

A SELF-STUDY OF MY LIFE WITH A CHRONIC ILLNESS

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Abstract

The following paper is a self-study identifying and examining obstacles I have encountered from living with a chronic illness (CI). In particular, I intend to connect my life experiences as both an individual and educator in academia. The focus of this paper is to reveal my life experiences with a CI, the challenges I encounter, and how I learn I can foster change in the community. A serious failure in my health from the rare chronic gastrointestinal illness I have been diagnosed with initiated a journey of questioning both my knowledge and understandings regarding my life. I was forced to reconnect with my body and yet again, accept the illness inside me. The findings from my recovery included four main themes that illuminate transformative learning with a chronic illness. The themes are betrayed by my body, trying to live, societal differences, and seeking wellness.

Individuals who are diagnosed with CI are being given further opportunities to integrate into society from advancements in outpatient care, technology, and survival rates. All of these components contribute to enhancing experiences for those living with CI (Asprey & Nash, 2006; Clay, 2004; Ironside, Scheckel, Wessels, Bailey, Powers, & Seeley, 2003; Martinez, & Ercikan, 2009; Maslow, Haydon, McRee, Ford, & Halpern, 2011). Furthermore, there is a rise in incidence rates of individuals with CI present in society as a result of the increases in medical assistance available (Ironside et al., 2003; Lindeman & McAthie, 1999). The increasing support for individuals with CI being given further opportunities in society is thoroughly encouraging. What remains to be understood is what life with a CI entails and how these individuals maintain optimal strategies to living with their CI.

Defining Chronic Illness

The term CI encompasses many diagnoses, symptoms, and treatments. Presently, there is not one unified definition and understanding of what a CI is. The medical model definition includes a persistent medical condition with the duration of 3 months or longer. Other definitions in literature include longer timelines of 6 months and/or include differing implications of the obstacles encountered from living with a chronic illness (Duggan, Medway, & Bunke, 2004; Martinez, & Ercikan, 2009; Shaw & McCabe, 2008; Worchel-Prevatt, Heffer, Prevatt, Miner, Young-Saleme, Horgan, 1998). For the purposes of this paper CI is defined as,

A disease or injury that has lasted more than 6 months and has caused an individual to significantly alter his or her day-to-day activities. Alterations in daily activities may be due to factors such as decreased endurance, mobility, or cognitive functioning resulting in a limitation of the individual's ability to continue his or her usual lifestyle. (Ironsides et al., 2003, p. 172)

Although there have been numerous studies investigating single aspects of life with a CI; there is limited but growing research examining the effects as a whole of a CI on a day-to-day basis. Singular research examples include solely investigating the impact of the illness without examining the complexities of living with a CI (Miller, Yanoshik, Crabtree, & Raymond, 1994; Monson, 1999). Researchers in the last decade have started to seek and integrate the intricacies of living with a CI and the shared experiences among individuals with CI (Clay, 2004; Ironsides et al., 2003; Öhman, Söderberg, & Lundman, 2003; Thorne, Paterson, Acorn, Canam, Joachim, & Jillings, 2002).

Depending on when the onset of CI is can impact the educational and vocational success of the individual. Maslow et al. (2011) utilized data from Wave IV (2008) of the National Longitudinal Study of Adolescent Health to compare between individuals with childhood-onset CI, adult-onset CI, and those who do not have a CI. Findings indicate that those with adult-onset CI have lower rates of college graduation and having an occupation compared to those without a CI. Research has also indicated differences among vocational and occupational status of those who do and do not have CI, and differences in transitioning from school into the workforce among those who have a CI and those who do not (Young,

Barden, Mills, Burke, Law, & Boydell, 2009). This further suggests improved support in the educational and occupational community is needed for individuals with CI.

Transformative Learning and Chronic Illness

In learning how one copes with a CI, transformative learning is suggested as a method to aid fostering optimal health with a CI. Transformative learning is described as a multifaceted process where the individual undergoes personal changes including their views, feelings, and understandings (Barclay-Goddard, King, Dubouloz, & Schwartz, 2012). In a broader sense, transformative learning is a term utilized to capture action-oriented learning approaches that commence with the lived experiences of individuals. Transformative learning is further a catalyst that aims to redefine and reassess the social inequalities and environmental dangers that are present in society (Goldin-Rosenberg, 1995). With regards to transformative learning and CI, the transformative learning begins with the diagnosis, followed by internalizing the meaning of life with CI, and ultimately engaging in action (Courtenay, Merriam, & Reeves, 1998; Mezirow, 2009).

Courtenay et al. (1998) conducted a study investigating patients diagnosed with HIV/AIDS. The study involved interviewing participants focusing on their meaning-making of living with HIV/AIDS. The findings of Courtenay et al. (1998) study revealed three phases. The first is the beginning reaction to the diagnosis, usually a negative experience followed by experimenting and further discovery, ultimately leading to the desire to meaningfully contribute to life. The second phase involves learning new ways of life and often included helping others living with HIV/AIDS. Phase three involves incorporating their new perspectives and understandings into their lives. Follow-up studies two years after the initial study revealed the participants continued to maintain their perspectives (Baumgartner, 2002). Transformative learning has also been studied and found evident in people with illnesses such as rheumatoid arthritis and stroke survivors (Dubouloz, Laporte, Hall, Ashe, & Smith, 2004; Kessler, 2007). Transformative learning in the lives of those with both mild and severe gastrointestinal illnesses remains an uncharted area of research. The transformative learning dimensions identified by Dubouloz et al. (2004) include a “definition (what it was), function (what was enabled), meaning (why it is

important), and assessment (how it was evaluated)” (p. 405). Transformative learning and chronic illness provides insight to how individuals come to understanding and living with their illness in a positive light. The transformative learning process is not solely for the individual but provides opportunities to support and care for others in similar situations.

Purpose

As an educator, I understand and value the importance of connecting my professional learning with personal reflection to foster growth. From my personal struggles with my health I was inspired to focus my career as a researcher in academia who investigated the experiences of other individuals with CI during their academic journeys. I was and continue to be determined to maintain a position within the educational context and workforce despite living with a chronic gastrointestinal illness. The main intention of my research continues to focus on giving voice to those who live with a CI. From my initial research findings I was able to identify four main categorized obstacles that include: physical limitations, psychological comparisons, social isolation, and academic implications. Each of the themes plagued individuals with chronic illness hardships beyond the direct effects of their illness (Wideman-Johnston, 2010). The findings of this study not only contributed to the limited literature about the educational experiences of individuals with a gastrointestinal CI, but I was also able to connect the experiences of others with the obstacles I had encountered. The numerous struggles I had were identified in my research; I was not alone. I thought from the literature I had studied, the findings of my research, and my personal experiences that I comprehended what living with a CI entailed and how to overcome the complications (Boyd, 2005; Donoghue, & Siegel, 2000; Shaw & McCabe, 2008; Silver, 2004). I would be able to balance my work as an educator, continue my educational aspirations, and pursue an active family life. Somewhere along the line, I forgot that I was not solely a researcher in this domain, but that I too have a CI. Knowing and understanding the physical aspects of my symptoms are simply one aspect of the illness. It is of utmost importance to incorporate the connections between the physical, emotional, intellectual, and spiritual. The integration of the physical, emotional, intellectual, and spiritual is especially important to assist with overcoming obstacles associated with living

with a CI (Steingraber, 2001; Swenarchuck, 2006). The purpose of this paper is to reveal my life as an individual with a CI and the challenges I encounter, as I continuously have complicated and invasive procedures to maintain my health. Furthermore, the study illustrates how I learned to persevere with the effects of my illness internalize and ultimately contribute to fostering change.

Methodology

The following research study is a qualitative self-study during my recovery from a lapse in my health as a result of the rare chronic gastrointestinal illness I have been diagnosed with. I have suffered from the symptoms of my gastrointestinal CI for the past nine years.

My methodology utilizes the self-study method described as research where the researcher is involved in the profession as an educator and personally (Bullough & Pinnegar, 2001). Furthermore, Mooney (1957) states regarding a self-study that,

Research is a personal venture which, quite aside from its social benefits, is worth doing for its direct contribution to one's own self-realization. It can be taken as a way of meeting life with the maximum of stops open to get out of experience its most poignant significance, its most full-throated song. (p. 155)

Self-study research includes “insider” research or may have biographical components (Hamilton, Smith, & Worthington, 2008, p. 18). Hamilton et al. (2008) describes a self-study to have five elements: self-initiated, focused on improvement, interactive, qualitative methods, and contains validity centred on trustworthiness. The goal of the self-study is grounded in creating a professional identity and knowledge basis as a researcher in education (Hamilton et al., 2008; LaBoskey, 2004). This research commenced as I began to review previous journal entries I had written during my recovery in attempts to understand who I am as an individual and educator with a CI. I reflected both personally and how my experiences impacted me beyond my apparent medical involvements. The data is compiled from my journal as I reflected during my recovery from my recent major surgery from the

time period May 2011–September 2011. As Gall, Gall, and Borg (2005) suggest I have divulged an accurate self-report of my thoughts and feelings throughout my recovery. The professional knowledge and understandings I have gained as a researcher in the field investigating the lives of those with CI must also be included. I have had many both formal and informal conversations with individuals impacted with CI, much literature review, graduate studies, and volunteer work. The multiple methods contributing to this self-study is consistent with Hamilton et al. (2008) notions that researchers will utilize the methods needed for both the evidence and context of their professional practice. Self-study focuses on reflection about the improvement of practice with the inclusion of both personal beliefs and professional efforts (Hamilton et al., 2008). The constant battle I encounter with my CI fosters many questions about my personal and professional life goals. How do I continue aspiring in my life as an educator, and how do my experiences as an individual with a CI contribute to my understanding of education and change?

Findings

The themes identified in my journal have been coded and categorized into four themes. The themes of my self-study include: betrayed by my body, trying to live, societal differences, and seeking wellness. The following passages are excerpts of journal entries I have completed throughout the duration of my recovery.

Betrayed by My Body

The betrayed by my body theme emerged at the beginning of my health lapse and remained consistent throughout my data. The negative emotions I was experiencing correspond to Courtenay et al. (1998) phase one findings of transformative learning with a CI. Betrayed by my body included descriptions and reflections concerned with feelings and questions associated with the deceit I felt my body had produced. The following is an excerpt from my journal describing the betrayal I felt.

I have been in the position I am presently in before recovering from surgery but this time it feels so much different. I feel weaker, betrayed, and ultimately defeated. I

feel that my life can be taken away in one moment and in that moment everything I have known is changed. I try to keep balanced and healthy by maintaining my CI as best I can but the question that lags me is “Does it really matter?” I know all of the positive phrases, “you get knocked down, and you get back up”...but how many times can I keep getting back up?

The deceit I felt from my CI continued to initiate questions pertaining to who I am and how I can continue with the constant invasion of my CI. The following journal entry describes the frustrations and hopelessness I encountered.

I realize now it is not the pain that has changed but rather me. I am struggling to build a normal life where I can work and study. How can I do this when my health always unravels? I hate the lack of control I have in my own life. Am I just a sick person? If so, what is the point in trying to beat my illness if it will win? Does my work and advocacy actually make a difference? Why am I trying so hard to live the life of a healthy person, when clearly I will never have that life? How do I learn to live with this illness?

The betrayed by body reveals the resentment I felt towards my CI. The constant invasions of my CI caused me to question how I can continue to live and sustain when my CI seems to always have control. As I reflect on this time period I am reminded of how my thinking replicates the mindset of having a broken body that needs to be fixed by the medical community (Roberts, MacRae, & Stahlbrand, 1999). I was at a loss to learn how to live with this CI, seeking further help and answers. I have an illness that is not a result of me doing something wrong. I lead a healthy lifestyle and yet, I have a CI. This question ultimately led to Courtenay et al. (1998) second phase of transformative learning.

Trying to Live

The trying to live theme focuses on the continuous attempts I had made to help me believe I am not solely a person with a CI. This theme is consistent with Courtenay et al. (1998) phase two of being diagnosed with a CI and learning new ways to live despite the diagnosis of the illness. Although I try my best not to feel I am defined by illness, the rapidness of how quickly the status of my illness can change and the continuous

interference I experience makes this belief a great obstacle in my life. My feelings are consistent with Donoghue and Siegel's (2000) notion that the loss of good health is not a reality and what remains is a presently incurable illness.

It feels that my life is an illusion and I am only able to achieve so much before I will get ill again. I worry is this the cycle of my life? How do I keep going? Will I always be the one to win against my illness, what if I lose? I feel I have no control. I cannot seem to regulate my ever changing body manifesting my CI. I am tired of hurting. I have all of these questions and most often I take it one day at a time. But to be honest, my future scares the hell out of me...how much of a future do I have? I am unsure what has changed to make this recovery so much more intense...I wonder if it is the constant pain. It seems as though it will never stop, not even for a few moments. Does anyone else experience these obstacles when trying to live?

This was not the first lapse I had experienced as a result of my CI but this experience seemed to have a much larger impact on the journey I thought my life would take. My continuous cycles of extreme life threatening experiences as a result of my CI have continued for years. Every time that I think I have figured out the key to being "better", I quickly resume all of my commitments and the cycle begins again. It is only in the last few months I have realized that my definition of a normal life is not at all a realistic goal for me to have. It has been my inability to accept the life I need to embrace that has completely eliminated my ability to live at all. I am only able to live when I acknowledge the care that I need and most importantly, that care is my norm. I have continued to live as though these adjustments in my life are temporary, but are rather needed as permanent changes. At times it feels this is a startling realization with an illness that continues to worsen. Donoghue and Siegel's (2000) research reveals the fear of continuous adjustments and exacerbations can instill fear into an individual with a CI with little time to cope. Fears can include: being a burden, of continuing to live in this way without being able to resume previous ways of life, and succumbing to the illness.

Societal Differences

The societal differences theme continues to focus on Courtenay et al. (1998) phase two of transformative learning with a CI. In particular, the societal differences theme focuses on the discrepancies I identified between how society portrays living with a CI and how society's view has contrasted with my experiences. One of the most salient differences I have experienced is consistent with the established idea of my body being a machine in need of "fixing" by the doctors and since I have yet to be "fixed" I must not want to get better (Boyd, 2005; Donaghue & Seigel, 2000; Roberts et al., 1999). Within the societal differences, I have found my experiences contrast greatly. The below journal excerpts are from a passage where I have endured septic shock.

In the movies people always have flashbacks to the best moments in their lives especially in the instance of extreme trauma and when medical events occur. In and out my consciousness during an episode of septic shock, I did not see beauty. I saw my husband's pain, my parents' worst fears, and my sister's hurt. Their faces haunt me. How could I have caused them so much stress and sorrow? They do not deserve this. I wish they never experienced this anguish my body has caused. It feels like it is my fault and yet I cannot control it.

I also felt responsible for the pain I had caused my family. I felt my illness was a reflection of who I am and that I could control the physical symptoms I was experiencing. I was guilty for causing them the pain they were experiencing. I remember constantly apologizing for the limitations of my body, as if I chose to have a CI. The constant apologies can result from living with a chronic illness and can include: low self-esteem, guilt, insecurities, and being a burden to surrounding family (Boyd, 2005; Donaghue & Seigel, 1999).

The above excerpts from my journals from the betrayed by my body, trying to live, and societal differences themes are what I refer to as my "dark days." These days were very challenging for me to overcome. Prior to this lapse in health, I felt I finally had balance and some measure of control in my life. I had at least found how to manage my day-to-day symptoms with diet, medication, and exercise. Of course days where my symptoms were out of control still did exist but, I had been working as an educator for the first time in years

at a profession I deeply valued, completed my Masters of Education, commenced my Doctor of Philosophy, and was the editor for the non-profit for the organization to assist others with the chronic illness I live with. My life despite my illness was coming together and I was ecstatic.

These months of bliss did not last long and unfortunately lead to years with many infections resulting in surgeries to remove and replace the permanent catheter I have in my chest for hydration purposes. I have had stretches in the past where I have been in the hospital for such lengths of time. I am always left wondering if a healthy person can comprehend how long and difficult it is to be in the hospital for such a length of time. During one of my hospital stays after two days of no fever, I had emergency surgery in the middle of the night. After my surgery I continued to have complications. I had such severe malnutrition the pain medications were not working. Pain medication needs to attach to the protein in the blood and my levels were extremely low, so pain medication would not work. I woke up from surgery and the pain was unimaginable. My husband and mom were panicked and the doctors did not know how to proceed. After an on call anaesthetist was brought in I received a nerve block that typically lasts 24 hours. I was lucky to get six or seven hours of pain and nerve blocks can only be given every 24 hours. I was fortunate to be brought to recovery for the next two days to receive two more injections. I was receiving high doses of narcotic pain medication to keep me comfortable. My post-operative days still remain a blur. But what I do remember is crying and apologizing to my family continuously. Even in my sedated state, I knew the strain and pain I was causing them. I know these images will never leave my mind. Those days were awful. I hate to know that those days even existed and that my family witnessed me in that state, but I also know without them, I would not have survived. My survival fostered the desire to continue to move forward.

I need to continue to learn and try to figure this out. I want to contribute to my family and those with this invasive illness. I can't be the only one struggling with a GI [gastrointestinal illness]?

I know now that these experiences have contributed to the person I am today and have fostered a journey I would not have embarked on. My desire to participate in helping those

with this illness and my further involvement with our non-profit organization has assisted me in healing and hopefully others. My feelings for this time are best revealed through Kull's (2008) words:

I've also come to realize that these entries aren't simply a record of my life...They are also a teaching tool for the future, a way for me to remember what I'm learning and will likely forget...Like Hansel and Gretel, I'm leaving a trail of crumbs to lead me home again. (p. 263)

Seeking Wellness

The seeking wellness theme involves my further integration of positive change and understanding in my life with a CI. The seeking wellness theme is consistent with Courtenay et al. (1998) phase three of transformative learning.

When I am in the hospital I have a "no visitor policy" that excludes my husband, parents, and sister. For many individuals this "policy" of mine is extremely difficult to accept. I know for many visiting the hospital is to show support and love for the person who is ill but I just cannot open myself to the people around me seeing me at my ultimate worst, my symptoms, my appearance, and my state of mind. All I want while in the hospital is to recover and get out of there. Many individuals find my request offensive and my response is always "do you like to see and have visitors when you have the flu?" The response is usually no, but that does not stop some individuals even when my doctors request I have no visitors outside of my immediate family. I felt deeply hurt when individuals around me would not respect my wishes. I was so embarrassed and ashamed of my illness and how poorly I was functioning. I realize now that I was also terribly afraid. I was petrified I would not be able to get through this. I never wanted those images of me to haunt their minds.

I know now from this experience something in me has changed. I am not sure exactly what it is but I feel different ...I am not even sure I will ever figure it out. I know I need to respect and appreciate the healthy days I hope to have ahead of me.

The need for hope and being positive is essential to being able to live with a CI. This does not mean I have not experienced challenges but that I need to allow myself the

opportunity to feel those emotions and to ultimately never let my faith and hope waver. This is not easy and I have yet to perfect it, but I know the necessity of keeping hope in my heart. Being positive, hopeful, and realistic are all crucial to me living well. Authors Donoghue and Seigel (2000), and Boyd (2005) reveal the critical mistake in continuing the pattern of thinking that I can say “yes” to everything promotes faulty expectations and assumptions. What I have learned is the need to learn from my story and to use my story to heal in my continued journey:

I treasure the idea of being a mother and seeing my children grow up alongside my husband. I want to continue to embark on this journey of sharing what life is like with a CI, but what I want for the most is time. I will continue to take the time I have to support those who have been diagnosed with this GI [gastrointestinal illness] and hopefully others who experience life being dependent on technology.

Keeping hope and faith alive in my life has been essential to moving forward. My hope for a future and being able to contribute to the world is what helps me continue to fight every day. My hopes do not focus on my professional contributions as I thought they might but rather on my family and those who have been affected by chronic gastrointestinal illness.

It is through this experience I realized that in order for me to advocate change in the educational community that I too can contribute by sharing my story. There are many possibilities for individuals with CI. I hope to bring meaning and reveal these possibilities to my colleagues and students by sharing the stories of those with CI. As educators we need to acknowledge and understand that living with a CI is a multi-faceted issue that needs to be shared, discussed, and reflected upon.

Discussion

From this self-study of living with a CI I was able to reveal the transformative learning I have endured from my experiences. The events that have occurred in my life and the themes identified from my journaling correspond with the three phases of transformative learning outlined by Courtenay et al. (1998). The betrayed by my body theme is centred in the first phase as an initial response to my chronic illness. The trying to

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live and societal differences themes correspond with the second phase including experimenting and exploring the limitations of my illness leading to the beginning desire to assist others in similar positions. The seeking wellness theme is consistent with the third phase by incorporating my learning into my new way of life and understanding the life I have (Courtenay et al., 1998). Transformative learning offers a positive approach to learning how to accept and live with a CI positively despite health limitations (Barclay-Goddard et al., 2012; Baumgartner, 2002; Courtenay et al., 1998; Kessler, 2007).

Throughout my recovery and during the process of my self-study, the questions that circled in my mind during my betrayed by my body, trying to live, and societal differences phase, I know aided me in realizing that I needed to address those difficult questions so I would fight. If I did not fight for my life, I would lose. The themes I have identified have fostered a journey where I have learned the importance of balance and acknowledging my bodily limitations. Do I wish I could attain what I could if I were healthier? Of course! But I have learned when I over exert myself; I am the one who suffers and causes my family further pain and stress. I know I am not able to foresee or control when my illness will be at its best and worst but I hope to recreate balance.

The vague definition that exists in defining CI further contributes to the lack of understanding of what life with a CI includes. Numerous illnesses, symptoms, and experiences all unique to the individual can unfortunately further inhibit an understanding of what life with a CI can entail. Further research and advocacy for those with CI will aid in creating a greater understanding of living with a CI. Research revealing educational and vocational experiences can contribute recommendations outlining the needs of those with CI. Furthermore, there is a strong need to continue to understand and incorporate the needs of those with CI into the educational and occupational community.

Many positive factors including advancements in community care, medical technology, and longevity have greatly improved the lives of those with CI (Asprey & Nash, 2006; Clay, 2004; Ironside et al., 2003; Martinez, & Ercikan, 2009; Maslow et al., 2011). Support and resources to those with CI has also improved contributing to enhancing the lives of individuals with CI. What does remain is the difficulty in learning to live with a CI. Learning how to differentiate who they are from their illness and feeling worthy continue to challenge the identity of those with CI (Boyd, 2005; Donoghue & Seigel,

2000). It has been through this self-study that I have identified my own transformative learning to making meaning in my life with a CI.

Future Plans

I know now more than ever, I will continue to share and give voice to those with CI. As an instructor, initially I was ashamed to share with my students that I have a physical disability. Over much time and thought I have changed by not hiding who I am and the life I lead. I now share openly with my students what my life with a CI is like. Not only do I share my life but I share the diverse experiences and personal stories of other individuals in a variety of situations. I find it truly refreshing to see the students in my classes lost in someone's story. I believe education is about sharing and giving voice to the unique stories and it is through these stories change becomes possible. I hope to continue to enhance the courses I teach, research I am involved in, and volunteer position I have to engage in to be mindful of and encourage the sharing and listening of peoples' experiences. Maybe the lesson for me is to appreciate life and to understand just how rapidly the circumstances in life can change. I truly hope these thoughts will remain in my mind every day of my life. My appreciation and knowledge allows me to see how precious every single day is. What remains to sadden me are the days that remain ahead that my illness will dominate. I strive to remain present and thankful for every day I have.

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