A phenomenological inquiry into elementary teacher wellness: Experiences with students who are living with congenital heart disease

by

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Abstract

The literature suggests that students with chronic illness have different needs within the school system than their typically developing peers. However, research has not adequately investigated how teachers feel about their experiences when teaching a student with chronic illness. This phenomenologically informed project explores teachers' experiences when teaching a student with a congenital heart disease and how this may affect teacher wellness. The participants include six elementary educators who are currently teachers or who have taught a student with congenital heart disease and who reside in Western Canada. All data were gathered by employing semi-structured interviews. Interviews were transcribed and analyzed according to phenomenological procedures seeking the essence of teacher experiences when teaching a student with congenital heart disease. Findings indicated that the participants felt that due to teaching a student with congenital heart disease, their experience and role as a teacher changed.

Supervisor: Dr. J. Roberts (Department of Educational Psychology and Leadership Studies)
# Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Title Page</td>
<td>i</td>
</tr>
<tr>
<td>Abstract</td>
<td>ii</td>
</tr>
<tr>
<td>Table of Contents</td>
<td>iii</td>
</tr>
<tr>
<td>List of Table</td>
<td>viii</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td>ix</td>
</tr>
<tr>
<td>Dedication</td>
<td>x</td>
</tr>
<tr>
<td>Chapter One: Introduction</td>
<td>1</td>
</tr>
<tr>
<td>Statement of the Problem</td>
<td>3</td>
</tr>
<tr>
<td>Purpose of the Study</td>
<td>3</td>
</tr>
<tr>
<td>Definitions of Terms</td>
<td>3</td>
</tr>
<tr>
<td>Boundaries of the Study</td>
<td>4</td>
</tr>
<tr>
<td>Summary</td>
<td>5</td>
</tr>
<tr>
<td>Chapter Two: Literature Review</td>
<td>6</td>
</tr>
<tr>
<td>Chronic Illness</td>
<td>6</td>
</tr>
<tr>
<td>Congenital Heart Disease</td>
<td>7</td>
</tr>
<tr>
<td>Developmental Stages and Congenital Heart Disease</td>
<td>9</td>
</tr>
<tr>
<td>Pre-school</td>
<td>9</td>
</tr>
<tr>
<td>School Age</td>
<td>9</td>
</tr>
<tr>
<td>Adolescence</td>
<td>10</td>
</tr>
<tr>
<td>Importance of Normalcy</td>
<td>11</td>
</tr>
<tr>
<td>Teachers Experiences</td>
<td>12</td>
</tr>
<tr>
<td>Teachers’ knowledge on chronic illness</td>
<td>12</td>
</tr>
<tr>
<td>Topic</td>
<td>Page</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>------</td>
</tr>
<tr>
<td>Discipline and academics</td>
<td>15</td>
</tr>
<tr>
<td>Peer interaction</td>
<td>16</td>
</tr>
<tr>
<td>Personal impact on the teacher</td>
<td>18</td>
</tr>
<tr>
<td>Suggestions to Support Teachers</td>
<td>18</td>
</tr>
<tr>
<td>Wellness</td>
<td>19</td>
</tr>
<tr>
<td>Teacher impact</td>
<td>19</td>
</tr>
<tr>
<td>Wellness and Congenital Heart Disease</td>
<td>20</td>
</tr>
<tr>
<td>Wellness within schools</td>
<td>20</td>
</tr>
<tr>
<td>Wellness Model</td>
<td>21</td>
</tr>
<tr>
<td>Defining teacher wellness</td>
<td>21</td>
</tr>
<tr>
<td>The Ardell Wellness Model</td>
<td>22</td>
</tr>
<tr>
<td>Mental domain</td>
<td>23</td>
</tr>
<tr>
<td>Meaning and Purpose Domain</td>
<td>23</td>
</tr>
<tr>
<td>Physical Domain</td>
<td>24</td>
</tr>
<tr>
<td>Summary</td>
<td>25</td>
</tr>
<tr>
<td>Chapter Three: Methodology</td>
<td>27</td>
</tr>
<tr>
<td>General Approach</td>
<td>27</td>
</tr>
<tr>
<td>Research Design</td>
<td>28</td>
</tr>
<tr>
<td>Researcher’s Assumptions</td>
<td>30</td>
</tr>
<tr>
<td>Participants</td>
<td>31</td>
</tr>
<tr>
<td>Data Collection Methods</td>
<td>31</td>
</tr>
<tr>
<td>Procedure for Data Collection</td>
<td>33</td>
</tr>
<tr>
<td>Procedure for Data Analysis</td>
<td>36</td>
</tr>
</tbody>
</table>
Chapter Four - Results
Participant Profile
Essential Experience
Categorical, Clusters and Thematic Structures

Category One: Meaning and Purpose
Cluster one: Relationship with student
  Apprehension
  Unexpected rewards
  Importance of normalization
  Discipline
Cluster two: Teacher attributes
  Humour
  Proactive/Resourcefulness
  Professional Knowledge
Cluster three: Concerns.
  Safety
  Absences
Category Two: Mental Wellness
Cluster one: additional responsibilities
  Individual support
Experiences of Teachers

Monitoring

Cluster two: Parental issues

Relationship with parents

Parental support

Cluster three: Limitations

Lack of support

Isolation

Lack of factual knowledge

Academic expectations

Lack of emergency preparedness

Category Three: Physical Wellness

Cluster one: Personal well-being

Stress

Concern for the future

Balanced life

Participant Recommendations

Summary

Chapter Five-Discussion

Summary

Research Contributions

Purpose One: Examine Teachers’ Experiences When Teaching Students with Congenital Heart Disease

Purpose Two: To Better Understand how Teaching a Student
With Congenital Heart Disease may Affect Personal Wellness

Meaning and purpose domain

Mental domain

Physical domain

Purpose Three: Identify Recommendations

Limitations of the Investigation

Implications of the Study

Implication One: Teachers

Implication Two: Administrators/School Boards

Implication Three: Parents

Implication Four: Medical Profession

Directions for Future Research

Final Summary

References

Appendix A: Wellness Model

Appendix B: Semi-structured Interview Guide

Appendix C: Certificate of Ethical Approval

Appendix D: Poster of Recruitment

Appendix E: Informed Consent Form

Appendix F: Bogdan and Biklen’s (2003) Pre-assigned Coding Families
| Table One: Categories and Clusters                  | 43 |
| Table Two: Category One: Meaning and Purpose       | 44 |
| Table Three: Category Two: Mental Wellness         | 56 |
| Table Four: Category Three: Physical Wellness       | 69 |
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Dedication

I want to dedicate this thesis to my loving parents. They are the ones that taught me I could do anything I wanted to do, if I put my mind to it. They always believed in me even when others or I didn’t. They taught me to never give up. For that I will always be thankful. Thank you for the endless love, support and financial assistance. You taught me to work hard and love fearlessly by example. I can only dream of being half the parents you have been to me some day.

I also dedicate this thesis to the memory of Sheena Bradley. Even though she could not speak in words, she taught me the power of love and determination. When I wanted to give up or settle for something less, I thought of her. She would never give up nor can I. I will always remember her gentle spirit, her smile, her laughter, and her love for everyone. Her life was short but will continue to impact my life for the rest of my days. I am thankful for the time that I was able to be with her.
Chapter One

Notice Me!

I know I'm not real small
I'm in between short and tall
I'm not hiding behind no wall
Does anyone even notice me at all?

My head feels like a locomotive train
The medicine tastes like acid rain
The doctors say the nerve is caused by strain
Do you notice me, that I'm in a lot of pain?

There's a lot of questions in my mind
Is there a chance I'll become blind?
When the x-rays are taken, what will they find?
Notice me now, for the experiment is of a weird kind.

I can't take this anymore, I've had this for over a year
I'm given a challenge, but I only hear one cheer
I'll have the run of my life, and I won't shed a tear
Do you notice me, cause on my face I have the look of fear.

If my class really looks at who I am, I wonder what they would see
They want me to open my mind up, but I only hold the key
My time may be cut short, yet they ask what will I grow up to be
At least I have one friend, and he DOES notice me.

I must be invisible to my teacher
She must think I'm an awful creature
Everyone looks past me as I sit all alone on the bleacher
"They NEVER notice me!" I confess to the preacher.

I wish I could soar up with the birds, and fly
I feel real empty inside, but I don't know why
When my soul is ready, it shall float to the sky
Oh, God notice me, I'm not ready to die.

My cries of pain when the doctors were wrong
Did they actually know, I would live this long?
Before I have to leave, play "Spirit in the sky" for my last song
Please notice me now, it's only a short time, and I'll be gone

(Nyla, 2004).
As the school year begins, excitement is palpable for students and teachers alike at the prospect of seeing old friends and meeting new ones. It is overwhelming and disheartening for teachers or friends to greet students who were healthy a few short months prior, but over the summer have developed the visible symptoms of chronic illness or terminal disease. Many emotions and questions arise when determining how to respond to these children and how to effectively meet their needs.

Being diagnosed with a chronic illness, such as congenital heart disease, marks the beginning of a change in a student’s life. Many aspects of a child’s life are affected by this altered future such as routines, academics, social life, and psychological needs (Bowen, 1985; Gupta, Guiffre, Crawford, & Waters, 1998). These behavioural changes not only affect the child and their family, but also the teacher. Educators often grieve for a child’s disability, and worry about how an illness will affect the student, but many teachers are also unsure of how to act toward, support, or teach a child with a chronic illness (Chekryn, Deegan, & Reid, 1987).

Increasingly, teachers are gaining first hand experience with students with chronic illness. Due to improved medical practice, many children, who were once labelled terminally ill, are now being placed in the category of chronically ill, and as a result, are able to attend school. The population of students classified as chronically ill has increased significantly in recent years (Kliebenstein, Broome, & Marion, 2000). Prominent literature on congenital heart disease in children has focused on the family-child dyad and school re-entry issues (Gupta et al., 1998; Sexson & Madan-Swain, 1993; Shiu, 2003). No research was located that explored the feelings or experiences of educators who teach students with chronic illness; as such teacher wellness appears to be an under-studied
issue. As a result, an investigation into how to support, and best meet the needs of teachers working with a student with chronic illness is required.

Statement of the Problem

There is limited research that looks at the personal impact of teaching a student with chronic illness. In response to this concern, the purpose of this inquiry is to answer the question: What are the experiences of teachers who teach elementary students with congenital heart disease? Due to the vast array of conditions or disabilities that fall into the category of chronic illness, and given the high prevalence of congenital heart disease, this particular disease was chosen to narrow the scope of the investigation.

Purpose of the Study

There are three purposes of this study; 1) to better understand the essence of teachers’ personal experiences when teaching elementary students who have congenital heart disease; 2) explore how personal wellness may or may not be affected; 3) recommendations on how to better support teachers who teach students with congenital heart disease. This study has contributed to a more comprehensive understanding of how teaching a student with congenital heart disease affects teacher wellness. These results might help school systems understand how to support a teacher’s wellness when teaching a student with congenital heart disease.

Definitions of Terms

The following definitions are offered to ensure an appropriate interpretation of the terminology used in this study.

Chronic illness: “A condition which lasts for a considerable period of time or has a sequel which persists for a substantial period and/or persists for more than 3 months in
a year or necessitates a period of continuous hospitalizations for more than a month”
(Thompson & Gustafson, 1996, p. 4).

Congenital heart disease: “A structural or functional heart disease that is present at birth, even if it is discovered much later” (Midence, 1994, p. 311).

Wellness: Giving care to the physical self, using the mind constructively, channelling stress energies positively, expressing emotions effectively, becoming creatively involved with others, and staying in touch with the environment. (Ardell, 2002).

**Boundaries of the Study**

As with any research, the methodological framework has influenced the design and, consequently, the outcome of the inquiry. It is vital to acknowledge these boundaries prior to the presentation of the study to provide readers with a framework to understand the results of the inquiry. The succeeding restrictions are acknowledged as a part of the present study.

1. In keeping with the objectives of qualitative methodology the study involved a limited number of participants, in this case, six elementary teachers;
2. The study involved elementary teachers who reside in Western Canada and who are currently teaching or have taught (within the last 15 years) a student(s) who suffers from congenital heart disease;
3. The study involved elementary teachers willing and able to participate in a face-to-face interview and who have given permission to have the interview taped;
4. The study’s data were collected between October 2004 and April 2005;

5. Teachers’ familiarity, experience, or training surrounding students with chronic illness may affect their comfort level with congenital heart disease;

6. All variables, conditions, or populations not so specified in this study will be considered beyond the scope of this investigation.

Summary

Chapter one provided a brief overview of the need to examine the experiences of teachers who have students with congenital heart disease in their classrooms. Additionally, relevant definitions of terms used throughout the study, and the delimitations of the study were identified.

Chapter two provides a review of the literature examining chronic illness as a whole, while focusing specifically on congenital heart disease. The school system experiences of children with chronic illness are explored as well as how this affects the classroom teacher and their personal wellness.
Chapter Two: Literature Review

Although there is an abundance of literature on chronic illness, there is a paucity of information specifically on congenital heart disease among children. Furthermore, there is little documentation that addresses the personal impact that teaching students with chronic illness has on teachers themselves. The function of Chapter Two is to: (a) review the extant literature on chronic illness and congenital heart disease; and (b) review literature on wellness, identify teacher wellness, and identify new areas in the field of teacher wellness that need further research. This chapter will be organized under the following headings: Chronic Illness; Congenital Heart Disease; Stages of Congenital Heart Disease; Importance of Normalcy; Teachers’ Experiences; Suggestions for Supporting Teachers; Wellness; and Wellness Model.

Chronic Illness

In the past, most children with chronic illness have not attended school. Due to advances in technology and medicine, and increased survival rates in children with chronic illness, there has been a massive increase in the number of these students present at school. It is estimated that chronic illness affects up to 20% of school age children (Perez, 1997). Consequently, teachers are gaining firsthand experience teaching students with chronic illness.

There is an array of terminology that defines chronic illness; however, a generally accepted definition is “a condition which: lasts for a considerable period of time or has a sequel which persists for a substantial period and/or persists for more than 3 months in a year or necessitates a period of continuous hospitalizations for more than a month” (Thompson & Gustafson, 1996, p. 4). Chronic illness differs significantly from acute
illness, where the illness is present for a short period of time with the patient recovering quickly (Shiu, 2001). In contrast, chronic impairments may develop slowly and can go undiagnosed or undetected for a long period of time. Unlike many other disabilities, chronic illness can be like a roller coaster: the illness can be unpredictable and individual needs can change daily (Nevile & Roberts, 1999). One of the most serious and prevalent forms of chronic illness is congenital heart disease.

*Congenital Heart Disease*

Congenital heart disease is a chronic illness involving a “structural or functional heart disease that is present at birth, even if it is discovered much later” (Midence, 1994, p.331). It is estimated to be the second most prevalent chronic illness in children (Tak & McCubbin, 2002); thus, there is an increased likelihood that educators will teach a student with congenital heart disease. Approximately 1% of children have a heart disease that is present at birth, referred to as congenital heart disease (American Heart Association, 2004). Perloff’s (1991) study indicated that advances in medicine and technology have resulted in approximately 85% of individuals born with a heart abnormality surviving to later life. Consequently, even with the good prognosis of leading technology, the American Heart Association (2004) states that, “91,000 life years are lost each year in the United States due to congenital heart disease” (How serious is the problem) and that congenital heart disease is the number one cause of death within the first year of life.

Children with congenital heart disease can be broadly divided into two categories: acyanotic and cyanotic. Acyanotic heart disease is a broad term for any congenital heart defect in which all of the blood returning to the right side of the heart passes through the
Experiences of Teachers

lungs and pulmonary vasculature in the normal fashion (Irishhealth, 2004). Frequent forms of acyanotic heart disease are obstructions to a valve or artery, or imperfections in one of the walls separating the chambers of the heart.

Cyanotic heart disease occurs when there is a mixing of pure oxygen-rich blood with venous blood (Heart and Stoke foundation, n.d.). Children who fall into the cyanotic category tend to have more pronounced problems such as fatigue, delay in growth, and underdeveloped motor function. As a result, children with cyanotic heart conditions are generally seen as having a more severe form of disability (Gupta et al., 1998). Due to the complexity of medical conditions that occur with cyanotic problems, these children may be at a higher risk for psychological and school re-entry issues (Gupta et al., 1998).

Identifying a congenital heart abnormality in a child marks the beginning of numerous adjustments, experiences, and changes for the child, family, and school. Children with congenital heart disease experience a number of struggles in each developmental stage of life (Bowen, 1985). Due to their unpredictable health and medical problems, anxiety (Bjornstad, 1995), medical fears, psychological impairment (Gupta et al., 1998), school difficulties (Masi & Brovedani, 1999), separation anxiety (Gupta, Mitchell, Guiffre, & Crawford, 2001), and behaviour issues, may arise (Gupta et al., 1998). It is crucial for professionals and families who interact with children with congenital heart disease to understand these children's unique needs, to plan appropriate interventions, and to support children with this disability (Bowen, 1985, Heart and Stroke Foundation, n.d.).
Developmental Stages and Congenital Heart Disease

Pre-school

It is an enormous undertaking for a pre-school child to understand and endure the frequent clinic visits, medical procedures, and tests associated with congenital heart disease. Young children often view their illness as a punishment for evil thoughts or bad behaviour (Davis, 1989; Sexson & Madan-Swain, 1993). In this developmental stage, the healthy pre-schooler yearns for routine, while the sick pre-schooler experiences many disruptions to the normalcy of life. Frequently, there are disruptions through dietary restrictions, physical limitations, and hospitalizations. Bowen’s (1985) study indicated that the major fears of a pre-schooler with congenital heart disease include “separation, loss of control, the dark, bodily injury, and mutilation” (p. 67). Bowen identified the most common coping strategies for this age group as, “regression, self-comforting behaviours (thumb sucking, clinging), and dependence on parents” (p. 68).

School age

When school-age children are sick they often perceive pain as a punishment. Many procedures that children with congenital heart disease undergo are painful and, as a result, these children may see their disease as a punishment (Bowen, 1985). School-age children will often hold themselves responsible for their illness, often have concerns about death, and express fear that they are dying (Bowen). The sense of helplessness, which often accompanies numerous hospitalizations, can cause these children to feel a loss of control that may lead to reactions such as resentment, rage, vengeance, guilt, or depression (Bowen). To endure the unknown but anticipated painful procedures, school-
age children may use physical resistance, sleeping, withdrawal, intellectualizing, or postponing the event as coping strategies (Bowen).

Adolescence

As a child matures into adolescence, he/she begins to understand their illness and the limitations and dangers caused by the disease. Concerns about physical differences from congenital heart disease, such as blue skin, clubbed fingers and toes, and surgical scars, may become more noticeable to the child and therefore more problematic (Bowen). With increased understanding of the disease, the teenager often becomes increasingly involved in the management of his/her plan of care. Similar to school age children, adolescents may also see illness as a punishment, which can lead to feelings of shame and guilt (Bowen, 1985). Youth with congenital heart disease may use coping strategies such as denial, withdrawal, intellectualizing, manipulation, abusive behaviour, or refusal to cooperate with medical procedures, as a way of coping with the enormous strain of having a serious illness (Bowen).

It is important for professionals to understand how children view their sickness in order to best support these students. Not only must the educator be aware of children’s views, but they must also be aware of how these students’ peers feel, support, and interact with sick students (Davis, 1989). The teacher is in a unique position to support the student with chronic illness as well as to improve the classroom atmosphere. It is vital for the teacher to understand the needs of the student with chronic illness, the needs of the other students, and their own personal needs to ensure that they can provide the best possible support to the class as a whole. As a result, teachers need to be reflective about
their feelings regarding the illness in order to maintain personal well-being by addressing personal needs that may arise.

**Importance of Normalcy**

As early as 1959, family physicians understood the importance of treating a child with congenital heart disease as a total person (Cooper, 1959). It is possible to achieve some form of normalcy despite illness severity. This can be achieved in a variety of ways in the school system. Papadatou, Metallinou, Hatzichristou, and Pavlidi (2002) reported that regular attendance in school and integration into school life increases feelings of normalcy. School can provide a normal, or at least relatively stable, environment for children with an illness; it may be the only setting where the chronically ill children are viewed as children rather than patients (Sexson & Madan-Swain, 1995). Children with chronic illness who are unable to attend school have lower self-esteem, feel devalued, become isolated, and fear that they are going to die (Sexson & Madan-Swain, 1993). Teachers are key to a student’s successful involvement in the school system.

Papadatou et al. (2002) identified four major potential problems with school re-entry:

1. **Disease and treatment difficulties**: Although most absenteeism is due to hospitalizations or check-ups, at times, the overprotection of parents, attitudes, and the fear of the unknown may exacerbate school re-entry difficulties for some children (Sexson & Madan-Swain, 1993).

2. **Child-related consistency difficulties**: Changes in appearance (Sexson & Madan-Swain, 1993), anxiety about peer acceptance (Neville & Roberts,
Experiences of Teachers 1999) and an inability to catch up with missed work (Shiu, 2001) are problematic for school re-entry.

3. Parent-related difficulties: Parents have issues dealing with guilt and anxiety that may result in leniency (Papadatou et al., 2002). This overindulgence may result in overly independent, argumentative, and uncooperative children (Bowen, 1985). The reality that the child may not have a long life expectancy can compound the feeling that school may be a waste of time (Shiu, 2001).

4. Teacher-related difficulties: Teachers may be emotionally affected by the diagnoses of the child. Concerns over a lack of knowledge of the disease, uncertainty of the child’s future and expectations, and an inability to handle questions from classmates are experiences that teachers have had when teaching a child with a chronic illness (Papadatou et al., 2002). This affects a teacher’s ability to provide a normal and supportive school atmosphere for the student with chronic illness.

Teachers’ Experiences

Teachers’ knowledge of chronic illness

Frequently, teachers are unprepared and receive limited or no training regarding the issues surrounding chronic illness and how it will affect students’ learning (Papadatou et al., 2002). It was found that 80% of teachers reported feeling inadequately trained to handle emergencies when dealing with the health issues of the chronically ill (Eiser & Town, 1987; Papadatou et al., 2002). Without a clear understanding of the medical implications of living with chronic illness, teachers are unable to provide either a safe or
supportive educational environment. One major aspect of creating a safe environment is providing a safe environment and caring for the health status of children. Having a student with congenital heart disease goes beyond awareness of normal health status such as fever; teachers are expected to monitor students and know warning signs of distress (American Heart Association, 2004).

Warning signs and distress symptoms are different for each unique heart condition; therefore, it is important for teachers to learn the warning signs for each individual child (American Heart Association, 2004). Before a teacher can detect the warning signs of a child in medical distress; the educator has to be able to recognize normal behaviour; breathing patterns; and physical appearance. According to Pyevich (2004), when a child with chronic heart disease is experiencing physical difficulty, he/she may show signs of respiratory distress (especially when active); tiring easily; fainting; swelling of the legs; stomach, and eyes; and bluish skin, fingernails, and lips (if the child is lacking oxygen in the blood). If teachers are aware of the warning signs and other signs that are unique to each student, they will then be better able to help monitor students’ health and provide a safe environment.

Teachers also need to recognize that children with chronic illness often exhibit more absenteeism than their healthy peers (Sexson & Madan-Swain, 1993). Theis (1999) found that “58% of students with chronic conditions routinely miss school, and 10% miss more than 25% of the year” (p. 296). Classroom teachers must be considerate of missed work, help devise a plan to make up work as soon as possible, and be sympathetic to the emotional impact of being sick and behind in studies that the student may be experiencing (Theis, 1999).
Establishing a partnership between teachers and parents to meet the specific needs of the chronically ill student is crucial (Roberts, Massie, Mortimer, & Maxwell, 2005). Effective lines of communication between teachers and parents regarding chronically ill students are not always present. Johnson, Lubker, and Fowler (1988) reported that only 30% of parents were providing appropriate information. This lack of forthcoming information from parents forces the teacher to find alternative sources of information about the illness. Teachers reported that 20% of their information came from school files, 15% from principals, 5% from nurses, and 4% from previous teachers who had informed them that they had a pupil with chronic illness (Johnson et al., 1988). Disturbingly, this study also found that 20% of the teachers were unaware of their students’ chronic illness prior to the study. Even though it is possible that some parents may not want to disclose information fearing that their child may be treated differently, it is important for the teacher to know about the illness in order to effectively understand, monitor, and support the student (Roberts et al., 2005).

Involving medical personnel is ideal and can enhance teacher knowledge of the illness, medication side effects, and prolonged outcomes (Heart and Stroke Foundation, n.d.). Teachers have indicated that they would like more professional medical advice on specific physical, cognitive, and psychological limitations caused by the students’ illnesses (Mukherjee, Lightfoot, & Sloper, 2000). Unfortunately, obtaining medical advice can be cumbersome due to the difficulties acquiring parents’ permission of release and also lengthy waiting lists to access the time of medical specialists (Shiu, 2001). Educators are often reluctant to ask parents for additional information for fear they may contribute to a perception that the school personnel do not have the necessary skills or
training to deal with the child’s illness (Mukherjee et al., 2000; Roberts et al., 2005). As well, teachers often do not want to add this extra responsibility to already overburdened parents. This dilemma of teachers not having the medical information indicates a greater need for open communication with health professionals (Mukherjee et al., 2000).

**Discipline and academics**

Bowen (1985) describes discipline as “helping a child to gain inner control and become self-disciplined by setting examples and limits” (p. 72). Parents of sick children often find discipline hard to achieve because of the natural tendency to protect and overindulge an ill child (Bowen; Papadatou et al., 2002). Overly lenient parental behaviour can result in maladjustments of the child’s maturity and psychological development. Whenever possible, parents are counselled to discipline the child with chronic illness in a typical manner (Bowen).

Similar to parents, educators find it increasingly difficult to know how to properly set boundaries for a child who has a chronic illness. Chekryn, Deegan, & Reid (1987) noted that teachers “found themselves in a dilemma about appropriate academic expectations” (p. 162) for a chronically ill child. One of the hardest quandaries for teachers is how to support a child who is working to the best of their ability, yet, due to the compounding factors of being sick, does not achieve a passing grade (Chekryn et al.). Educators worry that it would not be viewed as compassionate to deny children a passing grade if the student’s illness is affecting their academic progress. Keeping a chronically sick child behind a grade was viewed negatively due to the value placed on staying with the same peers who already know and accept the child (Chekryn et al.). Often, educators are unsure of how to balance expectations when working with a student with a chronic
illness: should they reduce their expectations when the child is tired or in treatment but expect more when the child is feeling well (Chekryn et al.)? Chekryn and colleagues found that educators and parents share concerns over these dilemmas regarding academic expectations. The following quote from a teacher illustrates the difficulties that educators may encounter when teaching a student with chronic illness.

Sometimes I find it hard to be strict with him because he’s good with his school work and he’ll get it done. But the days he comes in and his skin looks so grey and he looks so down...I think, what does it matter? His mom says no, make sure he gets it done. But, some days I feel sorry for him...I’d let him get out of it...I tend to get a bit worried myself, I’m not being consistent with him (Chekryn et al, 1987, p.163).

To develop a thorough knowledge and understanding of how medical implications need to inform teachers expectations of a student with chronic illness, teachers need opportunities for discussion in order to effectively discipline, evaluate, and encourage an ill student. With discussion opportunities, teachers may feel more comfortable when providing discipline to students with chronic illness.

Peer interaction

Teachers who are uncomfortable with changes in a student’s appearance, and uncertain about their own feelings towards the situation, may be unsure as to how to approach a child with chronic illness (Sexson & Madan-Swain, 1993). This awkwardness provides an additional problem given that the ways in which teachers interact with a sick child can also affect that student’s peer interactions (Nevile & Roberts, 1999). Peers tend to be accepting of the student and illness when teachers are also accepting (Sexson &
Madan-Swain, 1995). It is the teacher’s responsibility to help break down stereotypes that are related to chronic illness (Sexson & Madan-Swain, 1995). It has been suggested that children with chronic illness are perceived as ‘sick,’ less preferred as playmates, more isolated, and lonelier when compared to their healthy peers (Shiu, 2001). Regrettably, young children often perceive that they can catch the illness, or older children avoid interaction because they have a fear of being associated with someone different (Sexson & Madan-Swain, 1993). Again, teachers are in a unique and important position to positively influence and support the classroom environment.

There is debate over whether peers should be aware of a student’s diagnosis because of possible negative outcomes. Papadatou et al. (2002) found that 27% of teachers felt that a discussion with the class was dependent on the age, gender, and maturity of the students. Of the teachers within the study, 25% indicated that they would avoid conversations with other students while 48% argued that a discussion would be beneficial to the students.

Teachers can provide support regarding peer interactions in a variety of important and helpful ways. Due to prolonged absences, the chronically ill student may endure hampered friendships; therefore, educators can encourage peer relationships by allowing the class to stay in contact via cards, visits, audiotapes, and telephone calls (Sexson & Madan-Swain, 1993). Teachers’ and students’ acceptance and support can influence whether a student with chronic illness will continue in school. Shiu (2001) states that attending school “for the child who has developed a chronic health condition may be as critical for social-emotional survival as medical treatment is for their physical survival” (p. 273).
Personal impact on the teacher

Few studies have investigated how teachers are personally affected by having a child with chronic illness in their classroom. Chekryn et al. (1987) explored teacher experiences with this phenomenon and found that having a student with chronic illness did have a personal impact on teachers. The educators articulated feelings of shock, worry, uncertainty, and frustration. One teacher stated that, "The hardest thing is to not know just how serious this was. I mean, let's face it, just concern as a teacher and sort of a friend, too. Just how is this going to affect him? How bad is it going to be?" (p. 163). Many teachers want to provide emotional and educational support, but are unsure of how to do this. Chekryn et al. (1987) further noted that the school nurse played a minor role and thereby offered limited support to teachers because of their lack of accessibility and visibility. Instead, teachers drew support internally from other teachers and personal family members. In some cases, teachers gained some support from the child's family.

Suggestions for Supporting Teachers

Papadatou et al. (2002) provide three suggestions to help support and prepare teachers for students with chronic illness. First, informed specialists, such as psychologists, social workers, or doctors, need to be made available to answer questions or give guidance on day-to-day planning and how to establish an adequate emergency procedure. Although schools hope that there is not an emergency, teachers need to be prepared. According to the Heart and Stroke Foundation (n.d.) educators should learn how to identify the signs and symptoms of potential medical problems, each specific to the individual student. Further, they should know how and when to get emergency help, and should be provided
with information to share with paramedics or emergency departments. Increased training in child psychology should be made available to current and future teachers to help prepare them to meet the needs of chronically ill students. Third, education and guidance on loss and grief needs to be provided for educators in the event that a student with chronic illness loses their battle with that illness. This education should focus both on how to deal with death personally, as well as how to address the issue with the class and other students.

Wellness

Teacher impact

As previously outlined, the teacher plays a vital role in supporting the physical, academic, and social opportunities of a student with chronic illness. It is critical that teachers have a thorough understanding of how to best support the affected student. However, if the teachers themselves feel overwhelmed, frustrated, or emotionally drained, they will be less able to support the student or the class as a whole. As a result, teacher wellness is an important consideration when looking at the school system in relation to a student with chronic illness.

Teacher wellness in this context is influenced by a variety of factors. Teachers frequently feel unprepared to teach a chronically ill student; they lack the medical, psychological, and evaluative skills to effectively meet the individual needs of a student with chronic illness. Navigating this unknown territory can be particularly challenging for teachers. Extra support is usually not provided to educators when they have a student with chronic illness, leaving teachers to rely on their own devices. The situation leaves teachers facing a workload beyond the demands of a typical classroom. Teachers also
experience a lack of clear understanding of the medical implications which minimizes both a teacher's level of confidence and comfort. Due to this lack of support and appropriate training, teaching a student with chronic illness may affect teachers and their personal wellness.

Wellness and Congenital Heart Disease

The extant literature on congenital heart disease focuses on the medical procedures, effects on the child and their family, and on the school experience. However, the effects of teaching a child with chronic illness have received limited attention. The physical and emotional affect on teachers cannot be overlooked if the education system expects teachers to be effective when teaching students with chronic illness. Therefore, future studies need to explore these teachers' experiences and how a teacher's personal wellness is affected (Roberts et al., 2005).

Wellness within schools

Researchers have found that teachers in classrooms without students with chronic illness have health problems similar to the rest of the professional population and experience the same kind of unhealthy issues such as obesity, cigarette smoking, stress, and premature mortality (Blair, Tritsch, & Kutsch, 1987). In fact, 50% of all premature deaths can be correlated with unhealthy lifestyles in the adult population. Employee wellness programs, implemented in the workplace, have demonstrated a decrease in healthcare costs, a reduction in absenteeism, an enhanced productivity, and an increased general well being (Rasku & Kinnunen, 2003).

Teachers' work related stress can be linked to physical ill-health (Otto, 1986), mental ill-health (Fletcher & Payne, 1987), instructional planning, and career dedication
Kyriacou (1987) defines teacher stress as, “the experience by a teacher of unpleasant emotions, such as tension, frustration, anxiety, anger, and depression, resulting from aspects of work as a teacher” (p. 146). Teachers with increased levels of stress have been shown to suffer from increased absenteeism, job-related accidents (Tager, 1983), burnout, physical complaints, psychological issues, and work performance deterioration (Russell, Altmaier, & Van Velzen, 1987).

Wellness Model

Defining teacher wellness

Teacher wellness is an emerging field of research evidenced by an increase in related academic and popular articles on the subject. One problem with the concept of teacher wellness is the subjectivity inherent to the idea. Individuals perceive the concept of wellness from their own individualized perspective; this compounds and confounds a universal definition of wellness. To illustrate, Lauzon (2001) offered the following quotations from individual teachers that represent varying definitions of wellness.

1. I guess if I had to define wellness it would mean having the energy to deal with all the things that are going on in my life or in someone else’s life, so that would mean to have energy to be able to go to work, to devote to your family, or activities that would promote your wellness. (p. 145)

2. Physically I am well, but wellness also means feeling good, and feeling connected and being able to talk to friends and colleagues. (p. 144)
3. Balance is wellness, but that’s the part I struggle with. I wouldn’t do my report, my schoolwork or anything because I wanted to get the workout in. Whereas now, it’s the first to go and work comes first. (p. 144)

4. The part of wellness for me is having those around me whether they are personal or professional, support me, and provide support to me. I have a circle of support and without it I wouldn’t be well. (p. 147)

These individual definitions of wellness are unique; however, all quotations illustrate the need for wellness in the teaching profession. Naylor (2001) suggests that “teachers are sacrificing their physical and mental health, and in some cases their relationships, to maintain their programs and classes...this represents a severe and unsustainable imbalance in many teachers’ lives” (p. 5).

The Ardell Wellness Model

There are a few models that can be used to investigate the complex principles surrounding wellness (Ardell, 2002). However, one such model is Ardell’s (2002) multi-dimensional wellness model (see Appendix A). Ardell’s wellness model contains three domains, each containing a set of skill areas. The domains and skill areas are as follows: (a) the mental domain containing the skills of emotional intelligence, effective decisions, stress management, factual knowledge, and mental health; (b) the meaning and purpose domain containing the skills of relationships, humour, and play; and, (c) the physical domain containing the skills of exercise and fitness, nutrition, appearance, adaptations and challenges, lifestyles, and habits.
Experiences of Teachers

The Ardell model is not specific to teacher wellness, it was designed for adults in general (Ardell, 2002). Given that no teacher wellness model currently exists and that teachers are adults, Ardell’s model will be used to help understand the lived experiences of teachers who instruct students with congenital heart disease. Each domain of the Ardell model and how it relates to the current study will now be explained.

**Mental domain.** Within Ardell’s mental domain, factual knowledge has been identified as an important component. With regards to teacher wellness, factual knowledge would refer to the knowledge of physical, medical, and psychological needs of students with chronic illness; teachers who have a student with chronic illness require appropriate factual knowledge and protocols to make effective decisions. As already identified, a lack of teacher training and knowledge is a key area of concern for teachers of students with chronic illness (Papadatou et al., 2002). Without knowledge of the illness, teachers cannot make effective decisions regarding the student. This lack of knowledge can increase teacher stress by causing them to worry about issues such as medical risks, lack of knowledge regarding the danger signs, and an inability to handle an emergency. In addition, factual knowledge can be impeded when teachers lack certainty regarding how to properly discipline and evaluate a student with chronic illness. Therefore, mental wellness may be in jeopardy given the impediments to adequate factual knowledge.

**Meaning and purpose domain.** Meaning and purpose relate to our life objectives, our roles in society, our relationships, and our humor and play. When working with a student with congenital heart disease, the meaning behind what being a teacher may change. That is because their teacher role may expand, as they may be required to assume
Experiences of Teachers

Experiences of Teachers

a role similar to that of a social worker, counsellor, psychologist, nurse, or friend. While it is possible that all teachers will find their role as teacher expanding into the aforementioned areas, the need and likelihood of this occurring may increase significantly for the teacher of a student with congenital heart disease. The purpose of schooling and the purpose of the teacher in the classroom may be re-evaluated as teachers become concerned about an ill child's quality of life. Academics may become secondary to fun and enjoyment.

Increased attention to the chronically ill student can also change the relationship between student and teacher. One of the educators cited in Papadatou et al.'s. (2002) study expressed this difference in relationships in the following quote: "I become nicer towards him, I avoided criticism in order to not upset him or bring him in a difficult position" (p. 116). With changes to the direction of one's life, one's profession, and one's relationships with their students, teachers of students with chronic illness may be looking at continual readjustments in the meaning and purpose domain. Change can often increase stress. Teachers will therefore need support, encouragement, and an opportunity to express concerns with others.

Physical domain. Effectively managing a classroom of 20 to 30 students is a challenge at the best of times. However, this challenge increases when needing to support a student with chronic illness. With this addition, the workload and demands increase. These demands can have a detrimental effect on all skill areas of the physical domain. With an increasingly demanding schedule, planning nutritious meals and pursuing an active lifestyle become more and more difficult. Having a student with congenital heart disease may compound these issues even further as the teacher may have even less time
for themselves due to the continued need to monitor the student, and to assume the multi-roles required of the teacher. The need to frequently communicate with the parents and to participate in meetings regarding the student increases the physical demands on teachers.

One can acknowledge the constant battle teachers experience trying to balance their lives with their never-ending professional demands and this may be even more challenging for teachers who have students with chronic illness in their classrooms. As teachers’ roles within the classroom continue to change, with more responsibility and less paid time, Lauzon (1999) suggests that teacher wellness may be the missing link towards reducing burnout, stress, and premature retirement. Teacher wellness is an emergent field of research; however, there are still many areas surrounding teacher wellness that have not yet been investigated. One such area is how a child with chronic illness affects teacher wellness.

Summary

Chapter two has provided an examination of key literature on chronic illness and congenital heart disease. The findings indicated that there is an enlarged population of students with chronic illness attending school; therefore, more teachers will experience teaching a student with chronic illness. Teacher wellness was discussed and the Ardell model was introduced. The literature review indicates that there is a need for further research to understand teachers’ experiences and personal impact when teaching a student with chronic illness. Through continued research, the education profession will gain a better understanding of teachers’ experiences of working with students who are diagnosed with congenital heart disease.
Chapter three outlines the methodology used in this investigation. The researcher's assumptions and ethical considerations will be discussed. The criterion for selecting participants will be explained, as will be the method of data collection and analysis.
Chapter Three: Methodology

The research design implemented to investigate the question: “What are the experiences of teachers who teach elementary students with congenital heart disease?” will be described. A qualitative paradigm was chosen for this study and justification for its use is described at the beginning of this chapter. The research design has been developed from previous, similar studies. The criterions for selection of participants are discussed. The remainder of this chapter includes a review of the data collection methods, procedures for data analysis, authenticity and ethical considerations. Lastly, journal reflections are shared throughout chapter three and four, and these are indicated by italic font.

General Approach

The intention of this study was to develop a comprehensive understanding of the experiences of teachers who instruct children with congenital heart disease. A qualitative design was chosen for this study as it “attempts to understand the world from the subjects’ point of view, to unfold the meaning of peoples’ experiences, or to uncover their lived world prior to scientific explanations” (Kvale, 1996, p. 1). In addition, qualitative research primarily employs an interpretive approach where the researcher “sees[s] people, and their interpretations, perceptions, meanings and understandings, as the primary data sources” (Mason, 2002, p. 56). Furthermore, qualitative researchers not only view the outcome of their research as relevant, but also gain insight into how the process of the phenomenon makes sense to the participants’ lives (Merriam, 1998). All of these factors enabled the researcher to develop a comprehensive understanding of teacher experiences.
The goals of qualitative and quantitative research approaches are different. A qualitative approach typically examines an event through human experience, acknowledging that humans have subjective opinions and personal judgements (Valle & King, 1978). In contrast, a quantitative approach defines a phenomenon by strict measurable and observable merits. It is important to note that, unlike quantitative research, that strives to generalize findings from a sample to a defined population, qualitative research strives to represent findings that have similar cases of the phenomena (Anderson & Arsenault, 1998). Therefore, the results of this study will seek to sensitize or raise awareness of what it is like to teach a child with congenital heart disease rather than to generalize to the greater population.

Research Design

Phenomenology was employed to develop an understanding of the lived experiences of teachers who educate students with congenital heart disease. Phenomenology is a qualitative research method that focuses on the lived experience (Van Manen, 1984), or the meaning of a specific human experience (Polkinghorne, 1989). The purpose of phenomenology is “to come to a deeper understanding of the nature or meaning of our everyday experiences” (Van Manen, 1984, p. 37). Due to its focus on experiences, this design is congruent with the research question.

There are two broad types of phenomenological inquiries, which vary depending on the study and the philosophical approach used by the researchers (Lopaz & Willis, 2004; Seamon, 1982). The first philosophical approach is associated with Heidegger and the interpretive tradition of phenomenology. In relation to the lived experience, interpretive phenomenology goes beyond the essence of the experience and tries to
ascertain what the participants’ experience means rather than what they consciously remember (Lopaz & Willis). The founders of interpretive inquiry support the view that “humans are embedded in their world to such an extent that subjective experiences are inextricably linked with social, cultural, and political contexts” (Lopaz & Willis, p. 729). As a result, interpretative phenomenology focuses on what an individual’s experiences reveal about their environment. In this search to understand the world around us, interpretative phenomenology is philosophical in nature (Van Manen, 2002).

The second philosophical approach to phenomenology involves the ideas of Husserl and descriptive phenomenology (Van Manen, 2002). Within the descriptive phenomenology framework, subjective information is deemed critical to understanding human experiences. Unlike the interpretive tradition, the descriptive tradition does not focus on the culture, society, politics, or how the studied phenomenon affects the human experience, but rather focuses on the described experience (Lopaz & Willis, 2004). As a result, attention is placed on the details of an experience, rather than what that experience may reveal about the environment. According to Van Manen (2002), a descriptive approach is appropriate to use when researchers employ phenomenology in a professional setting. Consequently, a type of descriptive phenomenology is phenomenology of practice. Phenomenology of practice focuses on how a described experience can be used to adapt, alter, or to inform current practices. Given the current study’s focus on experiences and how these experiences can influence school practices, descriptive phenomenology is deemed to be a good methodological fit.
**Researcher's Assumptions**

Within Husserlian phenomenology, it is understood that the researcher must acknowledge beliefs, biases, assumptions, presuppositions and theories that “overlay the phenomenon that one wishes to study” (Van Manen, 2002, p. 28). This process is a crucial element when assessing the phenomenon in a non-abstracting manner. The objective is to achieve transcendental subjectivity, accomplished by constantly assessing biases and preconceptions through bracketing and self-reflection (Lopaz & Willis, 2004).

Acknowledging the researcher’s preconceived ideas can increase the rigor of the study by ensuring that the participants’ voices are heard, not solely the researcher’s; it forbids the researcher’s predetermined beliefs to influence data collection and analysis (Polkinghorne, 1989). Given that the researcher has experiences working with medically fragile children, it would be especially easy for preconceived ideas to leak into the study. The researcher’s goal is to hear and record the participants’ voices; therefore, journaling will be fundamental in identifying preconceived thoughts and expectations. Upon reflection, the researcher, as relevant to the study, identified the following assumptions.

1. The participants will be honest in their answers;
2. The participants are expected to feel free to express their own perceptions without ramifications;
3. As a phenomenologist researcher, it is believed that human experiences make sense to those who live it and that human experience can be consciously expressed (Cresswell, 2003);
4. For a successful experience, a team of people must support a teacher who is teaching a student with congenital heart disease;
5. Based on the literature, and my own experience, often teachers lack knowledge on how to teach children with chronic illness;

6. Teachers are often overworked and have many responsibilities added to their typical teaching workload; and,

7. The experiences of teachers who teach medically fragile children must be examined to optimize the experience of future teachers and students.

Participants

Within the current phenomenological study, criterion sampling was employed to ensure that all participants have experienced the phenomena being studied (Creswell, 2003). The participant criterion was specified as an elementary teacher who is currently teaching or has taught a student with congenital heart disease. According to Anderson and Arsenault (1998), within qualitative research there are no rules for sample size. The primary objective in phenomenological sampling is for all participants to have had first hand experience with the phenomenon in question. Teaching a child with congenital heart disease is a relatively rare occurrence; therefore the number of available participants was limited. Given that teaching can be a highly demanding profession, the number of teachers willing to participate was also limited. The use of six participants allowed the researcher to reach saturation of information across themes. The group of interest consisted of six teachers who teach within elementary schools in Western Canada.

Data Collection Methods

The preferred mode of data collection in phenomenology is to gain descriptions of the experience through face-to-face, in-depth-interviews (Creswell, 2003; Polkinghorne, 1989). Through everyday conversations, individuals gather information about
experiences, feelings, hopes, and information that can help them understand the world in which they live (Kvale, 1996). Interviews allow the researcher “to help the subject move toward nontheoretical descriptions that accurately reflect the experience” (Polkinghorne, 1989, p. 47). The researcher's role is to guide participants within the realm of the phenomenon and be alert for subtle meaningful cues in participant's questions, body language, and expressions (Leedy & Ormrod, 2001).

Characteristically, interviews are open-ended to ensure that the researcher can examine the phenomenon in-depth and develop an understanding of the participants’ lived experience (Polkinghorne, 1989; Roberts & Cairins, 1999) by not limiting the response. Consequently, the first interview question was an open-ended question that asked the participants about their experiences with respect to teaching children with congenital heart disease (Moustakas, 1994). Participants were allowed as much time as desired to freely describe their experiences. Each interview proceeded with follow-up questions that were informed by Ardell’s (2002) wellness model (see Appendix A) using his three domains: mental, meaning and purpose, and physical (see Appendix B for the interview guide). The purpose of the follow-up questions were to acquire a comprehensive description of the phenomenon (Moustakas, 1994) to ensure that the researcher capsulates the essence of the experience in reference to teacher wellness. If an interview question was unclear to a teacher, the question was asked again in a different way. To conclude each interview, teachers were asked to offer recommendations for supporting teachers who teach children with congenital heart disease in the future.

As indicated, the interviewer's follow-up questions were based on Ardell’s (2002) wellness model. Ardell believes that high level wellness means “giving care to the
physical self, using the mind constructively, channelling stress energies positively, expressing emotions effectively, becoming creatively involved with others, and staying in touch with the environment” (p. 10). As mentioned in Chapter Two, Ardell’s model is not specifically a teacher wellness model; however, it does apply to all working adults. Using his three domain model (mental, purpose and meaning, and physical), the researcher explored whether teachers who teach children with a chronic illness experience an effect on their own personal wellness as a result of educating sick children.

Procedure for Data Collection

After approval from the University’s Ethics Review Board (see Appendix C) the first step was acquiring participants for the study by gaining approval from the superintendents of the local school districts or independent schools. Following the approval from the appropriate administrators, the next step was to identify the principals of the schools that have students with congenital heart disease and to explain the purpose, benefits, and consequences of the study. Pending permission from the principals, a request was made to teachers for participation in the study. In addition, notices were placed throughout the education department of the local university, recruiting volunteers who have experience teaching elementary students with congenital heart disease. Interested participants called or emailed the researcher (see Appendix D).

From my journal: When I first wrote my research proposal, many months ago, I remember thinking, only six teachers that won’t take very long. Little did I know that it would actually take me five and half months. Thanks to my supervisor, I right away had a few leads to find some participants. Once I interviewed these teachers, I still needed four more. It was still thinking this wouldn’t take very long. I did realize that the time of the year was not the best time. I was the beginning of December. I was still hopeful I would be able to at least find a few
willing teachers before Christmas. I contacted two school boards. One of the boards had a database that identified where these students attended school, the other board did not. The first board that already identified the students had potentially 20 teachers that I could interview. I diligently followed my protocol of speaking with the principal gaining permission and then leaving letters of invitation to participate in my study. I heard nothing. The question was how long do I wait? I decided I would wait until Christmas. After the holidays, I would resend letters to the indicated teachers and then pursue other boards. With the second rounds of letters, I had two participants call me. I was so excited. Then nothing... I pursued two more boards. It was very hard to find out which schools had a student with congenital heart disease since there was no database. Eventually, I contacted over 50 teachers but yet I only had four educators contact me. This is when I questioned myself ‘if I was teaching a sick child would I want to make time for a study?’ I started to appreciate my participants’ time and energy even more. I felt panicky as month after month went by and I had no contacts. Would I ever graduate?

During the initial conversation, the researcher introduced herself and explained the purpose of the study. If the participant was interested, the researcher scheduled an appropriate time for an interview. All interviews were held in the participants’ homes to help participants feel more at ease. However, the choice of conducting the interview at the university was also offered. The researcher chose not to interview at the participants’ schools for two reasons: (a) to ensure the confidentiality of participants; and, (b) to ensure more freedom for participants to speak about experiences without worrying about external influences. Each interview lasted about forty-five minutes to an hour.

At the start of each interview, the researcher’s first goal was to build rapport with the participant by entering into a conversation about demographic information. The researcher repeated the purpose of the study and explained that, at any time, the
participant had the right to withdraw from the study. Before the interview began, the researcher reviewed the Letter of Informed Consent with the participant and, after making certain the teacher understood what was involved in the study, the participant was asked to sign the form (see Appendix E).

From my Journal: I did find it quite hard to be neutral in my interviews. My first interview was my hardest one. I identified with the educator regarding stress. She had increased stress through the experience of having a severe medically fragile student in her classroom without support. I too, have taught a little boy who had serious needs with very little support. I felt my own anger in this interview. Anger that there was no support for this special student. I had feelings of injustice for the student. Why was he over looked? Why did my school feel that he was not important enough to be safe at school? Without the proper supports, he was not safe. As a teacher, you often feel like you need to be an advocate for your student, however the fight is a hard, draining one and often without results. I heard these same thoughts from Amy, the first participant I interviewed. I found that I had to keep to the interview guide like glue and keep comments to myself in order to keep my own biases from leaking into the interview. However, after the interview was finished, I was able to support this teacher by sharing my experience with her briefly and this sharing encouraged both of us. Teaching children who are medically fragile can be quite isolating and this sharing helped us to know that others have felt this way too.

The interview process was conducted as outlined in Appendix B and recorded on audiocassette tapes to enable the researcher to transcribe the interviews verbatim at a later date. After each interview, the researcher explained to the participant that a transcribed and thematically analysed transcript would be mailed or emailed to them for verification.
The researcher also explained that once the participant had a chance to review the transcript, a second telephone interview would be set up to request verification of the credibility of themes within the research project. This was done to enhance the accuracy and validity of interpretation, understanding, and the explanation of the experience (Anderson & Arsenault, 1998). To ensure positive relationships, a thank you note with a gift certificate for a specialty coffee was sent out to participants for their involvement in the study.

*Procedure for Data Analysis*

Bogdan and Biklen’s (2003) method of analysis was used to examine and organize the data by breaking down the information into manageable parts, synthesizing, searching for patterns, and discovering what is important and what is to be learned. In accordance with Bogdan and Biklen, the researcher’s first step was to spend time away from the data to allow speculations or questions to arise after the transcription of the interviews have been completed. Ideas and reflections were entered into the research journal. As a second step, the researcher read the transcripts thoroughly to gain a sense of the data and to acquire an initial understanding as to the meaning of each participant’s experience. Marginal notes were made that reflected first impressions, thoughts, or ideas. Subsequently, the researcher examined the data for certain words, phrases, ways of thinking, or patterns of behaviour that could potentially be identified and assigned a code.

Preliminary coding categories were developed using Bogdan and Biklen’s (2003) pre-assigned coding families where applicable (see Appendix F), as well as researcher defined units. Each code was abbreviated for use on transcripts. Coding categories were modified and new codes developed as the analysis proceeded. Broad coding categories
were broken into smaller categories or sub-codes. Upon completion, when all data were assigned a code, the researcher was ready to mechanically sort the data using the coding system and the cut-up and put-in folders approach as outlined by Bogdan and Biklen.

As some of the data units were coded in more than one category, several copies of the transcript were made. Each data unit was carefully labelled with the interview and page number to prevent confusion. Several of the data units were placed in more than one of the folders as they fit under more than one content category. The transcripts were cut so that the units of data could be placed in folders that had been labelled with one code. With all the units of data in the respective folders, the researcher carefully examined the contents for patterns and themes. Themes were only considered if the researcher could identify a trend in two out of six of the interviews.

_from my journal:_ As I began to sort my data and identify themes, I had to decide how many participants must agree on a theme in order to include that theme. Majority of the themes were quite high in percentages and I could easily agree on 50% or more. However using this cut off point, I found myself excluding themes that I knew were important to my participants. These were issues that the participants discussed with emotion and items that resonated with me as I reviewed the transcripts. Although some of these themes were not prominent, they were salient and meaningful to their experiences. I felt responsible to make sure my participants’ voices were heard. Therefore I decided salience was the utmost important part, not percentages.

Themes were recorded on cue cards with phrases from the transcripts corresponding to the original transcript number. Finally, the researcher created categories by inspecting the themes and patterns to identify any alternate theme assignments.

To help with verification and validity, the researcher’s supervisor examined the extracted units to ensure validity and accuracy. When this stage was complete, the results
of the categories, themes, and codes were presented in tables. For a second check of analysis validity, the researcher mailed the transcripts along with the results in table form to the respective participants. A two-week time was allotted for feedback from the participants. Subsequently, the researcher then called or emailed to arrange the follow-up telephone interviews to validate data that were then conducted with each participant. Once theme clusters were verified by all participants, the clusters were used to create a composite description of the experiences of educators who teach children with congenital heart disease.

*Authenticity*

In order to encompass authenticity, implementation of the following multi-methods was used to confirm data. First, the interview guide was submitted and approved by the supervisory committee and for each participant the same framework of interview questions was used. Also, a pilot interview was done to ensure participants understood questions, as well as for the researcher to become comfortable with interview guide. Second, member checking was used as the researcher asked participants to confirm descriptions of the experience and the credibility of themes. Third, the researcher’s supervisor reviewed categories, themes and codes. Fourth and finally, self-reflection of the researcher’s bias was acknowledged for the readers by including parts of the researcher’s journal entries in the document (Creswell, 2003).

*Ethical Considerations*

Potential risks to the participants of the study were expected to be minimal; however, it could have become upsetting for the participants to discuss sick children. If participating in this study resulted in any emotional problems, the participant was
encouraged to use the school counselling services already in place. All participants signed a consent letter prior to the interview (see Appendix D). This letter outlined the purpose of the study, procedures, and the right to withdrawal at anytime. Anonymity was maintained by identifying each participant by a pseudonym. In addition, all data have been kept under lock and key and will be destroyed five years after the study is completed. There was no compensation offered to school boards or the participants, however participants did receive a thank you note and a small gift certificate for a speciality coffee.

Summary

In order to answer the question, “What are the experiences of teachers who teach elementary students with congenital heart disease,” a qualitative approach was employed. This approach is consistent with the study’s objective, which is to explore teachers’ experiences of teaching a child who has congenital heart disease and how this affects teacher wellness. A phenomenological design was chosen to examine the teachers’ experience of the phenomenon. This chapter provided the researcher’s assumptions, selection criteria for participants, data collection methods, and procedures for data collection, and analysis. Finally, authenticity and ethical considerations were also discussed.

Chapter Four will provide a description of the results of the data analysis derived from each interview. The essential structure of the experience is outlined, and an overview of the thematic, cluster, and categorical representations are provided. Participant quotations are provided to convey the meaning of the participants’ experiences, and the teachers’ recommendations are presented.
Chapter Four: Results

In Chapter Four the data analysis of six in-depth personal interviews with elementary teachers who have experienced teaching students with congenital heart disease is conveyed. This chapter is organized into four sections. The first section begins with a brief introduction of the individuals who took part in the study. Next, I provide an outline of the essential experience. Then categories, clusters, and thematic structures are investigated and described. They are derived from the quotations of the participants, to convey the meaning of the lived experiences. Lastly, this chapter concludes with recommendations from educators in the study. These recommendations are for schools, parents, medical professionals, and researchers.

Participant Profile

Throughout this study, participants have been assigned pseudo-names to protect their identity.

Amy is a retired teacher who has taught for 30 years in the public school system. She has taught pre-school to grade five, teaching all subjects including special education. Her favourite area of instruction is literacy because she feels reading is important. Amy has experience with one student who has congenital heart disease. This kindergarten student had very severe heart disease. This participant was so stressed in her work environment as a result of this experience she had to take a leave from school.

Karen's teaching career of 27 years has been in the private school system. She enjoys teaching physical education, computers, and math. She has taught kindergarten to grade five. Her favourite is grade five because in her view, they are still keen and have a
healthy competitiveness to them. She taught a student with congenital heart disease in the upper elementary grades. The student did not have a severe heart issue.

Betty has taught for seven years and supply taught for three years in the public school system. She has taught grades one to four. She enjoys teaching grade two because they have acquired some level of independence in activities such as reading. Betty taught a student with congenital heart disease in grade three. At the time of interview, Betty did not believe her student’s heart condition to be severe. However, information obtained after the interview indicated it was more serious than previously considered.

Judi has been teaching for 27 years in the public school system. She mainly teaches primary and special education. Her favourite age group is grade one because of the high learning curve required in grade one as students learn to read. She also taught a student with congenital heart disease in grade one. This child did not have a severe heart issue.

Kathy has taught for approximately 30 years. She has mainly taught primary, including special education. She enjoys kindergarten students because of their curiosity and their endless questions. She has experience in both private and public schools. Kathy taught a student with congenital heart disease in a primary grade. This student had a severe heart issue. Kathy also decided to leave her teaching position and took a new position that was less stressful.

**Essential Experience**

Teaching a child with congenital heart disease alters the role of the teacher. Rather than simply a guide or facilitator of learning, the teacher is also expected to
become a health professional. With parents away from their children, the teacher assumes responsibility for monitoring these children’s health status.

This expansion of a teacher’s role has many implications. Teachers need to know more about congenital heart disease, especially signs or symptoms of distress, and they need to develop a plan of action in case of an emergency. They need to be in contact with the parents and medical team. No longer are educators only focused on a student’s academics and social involvement, but they must now also focus on the health status of their students.

This changing role affects teacher wellness in a variety of ways. While the high involvement in a child’s life can be very rewarding, there is additional stress due to the increased workload and concern for the child. Some teachers do not feel prepared to take on this role, citing a lack of time, information, and resources. While all teachers must be observant of their personal wellness, having a student with congenital heart disease increases this challenge.

Categorical, Clusters, and Thematic Structures

The data analysis of each interview revealed three categories: (a) Meaning and Purpose, (b) Mental Wellness, and (c) Physical Wellness. The first and second category consist of three clusters each. The final category includes only one cluster. Table 1 provides a visual overview of the categories and clusters. Tables 2, 3, and 4 illustrate the themes within each cluster. All of the theme groupings contain a representation of at least one third of the participants.
Table 1: Categories and Clusters

<table>
<thead>
<tr>
<th>Categories</th>
<th>Clusters within each Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meaning and Purpose</td>
<td>Relationship with Student</td>
</tr>
<tr>
<td></td>
<td>Additional Responsibilities</td>
</tr>
<tr>
<td></td>
<td>Parent Issues</td>
</tr>
<tr>
<td>Mental Wellness</td>
<td>Teacher Attributes</td>
</tr>
<tr>
<td>Physical Wellness</td>
<td>Concerns</td>
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<td></td>
<td>Limitations</td>
</tr>
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*Category One: Meaning and Purpose*

Meaning and purpose in employment and relationships influences satisfaction and personal wellness. An ample amount of time during an educator's day involves teaching their students academics as well as helping them to develop social skills and peer relationships. The majority of the teachers had never before experienced teaching a student with a heart problem and expressed concerns when first informed of this new situation. The educators were forthcoming in expressing the differences in their relationship with the student and how this changed their role as a teacher.

The meaning and purpose category contains three clusters: (a) Relationship with Student, (b) Teacher Attributes, and (c) Concerns. The themes that emerged from the data analysis are arranged in three clusters that are presented in Table 2. Each cluster is then discussed and enhanced with the inclusion of participant quotations.
Table 2: Category One: Meaning and Purpose

<table>
<thead>
<tr>
<th>Clusters</th>
<th>Teacher Attributes</th>
<th>Concerns</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship with Student</td>
<td>Humour</td>
<td>Safety</td>
</tr>
<tr>
<td>Apprehension</td>
<td>Proactive/Resourcefulness</td>
<td>Absences</td>
</tr>
<tr>
<td>Unexpected Rewards</td>
<td>Professional Knowledge</td>
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Cluster one: Relationship with student.

Throughout the interviews, participants described their experiences of teaching a student with congenital heart disease and how this impacted their teacher-student relationships. These differences are centered around four themes: (a) Apprehension, (b) Unexpected rewards, (c) Importance of normalization, and (d) Discipline.

Apprehension. Throughout the interviews, participants expressed their apprehension of having a student with congenital heart disease in their classroom. This included lack of factual knowledge on congenital heart disease, unclear expectations of the teacher’s role, lack of training pertaining to warning signs of distress, and lack of emergency preparedness. Apprehension was first felt when the participants were told at the beginning of the year that they were going to have a child with congenital heart disease within their classroom. Jen spoke of this concern: “At first we were all
concerned, like how are these little guys, especially the oldest one, how are these little
guys going to manage in school? Are they going to be sick every five minutes?” Another
statement she made, “when this little person came into my classroom, I [had] never
experienced any kind of child like this so you’re thinking do you have to handle them
with gloves?” Kathy wished that more information and more training were given prior to
having the student. “If a teacher knows that they are going to have a child [with
congenital heart disease] then I think that they should be given some in-service prior to
having the child in the class.” Kathy was fortunate that she did have some medical
training before having her student.

I had taken my national life guard training, first aid, and CPR with not
knowing that I was going to have a child with congenital heart disease…it
gave me an added confidence that I could handle [having the student
within my classroom] but it wasn’t a requirement. It was just an added
benefit.

The participants’ apprehension did not diminish as the school year continued.
Amy constantly wondered what was going to happen to her student. “I did not know what
could happen to him at any time and I was concerned you know that something might
happen. That was constantly in the back of my mind.” Educators expressed that prior
training was essential. Even though one participant, Kathy did have prior training, she
decided to take a different teaching position that did not involve as much emotional stress
and apprehension, this new position did not have a student with congenital heart disease.
However, Karen, who had personal experience with heart disease, did find that having
her own knowledge made her less apprehensive about having a student with congenital heart disease within her classroom.

*Unexpected rewards.* Throughout the interviews, the educators were clear that although it can be stressful having a student with congenital heart disease within their classroom, there are also positive rewards.

When you are working with a child who needs extra support, as they get things there seems to be almost a little bit more of a reward, they pass or can move on or are capable of or you see a positive thing happening in their peer groups or they might get up in front of the class and do a speech and you didn’t think they could do that or you hadn’t been pressing them to do that for whatever reason, so those were some rewards in that way.

(Karen)

Amy expressed the rewards she gained when working with her student with congenital heart disease. “Delightful little guy, you know, he was just a sweet little person and I enjoyed him for being the person that he was.” Personalities of these children shone brightly as teachers spoke of their cooperativeness and zest for life.

I don’t know how much of this is his personality and how much it is [that he has congenital heart disease] but he’s very enthusiastic and he’s very, almost to the point of it being very surprisingly polite for example, if I say to him, “X, you’ve got this mixed up, so how would it be if you put this one over here and you did this one over again?” or something like that—“oh, sure! No problem, I can do that!” and off he goes back to his desk.

(Betty)
The teachers were clear that the rewards may not be because the student has congenital heart disease, but simply because they are children. They are just like any other child with personalities and just want to be loved for who they are.

*Importance of normalization.* Educators identified that both themselves and parents acknowledged the importance of treating a child with congenital heart disease the same as a healthy student. At times, this may not be possible due to health concerns, but whenever possible, teachers tried to treat all their students the same. Karen clearly articulates this point:

I have strived for throughout my entire career is fairness and I don't see fairness as being an immovable goalpost—these are the expectations for homework, you need to hand them in, if there is a problem of course the student and I could work on it together and then maybe the parent needed to become involved but I try not to treat any child differently regardless of health, mind, body, or soul.

Like several of the participants, Jen desired to treat her student as normal as possible "He's just a little child and I think they need to be treated like normal children but with the knowledge that they may not be able to do certain things." Amy added, "I enjoyed him for being who he was, I tried not to treat him any differently but he was special." Teachers also expressed how the parents of their students desired for their children to be treated like regular children. "The parents worked hard to make sure they were as normal as possible" (Jen). This need for normalcy is common for parents of children with other forms of special needs.
Most educators try to treat all their students equal and not make anyone feel different; however, the fact is that a student with a severe medical issue like congenital heart disease, will sometimes be treated differently. Teachers have to monitor these students; they have apprehensions that typical teachers do not have. A teacher’s role changes when they have a student with congenital heart disease. As a result, the relationship with the student may change, and at times, they may be treated differently. Discipline is an area where this is most noticeable.

*Discipline.* It can be challenging for teachers when they are required to discipline a student. This can make it awkward and stressful for the teacher, having to be sure that the correction is being done in a respectful way and in not emotionally harmful to the child. Discipline is necessary within the classroom, not only to have a positive learning classroom environment, but also to help mould successful citizens of the community for the future.

The need for normalcy, raised concerns for teachers when disciplining was an issue because often the student was not being treated the same. For example, Amy felt that, if it was necessary, she would discipline her chronically ill students like her other students, but with some caution.

In a lot of ways I try to treat them the same as every other child so if they were doing something they shouldn’t be then I would let them know, I might not have been quite as harsh or strong, depending what they have done, as I might with a regular child but I felt that they needed to know some of the things as well.
Judi spoke of making sure that her student was disciplined the same but also at the same time spoke about being warmer with her voice when disciplining her student with congenital heart disease. "I make sure that he gets warmer treatment but not extra special treatment."

The teachers explained that they are more cautious when it comes to discipline regarding the child with congenital heart disease because they do not want to add stress to the child's heart. "I think I would be mindful that I didn't want to put additional stress on this child so I think I would use humour to kind of steer and to guide them." (Kathy)

When I spoke with Betty during the second interview, she told me that the student she taught had gone for his yearly check-up after my interview with her and now his parents had been told to not put him under any stress. She felt that due to this change, she would now answer my questions differently regarding discipline. She is now unsure how to treat him, fearful of adding stress to his heart. She is uncertain how to balance the need for normalcy and appropriate discipline. She does not want him to become frustrated with schoolwork and is fearful of him having arguments with peers. This unknown of how to treat a student with congenital heart disease is problem for teachers. More research is needed in this area of normalization and discipline.

*Cluster two: Teacher attributes.*

Throughout the interviews, educators spoke of personal attributes that empowered them during the year when teaching a student with congenital heart disease. These attributes are centered around three themes: (a) Humour, (b) Proactive/Resourcefulness, and (c) Professional knowledge.
Humour. Laughter and humour were identified as being important in their classroom. The teachers felt that humour created a positive learning environment and motivated students. Jen felt that humour was integral to teaching.

You cannot be a teacher if you don’t have a sense of humour. You will not survive. You know, you have to be able to laugh at yourself, you have to step back out of situations, you can’t survive without a sense of humour in that job, it’s just gotten so tough in lots of ways.

Judi stated that, “I like to laugh! Sometimes I try to trick the children and we laugh a lot about it.” Laughing was also part of Karen’s philosophy of teaching.

My line is, if you are not laughing it’s not going in. If you’re not laughing, you’re not learning, if you’re not having a good time, you’re not learning, you don’t want to ever see anybody sitting at their desk just shaking because they can’t do something so lots, lots and lots of laughing is needed.

When asked if humour plays a role in the relationship with the child who has congenital disease, all teachers indicated that humour did not change for this specific child. However, they did not talk about the importance of humour regarding their own personal wellness or if humour was used in all areas of their life, not just as a teacher. Further research is needed to understand if humour was helpful in achieving personal wellness.

Proactive/Resourcefulness. Teachers felt the need to proactively research congenital heart disease on their own due to the lack of information they received from the school system. All participants described the actions they took to educate themselves
about congenital heart disease. Specifically, the educators spoke of talking with the parents “I asked his parents many questions” (Judi). It was interesting how the educators spoke of being proactive, going out and getting information. However, they only obtained information through parents. Teachers also described a desire to speak with the medical professionals involved in the treatment of their students.

Some of the teachers were proactive by doing tasks that a typical teacher does not do. Kathy was only the AM teacher; therefore, her PM teacher and the parents all needed to establish a way to communicate about the student. Some teachers may do this for a typical child, however, it is not typical to need a journal to discuss how the student is handling things physically or medically.

I was the AM teacher and there was a PM teacher so we would also consult and we would always leave a journal between us as to how her well-being was, her physical health, that we thought she should sit out in phys ed or something and that would be made note of that she needed a rest that would be made note of so it was ongoing communication with the other teacher and with the parents and we would get a journal from the parents as well to say how she was doing.

Again, the teacher’s role had changed; they were required, for this child, to do something that was not required for a healthy child. At the time when Kathy was teaching her medically fragile student, the internet was not available. None of the teachers in the interviews described using technology to help with the additional responsibilities of having a student with congenital heart disease. It would be interesting to further explore how to use of new technologies might
improve the communication about crucial information between teachers and parents.

*Professional knowledge.* Only two of the educators indicated having knowledge or training prior to teaching the student with congenital heart disease. Both teachers felt that this knowledge or training made them feel more prepared and confident.

I would consider that even before having a student I had a pretty good grasp on it. I have a heart murmur myself so I was aware, an innocent heart murmur, of where that was going and my physiology and anatomy background from phys ed gave me some sense of what a healthy heart would be and then any questions I had about any forms of heart defect or disease I knew I could get at my fingertips if I didn’t have something directly right on. (Karen)

Although both teachers indicated having training or knowledge of congenital heart disease and both felt this benefited them, only one teacher continued working with the student who had congenital heart disease. The other teacher opted for a different teaching position because of the stress and ongoing need to monitor the child’s medical status. The teacher who decided to stay with her student described her student as having a student with a less serious form of heart disease whereas the teacher who decided to leave had a student with a more serious form of congenital heart disease. Therefore, further research needs to be conducted to determine if the impact of prior training is dependent on the severity of the child’s heart condition.
Cluster three: Concerns.

Due to the uncertainty of what to expect when teaching a student with congenital heart disease, each participant had concerns regarding the chronically ill child. These concerns are centered on two themes: (a) Safety, and (b) Absences.

Safety. Having a student with a medical issue enhances teachers’ concerns about safety. In this study, teachers were concerned about their students’ safety because they were unsure of how to keep their students safe. Moreover, in almost all cases, teachers lacked an emergency plan.

Most of the participants taught primary children. In elementary school, fieldtrips are popular. Kathy felt that organizing fieldtrips added to the stress encountered when teaching a student with congenital heart disease. “With this child it was always a concern about safety and how do you manage her safely in the class and out of class and especially field trips, that was especially stressful.” (Kathy) The educators also spoke about the concerns about recess and physical education “I was always concerned about them keeping up with the other kids like in PE especially outside play I’d have to be a little more aware of where they were” (Jen). “Like recess, if I wasn’t on duty and [the student] was out on recess that sometimes was a concern. When she would come in from recess, I would see how she was because I didn’t particularly think that she was being necessarily monitored” (Kathy).

The teachers had safety concerns over day-to-day safety, field trips, physical education and recess. These issues were the key concerns to the two teachers who left their positions due to stress.
Absences. Children with medical issues generally have more frequent and longer absences from school. Students with congenital heart disease may require surgeries or experience a weakened immune system, thereby making them more susceptible to common childhood viruses. This weakened immune system causes the student with congenital heart disease to miss more days of school than a typical student. “If they were ill, unfortunately they were ill often, you know, a week or two longer than the other kids sometimes it just depends I don’t remember them getting chicken pox or anything but we had to be careful” (Jen).

Jen felt that, because her student spent a great deal of time in the hospital, this affected his development. “[He is not as] agile as the other kids and that’s simply I think because they had spent so much time in the hospital.” Although all other teachers reported that absences were not an issue specifically with peer relationships, Karen was unsure. “Peer relationships were something that this child struggled with and it may have been a result of previous absences.” Jen was not sure if absences were the only thing that affected her student’s peer relationships, but suspected that it may affect relationships to a degree. Although there were some contradictions in this section among the teachers, it was clear that these students do have more absences but teachers were unsure of the effect this of this had on their students.

Only one teacher reported her student requiring a stay in the hospital during the time she taught the student. Although, it was not required of her, Jen decided that she would visit her student while he was in the hospital.

I do remember one time going up and seeing the younger one in the hospital because he ended up with a problem and of course they had a
school program at the hospital and I remember giving a, you don’t have worksheets in kindergarten, but I had, I had a couple of little art projects that I had been doing as a kid, a couple of books that I, because I used to teach them in groups of things like if we were concentrating on some math things I made sure, I remember he had a I remember taking up a little bag of math stuff toys for him to work with if he felt up to it because he was in I remember about 2, 3 weeks he was in.

Typically, teachers do not make visits to the hospital unless they are teaching children with special needs, and these visits tend to be during the teacher’s free time. Seeing a young child in the hospital can be upsetting and in return, may affect personal wellness. Hospital visits demonstrate the compassion and thoughtfulness of educators; however, this extra duty changes the role of the teacher, and thereby likely affects personal wellness.

Category Two: Mental Wellness

Mental wellness focused on factual knowledge, effective decision making, mental health, and stress management of the educators when teaching students with congenital heart disease. The mental wellness category contains three clusters: (a) Responsibilities, (b) Parental Issues, and (c) Limitations. The themes that emerged from the data analysis are summarized in Table 3. Themes are then discussed and illustrated with quotations taken from the interviews.
Cluster one: Additional responsibilities.

Throughout the interviews, participants felt that teaching a student with congenital heart disease added additional responsibilities to their workload. These responsibilities are centered around two themes: (a) Individual support, and (b) Monitoring.

Individual support. Teachers described that the additional support required when a student with congenital heart disease was comparable to an identified special education student. This is a very interesting point, as the majority of the participants’ students did not qualify for a chronic health designation. Teachers reported that, although not all the students qualified for an individualized education program, their curriculum was modified or altered: “I had to adapt his program because he wasn’t getting enough
oxygen to the brain" (Amy). Her student specifically had a 50% blockage to his heart and the lack of oxygen severely affected his development.

Karen noted that because of the extra learning support, "there was more time spent [with the student who has congenital heart disease], there is more time with any child that needs a supplement to the curriculum." Some of the students did have an individualized education program, which also required additional work. "Once you have a student with an IEP, there is always extra work because you have IEP meetings and report card has to be written differently and all that stuff" (Betty).

It was clear that the teachers had duties above and beyond those of a typical teacher, especially when required to adapt the curriculum. Teachers described it as being comparable to having a student with an individualized education program in the classroom; however, the majority of the teachers in this study taught students that did not qualify for additional funding. It was perceived by the teachers that it was solely on their shoulders to know when and how to adapt the curriculum, if needed, for the student with congenital heart disease.

**Monitoring.** The teachers defined monitoring as "watching the student for any physical signs that the child's heart may be in distress." Unfortunately, the teachers were not clear on what exactly these signs were. The educators identified this lack of knowledge as being a problem. The parents of Betty's students told her, "He's fine, he can do any activities, you know, if there is a problem he will come and tell you."

However, Betty described how she was uneasy with this child monitoring himself and therefore also felt the need to monitor him. She further explained that she was unsure as
to what exactly she was monitoring. Judi was also not clear on what types of signs of
distress she needs to look for.

Sometimes I wonder if he just gets tired by the end of the day and just had enough
work. Or whether he can do it and just wants to get out of it. But I am thinking
now talking with you, that maybe he is just tired because of his heart disease.

Again, Jen struggled with not knowing what the signs of heart distress were or what
perhaps was avoidance behaviour on the part of the child. Is the child simply not wanting
to participate or do the work expectations of that grade? Or does this student’s congenital
heart disease affect him physically or academically?

Other educators spoke of the stress of having to constantly watch or monitor the
student with congenital heart disease.

We just would monitor her—it was more her colouring and just monitor
her colouring and her pulse and if she was really flushed we’d just say,
“maybe this, you know, just sit out a little bit,” and so it was more in the
physical activity that we felt we had to monitor and then on field trips we
were, you know, mindful of distances on field trips, how if it was going to
be stressful to her or not. (Kathy)

“I found I was constantly monitoring to see how they were doing, I had two in one class
and making sure they were safe and I found it took a lot of energy” (Jen). Again, teachers
are expected to change their role, that is to not only teach the student but to also monitor
their well-being. Generally, a typical teacher does not have the responsibility of
monitoring student health. Teachers have expressed that they feel unprepared for this
responsibility and need more training.
Cluster two: Parental issues.

Often parents with sick children face a demanding and lonely journey. It can be one of the most draining and difficult tasks parents may face. As the child with chronic illness begins school, further stress may arise as they let go of the constant supervision of their child. Caregivers are expected to allow the school to care for their children even though, in many cases, these schools have limited knowledge or experience with chronic illness. Consequently, parents can be overwhelmed as their children enter the school system. Throughout their interviews, teachers discussed two themes (a) Relationships with parents, and (b) Parental support.

Relationships with parents. Just as with typical students, having a positive relationship with the parents is important when teaching children with congenital heart disease. However, the educators felt that developing a positive relationship with the parents of a child with congenital heart disease is even more crucial. Parents are often anxious when their children start school because they have to trust others to monitor their child. Some of the participants were kindergarten teachers and this was particularly problematic as they are the first educators parents encounter:

They come into the school, they don’t know me, especially at kindergarten, at the time I might have been in the school 3 or 4 years so whether they knew me or whether I had a reputation in the district in the area, who knows and they are nervous. You’re nervous about them, you’re wondering how they are going to relate to you. However I was most fortunate that [Mom] was a very friendly, outgoing and we got along and that’s really important. If she didn’t like me and didn’t like what I was
doing it probably would have been a totally different experience but I was very fortunate she was most interested in what I had to do. (Jen)

It is difficult for parents to allow the schools to care for their children when their children have specific health needs that must be met. This apprehension and concern for their children can influence and change the relationship that they have with the teacher. Kathy explained that:

Whenever you work with parents, of special needs children, you end up getting close to the parents because it necessitates that you be in close conversation, in close communication so you know, children that I’ve worked with that are healthy. I haven’t needed to be in as much contact with the parent and so there is an additional responsibility to be in greater communication. With the healthy children you’re still in touch, you know, during reporting and their concerns but not the additional.

Amy spoke of how her relationships with the parents of her child were different:

We started out with a wonderful relationship but because of the outside situation, things changed. One situation was that when we finally had decided that we were going to have an assistant in the classroom to help him [the student with congenital heart disease], there was the whole issue around hiring this assistant. What happened was this person who was placed temporary really wanted the position but she didn’t have the seniority to have it. She worked with the mom and basically telling the mom, “I’m the only person that can take care of your child” and she did some really inappropriate things. We had interviews, got a nurse, who
works in a paediatric ward at the hospital. But this other assistant had so coloured [the parents] that this person stayed for 2 days and then she wasn’t back. She says, “I’m not going to deal with this mother because she doesn’t think I can do it.” I was furious with this mother for doing this to this person who was just going to be so wonderful.

Stress, expectations, and additional demands of parents affect the relationships with teachers. Frequent and consistent communication is required to ease parents’ worries and to monitor the students safely. This level of communication is above and beyond the expectations of typical teachers. Each of the teachers felt maintaining a positive relationship with the parents was very important; and that the relationship changed regardless of the level of severity of heart disease.

Parental support. While none of the questions from the interview guide specifically asked teachers if they had received parental support, this issue was discussed. Although some teachers did not perceive that they received parental support, those that did described how much they valued it. “You know, and I was lucky, very lucky, because they worked out very well, the parents were really helpful, they were supportive of the school, because you run into trouble with that sort of thing” (Jen). “They are very supportive, they volunteer in the school, and they are more then willing to support” (Betty). Amy, who went on stress leave, discussed having support from the parents at the beginning of the year, but as frustrations arose due to a lack of funding and perceived support, the parents became less supportive. As the parents became less supportive and Amy felt more isolated, she decided that she had to take a leave for her own health and wellness. Kathy, who also left her job for a less stressful one, spoke about the lack of
support and feeling like she had all the responsibilities on her shoulders. Therefore lack of perceived support from parents may affect teacher wellness and burnout. Further investigation is required to assess lack of support, isolation, and effects on wellness, but more importantly how home-school relationships can be strengthened.

*Cluster three: Limitations.*

Limitations such as lack of support, lack of knowledge, lack of an emergency plan, and isolation were expressed by the educators during the interviews. Understanding the source of these limitations as related to congenital heart disease are important to understanding how to best support teachers who are teaching students with congenital heart disease. Throughout discussions, educators provided insights into five main themes: (a) Lack of support, (b) Isolation, (c) Lack of Knowledge, (d) Academic Expectations and, (e) Lack of Emergency Preparedness.

*Lack of support.* Teachers stated that the main reason they felt limited in their ability to teach was due to inadequate funding. The teachers in this study explained how that even when having students with a serious heart disease, these students might not qualify for additional funding. Nonetheless, teachers then feel responsible to create an appropriate program. The teachers valued students with congenital heart disease, however, without proper supports, teaching students with congenital heart disease increased the level of responsibility and stress.

I really enjoyed it. I found the frustration of not being able to get support in dealing with this. I thought a seriously disabled child in you know, in his heart because he was, doctor said, “he could just drop dead at any time” and I just didn’t feel it right to have no support for that at all. (Amy)
Overall teachers described experiencing stress by having an ill child with little to no information, emergency plan, or support.

I don’t think it’s possible for a regular classroom teacher to be an expert on like everything you know, ADD, ADHD, several kids who obviously have problems but haven’t been diagnosed or haven’t been identified. The OCD, the heart disease, the speech problems, the we have a little girl who’s very, very behind developmentally because of birth problems and drugs and that kind of thing, fetal alcoholism. I just don’t think one person can be an expert in all that and be a regular classroom teacher and do all of that too and know all the programs and be able to teach everybody all of the subjects. So I really think with any of those kinds of disabilities we really need more support. (Betty)

This is a powerful statement: teachers cannot handle it all on their own. However, more and more is expected of teachers. Are other professionals expected to be an expert in all areas? Why is this expected with educators? Again, the teachers’ role is expected to change and teachers are expected to know how to adapt and change without any additional supports or training. Teachers were clear that a lack of support was detrimental to their well-being and also limited their ability to be effective educators.

In the interviews, teachers explained that due to a lack of funding, there were no teacher aids within the classroom to assist teachers with children who have severe heart issues. There was no one to be responsible for monitoring specifically for these students during lunch or at recess time.
That's a huge problem because I mean he's been identified I guess, to the best of our knowledge, that we've got and where it's supposed to be but you know, there's been like a freeze on testing in our district well we have 2 or 3 kids who have—we don't know. They are not working to capacity but we don't really know why and I'm not and neither is anybody else in our school even our learning assistance people are not qualified to figure out what's wrong with those kids and you want to catch them early to try to get them the programs they need but you can't because we don't have enough time.

Amy, now retired, assumed that the problem of designation was "probably getting worse rather than better because of the kids, they are designating less and less children and if they are not designated then they don’t have the support." Kathy stated that, "there just isn’t funding for them.”

Without proper funding or knowledge about how to access funding for these chronically ill students there will not be the proper supports built into the school system to monitor them at all times. Teachers felt stressed with the load of responsibilities they encounter when having a student with congenital heart disease.

Isolation. Due to the severe stress and lack of support, two teachers identified that they felt isolated. Interestingly, both of these teachers were the ones who ended up leaving their jobs due to the stress.

With the exception of the person I team taught with, I felt the responsibility was on my shoulders and I think it would be really
important that teachers feel that the school is there to support them and the needs of that child. (Kathy)

Amy talked about wanting to have someone to share the experience with her: “At least I would feel that I had someone to share it with and that we could work together. I felt alone. I felt really all alone.”

Isolation was a serious issue for these teachers and most certainly a feeling that would impact their personal wellness. More investigations are needed to further explore this finding; what made these two teachers feel so alone? Why could they not reach out to their fellow teachers or administration? Is the experience of teaching a student with congenital heart disease so different than other illnesses, that they were unable to share their thoughts with others? What can be done to prevent teachers from feeling isolated in the future?

_**Lack of factual knowledge.**_ When the educators were asked, “What kind of factual knowledge did you have pertaining to congenital heart disease?” all educators said none or very little with the exception of one teacher who described having her own personal experience with heart issues. The next part of the question dealt with how they acquired information. Each participant shared that information came from the parents. “The time I had those two little fellows, it was mainly I going after the parents, sitting them down, talking to them, asking them questions”(Jen).

Research has indicated that parents may need help in sharing information partly because it may be overwhelming for parents to “let go” when their child goes to school (Johnson et al., 1988). It is challenging for parents to transfer the responsibility to the school, especially, as they believe the majority of educators were not adequately prepared
Experiences of Teachers

for students with congenital heart disease. It is not, therefore, surprising that parents may not always be forthcoming with information. Betty spoke of the meeting that she attended where she was not confident that she had been given all the information she needed.

    We had the IEP meeting, reasonably earlier in the year and I was at that meeting and the parents basically said you know, "he's fine, he can do any activities you know, if there is a problem he will come and tell you, call us if there is a problem," right. Seemed like that, that seemed to be the only information that we needed.

Jen shared that,

    The only factual knowledge that I received as a teacher was the information that the parents gave me. One parent was very, very forthcoming and gave me a lot of information, the other parent—she faints, just step over, so I didn’t have a lot of a lot of facts. [It made me feel] unprepared for what I was doing and concerned that I would be doing the right thing and helping their child in the right way.

    This limited information about congenital heart disease is problematic and creates stress in teachers’ lives. They are not given adequate facts about congenital heart disease. For example how does this disease affect learning, the student’s life and, what type of warning signs can be seen when the child’s heart is in distress? If educators do not understand the ramifications of having congenital heart disease, why are teachers left on their own to create emergency plans? This added responsibility combined with lack of support and inadequate information, often created a high level of anxiety which significantly affected teacher well-being.
Academic expectations. Due to the limited understanding teachers have about congenital heart disease, teachers are uncertain of the effects of congenital heart disease on the student. Teachers referred to this uncertainty when they considered the academic troubles their students sometimes faced.

When you get into the heartbreaks of grade 6 there is some pretty high level things that she had either missed, and this is what we weren't sure of, had she missed it or was she not capable of it and if she wasn't capable of it did it have anything to do with the physical condition or was there something more? (Amy)

Judi expressed that sometimes she was unsure of how much her student’s congenital heart disease had affected him academically: “With the knowledge that he may not be able to do certain things. I’m not exactly sure how it affects him intellectually.” Teachers need more information to understand how congenital heart disease affects students learning and development. Interesting to note, even the teacher who had personal experience with heart disease was unsure of how this disease affected her student’s cognitive and academic development.

Lack of emergency preparedness. Lack of factual knowledge about congenital heart disease is a serious issue as it influences a teacher’s ability to react in an emergency situation. All except one educator spoke of not having an emergency plan in case something should happen to the child with congenital heart disease. Even Amy, who had a student with a severe congenital heart disease, had no emergency plan. She explained that after advocating again and again, they finally gave her a baby monitor so she could reach the office without leaving her room.
They finally did put a child monitor in my class, that I could buzz the office ... I didn't have [any way to contact the office] for a year and a half. I had no way to contact the office other than go to the teacher across the hall and say, "Will you watch my class, I need to go to the office?"

Other educators spoke of this issue of not having any way to contact the office without leaving the classroom. Jen's emergency's plan was to "run out and send somebody down to the office right away, I would send a quick little one down to the office." Some of these students with congenital heart disease could require medical attention at any given moment. The fact that teachers had no emergency plan was a problem. However, the fact that they could not contact the office was an even larger problem. How is a teacher supposed to handle a situation that demands medical attention immediately if they do not have access to a phone or the office? The lack of emergency preparedness needs to be addressed in the schools' board policy. Further research needs to be conducted to make best practice recommendations regarding the development of emergency plans. Parents and medical professionals should be involved in this policy development.

**Category Three: Physical Wellness**

The physical area of a teacher's wellness consists of exercise, nutrition, appearance, challenges, and lifestyle. Educators are increasingly being stressed and overworked (Lauzon, 1999). When teachers are overworked they have no time for exercise or other activities to enhance their physical well-being. These demands may have a detrimental effect on teachers' physical well-being. The category of physical wellness holds one cluster: (a) Personal well-being. The cluster is discussed and enhanced with the inclusion of participant quotations.
Table 4: Category Three: Physical Wellness

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<tr>
<th>Cluster</th>
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<tbody>
<tr>
<td>Personal Well-being</td>
</tr>
<tr>
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</tr>
<tr>
<td>Themes within the Cluster</td>
</tr>
<tr>
<td>Stress</td>
</tr>
<tr>
<td>Concern for Future</td>
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<tr>
<td>Balanced Life</td>
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_Cluster one: Personal well-being_

Throughout the interviews, participants discussed their experience of physical well-being when teaching a student with congenital heart disease. This discussion revolved around three themes, (a) Stress, (b) Balanced life, and (c) Concern for future.

_Stress_. Educators spoke of stress as having a detrimental effect on their everyday life and working environment. Teachers did not have enough information about congenital heart disease to feel confident and safe in their teaching practice. Teachers described having very little support and most had no emergency plans. They constantly worried about monitoring the child correctly. Jen expressed feeling fear at the beginning of the year with being told that she was going to have a student with a heart issue “[I had] fear at the beginning when I first had them I thought Oh God, are they going to have a heart attack on me.”

Fear that their student may not live through to the end of the year resulted in a great deal of stress. An example of how all consuming this fear could be is illustrated in
Amy's response to the question, "What were some unexpected rewards of having a student with congenital heart disease?" Her only reply was, "that he survived." The stress of not knowing if her student was going to live or die was overwhelming for her. Amy elaborated on situations that she encountered.

When he turned absolutely blue it was pretty scary and I ended up going on stress leave with this particular class, I'd had this child for a year and a half. [One time] he went to the washroom and he didn't come back and my heart was just you know and so I went down to see, because I didn't have any help in the classroom at that point. I had 2 hours in the mornings and none in the afternoon and I went down to the washroom and I was really expecting—said to myself, I could find something that I don't want to find. Oh, I was so stressed.

Teachers expressed that while teaching can be stressful, they felt it was even more stressful when having a student with congenital heart disease.

I have to cast my mind back but I did find it stressful although I found working with her in particular rewarding. I had an opportunity to take another job and I think it was a factor that in this other job I wouldn't be having to do on-going awareness of the physical well-being of the individuals so I think it played a factor, not significantly, like I wasn't unhappy in the job but when another position came available that would mean not having to attend to those needs I made a decision. I think I was less aware of how much stress it was playing out. (Kathy)
Two teachers felt such intense stress that they left their job. At that point in time, Kathy had not been teaching for a long time; however, Amy had taught for over 20 years. Lack of experience did not seem to contribute to the levels of stress in this study. More research needs to be done to find resolutions to how teachers' stress can be reduced when teaching a student with congenital heart disease.

*Concern for the future.* It is a teacher's role to help produce healthy, happy, productive citizens for the future. Teachers want their students to succeed in life and be happy. Several of the teachers were unsure of their students' futures. "I worry about him I guess when I think about the heart because I think there is maybe surgery down the road and I don't for sure, but you know, you kind of worry about him" (Betty). During the interviews, I witnessed caring teachers who reflected on past students wondering how they were now: "I still think about him whether you know, what's happened, has he been able to progress and how is he doing" (Amy). I interviewed loving and caring teachers who were concerned for their students' futures.

*Balanced life:* The importance of balance in one's professional and personal life was discussed. Educators expressed how this seemed to be a hard concept for teachers in general.

Often teachers forget that there is more to life then teaching, teachers need to learn to take care of themselves. I would see wellness as being having energy to participate in other than school activities and be able to set school aside and have other things in your life beside school (Amy).
Karen also expressed her desire to have balance: “I think that there has to be a good balance from your work life to your personal life.” Educators also indicated that wellness needed to be in physical, mental, spiritual, and health areas.

I think it’s when the teacher, or the individual, feels that they are healthy in terms of their cognitive, emotional, spiritual, and physical functioning and when they don’t feel healthy in any one of those areas they think that it’s potentially detrimental to their overall well-being.

It was unclear if having a student with congenital heart disease affected their lack of balance between school and personal life or if this was a problem across the board for all educators. Further investigation needs to be done in this area to illuminate the specific effect of teaching a student with congenital heart disease on creating balance in teachers’ lives.

**Participant Recommendations**

At the end of their interview, participants were asked to share recommendations for schools, parents, medical professionals, and researchers. Participants conveyed suggestions about what would make teachers feel supported and empowered when teaching a student with congenital heart disease.

*From my journal: I was surprised at just how many participants were hesitant on commenting on recommendations or suggestions with how to support teachers. The comment I heard most was “well I don’t have a lot of experience, I only had this one student.” It was almost like these educators felt like their experiences were not valid or important. They acted like they did not have a voice. In fact, the educators had similar experiences of not feeling supported, not have appropriate factual knowledge or have a
Experiences of Teachers

realistic emergency plan. As the participants started to share some recommendations, their voice also changed to confidence of understanding the experience and knowing what would help to make it the best possible experience. It was interesting how almost every single participant spoke of the same problem areas and had similar recommendation to empower teachers.

There were six recommendations made by the educators on how to make teachers who teach students with congenital heart disease more supported.

1. To create a team approach including medical professionals, parents, teachers, learning support, or community members in order to plan for and support the teacher and student with congenital heart disease;
2. To foster support from administrators, parents, and other professionals to aid teachers;
3. To create realistic written emergency plans that are in place prior to teaching the student;
4. To provide pre-training on factual knowledge of congenital heart disease and its effects;
5. To provide funding for substitute teachers to allow meetings during the working day; and,
6. To determine appropriate designation for children with severe chronic illnesses to allow for funding to support teachers within school.

Summary

Chapter four presented the analyzed data. The chapter began with an introduction of participants followed by an outline of the essential experience. Categories, clusters,
and themes were derived from the data. Direct quotations from the participants were used to further illustrate their experiences. Finally, recommendations from the participants were outlined.

In chapter five the study's findings in the context of the extant literature will be discussed. The limitations of the study will be discussed. Implications of the investigation and suggestions for future research also will be explored.
Chapter Five-Discussion

Chapter five, consisting of five sections, provides an overview of the study’s results. The first section provides a summary of the results and research contributions. The study’s results are further discussed in relation to the literature review and research questions. Research limitations and implications are then presented, as are directions for future research. This chapter concludes with a final summary of the present investigation.

Summary

The present study employed phenomenology to develop an in-depth understanding of the experiences and recommendations of teachers who have taught students with congenital heart disease. Interviews were used to gain insight into teacher experiences when teaching a student with congenital heart disease and how this may affect their personal wellness. Lastly, participants provided recommendations on how to support and empower educators when teaching a student with a congenital heart disease.

Research Contributions

While research exists on the experiences of school children with congenital heart disease, very few empirical studies examine the experiences of teachers who work with these students. Even fewer studies look specifically at teacher wellness. As a result, this study offers new insights to the field. Results are related to the existing literature where possible.

Purpose One: Examine Teachers’ Experiences When Teaching Students with Congenital Heart Disease

According to participants, having a student with congenital heart disease in their classroom changed their experience as a teacher. The experience changed because of
alterations to their role as a teacher. Alterations occurred in three areas: monitoring, academics, and discipline.

Each of the educators spoke about expectations around monitoring their student’s health. Participants shared that this increase in monitoring was similar to the increase required for students with disabilities, however, no additional funding was provided for the sick child. In addition this type of monitoring was a new role for them, as typically teachers do not monitor students’ health. This role change was problematic because the teachers interviewed were not prepared or equipped for it. Although research (Heart and Stroke Foundation, n.d.) suggests that all caregivers and teachers should know all warning signs and know when to call 911, teachers in this study did not have the appropriate information regarding warning signs of distress; therefore, they were not educated on how to effectively monitor health. Lastly, educators identified that they did not know enough about the medical side of congenital heart disease to have an appropriate plan of action if there was an emergency.

The most consistent finding among the extant literature is that teachers are unprepared, and have a limited amount of knowledge regarding chronic illness (Claire, 1985; Eiser & Town, 1987; Papadatou et al., 2002). All the participants’ in this study voiced that this lack of information is problematic. Without proper training or information the educators were not prepared to monitor students’ health. They needed to know the warning signs of distress, what to do if there is an emergency, and how congenital heart disease affects the student academically. Without this information, educators are left uncertain and unable to effectively monitor students with congenital heart disease.
Despite their lack of knowledge on congenital heart disease, schools expected teachers to effectively handle emergencies regarding these students with congenital heart disease. Participants indicated that, without proper information, they did not have an effective emergency plan. In fact, only one teacher even had a formal emergency plan. Surprisingly, the majority of the teachers also did not have a way to call the office or 911; instead, they intended to send a student to the office. The educators expressed concern over this state of affairs, but did not know how to address this problem. They desired more advice from parents, administrators, and medical professionals to create an effective plan in case of emergency. The need and desire for more support when creating an emergency plan is consistent with the literature (Mukherjee, et al., 2000; Papadatou et al., 2002; Shiu, 2001).

Research indicates that academics and homework is a problem for the students with congenital heart disease because of their frequent and prolonged absences from school (Papadatou et al., 2002; Sexson & Madan-Swain, 1993). This finding is in contrast to the experiences of participants in the present study. Although absences were acknowledged, none were prolonged or frequent. Only one teacher had a student in the hospital, however, academics were not an issue as this was a kindergarten student. Educators did identify that their student either had previous surgeries or anticipated surgeries in the future, however, this was not an issue at the time. Perhaps improving medical technologies are resulting in fewer school absences.

Participants shared that, while typical teachers assess, make a plan, and carry it out, they were unsure of how to carry out an academic plan because they were teaching students with congenital heart disease. They were uncertain of how the disease affected
learning and what types of expectations were fair for the student. Almost all educators spoke about adapting curriculum for the student even if they were not on an individual education program. The majority felt that they were not pushing as hard or had lower expectations with academics because of the lack of information they had regarding the effects of congenital heart disease. Therefore, teachers who teach students with congenital heart disease have different expectations and this affected their role as a teacher.

Regarding discipline, research indicates that children with an illness such as congenital heart disease should be treated like typical children in regards to discipline. However, parents with sick children often overindulge and become too protective of their child (Bowen, 1985; Papadatou et al., 2002). This overindulgence may result in overly dependent, argumentative, and uncooperative children. In contrast to this research, only one of the educators spoke of her student having any of these characteristics. The majority of educators felt their students were cooperative and had a zest for life. They were careful to point out that these cooperative students may just be the way they are because they are simply children, not because they have a heart disease.

Participants acknowledged the importance of treating a student with congenital heart disease normally, or just like any other student. Research speaks about how school is extremely important to children with congenital heart disease because school is one of the only normalizing environments where the child is not treated as a patient (Papadatou et al., 2002). The teachers in this study did not report this importance of not being treated as a patient as the motivation for equal treatment. Instead, teachers felt equality was important with regards to how they treated all children, regardless of illness. Despite
these strong views, educators struggled with always treating the student with congenital heart disease the same. It often took some thought and hesitation, but as educators spoke, they eventually concluded that, in fact, these students are different, so at times they needed to be treated differently.

One area teachers felt they treated the student differently was in the area of discipline. While discipline was not an issue for the majority of the participants, they did worry about how they would discipline the student with congenital heart disease, if needed. The student was treated differently because the educators had apprehensions and concerns around what the effect of discipline would be for the student. They worried about normal discipline procedures such as following classroom rules and if correction was needed, would this cause stress to the child’s heart? Teachers stated that they would have the same expectations of the student, but would approach the student in a softer or less threatening way. This softer approach was described by all participants, which is in contrast with research that states teachers are inconsistent with discipline regarding students with chronic illness (Chekryn et al., 1987). While teachers in this study were not inconsistent with discipline, students with congenital heart disease were treated differently, which may change or affect the relationship between the student and the teacher.

Some participants also discussed their relationship with the parents of children who have congenital heart disease. Congruent with research, educators spoke about the importance of open communication with the parents of a child with congenital heart disease (Roberts et al., 2005). Educators felt that they were required to go above and beyond typical expectations. Especially at the beginning of the year, it was essential to
ease the parents’ worries about transferring the responsibility of their child’s health monitoring and safety to the school. Helping parents feel confident about the teacher’s ability to monitor their child’s health status was hard for the teachers, as they themselves had limited confidence regarding the task. Teachers felt that they had to spend more time with these parents and reassure them more. The additional time with parents changed the types of interactions in the relationship between the teacher and parent.

Educators reported that their role as a teacher changed because of teaching a student with congenital heart disease. The additional responsibility of monitoring, and uncertainty regarding academic expectations and discipline, altered the role of the teacher. Teachers were unprepared for this change in roles resulting in experiences of increased anxiety and stress.

**Purpose Two: To Better Understand how Teaching a Student with Congenital Heart Disease may Affect Personal Wellness**

Within the parameters of this study, the participants shared that their role as a teacher changed as a result of additional responsibilities. Although the teacher role changed, additional support, or training was not provided. The lack of factual knowledge, training, or support minimized both the teacher’s level of confidence and comfort. According to the teachers interviewed, this lack of knowledge increased their levels of stress, anxiety, and uncertainty. There is limited research on how this affects teacher wellness. The analyzed data revealed effects in all three areas of the Ardell Wellness Model (2002): meaning and purpose domain, mental domain, and physical domain.

*Meaning and purpose domain.* While the meaning and purpose domain deals with all aspects of life (Ardell, 2004), this study specially examines relationships and meaning.
or purpose while teaching students with congenital heart disease. As already identified, teacher-student relationships and teacher-parent relationships were altered. This change in relationships sometimes caused anxiety and stress. Teachers are trained to be confident in classroom management and academics, however, the teachers in this study admitted that they were not confident in these areas regarding their student with congenital heart disease. They worried about disciplining a student with congenital heart disease and were uncertain about appropriate academic expectations. These worries led to a lack of confidence in their abilities and thus resulted in anxiety and stress.

Several teachers shared that the meaning and purpose of their job as a teacher changed when having a student with congenital heart disease. Instead of a focus primarily on academics, these teachers felt their responsibility related to their student’s health. Adaptations to curriculum and the lack of support were mentioned by several of the teachers. Some of the educators compared it to having a student with a learning disability, but without funding or additional help. Further, the uncertainty of the child’s health status and life expectancy played a role in changing their sense of their role responsibilities to the child. Teachers were faced with questions, for example: Does it really matter if a student knows their multiplication tables when the student may not be alive the next year? These are not typical issues that educators normally deal with, therefore, these issues affected how teachers viewed the purpose of their occupation.

*Mental domain.* The mental domain focuses on the degree to which one is able to intellectually cope with life and stress. The lack of factual knowledge about congenital heart disease contributed to uncertainty around decision-making that increased stress. Each of the teachers spoke about being proactive in trying to get questions answered by
parents. However, research from books, articles, or the internet was not mentioned. With their limited amount of factual knowledge, teachers felt ill-equipped to make effective decisions. This is congruent with Ardell’s (1986) belief that people are unable to make effective decisions when stressed. Teachers continually mentioned the word “stress” throughout their interviews.

**Physical domain.** Ardell’s (1986) model identifies the physical domain as key to personal wellness. Nutrition, exercise, balanced work, and recreation are very important. The management of these factors enable individuals to deal with their stress effectively. Given this study’s focus on how having a student with congenital heart disease affected teachers, data were not gathered on personal activities outside of school life. However, in relation to school, participants did share how their workload and stress increased when they had a student with congenital heart disease. This increase in stress and decrease in time available to balance one’s activities may have negatively affected participants’ personal wellness; however, it would be beneficial to conduct more research examining all aspects of life.

Research has indicated that teachers’ work-related stress can be linked to physical ill-health (Fletcher & Payne, 1987; Otto, 1986; Smith & Bourke, 1992). Educators spoke of stress having a detrimental effect on their everyday life and work environment. Without proper management of stress, one cannot reach wellness (Ardell, 1986). Teachers are stressed due to their lack of support, lack of information, and lack of emergency preparedness. Without having these key concerns addressed, teachers’ stress levels will likely not decrease and their wellness will not improve.
The participants strongly desired a life beyond school. They recognized that to have wellness, one needs to have a sense of balance between their work and personal life. To some teachers in this study, achieving this balance seemed like an impossible task given the demands they faced.

*Purpose Three: Identify Recommendations*

Teachers' recommendations for schools, administrators, parents, and medical professionals focused primarily on three areas: (a) the need for factual knowledge, (b) the need for additional support, and (c) the need for a formal emergency plan. These same suggestions can also be found in Papadatou et al.'s (2002) study.

Teachers desired factual knowledge specific to signs and symptoms of medical distress. Teachers felt hesitant; they were unsure of what a child would look like if their heart was in distress. Furthermore, what does it mean that a heart is in distress? How would teachers know as outside observers when “distress” was life threatening or, perhaps the child just needed to slow down? The participants felt that they could not make these decisions. Beyond knowing signs and symptoms, teachers also felt uncomfortable and unsure of their abilities to provide first aid treatment.

Participants acknowledge that they needed more support. For them this support takes three forms: (a) recognition by the school system that their responsibilities as a teacher have increased and changed as a result of having a student with congenital heart disease; (b) provisions of funding to allow teachers to attend meetings during the day and funding for additional support for a teaching assistant if needed, and; (c) additional training for teachers and staff such as lunch supervisors or recess monitors.
The last recommendation teachers desired was a formal written emergency plan. Teachers expressed that this was a major concern. The most formal emergency plan shared was that the teacher would send a student to the office if there was a problem. This is not sufficient. Teachers need to know when to call the office and perhaps even how to call the office. Teachers should be aware of when to call the parent and/or the emergency response team. Teachers also wondered who was responsible for administering first aid if needed. If the teacher was, then who is responsible for the rest of the students? Teachers expressed concern about how to plan for when the student was in another class, or at recess, or lunch or on fieldtrips. These situations should be discussed and all involved should have a clear understanding of what action should be taken in case of an emergency. By implementing these recommendations of increased factual knowledge, support and a clear emergency plan, participants believed that their stress levels would decrease.

Limitations of the Investigation

As with any research, there were methodological limitations to this study. In many ways this study was limited by its participants. This study was limited to six educators on Vancouver Island, British Columbia. Teachers from other areas of British Columbia or other provinces may have different experiences and therefore provide different recommendations. The nature of participants who volunteer for a study may only represent a group of educators who felt comfortable talking about personal experiences or secure enough in their employment to be able to express concerns or issues. There was only one participant who taught a student with congenital heart disease
at a private institution in this investigation, therefore, insights into private school needs may not be as prevalent as for those of public institutions.

Each participant in this study was female, therefore, this study lacked a male educator’s voice. There is little variation in age, teaching experience, ethnicity, or class across the participants. It would have been valuable to access participants from varied backgrounds, cultures, gender, ages, and experiences in order to develop a more comprehensive understanding of what it is like to teach a student with congenital heart disease.

It is also worth emphasizing that this investigation centered on teachers who taught children with congenital heart disease. Therefore, it may not be possible to generalize these findings to teachers who teach children with other chronic illnesses. Due to the numerous types of chronic illnesses, it would be valuable to further our understanding of the experiences of teachers who teach children with different chronic illnesses.

Teachers who are more forthcoming provided details of experiences while more reserved teachers did not. This variance in personality likely influenced the information received, the explanations, and the descriptions of their experiences.

Although, the results of this study are not intended to be generalized to other contexts, or teachers beyond the study, certain findings may resonate with the experiences of educators who teach students with congenital heart disease. As such, there are important implications that warrant further discussion.
Implications of the Study

The major implications of this study’s findings primarily relate to educators, administrators/school boards, medical professionals, and parents. Themes and recommendations have implications that may positively affect the experience of teaching a student with congenital heart disease. Four areas of implications are presented and discussed in this section.

Implications for teachers

The first implication applies to teachers who teach students with congenital heart disease. The teachers in this study spoke strongly about two things: a lack of factual knowledge and a lack of support. Therefore, if future teachers are aware that a lack of factual knowledge is a problem, they may be better able to gather information prior to having a student with congenital heart disease in their classroom. This gathering of information may be done through courses, internet sources, books, or articles. Teachers may even want to contact the Heart and Stroke Foundation of Canada or the Children’s Heart Network of British Columbia for assistance. Obtaining factual knowledge would decrease the anxiety and stress teachers have expressed when not having the information needed. With more information, future teachers will be better able to better understand the needs of children with congenital heart disease.

The second issue centered around understanding how important collegial support is. It is important that teachers are aware of the lack of support felt by teachers who teach students with congenital heart disease and make a concerted effort to provide support to these teachers. Requested forms of support involved (a) a recognition that their position of teaching a student with congenital heart disease is different, and often more stressful
than, teaching healthy students, (b) having colleagues available to listen to concerns or issues teachers have, and (c) having colleagues trained and informed about what to do if an emergency happens in case the primary teacher is not available. With this support from fellow educators, wellness may improve for teachers who teach students with congenital heart disease.

**Implications for administrators and school boards**

Administrators, school boards, and the Ministry of Education need to be aware that educators who teach students with congenital heart disease experience stress levels that negatively affect their wellness. This is detrimental as teachers' work related stress is linked with physical and mental ill-health (Otto, 1986; Smith & Bourke, 1992). Teacher stress levels may increase burnout. Two participants in this study felt so overwhelmed and stressed due to having a student with congenital heart disease, they either changed positions or took a medical leave of absence.

One aspect that resulted in this high stress was an increase in their need to monitor student health. Even though teachers were expected to increase their monitoring of students, there was no training provided in how to do this. Even though teachers required additional funding for these added responsibilities, they received none. Teachers also needed the opportunity to be trained appropriately and to hire substitutes to allow meetings to happen during the day. Teachers also expressed that they would like support in writing emergency plans. All participants indicated that they did not have an emergency plan or that the plan was inadequate. Not knowing when a situation is an emergency or who should administer first aid are issues that require discussion. The educators in this study shared that they would feel better supported if they used a team
Experiences of Teachers

approach to write a formal emergency plan and to brainstorm what to do with the what if questions, for example, what if the student is outside during recess or on a fieldtrip and there is a medical crisis? It is important that administrators and school boards be aware of these needs and advocate policies on behalf of their teachers.

Implications for parents

Parents can be a source of support for educators. In this study some participants felt that they were given limited or inadequate information from parents. For example participants were told if the child has a problem call me at work or home. This nonchalant approach did not help teachers feel more comfortable with understanding the warning signs or to prepare the needed precautions to support a student with congenital heart disease. Some of the participants in this study felt that parents could provide more information on congenital heart disease, for example, give input into an emergency plan, and information on future seminars.

Educators in the present study expressed their happiness when parents of students with congenital heart disease supported them. Parents may support teachers by being available to volunteer in the classroom, setting clear expectations, providing factual knowledge, and maintaining open lines of communication with the teacher.

Implications for medical professionals

Educators lacked support, factual knowledge, and emergency preparedness. Teachers felt a team approach would help meet these three needs. They were consistent when voicing the importance of having a representative from the medical profession at team meetings. Their sense was that, by meeting with a medically qualified person, the medical person would be able to answer and provide appropriate information, and help to
create an effective and realistic emergency plan. By not having medical input or an emergency plan teachers felt they were solely responsible for determining the needs of the child and how to meet those needs. By using a team approach and consulting with medical experts, teachers are able to share the responsibility with others who have more specific training. As a result, teachers in this study would feel more supported. This may then decrease their stress levels and improve their overall feelings of well-being.

Directions for Further Research

There are many directions for further research that emerged from this investigation. By exploring the essences of teachers' experiences when teaching students with congenital heart disease, this study revealed three key areas of concern: teacher support, factual knowledge, and emergency plans. Additional research investigating these concerns using a broader sample size would enable educators to generalize results reliably. It would be beneficial for further research to include both qualitative and quantitative measures. These three areas can be explored more specifically in the following ways:

1. The majority of teachers in the study indicated that they required assistance within the classroom, but most did not receive any assistance. An interesting investigation would be to determine if having assistance in the classroom in fact makes a difference in terms of stress levels or decreased apprehension. Research could also investigate whether disease severity affected the amount of assistance needed. Two teachers felt so stressed and neglected that they used the word isolated to describe their experience. Why did these two teachers feel so isolated? Why did they not
feel supported by their colleagues? Are there any commonalities when teaching other students with a different chronic illness? Would it help to talk with other teachers who teach students with congenital heart disease? Receiving inadequate support was a serious issue for these teachers and is an area that warrants more research.

2. Limited factual knowledge was also indicated as a problem for teachers. If teachers were provided with prior training, would this help teachers feel more confident in their ability to teach a student with congenital heart disease? One teacher in the study had a personal experience with heart disease and she was the only teacher who did not feel highly stressed or concerned. Is this due to the teacher's personal experience or other attributes of this particular teacher?

3. Lack of emergency preparedness was a major concern for teachers. If a team approach is used to create an appropriate emergency plan, will this decrease teacher stress and increase confidence? Is it important for the medical professional to know the student to assist in writing an emergency plan? Further research needs to be conducted in these areas.

Educators and students with congenital heart disease will benefit by having these three areas, identified in this study, investigated in further detail.

Final Summary

This qualitative study employed a phenomenological approach to explore the experiences of elementary teachers who teach students with congenital heart disease and how this affects their personal wellness. There is little research in this area and this study
begins to shed light on the issues and challenges faced by teachers who teach students with congenital heart disease.

This inquiry highlights the challenges and stressors of teachers when teaching students with congenital heart disease. While educators enjoyed having students with congenital heart disease within their classroom, they acknowledged feeling elevated levels of stress as a result of the medical fragility of these children.

According to participants, their role as teachers changed when having a student with congenital heart disease in their classroom. The teachers’ roles evolved as they were now expected to be medically responsible in a different way than with healthy students. Monitoring the health of these students created a sense of discomfort because teachers did not receive training on how to do this effectively. Due to this lack of information, teachers were also uncertain as how to most appropriately discipline students with congenital heart disease without increasing stress levels to the heart. They were unsure of how to formulate appropriate academic expectations and how the disease affected the student’s learning ability.

This study also provided recommendations on how to make this experience more positive for teachers. The areas in most need are factual knowledge, support, informed emergency plans and a team approach. Administrators, school boards, and parents need to be made aware of these needs.

Teaching a student with congenital heart disease affected teacher wellness. Anxiety and stress, increased by facing the medical fragility of a student with congenital heart disease, and confounded by a lack of support, knowledge, and emergency preparedness, affected wellness. Clearly, as this study demonstrates more research needs
to be done on how best to support teachers who care for medically fragile children like children with congenital heart disease.
References


Heart and Stroke Foundation (n.d). *Heart and Soul: Your guide to living with congenital heart disease*. (Available from the children’s Heart Network #166 – 1581 Hillside Ave, Victoria, BC, V8T 2C1)


Appendix A: Wellness Model

Appendix B: Semi-structured Interview Guide

Demographic Information

1. How many years have you taught?
2. What grades or subjects have you taught?
3. What is your favourite grade or subject to teach and why?
4. Have you taught outside Victoria?

I invite you to share with me your experiences as a teacher when having a student with congenital heart disease. The following questions will focus on your experiences of teaching and how, or if, teaching students with congenital heart disease has affected your well-being. Hopefully, through an examination of your experiences, we will be able to offer guidance on procedures for school systems on how better to accommodate, prepare, and support teachers' when teaching a student with congenital heart disease. If any of the questions I ask do not make sense, please be sure to ask for clarification and I will gladly re-word the question.

Open-ended Question

1. What is it like to teach a student who has congenital heart disease?
   Prompt: How is it different?

Semi-structured Questions

Teacher wellness

1. How would you define teacher wellness?

Mental domain

1. What kind of factual knowledge do you have pertaining to congenital heart disease?
2. Where did you acquire this information?

3. What is it like for you to discipline a child with congenital heart disease?
   Prompt: Can you give me some examples.

4. How do you go about curriculum programming or adaptations for a child with congenital heart disease?

5. With many absentees and hospitalizations, how do you help with continuation of peer relationships?

6. Has a situation with this child ever made you upset, concerned, or has affected the way you feel in any way? If so can you please tell me some examples.

7. Can you tell me about some of the unexpected rewards of teaching a child with congenital heart disease?

8. Do you feel adequately prepared for an emergency with your student with congenital heart disease?
   Prompt: Please tell me more.

*Purpose and meaning domain*

1. In what ways in your relationship with the student with congenital heart disease is the same or different as compared to healthy students?

2. In what ways if any has the meaning or purpose of your job been affected by having a student with congenital heart disease?

3. Tell me about humour in your classroom.

4. Does humour play a role if any in the relationship with the child who has congenital heart disease?
Physical domain

1. Have you found that having a student with congenital heart disease requires over and above what you would extend to healthy students?

   Prompt: If yes, does this interfere with your personal life?

2. What difference if any have you noticed in your working relationship between parents of healthy children and those with congenital heart disease?

   Prompt: Please tell me more

Closing questions

1. What recommendations if any would you make to schools, parents, medical professionals, or researchers about supporting teachers who have students with congenital heart disease?

2. Is there anything else you would like to tell me about your experiences?
Appendix C: Certificate of Ethical Approval

Human Research Ethics Board
Certificate of Approval

Principal Investigator: Tammy Lavigne
Graduate Student

Co-Investigator(s):

Department/School: EPLS

Supervisor: Dr. Jillian Roberts

Project Title: A phenomenological inquiry into elementary teacher wellness: Experiences with students who are living with congenital heart disease

Protocol No. Approval Date Start Date End Date
397-04 08-Nov-04 08-Nov-04 07-Nov-07

Certification

This certifies that the UVic Human Research Ethics Board has examined this research protocol and concludes that, in all respects, the proposed research meets appropriate standards of ethics as outlined by the University of Victoria Research Regulations Involving Human Subjects.

Dr. Richard Keeler
Associate Vice-President, Research

This Certificate of Approval is valid for the above term provided there is no change in the procedures. Extensions or minor amendments may be granted upon receipt of a "Research Status" form.
Appendix D: Poster of Recruitment

Have you ever taught a student with congenital heart disease?

I am interested in exploring for my masters’ thesis experiences of elementary teachers when teaching children with congenital heart disease. If you have taught or are teaching a child with congenital heart disease, I invite you to share your experiences with me.

Please call Tammy for more information at 598-7619 or email at tlavigne@uvic.ca
Appendix E: Informed Consent Form

A phenomenological inquiry into elementary teacher wellness: Experiences with students who are living with congenital heart disease

You are being invited to participate in a study entitled “A phenomenological inquiry into elementary teacher wellness: Experiences with students who are living with congenital heart disease” which is being conducted by Tammy Lavigne a Master’s student and the University of Victoria in the department of Educational Psychology and Leadership Studies. The study is being supervised by Dr. Jillian Roberts who is a professor in the department. Dr. Roberts may be reached at 721-7817, Tammy Lavigne may be reached at 598-7619.

Purpose:
The purpose of this study is to better understand teacher’s personal experiences when teaching elementary students who have congenital heart disease. The study intends to utilize this insight to develop a more comprehensive understanding of how teaching a student with congenital heart disease affects teacher wellness. These results will then help school systems understand how to support a teacher’s wellness when teaching a student with congenital heart disease.

Importance:
Congenital heart disease is the second most prevalent chronic illness in North America. Increasingly teachers are gaining first hand experience teaching students with chronic illness. There is limited research exploring the experiences of teachers when teaching a student with congenital heart disease and how this may affect their personal wellness.

Why I would like you to participate:
You are being asked to participate in this study because you have experience teaching a student with congenital heart disease. Gathering information on your thoughts and experiences will be valuable for this study and will help school boards better support other teachers in a similar position, and if necessary may affect change in school policies.

What will I ask you to do:
If you agree to voluntarily participate in this research, you will participate in an interview so that I can understand your experiences when teaching a student with congenital heart disease.

What kinds of risks and costs are involved:
Volunteering for this study will not cost you anything other than your time. I am not aware of any psychological risk to you other than the possibility of an emotional reaction to questions about a seriously ill student that they have had a relationship with. You are free to not answer any question that you are not comfortable with. If any procedure brings distressing personal emotional issues into awareness, I will help you in any way I can and encourage you to use the counselling services already offered through your local school board.

What are the benefits of participating:
Benefits of this study include a contribution to knowledge about the affect of instructing a student with congenital heart disease on a teacher’s wellness, as well as the potential to change school board policies such that teachers are better supported.
Voluntary participation:
Your participation in this research must be completely voluntary. If you decide to participate, you may withdraw at any time without consequences or any explanation. If you do withdraw your data will only be used with your verbal and written consent.

Anonymity and confidentiality:
In terms of protecting your anonymity all identifying information will be stripped from the self-report measures and replaced with a confidential ID number. Your confidentiality and the confidentiality of the data will be protected by keeping any papers and tapes that link your identity with the ID number in a secure location that only the investigator and her supervisor have access to. The signed consent form will be kept in the same way and both will be destroyed after five years.

Dissemination of results:
It is anticipated that the results of this study will be shared with others through a Master’s thesis, publications in a scientific journal and presentations at scholarly and community based meetings.

Contacts:
In addition to being able to contact the investigator and her supervisor at the above phone numbers, you may verify the ethical approval of this study, or raise concerns you might have, by contacting the Associate Vice-President, Research at the University of Victoria at (250) 472-4362.

Your signature below indicates that you understand the above conditions of participation in this study and have had the opportunity to have you questions answered by the investigator.

____________________________________  ____________________________  ________________
Name of Participant                 Signature                  Date

A copy of this consent will be left with you, and a copy will be taken by the researcher.
Appendix F: Bogdan and Biklen's (2003) Pre-assigned Coding Families

1) Setting and Context Codes

This term refers to codes with general information on setting, topic, or subjects. A thorough description of the context of the phenomena and setting of the interview is an integral and important aspect of qualitative research. Description enhances interpretation by painting a picture of the world from the participants' view and by describing the context. As description is applied to the data by field notes and commonalities, the researcher will separate and group pieces of data related to different aspects of the setting, events, key conceptual episodes, and participants' voices.

2) Definition of the Situation Codes

The purpose of this code is to allow the participants to define the setting and particular topic in their own words. This involves questions such as: What do they hope to accomplish; How do they define what they do; What is important to them; How they teach, theories, or beliefs on teaching, type of participant (younger teacher, experienced teacher), religion, politics or social class?

3) Perspective Held by Subjects

This code focuses on participant metacognitions regarding the phenomena such as shared rules and norms or general points of views.

4) Subject’s Ways of Thinking about People and Objects
This family code involves participant understanding of each other, outsiders, and objects or events that create their world. An example could be a teacher’s view of students based on their behaviour or appearance.

5) Activity Codes

These codes are data that involve regularly occurring kinds of behaviour. These are obvious codes of informal and formal behaviour including joking, lunch, or special education meetings.

6) Event Codes

These codes are directly correlated to specific events or activities that occur in the context setting or in the lives of the participants. Event codes discover if the activity happens frequently or infrequently. This is in reference to how the participant uses tactics, methods, manoeuvres, or ploys to accomplish various goals without alleging the motives to the participants’ behaviour.
Appendix G: Copy Right Permission

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August 31, 2005

Dear Dr. Don Ardell,

As to our email correspondences, I again would like to have your formal permission to reprint in my Masters thesis your 2002 wellness model found on the World Wide Web at http://www.seekwellness.com/wellness/wellness_models.htm. The thesis is entitled A phenomenological inquiry into elementary teacher wellness: experiences with students who are living with congenital heart disease.

If you have no further objections or concerns, please sign this letter below and fax to 250-721-6190.

Sincerely,

Tammy Lavigne

PERMISSION GRANTED FOR THE USE REQUESTED ABOVE:

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September 2, 2005
Date