

Art Therapy and the Lived Experience of Diabetes

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ABSTRACT

Art Therapy and the Lived Experience of Diabetes

Sylvie Linhares

The following paper utilizing a phenomenological methodology presents the experiences of four adolescents living with diabetes mellitus. The primary research question explored the following: through a phenomenological art therapy process, how do adolescents living with diabetes mellitus cope with and emotionally encounter the experience of living with diabetes? Diabetes mellitus is a chronic illness, which has both physical and psychological implications. The qualitative analysis of the verbatim transcripts generated the following four themes: Diabetes management, interpersonal aspects, challenges and coping strategies. These could be further reduced to the essence of *diabetes mellitus requires a high level of self-care, which introduces interpersonal and intrapersonal challenges, which induces both healthy and unhealthy coping mechanisms*. Art making and the artwork facilitated discussion within the group. The artwork supported many of the quotes but exhibited some incongruency as well allowing an outlet for aspects of living with diabetes mellitus to be expressed yet not verbalized.

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ART THERAPY AND THE LIVED EXPERIENCE OF DIABETES

Introduction

During adolescence much growth and change occur. Puberty, the period of sexual maturation, takes place, which may cause an uneasy preoccupation in an adolescent. Cognition also reaches its final phase in what is referred to as formal operations. Now the adolescent has the cognitive ability to reflect, predict, and interpret experiences (Piaget, 1967). Finally it is the stage where independence from parents, identity formation and peer interaction becomes highly significant. Adolescence is considered at times a turbulent period, therefore living with a chronic illness, such as diabetes mellitus, may create even more difficulties.

Diabetes mellitus is a chronic illness that places much of the responsibility of care onto the person living with the illness. Type 1 diabetes mellitus is primarily diagnosed during childhood and adolescence. Insulin injections, consistent glucose monitoring, healthy eating, diet restrictions and exercise are part of daily management. Type 2 diabetes mellitus is usually diagnosed during adulthood. It is however being diagnosed more frequently in children and adolescence. Oral medication, a balanced diet and exercise play an important role in management.

There is little literature available on the coping and emotional experience of living with diabetes although much has been written about the different coping interventions utilized with people living with diabetes mellitus. None include art therapy despite the literature demonstrating the effectiveness of art therapy with a variety of populations living with other physical illnesses. The objective of this research was to explore the following primary research question:

Through a phenomenological art therapy process, how do adolescents living with diabetes mellitus cope with and emotionally encounter the experience of living with diabetes?

Adolescence

Adolescence is a time of growth and change. There are physical, cognitive, and psychosocial transformations to name a few. This stage of development can pose many challenges both exciting and difficult for adolescents who, in most cases, emerge from it as healthy young adults with a bright future in front of them. Researchers throughout the years have examined the distinct aspects of the adolescence stage.

Puberty

With adolescence arrives puberty – the physical changes occurring within and to the body. For girls it begins between 10 and 13 years of age and for boys 11 and 14 (Geoffroy & Gonthier, 2003). There are the obvious physical alterations: breasts, body hair and voice changes but there are also hormonal variations within the body: secretion of androgen and estrogen. Even though adolescents may be expecting these changes, this transition may be nonetheless perplexing, especially if they are physically maturing at a slower or faster rate than their peers.

Piaget

Considering the primary position afforded to puberty, Piaget (1967) believed that not enough attention was given to the mental and affective processes of adolescents. He theorized that although the transition into adolescence created some instability within the mental and affective processes, eventually these processes fortified themselves with the integration of new cognitive abilities. Piaget referred to this period as formal operations.

At this developmental stage, according to Piaget (1967), adolescents are capable of developing plans and speculations about the world around them. The concept of abstraction now enters their cognitive framework. They are soon capable of reflecting on things and events that were, are, and might be. When adolescents reach this phase of cognitive maturity, they wield it like a sword, forming philosophies and schemes on how to modify the future for the better. Moshman (1999) disagreed with Piaget stating that many people never reach formal operations. He discovered through his own literature review and research that although formal thinking does begin to develop around adolescence it is not necessarily either integrated nor consistently applied, not even in adulthood.

In keeping with Piaget's (1967) theory, the adolescent's egocentric world embraces idealism. In relation to the adolescents' affective sphere, they can now utilize abstract thinking and reflection. They perceive themselves as equal to adults yet distinct because they trust this new found 'power' of formal thinking, and utilize it to generate possibilities that include a better and just society, one which adults have failed to create themselves. Piaget stated that the adolescent gradually achieves a balance between reality and idealism by comprehending the roles of reflection, prediction and interpretation of an experience. This is accomplished through peer interaction, which can broaden the cognitive process (Moshman, 1999).

Being highly social beings, specifically with their peers, adolescents come together and discover similar thoughts they have about the world, reconstructing what they believe to be a better one. As their ideals coincide with reality, balance is eventually restored, referred to as equilibration by Piaget (1967). Moshman (1999) goes further and

describes the critical role peer interaction has on formal thinking. Possibilities are generated together and realities are reconsidered in light of those possibilities.

Adolescents view themselves as equal to their peers; thus when they exchange ideas, thoughts, and experiences these interactions may broaden their subjective perspectives since they are more receptive to their peers than the adults in their world. This may create the probability for further reflection on an experience or point of view and strengthen the process of objectivity. While some researchers examined the cognitive world of adolescents others favored the psychosocial aspects.

Erikson

Erikson (1950/63) proposed the concept of eight psychosocial stages of development, identifying the stage related to adolescence as 'identity versus role confusion'. Marcia (1993) defines identity as "...a synthesis of childhood skills, beliefs, and identifications into a more or less coherent, unique whole that provides the young adult with both a sense of continuity with the past and a direction for the future"(p. 3) which begins to occur during late adolescence. Both Erikson and Marcia acknowledged identity formation as a life long process with the majority of it completed throughout childhood. Erikson (1968), however, emphasized that difficulty in accomplishing earlier stages created further obstacles at this stage.

Erikson (1950/1963) asserted that adolescence is the stage when identity versus role confusion comes into focus. Erikson defines ego identity as an increased confidence where harmony is established with how one perceives oneself and how others perceive one and that these views match the ones that have formed throughout one's life. Role-confusion is the inability to achieve a secure sense of identity thus creating a sense of

confusion over who one is. The main goal for adolescents, according to Erikson, is to establish a strong sense of ego identity and avoid role confusion. In order to circumvent feelings of confusion adolescents can be inclined to over identify with their peers for a brief time. This tendency to over identify with a group helps provide a perception of sameness and a sense of security. Difference is not easily accepted, if at all, in order to protect a fragile identity from being overwhelmed with confusion. Erikson referred to this over identification as an 'initial identity formation'. It is as though adolescents 'try on' different identities in order to obtain a positive fit with a particular one. In so doing, adolescents seem to demand increased autonomy from parents and appear inclined to place heightened significance on their peers' values, thoughts, and opinions over those of their family. Separating from parents and creating strong connections with a peer group is critical in eventually carving out a healthy identity. Consequently, having or being diagnosed with a chronic illness in adolescence may have adverse effects on accomplishing the tasks necessary to pass through this already challenging phase of life.

Diabetes Mellitus

Diabetes mellitus is a chronic illness. It is identified by the body's inability to produce or use insulin properly. The hormone insulin is produced in the pancreas by beta cells. It transforms glucose in the body into energy. Insulin allows the glucose to be appropriately absorbed into body cells. An inability for the body to transform the glucose leads to high glucose levels, which if not properly treated can eventually lead to organ damage, which will eventually occur even with a good control (Diabetes Division, 1999; Geoffroy & Gonthier, 2003). However, Geoffroy and Gonthier add that recent studies show a decrease in these complications. These authors describe two major categories of

long-term complications: micro vascular and macro vascular. Micro vascular complications refer to retinopathy, neuropathy, and kidney disease while macro vascular complications relate to cardiovascular disease.

Geoffroy and Gonthier (2003) identify two major types of diabetes. Type 1 diabetes (once known as juvenile diabetes) requires daily injections of insulin since the pancreas is incapable of producing it on its own due to the total destruction of its beta cells. Type 1 diabetes is generally diagnosed in children and adolescents. Type 2 diabetes (once known as adult diabetes) pertains to the body's inadequate production and use of insulin and is primarily treated with oral medication but not without exception. Type 2 diabetes is generally found in obese adults. Recent reports, however, have demonstrated an increasing prevalence of Type 2 diabetes in children and adolescents and attention has focused on how to prevent such a rise (Alberti et al. 2004; Wysocki, Greco & Buckloh, 2003).

Practically all aspects of a person's life are affected by the treatment needed to control glucose levels. Keeping glucose levels at a normal range consistently is needed to impede future physical complications (Diabetes Division, 1999; Geoffroy & Gonthier, 2003). The latter describe how food, exercise, stress and illness can have an effect on glucose levels and learning to balance all these factors on a daily basis is key in diabetes management. Insulin administration, frequent glucose monitoring, proper diet and exercise are part of the daily routine of self-care management (Geoffroy & Gonthier; LaGreca & Spetter, 1992; Schur, Gamsu & Bailey, 1999; Weinger, O'Donnell & Ritholz, 2001) which can be extremely challenging for an adolescent.

Acceptance and adaptation in living with diabetes is an ongoing process. Parents play a critical role in their child or adolescent's treatment adaptation (Wysocki et al., 2003). Each age has its set of challenges. For adolescents, puberty, independence, and peer relations are important factors. Geoffroy and Gonthier (2003) discuss how puberty may hamper diabetes control. Adolescents may resist treatment to exert a feeling of independence and separateness from their parents. La Greca and Spetter (1992) along with Wysocki et al. state that adolescents living with diabetes may feel different with peers and to rectify this feeling they may place diabetes management aside at times and that social gatherings with peers may interfere with proper care. Although the psychological impact of living with diabetes are many and may have negative consequences on diabetes control, interventions have primarily focused on patient education since self-care is a necessary requirement for treatment.

Coping with Chronic Illness

Maes, Leventhal and de Ridder (1996) discuss how difficult it is for patients diagnosed with a chronic illness to cope with their diagnosis. Although these authors recognize that no universal medical definition exists for chronic illness due to its varied characteristics they list three general principles: high occurrence, endurance and instability, cost to the health care systems and a high fatality rate. Maes et al. defined coping (and which I have applied to this paper) as the patient's ability to effectively deal with perceived challenging demands from external and internal factors. External factors concern the situation such as being diagnosed, administering medication and checking glucose levels regularly, while internal elements address the patient's emotional responses to the situation.

Coping responses to a chronic illness can be as distinct as the individual. People will employ different coping mechanisms when faced with similar circumstances. Devins and Binik (1996) describe a variety of psychosocial and adaptive challenges that patients diagnosed with a chronic illness may encounter. These include the unpredictable course of the disease, physical and or mental limitations caused by it, a strong reliance on health care professionals, stigmatization associated with a diagnosis and the illness interfering with daily activities.

Living with a chronic illness such as diabetes places much of the responsibility of self-care with the patients consequently, imposing additional psychological stress (Gillibrand & Flynn, 2001; Maes et al., 1996). These authors concur along with Schur et al. (1999) that no matter how well the disease is managed, complications are unavoidable as the disease progresses. Although Maes et al. found through their literature review that patients diagnosed with diabetes do effectively cope with their circumstances; they discovered that few studies directly address the coping and emotional health experience lived by individuals with diabetes.

Schur et al. (1999) conducted a qualitative study that examined the experience of eight adolescents and young people living with Type 1 diabetes. The participants included four females and four males ranging in age from 16 to 22 years old. In my study the four participants are adolescents, 15 to 17 years of age, with three living with Type 1 diabetes and one with Type 2; therefore the themes which surfaced may be different from the older group with Type 1 diabetes. The following two major themes emerged from Schur et al.'s study. The first addressed developing a relationship with diabetes. This included the shock of being diagnosed and learning to live with diabetes, along with

learning to live with it the best way possible. Fear was the primary emotion expressed in developing this relationship. Some participants expressed a sense of acceptance in living with their diabetes. The second theme surrounded managing threats from diabetes. This contained both intrapersonal and interpersonal threats and the coping strategies employed. The subcategories, which emerged from these, included adaptive denial, control, downward comparisons, feeling different, stigmatization, externalization, rationalization and sharing with others.

A variety of interventions have been identified (de Ridder & Schreurs, 2001; Devins & Binik, 1996; Grey et al., 1998) that can assist patients in effectively coping with their diagnosis. These interventions include cognitive-behavior therapy, education about the illness, psychotherapy, social support interventions and an integrative approach that encompasses most if not all the above-mentioned interventions. However, none of these sources examined the creative arts therapies as a possible coping intervention.

Medical Art Therapy

Malchiodi (1993) defines medical art therapy "...as the use of art expression and imagery with individuals who are physically ill, experiencing trauma to the body, or who are undergoing aggressive medical treatment such as surgery or chemotherapy" (p. 2). When someone is diagnosed with a physical illness, treatment becomes focused on treating the physical aspects of the condition (Councill, 1993; Malchiodi; McGraw, 1999) which art therapy can complement (Councill; Malchiodi). It can be used as an assessment tool (Councill; Malchiodi, 1993, 1999; Prager, 1995) as well as a therapeutic intervention (Councill; Malchiodi, 1993, 1999; McGraw; Prager).

Incorporating art into the treatment plan can be beneficial in meeting the psychosocial needs of a population diagnosed with a physical illness. Being hospitalized leaves a patient with a sense of helplessness while art making can help the patient regain a sense of control and preserve a sense of independence (Councill, 1993; Malchiodi, 1999; McGraw, 1999; Prager, 1995). These authors also agree that art making can help in addressing the psyche's response to the patient's condition and situation. McGraw adds that if psychosocial needs are not addressed they can have a negative influence on adjustment and recovery. According to Prager group art therapy can provide a sanctuary for some patients and Malchiodi (1993) and McGraw describe it as a supportive environment where patients with similar circumstances can share, consequently facilitating a healing process.

Medical art therapy is a growing field due to an interest in the area of psychoneuroimmunology and the body-mind connection (Malchiodi, 1993). Evidence has been accumulating throughout the years demonstrating the influence of the body on the mind and vice versa.

Psyche and soma

Jung (1964) believed that elements of our unconscious could appear through the use of imagery. In art making the unconscious can become conscious and both personal and collective symbols can surface. A Jungian analyst named Susan Bach (1975, 1990) studied hundreds of spontaneous drawings of children diagnosed with organic illnesses. Gregg Furth (2002) defines spontaneous drawings as images created without any outside inspiration or direction. Bach discovered that these images were reflections that could not be formed using words yet were crucial guides in revealing the relationship that existed

between the psyche and the somatic condition. Through her research, she was able to identify that certain themes, colors, and shapes may be indicative of a specific illness, as well as referring to a past crisis, a present state or future condition. For this reason, she postulated that spontaneous drawings created by physically ill children had a diagnostic and prognostic significance.

Bach (1975, 1990) furthermore believed that these spontaneous drawings could assist the clinician in understanding children's psychological processes in relation to their illness. The image then becomes a communicative device between patient and healthcare professional consequently providing the professional with a clearer awareness of the patient's reality. This new awareness can assist in developing a treatment plan that incorporates the whole experience of the patient. Bach's book *Life paints its own span* (1990) outlines her approach but cautions for a need to verify a symbol in relation to the other present graphic elements and to the symbol's multiple meanings.

Gregg Furth (2002) also adheres to the notion that images arise from the unconscious thereby, communicating suppressed elements to the viewer. Since the body and mind are connected, he believes they inform each other and images can be visible confirmations of this dialogue. Where he differs from Bach is that he stipulates that both spontaneous and 'impromptu' drawings can reveal aspects of the unconscious. He explains that 'impromptu' drawings are images created from a theme suggested by the therapist. Furth argues that just as there is a connection between body and mind there exists one between the inner and outer realities of the patient and that impromptu drawings validate this connection. The spillage of unconscious aspects into the artwork cannot be avoided even in directed work.

As where Bach (1975, 1990) primarily focuses on the diagnostic and prognostic value of these types of images, Furth (2002) stresses the therapeutic merit as well. He states that making the unconscious conscious may help patients come to terms with suppressed elements, integrating them, thus providing an opportunity for growth. He likewise describes the therapist's role as one of assisting patients in discovering their own ways of dealing with difficulty so that the patients can carry this out, independently, once therapy ends and how the image can facilitate this process.

Yvonne Pepin-Wakefield (1996) recounts her own personal experience of art making in relation to living with temporomandibular joint disorder (TMJ) and how it reflected both her unconscious and conscious feelings. Specifically she describes how in examining the art she created throughout the years led to the discovery of expressions and identification of her own physical illness. She like Bach (1975, 1990) is of the opinion that art making can be an effective diagnostic tool because it can directly access the psyche and the somatic aspects of physical illness. She hypothesizes that if a pattern of themes, colors and images are indicative of a specific disease and its stage then this could perhaps accelerate diagnostic work. Pepin-Wakefield discusses how the use of specific colors in the artwork can heal certain aspects of a somatic condition since drawings can indicate physical pain and the psyche's experience of that state.

Bayly (2002) and Zammit (2001) in examining the artwork of clients with cancer identified the relationship that existed between their psyche, body, and spirit and how these can all become visible within the art object. Bayly and Zammit, like Furth (2002), highlight art making's therapeutic value. Bayly writes that the art object can act as a container to express the effect of a diagnosis on the psyche. Art making can acknowledge

the presence of repressed feelings, which can lead to a reconnection of body, mind and spirit. Zammit states that art making allows for expression of these feelings leading to a transformation through better self-understanding. Like Bach (1975, 1990), Bayly states that the body can act as a container for psychological distress consequently, the images can reflect past traumas. The art object is a testimony to the inseparable connection that exists between the body, mind, and spirit (Bayly; Zammit). Bringing all this to conscious awareness through art making can help patients make these links and cope with their realities.

Chronic Illness, Coping and Art Therapy

Art therapists and other professionals use art as a coping intervention with patients diagnosed with a chronic illness (Baerg, 2003; Councill, 1993; Fenton, 2000; Hildebrand, 1999; Zammit, 2001). A diagnosis may lead a patient to harbor many negative feelings concerning their predicament. If left unexpressed, coping with their condition becomes difficult. These authors contend that art making provides a non-verbal opportunity to express these troublesome and tangled emotions, as words cannot always capture the essence of an experience. The situation likewise may be too difficult to discuss. Fenton states like Bayly (2002), Furth (2002) and Zammit that art allows for diversified emotions to be displayed concurrently. Thus, the art object acts as a container for all these feelings and provides a distancing for patients until they are prepared to unravel them. Hildebrand explains that art therapy then allows the patient to create order from the chaos they may be experiencing.

Creating art allows the individual to regain some sense of control in his/her life since he/she chooses what medium to use, theme to explore, and whether to vocalize any

aspect of their work (Councill, 1993; Fenton, 2000; Hildebrand, 1999; Zammit, 2001). This empowers them and may aid patients to become active participants in their treatment. Councill mentions using art therapy to identify difficult situations and explore possible solutions. She, as well as Hildebrand, discusses the supportive role that the art therapist plays during this process. In using art, patients can express and examine overwhelming emotions and experiences related to their illness and regain a sense of control, which can facilitate coping with their overall condition. Little writing has been done, however, on the therapeutic benefits of art therapy with individuals diagnosed with diabetes.

Diabetes and Art Therapy

I have been able to uncover a meager amount of literature that incorporates art therapy with a diabetic population (Borow & Wood, 1982; Daley, 1985; Harriet, 2000; Murray, 2001; Nuvoli, Maioli, Ferrari, Pala, & Chiaretti, 1989; Raghuraman, 2000). The majority of these have involved working with an adolescent population. Borow and Wood, Daley and Raghuraman used art therapy as a therapeutic intervention while Nuvoli et al., Harriet and Murray applied art therapy for assessment purposes.

Borow and Wood (1982) reviewed the artwork of diabetic children and adolescents partaking in an art therapy group. The graphic elements of the drawings were analyzed in relation to the psychological and behavioral features of children and adolescents living with diabetes described in psychosomatic literature. They found that certain color choices and the use of 'graphic overcompensation' expressed low self-esteem, however the method they utilized in measuring this was not provided.

Depression, grief over the loss of normal physical performance, and loss of self-control

was noted through suicidal drawings. Body 'damage' was also evident in graphic representation of injured organs and needle marked bodies.

Daley (1985) incorporated different group activities with non-compliant adolescents living with diabetes for therapeutic purposes since traditional therapy was failing. She ran the group once a month away from a medical setting. Some of the activities she organized included bowling, cookouts, live theatre and exposure to successful role models living with diabetes. One of these activities was an art therapy workshop facilitated by Violet Oaklander. Puppets, fantasy and image making were incorporated. During this activity adolescents expressed the desire to give up due to their illness. Daley stated that this exchange reduced anxiety in the adolescents because it gave them an opportunity to recognize that others shared a similar experience.

Raghuraman (2000) presents a case study of an adolescent boy living with diabetes and how art therapy was applied to help him cope with his condition, feelings and behavior. Art therapy was proposed to be an emotional outlet, an adaptive aid, and an opportunity for the client to feel in control. In addition, it was meant to help increase his self-esteem, psychologically assess the effects of his condition and develop effective coping strategies. It seems that there may have been too many goals to attain setting up unrealistic expectations since after six months of art therapy; only two of the goals were met. The client was able to use art to express his emotions and he acquired a sense of control through choice of media and images.

Nuvoli et al. (1989) compared self-projective drawings (Draw-a-person and Draw-a-sick-person) created by children with diabetes with those done by a control group. The participants for the diabetic group included 23 children aged 10 to 15 years of

age (17 boys and 6 girls) seen at the Antidiabetic Centre. The control group had 41 participants (20 boys and 21 girls) randomly chosen with the mean age of 13. The authors state that the children in the control group came from the same social-cultural background but do not mention from where they were selected. The authors found that the sick-person images drawn by the group living with diabetes showed 'regressive tendencies' associated with withdrawal, depression and low self-esteem, similar to Borow and Wood's (1982) findings. Nuvoli et al determined this from the location of the figures on the page and the figures' size. According to these authors, drawing figures in the middle of the page indicates a "well-balanced and adaptable attitude". They based this on Abraham (1963) and Passi's (1975) work. Large healthy figures, which were not defined, would indicate the same. Although more than 50% of the children with diabetes placed their figures in the middle of the page it was considerably less than those of the control group, indicating a statistical significance. They also drew large healthy figures almost 50% less frequently than the control group, however these results were not significant.

Nuvoli et al. concluded that children living with diabetes were not reconciled with their circumstances. They also suggested that the unsubstantial differences existing between the sick person and healthy person drawings may indicate a defense mechanism to normalize their situation and reduce anxiety associated with diabetes. From a research perspective there needs to be some caution applied in making conclusions from projective drawings because as Groth-Marnat (1997) has remarked 'no agreed-on interpretation or scoring systems exist, and there is a wide number of variations on administration' (p. 506). Perhaps the unsubstantial differences came from an acceptance of their circumstances on the part of some of the participants, since more than 50% of the

participants living with diabetes drew their figures (healthy and sick) in the middle of the page indicating, according to these authors, adaptation.

Both Harriet (2000) and Murray (2001) utilized projective methods and verbal interviews with diabetic adolescents. Harriet compared the drawings made by a diabetic group and a control group, each group consisting of three participants. They were asked to draw three self-portraits incorporating their whole body at three points in time: past, present and future. They were to include an object in each drawing as well. Five identical questions were asked about each image. Harriet found that the verbal responses by the control group contained fewer negative responses than the diabetic group. Negative verbal responses included replies such as “sad, stressed and ashamed” (p. 100). The images of the diabetic group when compared to those of the control group showed no noteworthy differences. This is in contrast to what Nuvoli et al. (1989) discovered. This may be due to the small sample size in Harriet’s study.

Most of the images by both groups indicated a well-balanced and adaptive nature, indicated by the placement of the drawn figures in the middle of the page. There is no clear explanation in the research paper indicating how this link originated. Two of the participants from the diabetic group had graphic elements that may insinuate a discomfort in relation to their future. This was assessed by Harriet (2000) through the graphic elements of the clothes seeming too small for one participant’s future figure and that for another the redrawn lines of the body’s outline may indicate awkwardness. For one participant there seemed to be a lack of control, which the author determined from the enlarged, hands that were drawn. For another, a realization that the illness can affect many aspects of the body was attributed to the drawing of an enlarged body. Harriet

based these findings on Bennett (1966) and Levy's (1950) theories. However, these are only impressions stated by the author and with such a small sample it was impossible to see any major similarities within the diabetic group.

Murray's (2001) research was exploratory in nature. She utilized the projective tests, draw a self-portrait and an ideal self, along with specific interview questions to identify any common themes, experiences and or difficulties that adolescents living with diabetes may encounter. All six participants were asked to draw a self-portrait and a portrait of an ideal-self. Murray audio taped the interview and analyzed the two drawings (self-portrait and ideal-self) and the interview content.

In the interview all the participants stated that they had difficulties sharing their feelings concerning their illness with others. For this reason most identified a feeling of isolation. Two thirds of the group described engaging in non-compliant behaviors in relation to diabetic treatment. All the participants acknowledged a degree of difficulty in maintaining good control. Half the group mentioned moderate to severe school difficulties and a sense of dependency on others to care for them and help monitor their behavior. Two participants admitted taking advantage of others through their illness. Two also reported dissatisfaction with body image. Murray (2001) used the projective drawings to gain more information from the participants since art making may allow a less guarded response than a verbal one.

From the data collected through her study, Murray (2001) suggested that group art therapy would be a beneficial therapeutic tool for adolescents living with diabetes. She identified several reasons for her rationale. The group format could reduce feelings of isolation by providing a chance to share related concerns, which Malchiodi (1993) and

McGraw (1999) address. As well it provides a forum to share information on diabetes management. Art making is a good outlet for suppressed emotions and offers an opportunity to exercise choices through media and theme selection, which can promote a sense of independence. As stated previously certain professionals have discovered this in their own work with medically ill patients (Baerg, 2003; Council, 1993; Fenton, 2000; Hildebrand, 1999; Malchiodi, 1999; McGraw; Prager, 1995, Zammit, 2001). The art object allows some distancing so that people can discuss the work rather than directly addressing personal issues. Fenton states that distancing permits the client to slowly come to terms with his or her situation. The artwork can help the participant recognize personal strengths and healthier coping strategies. Council has used this with children living with cancer in rehearsing difficult situations they may encounter such as treatment procedures. Lastly art making could be an enjoyable experience offering a distraction from the daily stresses associated with diabetes.

The Study

Purpose

The purpose of this study was to examine the lived experience of adolescents living with diabetes mellitus. Within a group art therapy format, these adolescents explored verbally and graphically their experience of living with diabetes mellitus. The primary question proposed within this study was: ‘through a phenomenological art therapy process, how do adolescents living with diabetes mellitus cope with and emotionally encounter the experience of living with diabetes’?

I became interested in the experience of living with diabetes mellitus because I am living with insulin-dependent diabetes mellitus (also known as Type 1 diabetes). I questioned whether or not others living with diabetes experienced the same or different thoughts and feelings as I, regarding the daily impact diabetes has on one’s life. In addition, I wondered if and how art therapy may assist in this type of investigation in communicating the lived experience of diabetes. I will further explore the personal aspect in the Reflexivity (Epoche) section. I decided a qualitative approach would best suit this type of inquiry and that phenomenology specifically would be an excellent method in acquiring this knowledge because phenomenology asks about the essence of an experience.

Theoretical Overview

The theoretical framework adopted for this study was phenomenological. Phenomenology as developed by Edmund Husserl (1967) emphasizes that a phenomenological investigation focuses on describing an experience by attending to what is present in our awareness. Polkinghorne (1989) mentions that phenomenology supposes

that truth is individual and unique. Phenomena are experienced subjectively and meaning is also attributed subjectively.

Husserl (1967) presents the elements involved in forming meaning. For the purpose of this study five of them will be introduced. First there is *intentionality*, which refers to the relationship, which exists between the “perceiver” and the phenomenon. The second, *directionality*, relates to the specific aspect of the phenomenon that the perceiver selects to focus on and how, for instance, cognitively or emotionally. Directionality, as well, alters as the perceiver’s focus shifts. For example a focus shift pertinent to this study would be discussing how overprotective they felt their parents became due to the diabetes then changing the spotlight on how guilty they felt in making their parents worry. *Temporality* centres on the subjective experience of time and how a phenomenon is experienced on a time continuum. For instance, some participants discussed how they felt when they were first diagnosed, comparing this to how they felt presently and their thoughts for their future. The fourth, *horizon* refers to the context in which the phenomenon is experienced by the perceiver. For example a horizon relevant to this study would be, never knowing what it was like to live without diabetes. Lastly, the *biographical situation* of the perceiver will influence how he or she experiences the phenomenon, such as how old they were when diagnosed, what diagnosis, and familial reactions. To summarize, the perceiver focuses on a specific phenomenon in a certain way that is experienced within a context, which includes both the perceiver’s unique biographical situation and a subjective time component. If one ascribes to Husserl’s ideas on how meaning is formed, and considers Polkinghorne’s (1989) suppositions regarding

phenomenology then one needs to acknowledge that a phenomenon experienced by two different people will likely be perceived uniquely.

The purpose of psychological phenomenology is to collect these varied descriptions of experiencing a particular aspect of human experience and generating clear, accurate and methodical accounts of it (Polkinghorne, 1989). In order to accomplish this, a researcher has a specific procedure to follow. Polkinghorne, as well as Moustakas (1994) state that a critical first step for the researcher is to “bracket” his or her own assumptions, biases and preconceived notions about the phenomenon under investigation. This process is also known as the *epoche*. Creswell (2003) further states that this reflection may be inserted within the study or presented in a separate section either within the description of the researcher’s role or as a summation.

The researcher then collects descriptions of the phenomenon under study from people who are experiencing or have experienced it. The researcher analyzes these descriptions in order to obtain common themes, which emerge from the experience under study, and from there a synthesis of the experience of that phenomenon is developed. Lastly, and this is not done by all researchers, the researcher returns to the co-researchers and verifies whether or not the essence of the experience has been captured by the researcher and if any aspect was neglected. Any alterations are integrated into the final report (Polkinghorne, 1989). Each step is vital in ascertaining a precise understanding of what it is like for a person to experience a specific phenomenon.

The researcher needs to collect a variety of descriptions in order to obtain a full breadth of different experiences in perceiving the phenomenon. This is not for generalizability since the data collected cannot be generalized to the population due to its

underlying belief that truth is individual. However, there will be commonalities of experience. The data collected, therefore, remains the truth until another description contradicts it and or transforms it (Polkinghorne, 1989). Once the researcher has collected from the co-researchers their accounts of experiencing the phenomenon under question analysis of these descriptions begins. In my research, I will utilize Colaizzi's (1973) method of analyzing the data collected. After reading all the interviews, the researcher selects crucial phrases from each interview, which directly relates to the phenomenon under investigation. The researcher then formulates the underlying meanings of these phrases and organizes them into themes. Revisiting the transcripts assists in validating these themes. Integration then follows as individual themes are distilled into common themes for all the co-researchers. This integrative process is further reduced into the essence of the phenomenon. The researcher returns to the co-researchers to verify the findings. I am especially attracted to this final step, which is not practiced by all phenomenologists. I believe this assists in acquiring some method of validity within the findings.

Method

Recruitment

A nurse at a public high school situated in an urban center recruited the adolescents. I met with each interested participant individually before the first group meeting. This was conducted at the high school. At this time I explained the exact nature of the research study and reviewed both the consent information page (see Appendix A) and the consent form (see Appendix B). Participants wishing to participate signed the consent form and the date and time of the first group meeting was communicated. During

this initial meeting I, in addition, asked some initial background information (see Appendix C). I wrote the participants' responses and audio taped this initial interview.

Participants

The four participants were aged between 15 and 17. Three of the four participants were diagnosed with Type 1 diabetes in need of daily insulin injections while one was diagnosed with Type 2 diabetes in need of oral medication. Of the four, three were female and one was male. The initial diagnosis of diabetes mellitus ranged from age two to age fourteen. Attendance ranged from three to five out of six sessions. I selected the pseudonyms to protect participant confidentiality.

| NAME | GENDER | AGE | TYPE | ONSET | SESSIONS |
|-------------|---------------|------------|-------------|--------------|-----------------|
| Max | M | 15 | Type 1 | AGE 2 | 5/6 |
| Samantha | F | 17 | Type 1 | AGE 9 | 4/6 |
| Beth | F | 17 | Type 1 | AGE 14 | 5/6 |
| Annie | F | 15 | Type 2 | AGE 13 | 3/6 |

Session Overview

The group met weekly for six weeks although nine sessions were initially proposed. One was cancelled due to an unscheduled pedagogical day and the two that followed were cancelled due to insufficient attendance. Each session was an hour long and all were audio taped.

The sessions were divided into four distinct sections. The first included a recap of the previous week, which allowed any of the members who did not attend the previous session to contribute their own reflections and as well allowed for verification and

elaboration from those who were present. At this time, another theme was introduced followed by a brief discussion. The adolescents were encouraged to generate their own themes for discussion. When uncertainty arose in initiating themes, I provided suggestions based on themes evident in past research (Beresford, & Sloper, 2003; Daley, 1985; Gillibrand & Flynn, 2001; Harriet, 2000; Murray, 2001; Raghuraman, 2000) and some from my own experiences.

Secondly, art was created around the theme introduced at the beginning of the session. A lot of discussion between members ensued during this art-making phase in relation to diabetes but not necessarily related to the theme. Materials provided included paper, pencils, pencil crayons, markers, oil and chalk pastels, tempera, collage images and materials, scissors and glue. The third phase occurred once everyone finished. Each group member took a turn discussing his or her piece. At this point, the person discussing his or her artwork was at centre stage. Questions and comments from others including myself were generally for clarification or further exploration concerning a remark made about the artwork. The final part was open for any additional comments and cleaning up.

Data Analysis

Each session was audio taped and after each session I would transcribe the tape, writing notes in the margins once the entire session was transcribed. Once the group ended, I reread the transcripts and analyzed them along with the participants' artwork, to identify themes. Within the transcripts, I wrote code words and underlined the relevant phrase or passage, which connected to this code. I then took all these codes and listed them on separate sheets. I created categories that reflected these codes. Twenty categories were initially developed. Transcripts were reread to determine if these categories

reflected the content of the description. The categories were again examined. While some were discarded others were developed further, depending on the amount and quality of verbatim support within the transcripts. Once individual themes were identified, I returned to the transcripts to validate the themes, which were then distilled into common themes for all participants. Finally, I returned to the participants individually to validate the findings (Colaizzi, 1973; Lincoln & Guba, 1985; Whittermore, Chase & Mandle, 2001). This final interview was also audio taped and transcribed. Any discrepancies were discussed and integrated into the findings. Four major themes emerged from this process: Diabetes Management, Interpersonal Aspects, Challenges, and Coping Strategies.

Researcher's Role: Epoche

Epoche is central to a phenomenological investigation so that the researcher's preconceived notions about the phenomenon do not become intermingled with the actual perceptions of the co-researchers' experience of the phenomenon. Moustakas (1994) emphasized the importance of the epoche when conducting phenomenological research, describing the epoche process as one that allows the researcher to become aware of his or her own biases. This in turn fosters an opportunity for the researcher to be receptive to the co-researchers' experience of the phenomenon in question. Moustakas "...see[s] it as a preparation for deriving new knowledge but also as an experience in itself, a process of setting aside predilections, and allowing things, events, and people to enter anew into consciousness, and to look and see them again, as if for the first time" (p.85).

A major role of a phenomenological researcher is to remain open to those perceptions that particularly do not match his or her own. Placing the researcher's biases out in the open assists in this process. The researcher begins the epoche process before interviewing the co-researchers. Moustakas suggests the "bracketing" needs to be an

ongoing process during the research as well. As the researcher listens to the experiences and perspectives of the phenomenon under investigation, described by the co-researchers, he or she remains opened to what is being shared and at the same time maintains an awareness of his or her own reactions to these descriptions. Once alone the researcher needs to document these reactions, such as feelings, sensations, thoughts, and actions, and examine them, teasing out what belongs to the researcher, what belongs to the co-researchers and what prompted the reaction. In so doing, the researcher continues procuring an awareness of his or her biases thus developing an even more open attitude for the subsequent set of descriptions recounted by the co-researchers. Creswell (2003) further sustained that the researcher's transparency is vital in a qualitative study; therefore, making this personal reflection a common characteristic of qualitative research.

My own experience living with Type 1 diabetes was the catalyst for this research study. I became interested in discovering what others living with diabetes mellitus experienced and since I was studying art therapy I wondered how and/or if, art therapy would be a beneficial tool in this exploration.

From the beginning I had strong beliefs, assumptions and biases, about what it is like to live with diabetes and was encouraged by my supervisor and phenomenological literature (Creswell, 2003; Moustakas, 1994; Polkinghorne, 1989) to write about them. As well, I was encouraged to document my reflections after the interviews, sessions and reading of the transcripts and analyzing the artwork. The feelings I experienced and questions, which formulated from this reflective process, I further pursued with my practicum and research supervisors. Some of my feelings included a resurgence of anger as they talked about their own anger with being diagnosed with this chronic illness. I too

felt “why me and what did I do to deserve this”; nonetheless with the common feelings and experiences discussed I also felt a sense of solidarity with the participants. I envied the fact that they stated they were not worried about the possible future health complications associated with diabetes. I carry this concern with me regularly and it’s especially evident when my glucose levels are elevated.

The reasons I selected an adolescent population to work with was that Type 1 diabetes is primarily a childhood chronic illness diagnosed more commonly in children and adolescents rather than adults (Geoffroy & Gonthier, 2003; La Greca & Spetter, 1992). Adolescents are closer in mental capabilities to adults (Piaget, 1967). Also Polkinghorne (1989) mentions that qualitative research places an importance on the co-researchers ability to provide vivid accounts concerning their experience. Secondly, selecting an adolescent population provided me with a structure that offered some objectivity and distancing. By this I mean that since I was diagnosed with Type 1 diabetes mellitus at 30 years of age and that my co-researchers’ were diagnosed within childhood or adolescence, I expected to discover differences in our experience. This in and of itself was an assumption I held. Consequently I was surprised with the similarities, which emerged.

The adolescents were also interested in my experience living with diabetes. All their questions were answered openly and honestly and I think facilitated their own rich and vivid descriptions. I also encouraged that they initiate their own topics. As previously mentioned, if they had difficulty I would suggest topics discussed in previous research or from my own experience. It was interesting to discover that when I did suggest a topic,

they would end up discussing and creating artwork related to another dimension of living with diabetes and this was the lead I followed.

The major differences that emerged between my experience and theirs may actually have more to do with age than any other factor. Within the theme of Interpersonal Aspects, specifically with parents, peers, and school personnel, which will be elaborated on later, were either non-existent or contrary to what I have experienced. However, when it came to discussing their relationship to doctors many of their experiences resonated within me. Specifically, we all felt that the relationship to our doctor was important on both a medical and emotional basis.

With the theme of Challenges, the co-researchers discussed the 'future' and how diabetes has impacted their thoughts about the future. While my thoughts are primarily physically oriented (how will diabetes damage other organs in my body) the group members were concerned about entering the adult medical system (switching doctors), obtaining a drivers license, and travelling. I was also surprised with the similarities specifically with Intrapersonal Coping. The mechanisms deployed by the participants at one time or another reflected my own experience, such as denial and rationalization.

One way to address validity in qualitative research is to return to each member with the findings and verify if these correctly represented their experience. Member checking is one way of establishing validity or trustworthiness within a qualitative study (Colaizzi, 1973; Lincoln & Guba, 1985; Whittermore, et al., 2001). This was done three months after the termination of the group.

Findings

After coding all the transcripts, four major themes emerged: Diabetes Management, Interpersonal Aspects, Challenges and Coping.

The following section describes the participants' experiences in each of these themes. Another way of addressing qualitative validity or trustworthiness is through thick descriptions (Lincoln & Guba, 1987) Therefore, quotes are included throughout so that the voices of the participants are heard. The quotes, which follow, substantiate the themes that were developed, with the most common theme presented first (Diabetes Management) and ending with the least common (Coping). The quotes were either obtained as the group members or myself introduced the theme, as a discussion unfolded between members as they created their art, or as they described their artwork.

Diabetes Management

In the participants' discussions the different facets of diabetes management emerged. This included the responsibility involved in managing their diabetes, the changes that have transpired since their initial diagnosis and their non-compliant behavior and its consequences.

Responsibilities

The participants living with Type 1 diabetes mellitus experienced a great sense of responsibility in managing their diabetes. This encompassed the need to adhere to a strict diet regime, adherence in taking their medication, maintaining a consistent and average blood sugar level, staying active, and recognizing high and low blood sugar levels and how to treat it. As the participants sat around the table to begin their artwork in the third session, Max began discussing the concept of freedom in relation to diabetes and how

becoming responsible in managing your diabetes allows more autonomy. Max used his artwork to emphasize the fact that he was ultimately the one responsible for managing his diabetes (Figures 1 and 2).

Ah the number one means I have to watch out for me and stuff. I can't depend on other people only (pause) because once in awhile I have to if I'm by myself...If I get low then I have to know what to do so I have to bring a snack before I leave and everything like that.

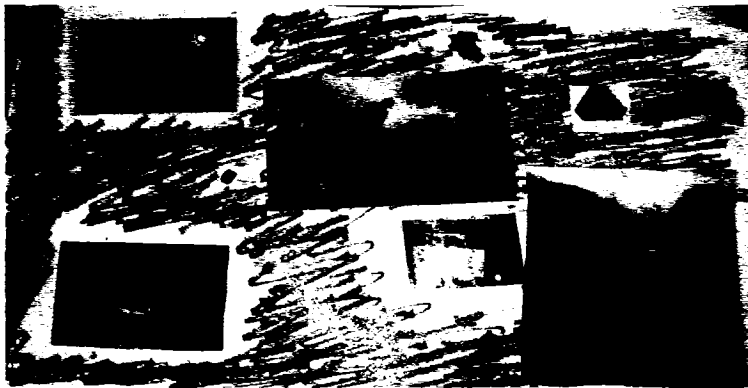


Figure 1: # ONE (On the license plate of red car)



Figure 2: Close-up

Samantha employed her artwork to comment on the importance of knowing oneself in acting responsible in managing diabetes (Figure 3).

'Know yourself' like that you have to know yourself pretty well. Like tell when you're low, you're high, you know you gotta know. You can't just say I think my sugar might be low. You have to know 'cause not everyone has the same, 'cause he says his stomach hurts. My stomach doesn't hurt so I have to know my own body.... 'Learn to teach

yourself' And I have to learn to teach myself to do my insulin all the time and test my sugar all the time.

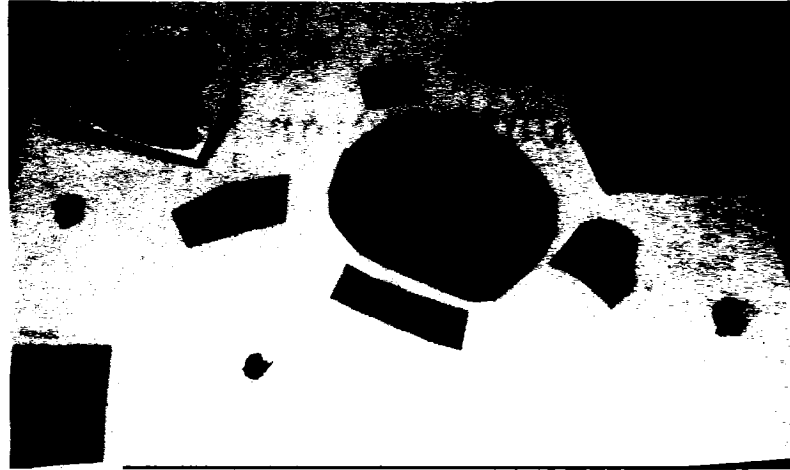


Figure 3: Know yourself....

As participants discussed their significant role in managing their diabetes they recognized how this management has changed since their initial diagnosis and how their non-compliance at times played into this. Annie's experience within this theme differed remarkably from the others due to the fact that she was responsible for taking oral medication in the morning and in the evening. She did not need to follow a diet, take insulin injections nor monitor her glucose levels.

Changes Over Time

Three of the participants noted that changes have transpired since their initial diagnosis and how this has impacted their experience of living with diabetes. These changes included the increase of insulin and injections, the markings on different body parts and the hardening of locations on the body due to use. Samantha mentioned the noticeable effects on her body. "Well I have little scabs from pricking.... My fingers are disgusting. You can see them...see it goes in and it comes out. It's so weird. I have

deformed fingers. I feel like a mutant sometimes”, while Beth introduced the increase of insulin and injections. “I used to be 6 in the morning and now it’s like at 55. I used to be on two needles, just breakfast and supper, and ‘cause I was ‘bad’ they put me on three.”

Non-Compliance

All participants shared that at times they engaged in non-compliant behavior, reflecting their struggle with following the strict management necessary to control diabetes. This ranged from not wearing a medical alert bracelet, not following the diet recommendations, not monitoring their blood sugar levels, to not taking their insulin or oral medication. Annie, for example, had difficulty in consistently taking her oral medication. “Yeah like I can take my pills and then I’ll forget one time and I just keep not doing it. Like if I forget then I won’t think about it and it just keeps happening”.

In her artwork, Samantha addresses her conflict in complying with food restrictions (Figure 3) and taking her medication and then she went on to describe what she did do.

The guy with the fish he looks like he’s stuck like he
doesn’t know what to do ‘cause it’s like in the ice. You
can’t eat it. It’s more metaphorical...he was stuck and I feel
I’m stuck between decisions about my diabetes
sometimes...Do I just, do I eat that extra cookie? Do I, you
know certain things like that is what I like you know do I
do that? Or can I skip it this time? Do I skip the insulin or
can I, you know decisions like that.

I didn't take my sugar I didn't take my insulin. I didn't do nothing. The first time I did it I was like I didn't die so you know obviously its not that bad but I kept doing it more. And after that I was just like where you know I can do it after I eat. Then I'd forget to do it after I eat.

Three of the participants expressed an acknowledgement of their considerable role in managing their diabetes. These same participants also recognized how living with diabetes had altered since their initial diagnosis. The entire group admitted having difficulty adhering to the high demands of self-care in managing their diabetes.

Interpersonal Aspects

All the participants discussed the different relationships in their lives and how living with diabetes had modified these relationships with family, peers, and school personnel and how it introduced new ones; specifically medical personnel.

Familial

There seemed to be an added vigilance on the part of the parents regarding their children who are living with diabetes. Parents seemed to constantly verify if their children were adhering to diabetes management. This seemed to change if they demonstrated that they were responsible. Participants were not only aware of how diabetes had impacted their lives but their families as well.

Beth described how her mother now reacts with her since the diagnosis.

...She freaks out. She's so worried for me...Since I was, she found out I was diabetic every little thing she worries about me. She's nervous when I go out with my friends and

I sleep over and that, she always calls me...did you take your needle? Yep. She'll wake me up. She's like do you need help with the needle, how high, how low, are you feeling well?

Trust seemed to develop once their child could show they were responsible, as Max described through an art piece he created (Figure 4). However the young boy looks angry and there is a combination of infantile stickers and of adolescents or young men (soccer players) possibly referring to Max's struggle for autonomy and uncertainty.

And the referee sort of like my mother always telling me bring a snack with you before you do a sport or take a juice or whatever. Like oh before I was younger I was never allowed to go out at all but I wasn't allowed going out by myself or with my friends and stuff like that. I wasn't allowed to walk to my cousins or anything by myself. My mom's very protective. And now since I showed her, since I know how to test myself now, give myself my insulin, measure and everything, she lets me go.



Figure 4: Mother and son

Although the adolescent living with diabetes is greatly affected by the illness they believe their family is not excluded from the effects of the illness, as Samantha explained in reference to her artwork (Figure 5).

I wrote that my family is affected when I don't take care of myself, like when I went into the hospital it was really my fault that I went into the hospital and my family was really affected by it. I see how upset my mom was and my little brother and my dad and stuff, so it's hard on them too. I'm not alone living with it, you know.

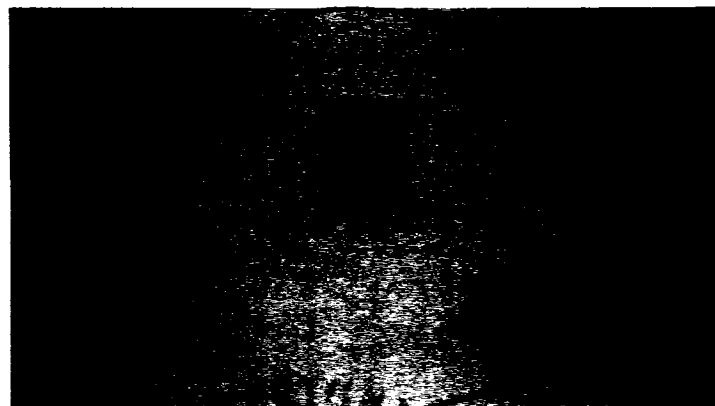


Figure 5: Impact on family

School Personnel and Peers

Certain participants discovered some difficulty in effectively dealing with diabetes within the school, as well as describing some school personnel as unknowledgeable about what it was like to live with diabetes. As the participants shared their personal experiences with school staff, Beth shared an incident with one of her teachers.

That's what I don't like. The school said they'd tell all the teachers. The teachers, Ms. Pelligrino, I don't even like that

because the fact that, she's 'well if you need any juice just tell me and you can go outside and drink it'. Well if I'm having a low I don't want to get up and move around. I want to drink it right there, you know. She's 'well it's so the other kids are going to see and they're going to ask questions why, it's not fair.'

Three of the four participants described their school peers as supportive during a sugar low while simultaneously being treated 'normally'. The other was adamant about not sharing the fact that she was living with Type 2 diabetes with any of her schoolmates.

Sam utilized her art as a catalyst in discussing the supportive nature of her friends at school (Figure 3).

...So the one with the two girls is friends. I mean my friends support me, they understand. They don't bring it up or anything. They know my sugar is low so they're supportive. They know. They always have something for me. They're, you know, take it or do it. They always tell me, sometimes when my sugar goes low I don't know what I'm doing.

Max, in discussing his friends, stressed the importance of normalcy when he was with his peers (Figure 6) writing that 'people forget or don't care if I'm diabetic'.

And the picture below it reminds me of me and my friends.... They make sure I buy the right stuff like snacks ...Seems like a normal person, that's what it looks like down at the bottom just little kids hanging around...it's normal that we're there...They don't care but they do care.... No matter even if I'm diabetic or not my friends or family still stay by me....

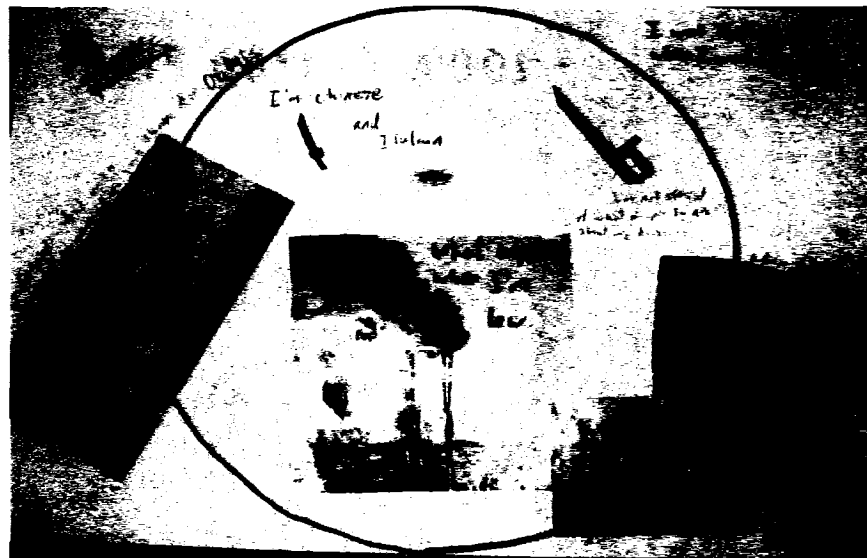


Figure 6: Friends - Normalcy

Annie felt quite differently about having her school peers know about her living with diabetes and this she referred to briefly as she discussed her art piece (Figure 7). "I put the school because none of my friends know that I have diabetes Type 2 except for my friend, which she don't go here."

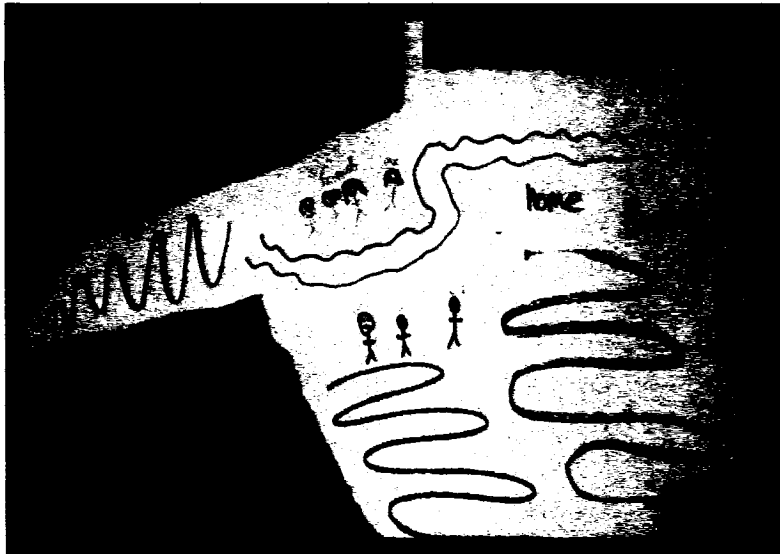


Figure 7: School, peers, family

Medical Relationship

All the participants acknowledged the importance of their relationship with their doctor. They all presented a positive rapport with their doctor yet mentioned the pressure they felt in demonstrating that they have been managing their diabetes consistently and correctly.

Annie shared with the group how she had lost her prescription and how worried she was about her doctor's reaction and relieved with the outcome. Her artwork (Figure 8) also seems like a tribute to her doctor.

She said next time don't worry just call me, leave me a message. She was a little bit upset but she understood. She's a very understanding doctor. She's never been really upset with me (pause). I remember I had a doctor that would get mad at me all the time and I really didn't like that.



Figure 8: Doctor

Beth joined in with a recent account of her experience with her own doctor.

Actually I went to the doctor this week, 'cause I have to go every three months and my doctor didn't know about the second time I went into the hospital. He found out a few days ago and I was so scared when I went to go see him (laughs). I was with my parents. I was 'oh my he's gonna get mad at me' but my hemoglobin was low it was good. He actually 'I guess the second time it helped, it scared you'. Um well, I was happy he was happy because I thought (laughing). Really it was just 'cause I was happy the doctor was happy.

Max referred to how his doctor raised expectations at each appointment and was critical of any oversight from Max, although he acknowledged its value.

Like say he asks me to do something and I do it, he expects a little bit more from me afterwards. It's kind of difficult if I miss a couple of readings. He's always in my face, 'you

should be doing it more often, you shouldn't miss anything'. It's for a good cause so I don't blame him.

All the participants recognized an adjustment in their interpersonal relationships due to living with diabetes, by mentioning an extreme level of parental involvement. School personnel were viewed as not knowledgeable or understanding by two of the participants. Peers were described as supportive and helpful with the exception of one participant who preferred no one at school knowing. All described their relationship with their doctor as positive with a lot of attention placed on managing their diabetes properly.

Challenges

All the participants identified a sense of isolation as a challenge, employing terms such as 'being different' and 'not understood'. Annie stated " I feel different, I just keep to myself about stuff like that". Beth felt that unless you live with it, it's impossible to know her experience. "...[T]hey say they understand but they don't have it so they don't exactly know and no matter how much they say it they don't know 'cause they don't go through it." Samantha added, due to this inability for understanding, there was no point in explaining your actions. "I didn't go on a mission to not do my insulin but that's what they thought I did. But you can't explain this to them 'cause they don't understand'.

Nevertheless, some challenges were different and these were based on how long the participants had the diagnosis, the type of diagnosis and their age. These challenges encompassed injection of needles, food restrictions and the future.

For example, Annie who does not inject herself with insulin or check her hemoglobin on a daily basis described her blood tests as uncomfortable.

Agh, I really don't like it. There's this one time I did it because they can't find the veins 'cause I have small veins so they do it in my hands. And like they take like a vial...like two or three of them and then that's like when I have to fast.... It's when it goes in and comes out. I don't like that feeling. Like the (pause) like a pinch, like a long pinch. A long pinch out and a long pinch in. Ugh.

Samantha identified in her artwork the challenge of avoiding the consumption of certain foods for a person living with diabetes (Figure 9).

The thing temptation I find everyday temptations and it's not usually a temptation to other people but to diabetics its you can't have it and some of those things are like juice. I love it...I love juice and I can't have it.



Figure 9: Temptation...

The older participants seemed preoccupied with additional challenges, those they would encounter in their future. This included switching doctors, obtaining a driver's

license and travelling. Beth addressed, in her artwork, the difficulty she may confront if she decided to travel (Figure 10).

The first one with the girl in the red with the thing,
(suitcase) I was wondering well if I can travel because my
doctor always told me if I ever go on school trips or
whatever I have to let him know. And I always think about
if it was going to be harder for me to travel worse than
other people 'cause the medicine you have to bring.

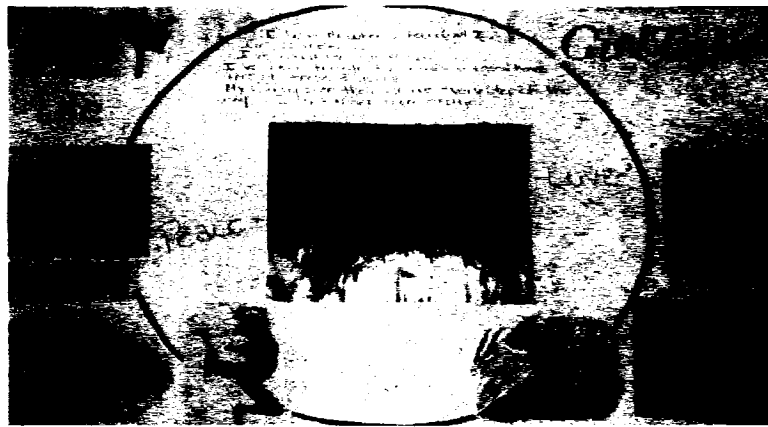


Figure 10: Travelling....

Samantha discussed her apprehension regarding switching to an adult clinic and not seeing the same doctor, which Beth seemed to address through her artwork (Figure 11).

Oh (inaudible) I've known him for so long. We have to
switch soon to go to adult. Oh my God. I don't want to. My
doctor really cares about me. When I go to the hospital he
comes and finds me and talks to me.



Figure 11: Turning 18

In Figure 11 Beth placed the hospital she was being followed at, at one end of the page while drawing turning 18 with the word NEW at the other end. This may represent her apprehension about entering the adult system.

All participants identified isolation as a challenge. The other challenges varied according to onset and type of diabetes and the age of the participants. These included needles, food restrictions, traveling, and switching to an adult clinic.

Coping

Participants utilized different methods of emotionally coping in relation to living with diabetes. These mechanisms ranged from acceptance to denial. Most of them fluctuated between each of the mechanisms. As well, the participants have utilized various coping resources.

Intrapersonal Coping

Before the art making, the members initiated a conversation regarding how they were coping living with diabetes and one member utilized the art to emphasize how she was coping with the situation.

Acceptance.

Max described a sense of acceptance and complete integration in living with diabetes although his artwork from two different sessions seems to contradict this (Figures 4 and 6).

Yeah...it doesn't really bother me at all. I've never thought of me not being diabetic.... I'm not afraid of myself having diabetes and what people think of it. If they say okay you have diabetes and they make a big deal out of it I just go along yeah okay. I don't really care....

In Figure 4 Max selected an image of an angry boy perhaps reflecting that at times living with diabetes stirs up anger. In Figure 6 Max identified himself as the young man in the wheelchair. Although he mentioned the importance of 'normalcy', the young man's disability is visible and cannot be hidden. Max may unconsciously feel that sometimes living with diabetes interferes with 'normalcy'.

Rationalization.

Beth reasoned that others had worse illnesses to deal with and justified that living with diabetes was not all that bad considering what else is out there.

Well this year I started actually accepting it, you know. I have to live with it. The first two years were horrible. Having to realize that I have to do this. I have to accept it. I can't ignore it and I have to be happy that I am still alive like some people are in the hospital with cancer.

Anger.

Samantha responded that she had once felt the same as Beth but that anger had replaced these sentiments.

Yeah, I used to accept it but I think its gotten worse since I got older where it usually gets better but, or I feel...get mad that I have it. Why? Why to we have to have it? When I was little I used to say why do I have to have it? What did I do wrong, you know?

Denial.

Samantha's artwork (Figure 5) done within the same session, addressed her desire to deny living with diabetes altogether, as though she wished to escape from it.

The picture of the birds, I feel sometimes I just want to fly away I guess. Yeah, like sometimes, I don't know, birds look so carefree and they have nothing to worry about, and I just wish I could fly away sometimes. So when things get hard it's not some solution but I don't know it would just be easy.... The one hanging feels I'm just there and sometimes I just want to let go of the diabetes sort of thing...I don't know if that makes sense. It's kind of like the ropes are the diabetes and I want to let go.

Interpersonal Coping - Resources

The coping resources identified by the participants included Diabetes camp, family members, friends and the group.

Samantha recommended attending the Diabetes camp, which she has attended since the age of nine and described as extremely beneficial.

I was nine when diagnosed. I've been going to camp ever since then and it's helped me a lot. I find diabetes, like everyone is diabetic and you don't have to be the outsider, kind of, I guess. When you're at camp everyone's the same. You're more carefree, I find, more carefree. I was diagnosed in May and I went in June. It's two-week sessions, but when I was younger I went for two weeks and I started going the whole summer. Last year I was there for six weeks. And I have a lot of friends that I still talk to, really good friends with at camp.

Max described how his family has been a helpful resource with his own experience in living with diabetes.

My uncle too because he has well he's Type 2.... I also speak to my aunt 'cause when she was pregnant with my cousin, she had diabetes also (inaudible). And so I got two different diabetics. So they have different things that come out of them...Also my grandmother she makes these special soups like these Chinese broths. So I drink it. It's that so it steadies my blood for some reason and it's, ugh, good for me.

Beth explained the reasons the art therapy group was more resourceful for her than discussing her experience with the professionals at the hospital.

I didn't want to talk about it so the second time I was okay
God (laughs) she's coming back again. I'm no. I talk about
it at school and she's do you want um we can get you
people in the hospital who are diabetic if you need to talk.
I'm, I don't know them at least the people at school I know
so I'll talk to them.

Two types of coping were identified: intrapersonal and interpersonal. Intrapersonal coping implicated emotion-focused strategies, for instance denial and anger while intrapersonal coping related to the resources utilized and identified by the participants as helpful in living with diabetes, such as a supportive family and diabetes camp.

In brief, the results indicated that four major themes emerged: Diabetes Management, Interpersonal Aspects, Challenges and Coping. In addition, each major theme had different subcategories surface. Diabetes Management included responsibilities, changes since initial diagnosis, and non-compliant behavior. Interpersonal Aspects consisted of family, friends, school personnel and medical professionals. Challenges encompassed feelings of isolation, food restrictions, testing, traveling, and entering the adult medical system. Lastly, coping contained both intrapersonal strategies such as acceptance and rationalization and interpersonal strategies such as seeking support from family members, peers and groups. Both the opportunity for verbal exchange within the group and art making seemed to facilitate an honest and

transparent exchange about what it is like for an adolescent to cope with and emotionally encounter the experience of living with diabetes.

Discussion

The objective of this project was to attend to adolescents' experiences of living with diabetes mellitus. Utilizing a phenomenological approach, a group of four adolescents explored their experience of living with diabetes, verbally and graphically, within an art therapy format over a six-week period.

The primary research question was:

- ◇ Through a phenomenological art therapy process, how do adolescents living with diabetes mellitus cope and emotionally encounter the experience of living with diabetes?

Qualitative analysis of the verbatim transcripts generated the following four major themes: Diabetes Management, Interpersonal Aspects, Challenges and Coping Strategies. Phenomenology involves capturing the essence of the phenomenon under investigation (Polkinghorne, 1989). In this study, the four themes were further reduced to the essence of *diabetes mellitus requires a high level of self-care, which introduces interpersonal and intrapersonal challenges, which induces both healthy and unhealthy coping mechanisms.*

This essence was determined by reviewing the quotes supporting each theme as well as the artwork relating to the themes. Key words and ideas that were utilized frequently by the participants were identified such as, lots of responsibility, guilt making parents worry, not feeling understood or forgetting medication. From here a phrase was developed to encapsulate the fundamental meaning of these four adolescents' experiences of living with diabetes mellitus. In the following discussion, past research is utilized to explore both the themes, which emerged and the participants' artwork.

Diabetes Management

In living with diabetes mellitus, much of the responsibility for care falls on the individual living with the diagnosis, (Geoffroy & Gonthier, 2003; Gillibrand & Flynn, 2001; La Greca & Spetter, 1992; Maes, et al., 1996) as it infiltrates all aspects of daily life (Wysocki, et al., 2003). This becomes more evident as they become older (Geoffroy & Gonthier). Within this theme, three secondary themes emerged: a sense of responsibility, changes, and non-compliance.

Responsibilities

- ◇ The participants described, and the artwork supported, the feeling that they were the primary caretakers of their illness. They needed to be prepared and know themselves explicitly in order to be able to take care of the demands associated in maintaining good control over their diabetes. This was only prevalent for those with Type 1 diabetes. Councill (1993), Malchiodi, (1999), McGraw, (1999) and Prager (1995) discuss how art therapy can depict the psyche's response to an illness and situation that he or she is experiencing. In Samantha's artwork (Figure 3) she illustrates the importance of knowing yourself and learning in order to manage diabetes effectively.

Changes Over Time

- ◇ There was recognition for those with Type 1 diabetes that its management causes physical changes to their bodies and that their bodies' requirements alter as well. Borrow & Wood (1982) also found in graphic representations created by those living with diabetes damaged organs and needle marks, while Harriet's (2000) impression of one of her participants was her awareness that

the illness can affect many aspects of the body. Although none of the participants in this study drew themselves with damaged body parts, Max identified himself as the individual in the wheelchair (Figure 5). Connecting himself with someone in a wheelchair may indicate an unconscious awareness that damage to vital organs may eventually occur, which may be too difficult to verbalize. Art therapy can make the unconscious conscious (Furth 2002) and the art piece can provide distancing until the individual is prepared to confront the subject (Bayley, 2002; Furth; Zammit, 2001).

- ◇ There is also a sense that if they managed the diabetes more effectively some of these changes could have been avoided. This concept of effective management may be related to the high demand of self-care (Geoffroy & Gonthier, 2003; Gillibrand & Flynn, 2001; La Greca & Spetter, 1992; Maes et al., 1996; Wysocki et al., 2003).

Non-Compliance

- ◇ The necessity for being conscientious in managing diabetes created conflict within all the members, each struggling with giving into temptation or not complying with the procedures involved in diabetes management. There is literature that addresses the difficulty in complying with the demands of living with diabetes (Daley, 1985; Geoffroy & Gonthier, 2003; Maes et al., 1996; Murray, 2001; Raghuraman, 2000). Anderson, Brackett, Ho, and Laffel (1999) and La Greca and Spetter (1992) mention how adolescents living with Type 1 diabetes have a difficult time maintaining effective glucose control. Geoffroy and Gonthier state that non compliant behavior may be a means for

an adolescent to exert his or her independence over the parents. As well, Erikson (1968) mentions the idea that adolescents do not easily accept difference. La Greca and Spetter, along with Wysocki et al., (2003) found that in order to fit the model of their peers they may deny living with diabetes by avoiding its management thus becoming accepted by their peers. As we saw in Sam's image (Figure 5) she wishes she could be a bird and fly away to escape her diabetes or just let go of it like the person on the rope. Murray's (2001) research also found that two thirds of the author's six participants engaged in non-compliant behavior. All the participants in the present study mentioned the importance of friends and included graphic images of friends (Figures 3, 6, 7, and 10). Participating in social functions with peers may be at the cost of competent diabetes management.

Interpersonal Aspects

Being diagnosed with a chronic illness such as diabetes alters the relationship dynamics between the individuals living with diabetes mellitus and the significant people in their lives. Likewise, new relationships are created within the medical community.

Familial

- ◇ The adolescents related that their parents played an active role in their physical well being, due to the diabetes. This may be due to the fact that as Geoffroy and Gonthier (2003) remark parents become the centre of their child's health care. Parental involvement, however, may cause conflict (Anderson et al., 1999) especially if perceived by the adolescent as intrusive and or condemning (Weinger et al. 2001). The participants described their

parents, as over protective and concerned, constantly monitoring their correct management of diabetes. This was evident in some of the artwork (Figures 4, 5, and 9).

Max (Figure 4) compared his mother to a referee overseeing his management of diabetes. Below there is an image of an angry boy; perhaps as a reaction to his mother's monitoring. In Sam's artwork (Figure 5) she wrote next to an image she identified as her mother, "people don't understand when you try to explain it" and in Figure 9 we see a child walking away perhaps upset under the pointing finger, of an adult, as if being punished. As Zammit (2001) describes the art object allows one to acknowledge the presence of repressed feelings. At its simplest form art therapy can act as a communicative device (Bach 1975, 1990). Giving these adolescents the opportunity to communicate these feelings repressed or not provides an outlet for something that may be difficult to mention to people in question, in this case, family.

- ◇ There was mention that the illness further impacts the entire family not just the one living with it and that mismanagement is not a solitary consequence. Geoffroy and Gonthier (2003) support this as they describe how the child may feel responsible for his or her parent's feelings of worry and sadness. Sam's artwork addressed this (Figure 5). This art piece became a catalyst for her to discuss the guilt she felt over worrying her parents especially when she did not take care of herself. Baerg (2003), Councill (1993), Fenton (2000), Hildebrand (1999) and Zammit (2001) concur that art therapy allows an

opportunity for the non-verbal to be expressed, which may be extremely painful to discuss.

- ◇ Some of the participants stated that when they prove themselves responsible, parents give them more autonomy. In Weinger's et al. (2001) study there was minimal discussion regarding parental support. Nonetheless, it was mentioned that many years of living with diabetes might have led to parents' grasp of the complexities associated with diabetes consequently leading to a supportive role from the parents.
- ◇ All four participants had family members in their images as both supportive and non-supportive (Figures 4, 5, 7, 9 and 10) possibly denoting the critical role family plays in their lives.

School Personnel and Peers

- ◇ Some complained about the lack of informed teachers regarding their condition as well as a lack of comprehension from those who were informed. The implication, cooperation and comprehension from school personnel at all levels is essential since immediate treatment is necessary during a hypoglycemic episode (drop in blood sugar) whether in class, hallway or school yard (Geoffroy & Gonthier, 2003; Wysocki et al., 2003). Annie preferred that the school remained uninformed and she illustrates this in her artwork (Figure 7). Her school is drawn on the top right side and there are lines dividing the upper and lower parts of the image. In the lower part, she wrote the words home and freedom. This may be indicative that at home she is free to be herself but at school she cannot.

- ◇ Annie also addressed in this image her feelings concerning her peers knowing that she is living with diabetes. She separated her peers from the word freedom by drawing many lines between the two. In addition, all three friends have orange hair and she has brown hair perhaps indicating that she feels different and she may feel telling her peers may accentuate this difference. This is contrary to what the other three participants stated. They reinforced the importance of a balance between being treated like everyone else by their peers but simultaneously acknowledging the importance of having friends know what to do if something goes wrong. These two qualities signified a supportive peer relationship. Erikson (1968) stated a primary concern for adolescents is how their peers perceive them. To be living with a chronic illness during this stage may pose additional challenges. Adolescents want to be accepted by their peers, therefore being perceived as similar by them is essential (La Greca & Spetter, 1992). Max addressed this in the bottom right side of his image (Figure 5). A few friends sitting together in a library represented for him normalcy, which was important for all the participants. Peer relations according to Wysocki et al. (2003) can be either an impediment to appropriate diabetes care or a source of support.

Medical Relationship

- ◇ The group described the need for their doctors to be concerned for their health as well as understanding from them when they 'failed' to meet their expectations. There seems to be a sense of pressure to adhere to proper glucose levels and diabetes management and a mixture of fear and guilt when

they do not. This may be in part due to the emphasis placed on education by the medical professional (Grey et al, 1998). Toombs (1992) clearly identifies the need for the physician to understand implicitly and explicitly what it is like for the 'patient' living with an 'illness'. This is imperative in order to maintain a therapeutic relationship that can assist in this case the adolescent in accepting and managing the illness. As much as the parents are implicated in the treatment, this medical relationship is as much an imperative part of treatment. Nonetheless each member described a positive rapport between themselves and their physician a majority of the time. Annie's image (Figure 8) may be viewed as paying homage to her doctor. These findings are contrary to Beresford and Sloper's (2003) study, which found that adolescents believe their doctors do not look beyond the diagnosis, sensing that the impact of living with a chronic illness on a daily basis cannot be broached with doctors. The adolescents involved in that study, however, were living with a variety of chronic illnesses such as cystic fibrosis, epilepsy, and diabetes, which may be a reason for this contrast.

Challenges

- ◇ Each participant clearly identified feeling distinct and expressed a lack of comprehension from those not living with diabetes. Geoffroy and Gonthier (2003), Murray (2001) and Schur et al. (1999) address that adolescents living with diabetes feel different from their healthy peers which in turn may create a state of isolation. Sam (Figure 5) and Max (Figure 6) seem to explore this aspect of living with diabetes. Max identifies himself as the person in the

wheelchair clearly different from the person reading next to him. Sam in her image states that others do not understand what it is like to live with diabetes. She selected an image of a sole person hanging precariously from a cliff probably representing her solitude and the challenge she experiences living with diabetes. The use of images allows someone to express something that possibly words cannot (Baerg, 2003; Councill, 1993; Fenton, 2000; Hildebrand, 1999; Zammit, 2001) and in a more pointed manner.

- ◇ Some challenges varied according to onset and type of diagnosis and present age. For Annie, who was diagnosed two years ago, the challenge involved becoming accustomed to needles. This may be even more challenging because unlike Type 1 diabetes where needles are a daily fact, Annie, living with Type 2 diabetes, is only exposed to needles every few months for a blood test.
- ◇ With the exception of Annie, the others discussed the need to avoid certain foods that to those living without diabetes take for granted, as seen in an image created by Sam (Figure 9). Drawn are chocolate, cookies, candy and cake, which may be classified as unhealthy snacks. Juice is included as well, which is considered healthy, but something to be consumed in moderation or during hypoglycemic episodes by those living with diabetes.
- ◇ The older participants, Sam and Beth, described obtaining a driver's license, travelling and entering the adult medical system as huge concerns that they would soon have to face. Geoffroy and Gonthier (2003) examine each of these challenges. Obtaining a driver's license can be perceived as symbolic of becoming an adult. For someone living with diabetes, the restrictions are

many and good consistent control of glucose levels needs to be demonstrated. Sam seemed to indicate in her image (Figure 9) that she did not want to wait for all the testing and monitoring to be complete in order for her to obtain her license. She seemed aware of the challenge she would encounter especially in view that metabolic control is a formidable task for adolescents (Anderson et al., 1999). Travelling as well becomes challenging. Many steps need to be followed before departure involving a great deal of preparation. This includes seeing your health professionals, bringing all the medical equipment and enough medication for the trip and protecting it from heat or cold as well as maintaining a regular routine while travelling. Beth picked an image of a girl with a suitcase (Figure 10) which provided a starting point from which she could discuss her fears regarding travelling now that she is living with diabetes. Lastly, leaving the pediatric system, particularly a doctor with whom you have developed a positive rapport with over the years, may be deemed frightening and overwhelming. In Beth's drawing (Figure 11), she touches this topic by depicting the hospital in one corner and the age of 18 and the word NEW at the opposite end. Art making may have provided Max, Sam and Beth with the distancing (Bayly, 2002; Furth, 2002; Zammit, 2001) necessary to express and explore these challenges.

Coping

Each member found and named internal and external methods of coping in living with diabetes mellitus.

Intrapersonal Coping

- ◇ These emotion-focused coping strategies included acceptance, rationalization, anger and denial. A majority of the participants fluctuated between them. Grey et al. (1998) stated that due in part to adolescent's coping styles they are more susceptible to poor glucose control, hospitalizations and eventually long term complications. Coping utilizing mechanisms such as rationalization, anger and denial may contribute to non-compliant behavior and poor glucose control. Schur et al. (1999) found that the participants in their study ranged in what they identified as adaptive denial. For some this helped manage their fears while for others it helped develop an identity free of the illness. In Sam's image (Figure 9) she described the top right cut out as the parts of her life that had nothing to do with diabetes. This image occupies a small portion of the entire page but it may still be important that she maintains this distinction which in turn may effect her diabetes management considering she has completely stopped taking her insulin at times. Denial is more evidently expressed in Sam's discussion regarding Figure 5. She compared the ropes to living with diabetes and that she wished she could let go or fly away and escape like birds do. Beth utilized rationalizations or what Schur et al. referred to as downward comparisons such as 'it could be worse, I could have cancer'. Sam stated that she once felt like Beth but as she became older it worsened. This may be associated with the stress of being an adolescent. Seiffge-Krenke and Stemmer (2003) found in their study that adolescents living with diabetes with both good and poor glucose control identified peer relations as a high

source of stress. As Sam entered adolescence perhaps living with a chronic illness produced feelings of anger within her. Max, on the other hand, stated that he accepted living with diabetes. This may be related to an active coping style such as discussing feelings and problems with others that are supportive since Max revealed he did with various family members. This can additionally be associated with what Schur et al. identified as externalizing the problem indicating that the problem stemmed from others. This lessens anxiety if his or her peers are not accepting. Max stated that he accepted being diabetic and that if others made a big deal about it, it was their problem. In Max's image (Figure 6) it seems that he recognizes a difference since he identified himself as the person in the wheelchair. At the same time he wants to be accepted and viewed like his peers; denying a difference exists as seen with the kids sitting together in the library.

Interpersonal Coping

- ◇ All participants identified a variety of external methods of coping. These included family members and friends. Some mentioned the group and one praised the Diabetes camp she attended each summer since her diagnosis. Examining the coping resources utilized by the participants it seems to have helped Max to have family members who could relate to his condition. Wysocki et al. (2003) remarked that social support, provided by family members, can have a positive effect in the adaptation process of living with diabetes; while Maes et al. (1996) stressed that lack of social support may have a negative impact on how the demands of an illness are coped with.

- ◇ For Sam, Diabetes camp was extremely helpful to her since her initial diagnosis and continued to be a source of support each summer. Diabetes camp according to Wysocki et al. (2003) has demonstrated as having a positive increase in “psychosocial functioning” (p. 306).
- ◇ Three of the four participants mentioned the positive feelings they had about participating in the art group. Daley (1985) and Schur et al. (1999) refer to the benefits of sharing with other adolescents living with diabetes. Group art therapy can reduce feelings of isolation (Daley, 1985), provide a sanctuary (Prager, 1995) for those who have an illness and provide a supportive environment (Malchiodi, 1993; McGraw, 1999); therefore a place where everyone is alike and no judgements will be made.

Limitations

This study has methodological limitations, which need to be addressed. The sample size was small and there was a combination of participants living with both Type 1 and Type 2 diabetes. Most of the research available on adolescents living with diabetes focuses on those living with Type 1 diabetes mellitus.

The participants were primarily female in this study. A larger sample with a more proportionate number of males and females may demonstrate if there are any distinctions between the two genders living with diabetes that are noteworthy.

The study was phenomenological in nature. As Polkinghorne (1989) states a basic tenet of phenomenology is that truth is individual and thus people attribute meaning to an experience in a subjective manner and that these attributions remain the truth until it is changed or overthrown by others truths. In summation the findings in this current study

may be different with another sample. For the reasons listed above generalizability cannot be achieved.

Areas for Further Research

It would be interesting to conduct two different studies each with a larger sample size. Each group could focus on a different type of diabetes mellitus especially since Type 2 diabetes is increasing within the adolescent population (Alberti et al., 2004; Wysocki et al. 2003).

A pilot project could be developed in conjunction with the child and adolescent diabetes medical team. It would be important that this program be facilitated away from the hospital or clinical setting because as Daley (1985) mentions there is much tension related to medical professionals. Beth echoed a similar sentiment saying that she preferred discussing her difficulties in the art therapy group at school than with anyone at the hospital. Daley also mentioned that regular counseling groups with adolescents living with diabetes have a high failure rate. Art therapy may be viewed as less threatening and more fun to engage in.

This pilot group art therapy program can focus on assisting adolescents in developing coping strategies that can aid in attaining better metabolic control and reinforce compliant behavior. Art therapy can assist in gaining a better understanding about what how an illness can impact us and with enlightenment an opportunity is afforded to change (Zammit, 2001). Art making can provide adolescents living with diabetes with an opportunity to express difficult and conflicting emotions (Baerg, 2003; Councill, 1993; Fenton, 2000; Hildebrand, 1999; Zammit). Since art making allows the unconscious to become conscious (Furth, 2002) the art therapist can identify what the

psyche's response is to the participants' circumstances (Council; Malchiodi, 1999; McGraw, 1999; Prager, 1999). This can facilitate the process of exploring through art making how adolescents feel helping them integrate these feelings and assist them in developing coping strategies to effectively encounter feelings and or circumstances that they may find troublesome. This may in turn have a positive impact on how they confront the challenges and responsibilities of living with diabetes.

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Appendix A

Consent Information Letter

Art therapy and the lived experience of diabetes

Art Therapy Student: Sylvie Linhares
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Department of Creative Arts Therapies
1455 de Maisonneuve Blvd. W. S-VA 264
Montreal, Quebec H3G 1M8
514 595-2050

Research Supervisor(s): Suzanne Lister, Assistant Professor, Concordia University
514 848-2424 ext. 4799

PURPOSE

In considerable research on diabetes, adolescents' expressions of their subjective experience of living with diabetes have been neglected. To address this inattention, this study will facilitate expression of participants' experiences of living with diabetes through art making and discussion. The artwork of participants and what they say about its relationship to their lives will be used to identify and relate themes emerging from these accounts and contribute to the existing research literature.

These sessions are not educational with respect to medical treatments for diabetes nor are they psychotherapeutic. They are a chance for participants to explore their own coping and emotional experiences together in a supportive environment.

PROCEDURES

The researcher will lead between eight to ten successive weekly art-making sessions, each lasting 1 hour. Participants will be invited to share their experiences of living with diabetes and how it impacts on their daily lives through both art making and open discussion.

Before the sessions begin, each participant will be asked to take part in an individual interview with the researcher to determine whether such art making sessions would be favorable for the participant and to gather background information. This interview will last approximately 30 minutes. Participants will be asked to commit to attending all the sessions and a follow-up interview, and to let the researcher know in advance of any absences, when possible. During the last session each participant will receive a \$10.00 HMV gift certificate.

All the sessions will be audio taped and the artwork photographed. Agreement to be audiotaped is a condition of participation in this research study. Audiotaping ensures that the researcher accurately hears what the participant says. Consent is requested from participants for the photography of their artwork for future educational presentation and publication.

Participants' confidentiality will be respected in every way possible. Names and identifying information will be kept locked and separated from the audiotapes and artwork. Only the researcher will hear the tapes of the sessions. A transcript of selected portions, with pseudonyms for participants, may be shared with the research advisor. Participants may withdraw their consent to participate in the study at any time, without giving a reason, by phoning the researcher at the telephone number above. Furthermore, they may remain in the group if they wish.

Approximately one month after the end of the sessions, each participant will be asked to participate in another individual interview with the researcher. The intent is to offer each participant an opportunity to discuss her or his experience of the group. This will be audiotaped as well. In addition, the researcher will present the participant with a summary of primary themes she has observed in the participant's artwork and contributions to the group for verification.

The researcher will keep the artwork for the duration of the sessions, after which it will be returned to the participants. The audiotapes will be destroyed once the research paper has been submitted to Concordia's Graduate Studies.

The final research paper will include narrative accounts of the sessions describing aspects of participants' experiences using pseudonyms, in keeping with the respect for confidentiality described above. Bound copies of the paper will be kept in the Program's Resource Room and in the Concordia University Library.

RISKS

To the researcher's knowledge, participation in this group holds no risks for participants however certain persons may experience uncomfortable feelings or reactions because of the personal nature of this exploration. If a participant finds that these feelings continue, the researcher will be available to discuss these concerns and provide a referral, if needed, in consultation with a relevant professional.

BENEFITS

The goal of these sessions is to provide a supportive group environment in which participants can make images and discuss their experiences about living with diabetes. This may help participants both accept and understand their feelings and learn more about their and other's experiences of living with diabetes. Through this shared experience in this study, participants can feel they are contributing to increasing the knowledge about living with insulin-dependent diabetes. If you have any question regarding this research study, please call the student or supervisor listed above.

If at any time you have questions regarding your rights as a research participant, you may call Adela Reid, Compliance Officer, in the Office of Research.

Adela Reid, Compliance Officer

Office of Research, GM-1000, Concordia University, Montreal, Quebec H3G 1M8

Phone: 514-848-7481

Email: adela.reid@concordia.ca

Appendix B

Consent Form to Participate in Research

Art therapy and the lived experience of diabetes

Art Therapy Student: Sylvie Linhares
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Department of Creative Arts Therapies
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Montreal, Quebec H3G 1M8
514-412-4400 extension 22210

Research Supervisor(s): Suzanne Lister, Assistant Professor, Concordia University
514 848-2424 ext. 4799

I agree to participate in the research study conducted by Sylvie Linhares, entitled *Art therapy and the lived experience of diabetes*, as part of her Master's studies in the Creative Arts Therapies Program at Concordia University.

I have carefully read and understand the consent information about the above study. Its purpose and nature have been explained to me. I have had the opportunity to ask questions about it, and I am satisfied with the answers I have received.

I understand that I will participate in eight to ten weekly, 1 hour session, during which I will have the opportunity to make images about and discuss my experience of and feelings about living with diabetes. Another 30-minute individual interview with the researcher will take place approximately 1 month after the end of the sessions in which I will be given an opportunity to respond to the researcher's summary of my artwork and contributions to the group. I can discuss my experience of the sessions and ask any further questions I may have regarding the research project.

I understand that my identity will be kept confidential, and I agree to protect the confidentiality of the other participants by not mentioning their names, the experiences they have shared, or their artwork to persons outside the group.

I understand that the sessions will be audiotaped. No one except the student researcher will listen to these tapes, although the student's advisor may read transcripts of sessions with participants identified through pseudonyms. The audiotapes and the artwork will be stored separately and locked without any identifying information

attached. The final research paper will include verbatim quotes and narrative accounts of the sessions, describing aspects of participants' experience, with identities kept confidential. Photographs of my artwork describing my experience living with diabetes will be used but my name will not be disclosed in the research paper, or in any future presentations or publication of the research. I understand that at the end of the project, my artwork will be returned to me and once the research report is written and submitted to Graduate Studies the audiotapes will be destroyed.

I understand that I have the right to withdraw my consent at any time. I understand the purpose of this study and that there is no hidden motive of which I have not been informed.

I understand that copies of the research paper will be bound and kept in the Creative Arts Therapies' Resource Room at Concordia University and in the Concordia University Library.

I HAVE CAREFULLY READ THE ABOVE AND THE INFORMATION LETTER AND UNDERSTAND THIS AGREEMENT. I FREELY CONSENT AND VOLUNTARILY AGREE TO PARTICPATE IN THIS STUDY.

___ In addition, I authorize Sylvie Linhares to photograph my artwork under the conditions of confidentiality outlined above.

Name (please print) _____

Signature: _____

Witness Signature: _____

Date: _____

Appendix C

NAME:

GENDER:

AGE:

ETHNIC/CULTURAL BACKGROUND:

ONSET OF DIAGNOSIS:

TYPE OF DIABETES:

ANY FAMILY MEMBERS WITH DIABETES:

YES NO

FAMILY MEMBER:

TYPE:

HOW LONG:

PLEASE FEEL FREE TO EXPAND OR ADD TO ANYTHING THAT YOU FEEL WOULD BE IMPORTANT TO IMPART?

What were your thoughts and feelings when you were first diagnosed with diabetes?

What was your family's reaction?

Growing up living with diabetes how was it for you at home?

-at school?

-with friends?

How has it affected your relationship to your family?

-peers/friends?

-school personnel?

What is your relationship with your Doctor and/or medical team?

What is most difficult about living with diabetes for you at the present time?

What kind of issues/themes would you like to have discussed in a group for adolescents living with diabetes?