear, panic, shock, helplessness, frustration and loss of activities. Three themes that emerged for successful adjustment were:

1. Prior life experiences: past success with hardship, love and support in earlier life
2. Internal resources: positive attitudes, humour, ability to solve problems, resolve to remain active and productive and religious beliefs
3. External resources: recognition and appreciation, help from others (personal and professional)

This research is interesting in that it focused on the positive aspects of having a chronic condition.

2.6 Purpose of the Study

My goal is to increase understanding of the experiences of individuals living with CD. I explore this subject from the standpoint of the personal experiences of the six interviewees. By documenting these experiences other CD affected individuals can use this information to reflect on their own experiences.

My primary audience is people living with CD. Secondary audiences include family members and friends of people with CD, and interested medical and health-related professionals. This research is not intended to build theory

but is about “knowing” (Lloyd, 2000) and is an understanding-oriented micro-level study (Drisko, 1997, p. 188).

CHAPTER 3

METHOD

3.1 Subject Selection

The study sample was selected from members of a local dystonia support group, those subscribing to the monthly newsletter of the support group and patients of the medical practice where I work. People selected to participate in the study had a diagnosis of CD which was not post-traumatic, no other focal dystonia and no other major medical condition. I attended one of the monthly support group meetings to present my intended study subject. I also provided an introductory letter to each of the support group members attending the meeting. (Appendix A) Since the response from people meeting the study's criteria within this group was insufficient I posted an advertisement (Appendix B) in this group's newsletter.

Mertens (1998, p. 14) has stated, "...perceptions of a variety of types of persons must be sought." Since there were only six respondents that met the criteria all were accepted into the study. Demographics of the participants and me are provided as each person comes to the research process with historical factors that influence their reality.

3.2 Sample

The sample was comprised of six participants, three women and three men. All were Caucasian and ranged in age from 41 to 61 years, with a mean age of 54.8 years. Of the three men, two were married and resided with their spouse and one, a celibate homosexual, resided with his mother. Of the three women, one was separated, one was widowed and one was residing with a same-sex partner. All the participants had at least a high school education; three were also college or university educated. Two participants are still able to work in full-time administrative positions. One participant is working from home as an investment manager. The other three participants are receiving a disability pension. Two of them were previously in managerial positions and the other was a homemaker. With regard to religious preferences, five were Christians and one was agnostic. This relatively small number of participants allowed for a more in-depth study.

At the time of the interviews, all participants had had CD from five to 20 years, with a mean of 11.8 years. Age of onset ranged from age 18 to 55 with a mean age of 38.6 years. Two participants described their CD as mild, three as initially severe and presently moderate, and one as severe. Five participants were receiving Botox injections and taking oral medication. One of these five was contemplating surgical intervention. The sixth participant was taking oral medication, having developed an immunity to Botox, and had undergone selective peripheral denervation surgery. All participants were in good health with the following self-exclaimed exceptions:

- one had mild arthritis
- one had mild arthritis and obesity
- and one was obese

Two participants were actively involved in the dystonia support group, two were former group members, and two had never been to the dystonia support group.

All the participants in the study are patients of the medical clinical where I work. While this facilitated establishing contact and a connection with them I was concerned that they might feel obligated to participate in my study because of this connection. Although a medical secretary is not usually considered to occupy a position of “power”, I am the liaison between the patient and the physician. As well, as a researcher I am a liaison between the information confided to me and the information which is presented in the final research paper. “...[A] file or dossier is likely to attain a legitimacy and authority that is lacking in more informal types of communication” (Wheeler in de Montigny, 1995, p.213). Therefore, as an introduction to recruiting volunteers for this study I discussed my affiliation with the physician with whom I work making it clear that this research is a requirement of completing my Masters’ Degree and not a part of my professional duties. I am somewhat of an “insider” because I have professional contact with CD patients and have developed a personal interest. However, as a researcher and someone who does not have CD I am an “outsider”. “...[T]he personal and theoretical can [not] be separated, the two are intertwined...” (Dunk, 1991, p. 12). Potential participants were clearly advised

that they had the “freedom to choose” to participate. While emphasizing the voluntary aspects of participation may lead to a decline in participation, it is ethically important that participants are informed and free to choose (Palys, 1997). I interviewed each volunteer by telephone prior to participation to discuss in detail the implications of my dual role. Ethically, participation in a study must be solely voluntary and those recruited must not feel coerced either directly or indirectly. Participants were given “...sufficient information about factors that might potentially influence their decision” (Palys, 1997, p.98). Volunteers were also informed that participation or non-participation in the study would in no way affect the medical treatment they receive. They were also assured of confidentiality. (Appendix C) Fully informed consent was somewhat problematic in that I did not know all the outcomes of the research. I explored possible outcomes with others involved in research and was conscientious in protecting the participants’ dignity and welfare in other respects (Palys, 1997).

I am a Caucasian 40-year-old heterosexual Jewish woman. I am divorced and live with my three children. I am in good health and have never experienced loss of health except for a whiplash injury in my early 20’s. My most significant experience with loss is that of my parent’s divorce as a child and my own divorce as an adult.

3.3 Design

Historically, research has been conducted using a positivist or post-positivist paradigm. The ontological position of the positivist paradigm is that there is one reality and that it is the researcher's job to discover this reality. The post-positivist paradigm is similar in that it also believes that there is one reality but that this reality can only be imperfectly discovered because of human limitations – though a theory cannot be proven, a strong case can be made for it by eliminating alternative explanations (Mertens, 1998). I do not believe that there is one reality but that reality is socially constructed and therefore these paradigms are not appropriate to address my research question. When first contemplating this study I wondered whether the ability to therapeutically grieve the loss of a person's pre-CD self would enhance that person's ability to adjust to living with CD. Since my preconceived notions as a non-affected individual may be at variance with the actual experiences of the participants, open-ended questions were used to allow the participants truth to be expressed. Lather (1995) when interviewing people with AIDS "...thought that she was going to learn about dying and yet she learned about living" (p.47). Since my primary audience is those with CD rather than the medical community I explored my research question using the interpretive/constructivist paradigm. "The basic assumptions guiding [this] paradigm are that knowledge is socially constructed by people active in the research process, and that researchers should attempt to understand the 'complex world of lived experience from the point of view of

those who live it” (Schwandt in Mertens, 1998). “Feminism, disability and minority are socially constructed phenomena that mean different things to different people” (Mertens, 1998, p.11). The ontological position of the interpretive/constructivist paradigm is that there are multiple constructions of reality that may be in conflict with one another and that perceptions of reality may change throughout a study. As well, there is not an objective reality that can be known and therefore a researcher’s goal must be to attempt to understand the multiple social constructs of meaning and knowledge and allow for the concepts of importance in the study to emerge as constructed by the participants (Mertens, 1998, p.11-13).

My personal values will affect the research process. “The inquired and the inquired-into are interlocked in an interactive process; each influenc[ing] the other” (Mertens, 1998, p. 13). My personal belief is that it possible for people with CD to lead fulfilling lives. Also, I believe the sharing of the personal experiences of people with CD will benefit those participating in the study and others with this disease. This position was communicated with the participants and was open for feedback and reflection. My research question was a standpoint from which to begin and through the interactive nature of the research the central focus of the study emerged.

3.4 Procedure

The first interview consisted of a single question, “I’d like to invite you to share with me your everyday lived experience of having cervical dystonia”. The

purpose of this single question was to, "...let the participants tell their stories with minimal interruption..." (Morse, Field, p.90). An open-ended interview methodology allows, "...the opportunity to step into the mind of another person, to see and experience the world as [he or she does]" (McCracken in Kleinschmidt, 1992, p.2). This single question led to the participants sharing with me:

- how they experienced their initial symptoms
- the path which led to diagnosis and treatment
- the losses they experienced in their daily lives
- the adjustments they made to cope with their losses
- the growth they experienced as a result of having CD
- their underlying fears and hopes.

Most participants started their story by sharing how their symptoms began with their story unfolding in a sequential fashion ending with how their life with CD was experienced today. The information from the first interview led to eleven open-ended questions being formulated to provide a framework for the second interview. (Appendix C) These eleven open-ended questions were aimed at either clarifying common themes or exploring avenues that were raised by some and not by others to see if there were further commonalities. All the interviews were transcribed verbatim and given to the participants so that they could make changes and advise whether the text reflected the meaning they

wished to convey. Together we created the meaning of their experiential world (Neimeryer in Kelley, 1997).

3.5 Setting

The preferred location for both interviews was the participants' homes. This way the participants could be in familiar and comfortable surroundings and the impact on their time could be kept to a minimum. If the participant preferred, the interviews could be conducted at my own home or an agreed upon neutral territory (Palys, 1997). Three participants chose to be interviewed in their own homes, one chose to be interviewed in my home and one chose to have the first interview in my home and the second interview in an office. Each interview was tape recorded using two tape recorders in case one malfunctioned.

3.6 Data Analysis

The data was processed and analyzed using content analysis in the following steps:

- the tape was replayed and listened to carefully for content
- I transcribed each tape word-for-word, except for identifying information with all pauses and exclamations included
- the transcription was checked against the tape for accuracy
- the transcript was mailed to each participant to check that the content was accurate and reflected their meaning
- using content analysis each interview was read and several important topics were identified. These topics became the primary categories

- information that fell under these topics was written underneath them with new categories or subcategories being added if needed
- significant passages were extracted and filed with the appropriate category (Morse et. al., 1995).

Interpretation of the data conveys the participants' perspectives but how these are consistent with, or conflict with, external interpretations were explored. While researching the literature for this paper I was aware of my use of language. There is a discursive language for disability. I have not used words like "patient", "suffering", "debilitating" in this study unless it reflects the language of the participants as this is medically oriented discourse. Differences in individual and structural interpretations of language are addressed. Interpretation of the data is a collaboration between the participants and myself and were challenged and/or affirmed thus meeting the requirement of confirmability (Drisko, 1997, p. 191-192). The two interview sessions allow for saturation of data collection and establishment of confirmability. "...[S]aturation means asking participants to say a little more when they claim to have said it all, and working on in the face of considerable repetition" (Drisko, 1997, p. 192). Having two interviews also meets Lather's (1991) criteria of collaborative interactive interviewing. Repetition is used to unlock deeper levels of experience based on feelings aroused in the first interview on the same issue or question. The feedback generated added to the validity of my interpretation (p. 60-61). Focusing on fundamental contradictions of current understandings of living with CD provides the possibility for an alternative ideology that might serve the participants' needs better. Alternative ideologies will not be imposed but created through a reciprocal relationship where "every teacher is always a

student and every pupil a teacher” (Gramsci quoted in Femina in Lather, 1991, p. 63).

Since the interviews were transcribed verbatim the criteria for descriptive validity was met. Descriptive validity refers to the accuracy of what the researcher reports having seen or heard and not that which is inferred from other data (Maxwell, 1992, p. 287). Interpretive validity “...what objects, events, and behaviors mean to the people engaged in and with them [,]” (Maxwell, 1992, p. 128) is also accounted for by the design of the methodology. The transcripts of the tapes were given to the participants so that the information could be checked for accuracy and edited if the message conveyed did not reflect that which the participant intended.

Consensus for the terms used in interpretation of data involves the researchers and the community being studied. Therefore, the analysis is shared with the participants so that it is reflective of their language and their meaning. This study was not designed to be externally generalizable, but was expected to be internally generalizable within the group studied. (Maxwell, 1992, 284-296)

3. 7 Reporting

Reflective reporting will be used which is characterized by the presence of the researcher’s voice (first person). This is a more literary freedom of expression and is commonly used in qualitative research (Anderson, 1998).

CHAPTER 4

RESULTS

4.1 Initial Reaction to CD

Symptoms

The onset of CD can vary from being quite rapid (a few months) with painful spasms and turning of the neck to quite insidious (a few years) with vague, but slowly progressive symptoms of neck strain and pulling. Similarly the description of feelings regarding the initial recognition of symptoms varied from that of “**surprise**” or “**shock**” to that of “**curiosity**” or “**annoyance**”. One man with rapid and severe onset of CD shared that the pain of CD was so disabling that knowing that suicide was an option was comforting to him. He knew he had no control over his neck but at least he could control whether or not he lived. Knowing he had a way out, if necessary, helped him to live through the months of severe pain (this pain was significantly reduced once regular Botox injections were started). Although he admits that he was initially depressed during that early difficult period his thoughts of suicide were not related to depression, instead it was just a matter of needing to know he still had some control:

“It wasn’t that I wanted to commit suicide but it was comforting to know that the option was there, somewhere out in the distance.”

In reflection he says:

“Getting the dystonia was like being forced to join a club that I did not know existed and did not want to join. Kind of like a form of conscription.

This same man also says that developing CD was:

...almost like a mini death in a way, and as time went on it became apparent that I was never going to be normal again, I almost felt, over the course of one or two years, I almost felt that I had to go through a grieving process.... I had to grieve the person who wasn't there anymore.”

Another man shared that:

“...the lowered expectations in a day plus the lack of social stimuli probably has put [him] in a downward spiral into a bit of a depression.... they say the, ah, the man has his, ah, little cave that he recedes to. Well I [had] mine, and I [spent] an awful lot of time in it.”

One woman developed CD while her children were still young. She was so devastated by her inability to care for her children and household the way that she had been used to that she attempted suicide because:

"...we feel, we feel useless, we feel helpless. There's no light at the end of the tunnel. It's always pain. It's constant pain. It's the social thing when we go out and people look at us funny."

She was also very concerned about the effect of her CD on her children since she was their primary caregiver.

Another woman with a milder case of CD said:

"This isn't a bad life. There are other things a lot worse. If I was more disabled with it then it might be a different story."

Another described it as:

"...a relief to know that I did have something wrong with me. It had a name and it wasn't life threatening because I think that I was thinking of Parkinson's disease and you know some really serious condition that got progressively worse so I guess with the diagnosis that was a good thing for me to know what was the matter with me. Yeah its sort of if you are going to have something it is not too bad."

Another woman who developed CD later in life said:

“Because I went through this post-menopausal I think it’s easier...I think age...helps you accept more.”

Diagnosis

CD can only be diagnosed by observing the person. There are no blood tests or x-rays etc. that can be used to confirm a diagnosis. Therefore, an accurate diagnosis is solely dependent on the knowledge and expertise of the attending physician. There was a great variance from time of onset to time of accurate diagnosis and treatment ranging from two months to thirteen years. Only two participants were accurately diagnosed by their family doctors and then correctly referred to a neurologist. These two participants were then further referred to a neurologist specializing in Adult Movement Disorders. One woman felt, “**shattered**” when her physician incorrectly told her that her:

“...nerves were bad...there’s no need to see a neurologist. I have patients whose head turn more than that and its just nerves.”

She said she knew that she was not a “**calm person**” but “**...it just didn’t make sense.**” She eventually changed to a new family doctor who diagnosed CD and referred her to a neurologist. In response to finally getting the correct diagnosis of CD she said:

“...it was kind of a relief when you know yes that something is wrong with you, it’s not all in your mind.”

Another affirmed:

“You know we live in a society that often labels things, labels people...it’s great to have a label for this...because I went for decades, over a decade, not knowing what I had.”

One man said:

“Never once was it suggested to me that I was doing this to myself, as I know a lot of ladies run up against that problem.”

He suggested that as a successful middle-aged man he had been taken more seriously perhaps than if he had been a female and in different socioeconomic circumstances. He never doubted that his condition was anything but neurological and presented himself to his physician for a referral to a neurologist.

In the early 1980’s an 18 year old man who developed a “rapid onset of CD” with severe pain and head deviation was correctly diagnosed with spasmodic torticollis but informed it was psychiatric in origin despite mainstream neurologic opinion of the time. He was not referred to a neurologist, in fact he

was warned against seeing one. Treatment modalities included hypnotherapy, oral medication including Haldol (which is contraindicated for dystonia), and relaxation techniques. When these treatments were unsuccessful and his condition worsened he was admitted to a psychiatric institution. There he was heavily medicated and underwent psychotherapy, physiotherapy, acupuncture, massage therapy, and cervical traction. The cause of his CD was blamed on everything from childhood trauma, homosexuality, an overly attentive mother to incorrect thinking. After seeing a newspaper article in 1999 on CD he insisted on a referral to a neurologist specializing in Adult Movement Disorders. He remembers:

“...he showed me the film, the video of the before and after, people with dystonia and the Botox and it was nirvana. I was so happy. You have cervical dystonia and that was like the heavens opened up. Thank God. There’s a name for this. And this is what I have....I knew that I was with, I was seeing the right physician and that I knew I was going to get a positive effect [of Botox] and Dr. (Name) was sure also.”

Treatment

While this study was being conducted all six participants were being treated by the same neurologist. Descriptions of their experiences with this physician included, **“I was impressed”**, it was a **“blessing”**, a **“God-send”**, a **“relief”** and he was someone **“who cared, who was interested”**, and he was **“compassionate”**. All felt that their experience with this neurologist led to a better understanding of their CD and just as importantly, reasons to be optimistic. One man shared:

“... not only did he take the time to explain everything to me, ahm, but he was very encouraging.”

All six participants have undergone treatment with Botox (botulinum toxin type A). Five out of the six initially had a good response. However, one of these five subsequently became immune to Botox due to the development of botulinum toxin antibodies. The sixth participant had a poor response to the Botox injections and is considering surgical intervention. Botox treatment involves the injection of botulinum toxin type A directly into the neck muscles that are behaving abnormally. Each abnormal muscle is usually injected in several places. These injections typically have to be repeated every three or four months. One woman says that:

“... [T]hey are not pleasant. It’s only five minutes, less than that it’s only a minute.”

Another says:

“You know the Botox doesn’t cure it but you do reach a point where you really do, able to drive, comfortably, and walk comfortably, write. These are all things that are really difficult.”

Botox has received a lot of attention in the media since it has been used cosmetically to treat wrinkles. In response to this one person said:

“It is not a cosmetic drug, it’s a lifesaver.”

Another says:

“I have a very rapid reaction to the Botox, a very positive one. “

Another describes their response to Botox as:

“It’s not perfect but it’s a heck of a lot better than it used to be.”

Another says:

“I don’t seem to notice the improvement because I guess I’m getting closer to just normal.”

Age of Onset

When asked whether age of onset might affect their reaction to developing CD all six participants said that getting CD earlier in life would have been more difficult.

“Oh I think it would have been horrible.... There was a 21-year-old female who had just started university or something and now she gets cervical dystonia. Their life hadn’t even started, they hadn’t had a partner etc. etc. and so on so it would be, so that goes once again with well I got it at 42 and it really slowed me down at 45 or whenever it was and I felt really lucky. If it had happened when I was in my 20’s then it would have been a lot different.”

A woman who developed CD in her late 50’s says if she had developed CD earlier in life:

“...I don’t think I would have been able to deal with it as well. I don’t know what, how my life would have been different but I think it could have been a more depressing thing at an earlier age. Yeah I would say that, and certainly it would

make me more introverted. To just stay in and let it take hold.”

Another man agrees:

“Ah, earlier in life would have been more challenging depending upon what age. When you are in your 20’s you’re invincible and when you are in our 30’s you are somewhat immortal. You still can’t see the end of the road. And even into my 40’s I was a fairly active person. Ah, and worked hard at my job and I was fairly dedicated at work so if I had gone on full-time disability due to an inability to work at a younger age I think I would have reacted more strongly in not accepting it or being upset.”

Even though he was older when he had to quit working and go on disability he admits:

“I really haven’t found anything as a viable substitute for work...I don’t have the same feeling of accomplishment that I would have if I was working.”

4.2 Effect on Daily Life

Five out of six participants found that their CD greatly impacted their daily lives in terms of limitation of activities because of social embarrassment, pain and physical limitations. One person found himself:

“... watching people’s faces more than I have in the past just to see if they’ve notice anything about myself.”

Another wonders:

“...do people know what’s the matter or are they going to be looking at me and think, you know, what’s the matter with her?”

So, she finds that she is only comfortable with people she knows and therefore restricts activities that involve meeting new people.

Another shares:

“To talk and carry-on with a conversation with someone is difficult because talking precipitates an extra move which causes pain and discomfort. And also at the same time there’s the social embarrassment in that you know you are presenting yourself quite differently than other people.”

Another man says:

“As much as I enjoy interaction with other people, ahm, it causes my dystonia to flare-up....Once that trigger is removed, and that person would leave, and I would be left alone again it will take a long time for the symptoms to go away. So it only takes minutes for it to flare-up and then it will take two hours for it to go back again, for me to get back down to a comfort level.”

One woman describes:

“...like I constantly have a thing about people being on my right hand side because my head just kinda, like my husband used to say, it makes him think of that movie where the head was spinning [laughter] what was that? The Exorcist.”

Another describes himself as feeling like **“Quasimodo”**, the hunchback of Notre Dame. This same man also said that although he was no longer able to join his family in many activities he very much wanted for the CD to be his, **“...disease not their disease”**. He therefore encouraged his family to go out and live their lives fully. Meanwhile he admits to becoming reclusive and shares:

“...[CD] stops me from doing a lot of things that I would like to do. It stops me from traveling for instance. It stops me from maybe getting further education. It stops me from enjoying family gatherings. It stops me from enjoying my daughter’s wedding. I was not capable of walking my daughter down the aisle.”

Another says:

“I avoid certain places that have given me a bad social feedback.”

Another found he avoided engaging in intimate relationships not wanting to **“put somebody though what [my family had] gone through.”** He admits, though, that now his CD is improved he noted that he uses his CD as a **“crutch”**, as an excuse to avoid the emotional risks of intimacy. Conversely, one participant found that her CD has almost forced her to become more out-going because her head deviation makes her visibly different and her discomfort forces her to speak up for herself in order to ask for things that will increase her comfort level.

One participant shares that he was embarrassed socially by his inability to work. It is common when meeting someone for the first time to be asked, **“What do you do for a living?”** How we choose to earn money has become an important part of our identity and self-worth. He stated:

“Well, it’s easy to justify your self-worth when you are supporting a family, doing a job, paying your taxes and making some kind of a contribution to society.”

He is older now and is pleased that he can at least say, **“I’m retired.”**

Five out of six participants found that their head deviation and discomfort also interfered with many other activities of daily living including housework, biking, walking, golfing, dancing, keyboarding, reading, watching television, and gardening. One man also found his sexual drive had diminished and thought this to be medication related. He shared:

“...the really big change in daily life was trying to put up with pain and aggravation in virtually every thing that you do.”

Not only did he have to give up working, but he also says he couldn’t even pull his weight at home with the housework.

“Even the, ah, easiest task of say vacuuming a floor is a chore. Ah, any kind of arm movement, even movement of the hands on the computer. I can’t operate the computer for extended periods of time, extended period being half an hour.....Just simply because moving the hands on

the keyboard causes the neck to move which makes it difficult reading the screen which causes eyestrain.”

Another man described his pain as excruciating. **“It was just...it was pain that even my hair hurt.”**

Another said:

“...I felt completely trapped at home because I couldn’t drive, I couldn’t walk any distance and the pain was, the pain was such, that I really didn’t, moving just simple movements, bending down, leaning over to pick something up, even sitting down on a chair and eating was almost impossible because of pain.... Pain has a way of focusing all your thoughts and all your emotions and putting everything else out of your mind. And that’s what was happening with me. I wasn’t caring about anything.”

Driving was found to be difficult but manageable for short distances in the five out of the six participants that drove. All five found long distance driving difficult, restricting their ability to visit friends and relatives who live further away and interfering with vacationing.

Eating was commonly problematic for most participants. For some the problem was the actual physical act of putting food into their mouth because their mouth moved with the action of lifting up the utensil. For others the problem was the discomfort of trying to speak to people who were seated at the dinner table on the side that they had difficulty turning their head towards. Dining was also difficult because of the inability to hold their head still whilst eating, or to eat and interact with other people at the same time.

“Dinners out are really difficult. Mm, eating because, drinking things like that, my head just turns so. Going out to dinner isn’t the real treat it used to be.”

Two participants found that having CD affected their sleep due to an inability to keep their head still while trying to fall asleep. However, both noted significant improvement in sleep following Botox injections.

Three of the six participants were still employed. One woman with mild CD does not find that her disease impacts her ability to work. One woman found her CD impacts her work but says that she enjoys a supportive and accommodating work environment. Adjustments were also made to her workstation to accommodate her head deviation. One man works from home. Of the three participants no longer employed none discontinued working because of a hostile work environment; rather they came to the decision themselves

because of their inability to perform their duties satisfactorily. One man stated that he:

“found [himself] putting all [his] energy into pretending to work. Pretending that things were normal.”

4.3 Adjustment to Living with CD

Social and Financial Support

Five out of six participants felt that their family was a great support system and all participants really enjoyed meeting other people with CD whether it is at a support group meeting, in the neurologist's waiting room or as a research volunteer. Having the support of others allowed them to focus on coping and adjusting with CD in an understanding and loving environment.

“Underneath me I had a good safety net.... Yeah I had good kids, I had a good wife and I had two good parents at the time who were functional at the time. So I had a safety net to fall back on.”

One woman in reference to the support group said:

“It is just a great feeling to be amongst people who have the same thing as you.... You learn from everybody because everybody is trying

things. That it's just such a comfortable situation that you can just sort of be yourself."

Financial support was considered a very important factor. As one man said:

"One of the biggest thing that probably helped me was having good insurance."

Another said that:

"I knew in the back of my mind for instance that I had disability insurance, so even if I couldn't return to work I knew that hopefully there was a financial safety net there."

Another woman who was presently working said:

"And so I'm kind of at that nice situation where I could retire anytime.... which is a nice position to be in."

Personality

Inherent personality affected the ways in which participants responded and adjusted to having CD. Persons with type "A" personality have the following characteristics:

- impatient
- hurries

- feels under pressure
- prompt and often early for appointments
- watches the clock
- walks/talks/eats rapidly
- does multiple activities simultaneously
- lives in the future/always planning
- feels that 'there's never enough time'.

Whereas persons with type “B” personality have the following characteristics:

- relaxes readily
- focuses on the quality of their life
- paces themselves
- easygoing
- has a 'one day at a time' approach
- is less ambitious
- often has lower incomes/grades
- less irritable. (Zuckerman, 1992)

Personality type affected initial reaction and adjustment but also having CD also changed some characteristics of personality as well.

A man shared that being:

“...a fairly laid back person, ah the personality type made it easier for me to deal with.... You know human beings have an amazing capacity for adjusting and I guess over the years that's

just what I've done. I've adjusted to the limitation and I think that again I've been very lucky to the extent that I was not particularly an ambitious person, and the fact that I lost the career, uhm, it was a blow but it wasn't the kind of blow that maybe it would have been to some other people. ...Because, ah, you know, I am to a certain extent content to lay back and just let life blow over me now maybe. As well, I'm an only child. Another aspect of my background, which I think, helped me. Because as a child there weren't playmates around. I had to rely on myself. So I think there's been a huge amount of self-reliance in my life. And now having dystonia I think that being an only child and being self-reliant has stood me well.... Another thing I think that has stood me in good stead is not taking life too seriously. I don't think I ever did and I don't think I do now. The other thing that I think is very important is maintaining a sense of humour and I've always had a good sense of humour and I've always been able to make fun of myself and again not take myself too seriously. ...Dealing with dystonia the doctor can only take you so far.

You know he can do the technical aspect, he can give you the pills and what not, but you're the one at home dealing with it. You've got to kind of find your own way....I think it's aged me but also matured me. Ahm, maybe taken away some of the fear of death. That's a pretty profound statement but... You know when you are young and you've got everything going for you the one thing that could always come along and upset your apple cart is to die.... Whereas now that just seems to me like perhaps more of a normal process. Part of the cycle."

Another man shares:

"I have always been rather rational and sort of calm and accepting about certain things....so when I got this I didn't react with disdain, 'Why in heaven name me?' or get angry and become unlivable in the house. It was just something that I more or less accepted. 'Okay I've got it what do I do about it?' Let's try and find out information about it because we had the Internet available at home. So research and understanding was the key."

He admits to experiencing a change in personality though and went from being a kind of “**jokester**” to a more of a “**hermit**”. He also found that the medication he was taking to try and reduce the pain and spasm resulted in lethargy and decreased libido and with that came a change in personality making him a lot quieter than he used to be. Another man said:

“When I was 18 and this first happened to me I was more withdrawn personally. Ah, very much unsure about myself because that was being reinforced by the treatment I was receiving. I was being told that there was something wrong with you psychologically.”

He now describes himself as an “A” personality but that having CD changed his personality a little:

“...it’s forced me to be patient with myself and to understand that I’m getting older and I do have limitations, physical limitation. My physical limitations has lessened as the condition, as this particular onset of the condition, is getting better. I am able to do more things. So it’s made me more patient with myself....”I’m self-conscious at times but more so in the beginning than right now because I know what will trigger, I know the

triggers that will set, that will set the neck off or cause a contraction. Ah, being more, being more comfortable in a social situation with people, especially people I don't know, that I haven't met before. Before my neck would, I would go into spasms at times or it would start to pull and now I have learnt to overcome that just with relaxation techniques. Ah so I would say I'm not as self-conscious as I was before when meeting people who didn't know about dystonia. And I felt at times that I needed to explain my condition, more so in the beginning, now I don't."

A woman describes herself as someone who tended to keep more to herself and having CD exacerbated that tendency. At the same time, though, it has forced her to **"grow a bit with it"**. Attending the support group allowed her to meet other people with similar conditions and gave her the opportunity to talk about her feelings. Being in pain with CD forces her to ask others for what she needs to make herself feel more comfortable.

Spiritual Growth

Four out of the six participants shared that they had experienced spiritual growth as a result of developing CD. One man talks about how before CD life was always giving things to him - education, family, house, job, and then with

the development of CD life began taking things back. With the loss of his ability to work and participate actively in social activities he gained increased time to think about the greater meaning of life and came to the conclusion that:

**“...it wasn’t so important what happens to you;
what was important was how you felt about it.”**

He said:

**“I think there’s been a lot of gifts with dystonia.
You know, the gift of wisdom, the gift of
increased spirituality, the gift of appreciating
what you’ve got, appreciating the here and now.
Maybe realizing that things don’t go on forever
and you should experience and appreciate the
things in the here and now.”**

He also finds that he has become a more accepting and compassionate human being.

**“I found myself listening to people that in the
past I would have dismissed as being people of
no consequence. Now all of a sudden they were
saying things at this support group meeting that
made sense to me. I found I was, dare I say,
growing as a person.... It kind of taught me that**

everybody has their own strengths. It's a little bit like saying you have to be tough to endure old age....when I was starting to search around for a silver lining because I had all this time to myself I decided to get involved in doing some volunteer work. And one of the things I did was I went to the M.S. society and volunteered as a friendly visitor. Okay so they hooked me up with this one individual and we got along very well. I still see him to this day so I have been visiting him for about eight years. I have watched his...as I had kind of, um, more stable, more used to my condition, I have watched his condition get worse. So he's now at the point whether his Multiple Sclerosis has affected him everywhere except his head. So the only thing he can move now is his head. So when I visit him, I spend an hour with him once or twice a week, when I visit him now I find, and I have been finding this for a long time, that after being with him I am so grateful and so thrilled that I can walk down the street. That the mere fact of being able to walk independently and move my body is, once again I

have to use this expression, but it's almost a spiritual experience...."

Another stated:

"I like to be able to reach out a hand and help someone, whether that be just talking with them, just sitting with someone who might be in pain, whether it be physical or emotional. It's not so much the monetary, ah, thing, ah, and acquiring things that are important it's, it's experiences with other people, relating to other people, helping other people, and being helped, [and] allowing other people to help me."

He notes that he has learnt to:

"Appreciate the simpler things in life." Saying, "But you know you really don't understand until you've lost it....I was constantly walking into things. So just being able to walk without bumping into a wall."

He further stated:

“...the condition doesn’t rule me, it doesn’t have to limit me from what I can do and from who I am.”

One woman describes how CD has made her into a stronger person:

“I know I can get through anything, and I can deal with anything that comes my way because that was the hardest and most depressing part of my life and when I got better I just took this positive attitude and never looked back again.”

Another man also noticed spiritual growth but still struggles with acceptance of his condition. Although he finds reading difficult because of jerky head movement he does not want to get taped books saying:

“I’m having a hard time admitting to myself about being that far gone that to me getting a tape is like say, ‘Okay, you are a cripple.’...So I guess it’s a way of self-denial that, ah, I’m not going to prove to myself that I can’t do it by just not doing it. And maybe that’s why I don’t do other things, ah, that I should be doing. Or I put them off

**because I don't want to prove to myself that I
can't do it."**

Fear and Hope

While all participants were quite well informed about CD and had access to information through their physician, support groups, newsletters and Internet some still harboured fears and misconceptions regarding etiology, treatment and progression. One woman said:

**"One thing, one that that is a really big question
mark in my mind about dystonia is our
environment and what it is doing to our bodies."**

Another with regards to treatment stated:

**"...I know the Botox doesn't work forever and
that's kind of scary...I think that's why I push the
appointment you know thinking that if I don't get
it too often it will, I will have it longer, I think I will
have it working for longer."**

Another participant wondered whether there was a connection between CD and other neurologic conditions such as Parkinson's disease or Alzheimer's disease. As well, fear of their CD worsening or spreading to other areas of the body was also a concern.

“So I guess that’s always hanging over you. But that, you shouldn’t let that change your life. Like worrying if you might get hit by a car.”

Part of their coping strategy included the hope of remission:

“remission, partial remission. Well this was all like, you know, The Promised Land, and hope for a cure, I don’t even, even after four years, I don’t think I’ve really accepted the fact that this is it. Ah, cos I’m kinda hoping that a, a miracle will happen....”

One man who had experienced remission described it as almost like being **“reborn.”** He also admits that he is very self-conscious of the need to protect his neck and to somehow not cause his CD to be exacerbated again.

CHAPTER 5

DISCUSSION

5.1 Major Findings

CD definitely impacted negatively on the everyday lived experience of people with CD and this impact increased in relation to the severity of the symptoms, especially with the degree of pain experienced. Receiving appropriate medical treatment certainly decreased the severity of symptoms and therefore improved some aspects of quality of life. It appeared, however, that the participants who described their CD as severe, whether previously or currently, in time experienced changes which helped them cope in their daily lives. One significant change was in their level of spirituality. Spirituality can be described in broad categories, including such phenomena as belief in a power greater than oneself; purpose in life; faith; trust in providence; prayer; meditation; group worship; ability to forgive; ability to find meaning in suffering; and gratitude for life, which is perceived as a gift (Hatch in Post, Puchalski, Larson, 2000). This increase in spirituality could account for the perceived differences in ability to adjust to having CD independent of severity. With time the CD is incorporated into their identity and yet does not encompass them. Developing CD almost seemed like a wake-up call to appreciate the gifts of life and to search for higher meaning.

Other factors possibly influencing ability to cope with CD and its impact are: inherent personality, prior life experiences, and support systems. One of the participants described himself as “laid back” and believed that this personality trait was especially helpful in accepting the limitations that his CD has imposed on him. Although I had expected prior life experiences to have a greater impact on coping ability only one woman stated that having gone through menopause helped her to cope with CD. And, yet, when asked whether getting CD earlier or later in life would have affected them more all participants stated that getting CD earlier in life would have been more detrimental. Perhaps, though, this has more to do with the length of time you would have to live with having CD rather than the coping strategies that prior experiences may have provided. All but one participant lived in a positive and supportive environment. The participant who was in an unstable home environment was seeking help through the support group and through psychotherapy.

With time and treatment all but one participant noted improvement in their CD. As well, over time, accommodations in lifestyle were made and coping mechanisms were gained. Common accommodations involved discontinuation of work and decrease in social and recreational activities. Of the three participants no longer working all chose to stop working due to inability rather than because of a negative or unaccommodating work environment. Of the two women working one finds her CD only slightly impacts her ability to work and the other was able to work more effectively once her workstation adjusted to decrease the strain caused by her abnormal head posturing. Neither participant

felt embarrassed in their place of work because of their head deviation as both had worked in their jobs for an extended period of time and found it to be a supportive atmosphere.

One of my assumptions was that people with CD can live fulfilling lives despite their chronic condition. All participants felt this supposition to be true. Each person found ways to enhance their quality of life whether through the establishment of meaningful relationships, hobbies, volunteer work, or exercise. Culturally defined norms in terms of aesthetics significantly impacted three of the six participants making them self-conscious about their head deviation. As well, two of the men who were no longer working had a lowered sense of worthiness because of their exit from the workforce.

5.2 Limitations of the study

Qualitative research is valuable because it allows for a rich description of the perspectives of a small group of people. However, since this study only had six participants, it is not possible to generalize its findings onto a broader population. This is an obvious limitation of qualitative research.

When the six participant sample was analyzed demographically, differences in gender, age of CD onset, CD duration, religion and sexual orientation were represented. There was not racial, educational or socio-economic diversity in the sample as all six participants were white, relatively well educated, and had comfortable living situations. Lack of a diverse sample on these important dimensions also makes it impossible to generalize the findings.

5.3 Implications for Practice

From this study it appeared that an accurate and timely diagnosis improves a person's ability to cope with manifestations of CD.

There was a direct relationship between the severity of a person's CD symptoms and the impact these symptoms had on their quality of life. The more severe the symptoms, the greater CD impacted on quality of life. However, that was not the whole story. There were other factors that seemed to influence quality of life. These included, how long the person had been living with CD, their successfulness in developing positive coping strategies, their personality traits and how effective their personal belief system was at helping them live with a chronic illness.

There seems to be less awareness of CD within both the medical community, as noted by the delay in accurate diagnosis in four out of six participants, and the general public than other neurologic disorders that occur at similar rates, like Multiple Sclerosis. I wonder whether CD is not as well recognized because it is non-life threatening and there are no x-rays or blood tests etc. to aid diagnosis? Clearly there is a need for a broader awareness of CD within both the general public and the different disciplines of the medical community.

In addition to standard medical treatment for CD there are no doubt other methods that could be used to improve the coping strategies of people with CD, and therefore improve their quality of life. Psychotherapeutic counselling is one

technique that might be of use. Another method could be to actively encourage people with CD to seek out the help of the many community based organizations that exist in one form or another to help people.

Is it possible to improve the chances of people with CD discovering 'the gift of disability' which could influence their perspective and lead them to a better quality of life?

If we cannot change a person's personal experiences and circumstances with respect to CD, are there ways to make them feel more emotionally comfortable and accepting of these experiences and circumstances? To paraphrase a common expression, can we help people to discover their own personal silver-lining in the cloud of CD? As well, how important is hope of improvement, remission or cure for people with CD? What is the physician's responsibility in providing hope?

Severity of CD, in terms of head deviation and pain, clearly impacted quality of life. Other mitigating factors included personality, longevity of CD, and the development of positive coping strategies including spiritual growth. These findings support the need for continued education of physicians and other health-related professionals such as chiropractors and physiotherapists in helping their patients deal with CD. As well, perhaps there is a greater role for the inclusion of psychotherapeutic counseling and spiritual-based groups to aid patients with CD in coping with the impact of their disorder on their daily lives.

5.4 Implications for Future Research

In-depth interviews with participants can provide unique insights into how people perceive, define and explain their experiences. As these insights emerge more questions naturally follow. Additional research is therefore warranted.

Here is a list of subjects that could be studied. This list is not intended to be exhaustive.

- The relationship between socio-economic status and quality of life in people with CD. Are there distinct differences in how members of other socio-economic groups respond to CD?
- The relationship between the intrinsic personality of a person and their ability to develop coping strategies.
- The role of psychological therapy in the development of coping strategies.
- The role of the physician/patient relationship with respect to treatment outcome.
- Are there distinct differences in how members of other ethnic groups cope with CD?
- What is the impact of a poor or nonexistent support system and a lack of financial resources on a person's ability to cope?

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Appendix A

Letter to CD Support Group Member

Dear Cervical Dystonia Support Group member:

I am writing to you in regards to a study I am conducting towards completion of my Masters' Degree in Education (psychology) at Mount Saint. Vincent University. I am interested in exploring the impact that living with cervical dystonia has had on your lived daily experiences. To be included in the study you must have cervical dystonia that is not a result of an accident, and no other major medical illnesses. This study will be carried out under the supervision of Dimitri Manos, Department of Education, Mt. St. Vincent.

The study process will involve:

- Two tape-recorded interviews approximately one and a half to two hours in length in your home or another comfortable setting of your choice. The first interview will be unstructured and aimed at allowing you to tell your story about having cervical dystonia. The second interview will be arranged after all my first interviews have been completed and the tapes have been analyzed for common themes. The aim of the second interview is to clarify and elaborate on the common themes. Your transcripts will be given to you to read and to confirm that the information is complete and reflects what you wanted to convey.

This letter is to invite you to take part in this research. I hope that these interviews will help to increase what is known about living with cervical dystonia and be of help to others who have this condition. The results of this study will be used in my thesis publication. Tape-recordings of our discussions, their transcriptions and all raw data will be kept in a locked storage cabinet. The information gathered will be held in the strictest of confidence and no person will be identified in any reports. **You are under no obligation to participate, participation is completely voluntary and no one will be informed of who participates and who does not. You may withdraw from the study at any time should you wish to do so. I have attached a consent form detailing my ethical responsibility to you. In order for me to interview you I require the attached form to be signed and returned to me. I will contact you to schedule the first interview.**

If you have any questions or require further information, please feel free to contact me at the number below. Thank you for your cooperation and assistance with this project.

Sincerely,

Joanne Nathanson Williams
Masters' Student
University of Mount Saint Vincent

Appendix B

Advertisement for the Study

PARTICIPANTS NEEDED FOR STUDY ON CERVICAL DYSTONIA

Joanne Williams

To complete my Master's Degree in Education (Pysch.) I am conducting a study on cervical dystonia (CD). People included in the study need to have a diagnosis of dystonia in the neck region only, that is not post-traumatic (resulting from an accident) and no other major medical condition. The study consists of two unstructured, open-ended confidential, 1½ to 2 hour, one-on-one interviews. During these interviews you will be asked to describe your experience of having cervical dystonia and how it affects you everyday lived experience.

For more information please contact:

Joanne Nathanson Williams

Appendix C

Informed Consent Form

PROJECT TITLE: The everyday lived experiences of people with cervical dystonia: a qualitative approach.

INVESTIGATOR: Joanne L. Nathanson Williams Phone 416-638-8129

The purpose of this research project is to increase our understanding of people's experiences of living with cervical dystonia. Two open-ended interviews will be conducted, and each interview will last approximately 1 ½ to 2 hours. During the first interview you will be asked to tell about your experiences of having cervical dystonia and how it affects your everyday life. The second interview will be aimed at clarifying common themes. These tapes will be confidential within the study and will not be shared with your physician. The typed document will be available for you to read to confirm that the information obtained contains the information which you would like to convey. The final report, containing anonymous quotations, will be available to participants at the end of the study.

There may be no direct benefits to you as a participant of this study, but there will be an increase in the knowledge about living with cervical dystonia.

THIS IS TO CERTIFY THAT I, _____ (print _____ name)
HEREBY agree to participate as a volunteer in the above-named project.

I understand that there will be no health risks to me resulting from my participation in the research.

I hereby give permission to be interviewed and for these interviews to be tape-recorded. I understand that, at the completion of the research, the tapes will be erased. I understand that the information may be published, but my name will not be associated with the research.

I understand that I am free to deny any answer to specific questions during the interviews. I also understand that I am free to withdraw my consent and terminate my participation at any time, without penalty.

I have been given the opportunity to ask whatever questions I desire, and all such questions have been answered to my satisfaction.

Participant

Witness

Researcher

Date

Appendix D
Demographic Form

Demographics

Name: _____

Address: _____

Telephone Number: _____

Date of Birth: _____

Sex: _____

Ethnicity: _____

Marital Status: _____

Religion: _____

Education: _____

Occupation: (previous/current) _____

Year of Onset of Symptoms: _____

Year of Diagnosis: _____

Associated Pain: _____

Neurologist: _____

Medication: _____

Treatment: _____

Appendix E

Second Interview Questions

1. What life experiences have contributed to your ability or difficulty in adapting to living with cervical dystonia?
2. How do you feel about the medical treatment you received and the course you took before receiving it?
3. What impact has your personality/nature had on the way that cervical dystonia effects your life?
4. What effect, if any, has cervical dystonia had on your personality?
5. Imagine you developed cervical dystonia earlier or later in life. How might it have affected you differently?
6. When you think about “self-worth” what characteristics contribute to a positive feeling of self-worth?
7. What is your personal understanding as to the cause of cervical dystonia?
8. What impact has dystonia had on your ability to sleep? Do Botox injections change that ability?
9. One person describes an internal rage, a sort of churning inside that is distracting. Do you experience anything like that?
10. Have you had to grieve the loss of the “normal” you?
11. Has cervical dystonia changed you spiritually?