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THE IMPACT OF DIAGNOSTIC LABELS

By

Janice E. Dinsmore Czechowsky

Masters of Theological Studies, Waterloo Lutheran Seminary, 1993

DISSERTATION

Submitted to the Faculty of Waterloo Lutheran Seminary

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Abstract

To determine whether there was a difference between a physical or mental health diagnosis on well-being, identity, relationship with God, and ability to use faith as a source of support, quantitative and qualitative studies were conducted using surveys and three focus groups. Of the 360 surveys returned 54% failed to indicate whether they experienced a physical or mental health issue, resulting in the quantitative data being unusable. Focus group participants reported feeling safe during the group to disclose their health issue, but not prior, resulting from previous experiences with stigma. Mental health diagnoses still carry stigma. Participants reported a strong relationship with God but not with a faith community, and diagnoses impacted on their sense of well-being and identity.

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Chapter 1

Introduction

Throughout the formative years of my career as a therapist, I had the privilege of working for the Canadian Mental Health Association of Waterloo Region. As a result, I had the opportunity to work under the direction of John Jones who was the Executive Director at the time. During this same time period, the work of Jean Vanier and Henri Nouwen also became influential in my life. As a result, Jones, Vanier and Nouwen have all had a significant impact on how I view the world, particularly the world of inclusion, and specifically when individuals may face challenges due to a significant mental health issues. When I speak of someone having a significant mental health issue I am using the Province of Ontario's definition used to determine eligibility for the Ontario Disability Support Program. The medical diagnoses include schizophrenia, depression, bi-polar disorder, paranoia and head injury.

However, regardless of the diagnosis itself, how we speak about the illness can have a significant impact on the individual experiencing the illness. Each of us has many parts or threads like those in a tapestry that make up who we are. The threads, though, do not determine who we will become or what "the picture" will be on our tapestry. Each of our tapestries is different, depending on the threads that are woven together to form this picture. These threads may include our gender, roles, sexual orientation, faith, cultural background, experiences, trauma and illnesses. Any illness or diagnosis we may have experienced is just one more thread, though an important thread in the tapestry

of our life. However, it is only one small part of who the individual is as a person of worth and value who deserves to be treated with dignity and respect regardless of the diagnosis.

In my clinical work in private practice for 12 years, in a shelter for homeless women and children, in two long-term residential drug and alcohol recovery homes, and in working with individuals with significant mental health issues requiring support, I have seen that isolation and lack of understanding appeared to keep people stuck in unhealthy and pain-filled situations.

Individuals reported that they believed the very places, like the church, where they thought they would be able to access support, were the very places they reported experiencing the greatest judgement, shaming and ridicule, which resulted, according to these individuals, in more isolation. For many of these individuals their faith or spirituality played an important role in their lives; yet, participation in institutions of faith was limited.

It was these interactions and experiences of being with people with significant mental health issues that prompted me to explore the impact that diagnoses have on an individual's sense of well-being, their relationship with God and how they view themselves.

The questions for the survey as well as the questions for the focus groups are all derived from face to face encounters with individuals who have a mental health diagnosis as one of the threads in their tapestry of life.

Chapter 2

Literature Review

Relationships are the heart of all our interactions within society.

Regardless of the context, whether within the family, couple, school, work, or community how we come to know ourselves and whom we are is driven by these relationships. From the moment of birth to the last breath someone takes, we find ourselves interacting with others, either positively or negatively on an ongoing basis. We are people of relationships.

Consequently, in this view, the way in which each of us understands our lives will be impacted by a variety of relationships and filters based upon our experiences within the social institutions, environment, school, culture, media and surroundings (Wahl, 1995). We learn to pay attention to some details while ignoring others. What I choose to continue to pay attention to will depend on how I have assigned meaning to that circumstance or situation. In symbolic interaction the emphasis is placed on the social interaction between people through the use of symbols (Blumer, 1986). The use of symbols in communication and interaction with others, as well as the interpretation or understanding of these symbols, becomes part of how we interpret what the other person means by their action. Our understanding is then construed through these interactions as well as our communication with others. Flexibility in how we apply this new meaning to these new situations and to our lives becomes part of the social fabric of interactions. This process of assigning meaning or attempting to make sense of our environment and experiences will be impacted by the role socialization played

in our development.

Symbolic interaction theorists such as Pierce, Dewey, Cooley, Mead, Blumer, Becker, Goffman, Denzin and Hochschild (Eschleman, 1988) insist that social facts are relevant only to the extent that people attach meaning and significance to them. On the one hand, most people are the creators of society not just the passive recipients. They create, interpret, plan and control their values and environment either consciously or unconsciously. All of these human interactions happen through the use of symbols by interpreting meaning or by interpreting someone else's actions or reactions. The focus here is on the social behaviour and interactions found in everyday life and exchanges. It is also important to understand how people, who possess free will and the ability to make decisions are able to create and define their situations. However, on the other hand, some individuals with significant mental health issues find themselves being the passive recipients of their environment rather than the creators of it.

While symbolic interaction is a process of socialization, it is also highly individualized, based on the meanings that each one of us assigns to a given situation. Eschleman (1988, 2001) and Wilson (2001) described socialization as the process of learning the rules and expectations for behaviour in society. Wahl (1995) reported that whether at the local pool, school, or community centre, each of us learns rules and expectations for how we ought to behave as well as what behaviours are deemed unacceptable. When we are born into this world we are neither social beings nor anti-social beings but we learn through interaction with others. Eschleman (1988) argued that we learn what is good or bad, accepted or

unaccepted behaviour. It is all learned, and anything that is a learned behaviour can also be unlearned or re-learned within a different context.

Socialization, then, encourages people to play by the rules. Most people strive for acceptance and public approval by adhering to the rules in order to be seen in a favourable light by those individuals who matter most to them.

However, regardless of how hard someone might try to abide by unspoken rules, regional differences, culture and gender roles may trip us up, and result in the creation of a “black mark,” or something to be held against us.

Goffman (1946) and Scheff (1984) identified this “black mark” as something that discredits the person, resulting in them having a spoiled or tainted identity. This tainted identity can result from anything that might be viewed as different from another person’s norm. This difference then appears to make it easier for the individual to be discounted or excluded. When we as members in a society believe the qualities attributed to a label, we treat the person differently, often without realizing it; we then reduce their life chances and opportunities (Riesman, 1951; Goffman, 1963). People tend to be hesitant of that which they do not understand. If someone does not fit into our preconceived framework, we tend to pull back.

Rabin, Rosser & Butler (1993) found that the label or diagnosis that an individual was assigned as an experimental variable, impacted how the participants in research viewed the person’s abilities. Individuals with mental health conditions were consistently assigned lower scores than individuals with a physical health condition. Blaxter (1987) reported in another study utilizing a

random sample of individuals 18 years of age and over, that views on health status revealed differences between social classes as well. The purpose of that study was to measure the impact diagnostic information had on values people assigned to selected states of disability, distress and discomfort or pain. Blaxter (1987) concluded that clinical diagnosis does affect how people are viewed but that the viewpoint can be raised or lowered depending upon which condition is being considered. However, the most striking finding of this study was the consistently low scores assigned to individuals exhibiting significant mental health issues. The reasons given for these low scores were that the symptoms were perceived as being serious and undesirable, according to this study.

This undesirable label then becomes an attribute that individuals wish to avoid in order to minimize the degree of stigma they experience. However, it is not only the individual with the diagnosis who wants to minimize the experiences of being labelled; the families do as well. Wig (1997), Wahl (1999) and Lefley (1989) all reported that as a result of a family having a mentally ill family member, the family also experienced social ostracism.

Lefley (1989) also noted that mental health professionals who had an ill family member experienced more personal burden than co-workers with no unwell family members. This then resulted in role conflict in the workplace when colleagues spoke poorly of or made derogatory comments towards mentally ill individuals. For these mental health professionals, this contradiction between training and their lived experience was difficult. In this same study, 90% of the participants reported having heard colleagues frequently make negative remarks

about family members of people with a mental illness. As a result, it was no longer a safe option to disclose to co-workers if they had a family member who experienced a significant mental health issue.

Unfortunately, some professionals continue to delineate in a negative fashion between the two groups, the well and the unwell. They attempt to create required criteria or characteristics for membership in both of these groups, in order to maintain the “us” and “them” categories (Lefley, 1989). Lefley argued that these professionals seem to believe that if they fail to maintain these two distinctly different groups, then they might have to face the potential within themselves that they too might become unwell at some point in time. For many people this thought is far too difficult to deal with; consequently individuals use a variety of methods in order to maintain this constructed distinction. As a result, a special kind of relationship develops between these characteristics or attributes and the resulting stereotype that is formed (Goffman, 1963). While these diagnostic groupings and labels may be useful for treatment, they are not helpful for the total care of the individual (Atkins, 2005) and often result in isolation.

Maintaining this demarcation between the two groups of people, “us” and “them”, gives permission to treat the stigmatized person differently. According to Riesman (1951), active discrimination through which we effectively reduce the life chances of the labelled person becomes part of the norm. Riesman also argued that we construct what might be known as a theory of stigma to explain this perception of their inferiority and in order to address our own personal fear of the diagnosis and to account for any danger we perceive this person might

represent as a result of their diagnosis. We come to believe that people with different diagnoses represent a greater risk to those around them.

Unfortunately, this creation of danger still occurs today. It is not uncommon to read the headlines of the local paper or hear on the local news that someone, usually a male with a significant mental health issue has become violent. Corrigan et al. (2005) reported in one study 39% of all stories involving some aspect of mental health focussed on the relationship between the diagnosis and the individual being dangerous and violent. Most often these news reports were found in the front section of the newspaper. Philo et al. (1994) reported in another study that 40% of the participants believed mental illness and violence were linked and most often these individuals cited the media as the source of their information. This might suggest that every individual experiencing a significant mental health issue ought to be feared because of a perceived correlation with violence. Gerbner et al. (1980) found that individuals with a significant mental health issue are more likely to become the victims of violence than the perpetrators.

Link et al. (1991) noted that our reactions to someone who has been identified as having a mental illness would be affected by the stereotypes or attitudes that we believe to be true, regardless of whether or not their behaviour is inappropriate. While Tausig et al. (1999) reported that there is an increasing degree of knowledge within the general population around mental illness, people still do not appear to think of mental illness in the same way as physical illness and that “to be sick is to be among the damned; to be healthy is to be among the

elect” (Tausig et al., p.164). Gassert & Hall (1964) stated that there is a relentless myth that mental illness happens only to other people and that “normal” people have nothing in common with the mentally ill because they are so different from us. Those who are “normal” are seen as having full control of their lives and their futures.

On the other hand, individuals who have experienced being labelled or stigmatized do not appear to have that same control in their lives. They do not appear to be able to exert the same control by being creative with their plans and how they interpret their lives as others within the same community (Menninger, 1938). Scheff (1984) argued that people who are labelled as *mentally ill* develop an identity as *mentally ill*. Individuals then begin to “act” as if they are mentally ill with behaviours such as declining hygiene, failure to attend appointments and a reported inability to remember important things. The formation of this new identity then actually confirms the original diagnosis because of their new behaviours. Since the label is also stigmatic it leads to isolation and exclusion along with a variety of rewards and punishments.

There is a debate within the therapeutic community as to whether or not labels actually cause the individual to redefine themselves as having a significant mental health issue, because labelled individuals appear to act in ways that are significantly different from their non-labelled counterparts in the same community (Link et al., 1991; Link & Cullen, 1990). Anecdotally, one individual reported that they took one afternoon off each week because their supervisor had made allowances for it based upon their previous experience with individuals with

mental health issues. This afternoon off was not scheduled and the individual could take it whenever they wished to, resulting in the image of an unreliable worker being the new norm. Labels do matter because it is the label or stigma that affects how we view the person and how the person then views themselves (Link et al., 1991). Wink (1995) argued that perhaps the issue is not with the diagnosis itself but with our concept of normalcy. One person might have high blood pressure, another might be near-sighted, while another might have an irregular heartbeat. He noted that while some people are believed to be “normal”, upon closer examination all have aspects of themselves that have the potential to be deemed abnormal. Thus instead of the continuum being between normal and disabled, the continuum ought to be between slight disabilities to severe disability.

Stigma can be found in three different forms. Corrigan (2004) identified two types of stigma that individuals experience as public stigma and private or self-stigma. Corrigan et al. (2005) included structural stigma as the third form. Public stigma is the stigma that is perceived by those around the person identified as ill whereas private or self-stigma is the understanding the individual holds and believes to be true about themselves. Structural stigma occurs when an institution within a society creates and promulgates stigmatizing messages about mental illness. These messages encourage people to view individuals with a significant mental health issue as possibly violent creating fear and causing social avoidance (Corrigan et al., 2005).

Individuals with significant mental health disorders tend to attempt to

avoid the public stigma and diagnosis by not seeking treatment, by not disclosing the diagnosis, or by isolating themselves so that the public stigma is kept at a minimum (Corrigan, 2004; Corrigan & Matthews, 2003). Stigma is the most cited reason individuals give for not seeking treatment for a mental disorder (Corrigan & Penn, 1999; Corrigan, 2004, Kirkwood et al., 2006). Andrews et al. (2001) reported that less than 40% of individuals with a mental health concern seek any form of treatment or professional help. Kirkwood et al. (2006) noted that individuals with mental illnesses often face hostile, oppressive community environments filled with bias and discrimination which result in them being isolated from community life. As a result of these barriers, many people with mental illnesses are prevented from living full, productive and participatory lives within their communities. In order to avoid this isolation, Link et al. (1991) reported that labelled persons go to great lengths to minimize the number of people who are aware of the diagnosis by concealing it, by withdrawing from activities or by attempting to educate those individuals who are aware in order to reduce the stigma they experience.

Corrigan (2004) stated that self-stigma results in a lowering of the person's self-esteem or self-worth as a result of viewing themselves as socially unacceptable. Research has shown that people do internalize negative perceptions when dealing with mental health issues (Link et al., 1987, Link & Phelan, 2001; Corrigan, 1998, 2004; Holmes & River, 1998) and that being labelled mentally ill can lead to lower levels of self-esteem (Link, Strueing, Neese-Todd, Asmussen & Phelan, 2001). Consequently, a person may decide not to seek treatment in order

to maintain a positive self-image (Ames, 1983, Miller, 1985) because seeking treatment or help from someone else may be perceived internally by the individual as an indication that they are inferior or inadequate (Vogel, Wade & Haake, 2006).

However, if the stigmatized individual does attempt to find his or her voice and speak out against the label that has been placed on them, others may perceive this as a defensive response to their situation, and use this as justification for the way they treat them (Goffman, 1963). It appears that we attempt to justify our treatment of others, particularly if we are treating them poorly or feel guilty about how we are treating them. Tausig et al. (1999) noted that when we observe behaviour that we are unable to readily understand, we become uncomfortable and tend to label it so that we can feel as if we have a sense of control over it. This permits our own comfort level to rise to a point where we can cope more effectively.

Unfortunately, if enough people treat the stigmatized individual poorly, over time they too are likely to begin to believe that there is something wrong with them. When individuals begin to assign this new meaning or understanding to their illness, their behaviours, choices, and thoughts begin to shift (Scheff, 1984; Link et al., 1991; Atkins, 2005). Frequently, it is that shift in behaviour that leads others to think of the individual as “deviant”. When situations do arise where someone has been labelled, it becomes difficult for the stigmatized individual to maintain a sense of identity apart from the label. Slowly, the individual begins to accept the beliefs of others (Goffman, 1963) and their stress

levels rise, impacting on their ability to function and cope. So, according to Scheff (1984) to be labelled as mentally ill is to have a label conferred that results in exclusion and sanctions or social control. The label can have profound negative effects on the lives of persons so labelled. One must ask the question, “What then is the role or purpose of the label itself?” Is it for diagnostic or the therapeutic treatment purposes, or is it to withhold a status? Is the label intended to help or to point out what is wrong with the person?

Sometimes these changes in behaviour that are identified as deviant behaviour are thought to be indicative of a mental disorder. This recognition then is the outcome of a social process that depends on the reactions of others and on the labelling of an individual as mentally ill. Mental illness labels have significant consequences for the labelled person. Tausig et al. (1999) noted that it is the label that shifts the person into a world of treatment that most of us will never experience but that has a profound effect for the person who has been labelled.

Atkins (2005) noted that if the individual believes that they ought to be excluded from normal interactions then they fall prey to the stigma, which results in the individual “becoming” the disease itself. The disease overtakes the person. Rubington and Weinberg (1987) noted that once individuals learn they have had a “deviant” identity conferred on them, issues arise. They must make a decision about how much or how little of the label they want to integrate into their personal identity within a social context. They make a decision about whether or not to become the label or the diagnosis. This label then marks the person as

different or bad, and there is a great deal of fear associated with stereotypes of the mentally ill.

However, there are times where this fear has nothing to do with the individual's behaviour but has more to do with the language that is used to describe the person that creates the barrier. DSM-IV-TR (2000) acknowledged this because "a common misconception is that a classification of mental disorders classifies people, when actually what is being classified are disorders that people have" (Erk, 2004, p.7) and as a result the text does not use terms such as "schizophrenic" but utilizes terms such as an individual with schizophrenia which recognizes that "the sum of the total of symptoms does not equal the total [person]" (Erk, 2004, p.7). The diagnosis does not transform the person into the label.

Yet language often creates the illusion that a transformation has occurred. This transformation erodes the person's sense of being a self with rights, responsibilities, privileges and expectations both from others and towards others. "Each individual living human document has an integrity of his or her own that calls for understanding and interpreting not categorization and stereotyping" (Gerkin, 1984, p.38). We cannot successfully understand people based solely on their labels, diagnoses, stereotypes and false assumptions. Vanier (1998) reminded us that people are more than their label. Even though each of us is made up of a variety of attributes or facets, people are more than the sum of their parts.

The National Cristina Foundation offered a \$50,000 prize to the individual who was able to create a term that was not negative or exclusionary towards individuals with disabilities. B. Freer Freeman was awarded the prize for his expression “people with differing abilities” (Lederer, 1991, p.67). It appears Freeman had been able to focus on the giftedness of people rather than their challenges, which resulted in the award.

Language can open up conversations and relationships or it can shut them down, creating barriers and isolation. This isolation can be readily identified not only in people’s lives, but within social structures as well. I have had the privilege of working with a wide variety of individuals who face many different challenges and life struggles. It has been the individuals with significant mental health issues who reported that the label, the isolation, and the lack of understanding that they encountered in the community, were the barriers to participation that keep people stuck in unhealthy and pain-filled situations. Individuals reported that they believed the very places, like the church, where they thought they would be able to access support, were the very places they reported experiencing the greatest judgement, shaming and ridicule which resulted, according to these individuals, in more isolation. For many of these individuals that I have encountered, their faith or spirituality played an important role in their lives.

Hodge (2000) defined spirituality as a relationship with a “transcendent being” that develops and promotes a sense of meaning, purpose and well being in a person’s life. Others differentiate between spirituality and religion. While

religion flows from spirituality, religion refers to the day to day practices, rituals and beliefs held by a group of people who have firsthand knowledge of similar spiritual experiences (Anderson & Worthen, 1997; Wuthnow, 1998; Roof, 1999; Hodge, 2000; Wink & Dillon, 2003). According to one Gallup poll (1990), 85% of Americans consider religion very important or fairly important in their lives while 95% reported believing in God. The same study also noted that 66% of all individuals surveyed preferred a professional counsellor who is religious (Ross, 1993). Bergin & Jensen (1990) noted that 72% of the general public agreed with the statement “my religious faith is the most important influence in my life”. Within a Canadian context, Bibby (2005) reported that 82% (n=1600) responded affirmatively to the statement “Do you believe God or a higher power exists”. Bibby (2007) in another study identified that 85% of participants indicated they have a religion and 77% say they attend worship services. Attendance in this study ranged from once a week to occasionally.

Faith and spirituality have been positively associated with creating resilient families (Walsh, 1998) and thus resilient individuals, and with helping families cope better and recover better from a crisis (McCubbin, McCubbin, Thompson, Han & Allen, 1997). Furman & Chandy (1994) also reported that rural families appear to exhibit even higher degrees of religiosity than urban families and that in rural families God is believed to play as important a role as anyone else in the family. Also of note in this study, families from rural areas appear to experience spirituality as the most important facet in family dynamics. For some families, their faith appears to provide a framework that enhances their

“well-being, lowers distress and may facilitate faster and more effective cognitive restructuring of severe loss and emotional trauma” (Weaver et al., 1997, p.15).

Studies spanning many decades have demonstrated that Americans tend to seek help from clergy early on to deal with personal problems. Weaver, Koenig & Larson (1997) noted between 1979 and 1992, 13 different studies with both rural and urban clergy demonstrated that individuals seeking pastoral counselling bring problems related to marriage and family issues (Abramczyk, 1981; Benner, 1992; Gilbert, 1981; Ingram & Lowe, 1989; Lau & Steele, 1990; Lowe, 1986; Mollica, Streets, Boscarino & Redlich, 1986; Ruppert & Rogers, 1985; Veroff et al, 1981; Virkler, 1979; Wasman, Corradi & Clemens, 1979; Wright, 1984; Wylie, 1984). In another study, Wasman et al. (1979) reported that 85% of parish-based clergy reported family problems were the most difficult and frequently requested issues they were asked to address. In still another study by Privette, Quackenbos & Bundrick (1994), frequent church attendees indicated they were 7 times more likely (86% vs. 12.5%) to request help from clergy than from non-religious mental health specialists for problems related to marriage and family issues. In another study by Leavey, Loewenthal & King (2007) clergy were seen by parishioners as being better equipped care givers than psychiatric professionals; however, these studies were based upon hypothetical situations, not on actual experiences with patients. Leavey, Loewenthal & King (2007) noted that while clergy are well known to be of assistance through distressing life circumstances, the amount of care and counselling given in cases of anxiety and depression is unknown. It appears that clergy are contacted when it is a physical

health issue, a family problem or a marital issue; however, it does not appear to be the case where mental health issues are concerned (Leavey, Loewenthal & King, 2007).

Clergy themselves reported they had received little or no training in mental health issues as part of their ministry development, and acknowledged feeling unprepared, vulnerable and intimidated (Leavey, Loewenthal & King, 2007). One rabbi from an Orthodox tradition noted that he found it very difficult to deal with people in his synagogue who have mental illness (Leavey, Loewenthal & King, 2007). Still another member of the clergy acknowledged that he believes that “somehow there must be a way of excluding the ‘lunatic fringe’ as he calls them, from the church” (Leavey, Loewenthal & King, 2007, p.554). Also from this same study, there appeared to be a consensus amongst the clergy that religion attracts people with significant mental health issues; however, the clergy appear to respond to the requests for mental health support with caution and sometimes rejection, even though clergy have traditionally been viewed as sympathetic, caring and nurturing. Ross (1993) also pointed out that clergy themselves report feeling unprepared to recognize and address mental health problems in individuals seeking help.

As an example, the Pentecostal church forms the largest non-Catholic group of Christians in the world and more than 65% of Pentecostal pastors report having had limited or no acquaintance with mental health resources in their community (Trice & Bjorck, 2006). This is worth noting because clergy appear to play a significant role as “gatekeeper” to mental health resources in many

communities. Some clergy report discouraging parishioners from seeking help from secular professionals because they believe it would interfere with spiritual interventions. Pattison et al. (1973) argued that negative emotions, including depression, are caused by “works of the devil” and the solution to this illness is confession and repentance (Vining & Decker, 1996).

Weaver, Flannelly, Koenig & Smith (2004) reported that religion or faith are tools that many individuals use to help them cope with illness through prayer, reading of scriptures and leaning on God. In this same study, nearly 90% of the participants reported using their faith as a coping mechanism to at least a moderate degree.

In one study over a seven-year period in New York conducted around usage of hospital chaplains, 39% of 1000 patients were referred (Fogg, Weaver, Flannelly, & Handzo, 2004). The authors found that 81.74% of all referrals were made by nurses, 11.74% by social workers, 4.08% by physicians and 3.8% by community clergy. Of the 1000 referrals, only 17 were self-referrals and these referrals came primarily from individuals with physical health issues. In this study individuals with significant mental health concerns were not the ones making the requests for service.

Cutting, Grosch, and Browning (2007) noted that while the religious needs of individuals with physical health issues and those with mental health issues do not differ significantly, the resources available to those with mental health issues are significantly reduced. While individuals want to participate, individuals with significant mental health issues are less likely to belong to a faith group or to

attend religious services (Stark; 1971; Fitchett, 1997). Cutting et al. (2007) also reported that issues related to transportation, past experiences of being made to feel unwelcome, fear of being made to feel unwelcome, not having the proper clothing, difficulty sitting through the service, being uncomfortable with groups of people, not having money for the offering and time of the worship service were barriers to worship for individuals with acute and chronic psychiatric issues. These findings appear to be consistent with reports from individuals experiencing significant mental health issues that I have supported in the past. As a result of my experiences and the research that has already been done, I wanted to fully explore the area of how individuals see themselves in light of a diagnosis, how their relationship with God is impacted, how their quality of life is impacted, and whether the nature of the diagnosis makes a difference to the individuals perception of their illness and themselves.

Chapter 3

Methodology

The design of this research was both quantitative and qualitative. All of the participants were individuals who lived or visited in the Waterloo Region of Ontario between November 1st, 2004 and March 15, 2005. Prior to the collection of any data, approval for this study was obtained from the Wilfrid Laurier University Research Ethics Board.

Quantitative Study

Procedure:

One thousand surveys were distributed to churches of many different denominations, a Hindu temple, shelters for homeless individuals, second stage housing, pharmacies, community centres, senior centres, seminaries, Bible colleges, mental health resource centres, service clubs and the Mood Disorders of Ontario Association between November 1st, 2004 and January 15th, 2005.

Packages were left at each of these sites with an invitation to participate in the survey as well as the focus groups to follow, an informed consent statement, and the survey form. Please see Appendix 1 for a sample of the survey and Appendix 2 for a copy of the Informed Consent Statement.

Participants were invited to complete the informed consent statement, and the survey, put them in the attached envelope, and leave it at the site for the principal researcher to collect.

Instrument

The survey utilized a 9 point Likert scale (1 = strongly disagree, 9 = strongly agree, 5 = no impact) to explore the relationship between health issues, self-concept and community resources. For questions pertaining to faith-based issues, a 10 point Likert scale (1 = strongly disagree, 9 = strongly agree, 10 = not applicable) was used. The questions for the survey were developed, with input from my doctoral committee, from the literature review and from my clinical experience of working with individuals with both physical health and mental health issues.

Participants

There were 361 surveys returned; however, one survey was unusable because the handwriting was illegible. As a result, there were 360 participants. Participants ranged in age from 18 years to over 80 years of age. The sample comprised of 142 men and 217 women. The marital statuses reported were 116, single; 18, widow/widower; 188, married; 7, common law; 28, separated/divorced; 1, separated/divorced and common law. Two surveys provided no response to this question. Two participants reported no health issues, 122 reported physical health issues, 16 reported mental health issues, and 12 reported both physical and mental health and 203 surveys contained no response to this question. There were 271 participants who reported being involved in a spiritual community, 87 who reported no involvement and 2 who reported yes and no. There were 315 individuals living in urban settings and 42 living in a rural setting. One individual reported living in both urban and rural

settings and 2 surveys provided no response. Regarding housing, 230 participants reported living in houses, 10 reported living in shelters, 2 reported living in trailers, 86 reported living in apartments. Five were living with friends, 15 reported living in townhouses, 11 reported living in other types of structures, and one survey contained no response. Individuals reported their faith traditions were as follows: 300 were Christian, 4 were Jewish, 2 were Muslim, 1 was Hindu, 2 were “Christian and all faiths”, 2 were Christian and Jewish, 24 reported having no faith, 23 reported having an alternative faith and 2 surveys contained no response.

Qualitative Study

Procedure

An invitation to participate in a focus group was included in the Informed Consent Statement. Individuals were informed that participation in one of the focus groups would require between one and one and a half hours (1 - 1 ½ hours) of time. Each group was conducted in a wheel-chair accessible building so all individuals, regardless of differing abilities, would be able to participate. Three focus groups were held, at the KW-YWCA Mary’s Place, at the Lincoln Road apartments and at a local counselling office in the community. The KW-YWCA Mary’s Place is a shelter for homeless women and children between the ages of 16 and 96 years who are in need of emergency housing. Mary’s Place houses approximately 70 women, children and families each night in the downtown area of Waterloo Region. The Lincoln Road apartments provide Second Stage housing for women and children and are also operated by the KW-YWCA. They provide

long-term supportive and stable housing to women and their children who might otherwise find themselves homeless. The community-based counselling office was located in a business condominium complex and provides counselling and trauma services to a wide variety of individuals and organizations.

The Informed Consent Statement noted that confidentiality could not be guaranteed by the researcher because all participants would hear what was being said, but that confidentiality would be encouraged and that identifying features would not be included in the final report.

Participants

Thirty-seven individuals chose to participate in the focus groups; they were assigned to groups based on ease of access, but were allowed to change the assignment if they wished. The only exception was that males were asked to join the community-based group that met in the counselling office because of the restrictions at the women-only facilities. All participants were between eight (18) and eighty (80) years of age, 2 were male, 35 were female.

Before participants left the focus groups, the principal investigator conducted a group debriefing utilizing the Mitchell model for group defusing. Individuals indicated that they felt comfortable with the process and felt heard by the researcher. One individual asked repeatedly whether anyone from the government or the university would be able to identify who had said what during the group session and was told that no one would be able to identify anyone in the groups and that no identifying features would be included in the research report.

Focus Group Guide

The researcher asked the same three questions of all groups; however, the groups appeared to go in different directions with those questions. Please see appendix 3 for the three questions.

After the completion of the focus groups, individuals were invited to view the transcription by contacting the researcher but no one chose to either review the written transcripts or make any comments. Each of the focus groups was audio recorded and transcribed by the principal investigator. A research assistant took written notes and recorded them on a flip chart. These written notes were used for clarification purposes only during the transcription process.

Analyzing the data

I chose to use grounded theory because of the way the theory has the opportunity to grow out of the data. When I speak about grounded theory, I am referring to a “theory that was derived from data, systematically gathered and analyzed through the research process” (Strauss & Corbin, 1998, p.12).

The three focus groups had between 10 – 17 participants. Following the transcription of the data, I wanted to ensure that the voices of the participants would be heard. I began the process with developing the open codes, then the axial codes and finally the selective codes that allowed the participant’s voices to be heard and a story to grow and develop.

Phenomenon	Concepts	Categories	Properties	Dimensions	Subcategories
Dog	Ears	Pointed	Furry	Fine	Colour
				Coarse	Colour
			Woolly	Fine	Colour
				Coarse	Colour
			Hairless		
		Floppy	Furry	Fine	Colour
				Coarse	Colour
			Woolly	Fine	Colour
				Coarse	Colour
			Hairless		
	Tails	Short			
		Long			
		Docked			
	Nose	Short			
		Long			
		Wrinkled			
	Legs	Short	Thin	Fine boned	
			Stalky	Heavy set	
		Long	Thin	Fine boned	
			Stalky	Heavy set	

Open coding is “the analytical process through which concepts are identified and their properties and dimensions are discovered” (Strauss & Corbin, 1998, p.101) from the data. Axial coding is “the process of relating categories to their subcategories” (Strauss & Corbin, p. 123). The term axial is used because “the coding occurs around the axis of a category” (Strauss & Corbin, p.123). Selective coding is the “process of integrating and refining the theory” (Strauss & Corbin, p. 161). To further explain how coding is done I will explain the chart found on the previous page. I would like to use the example of a researcher exploring the phenomenon or topic of dogs. Phenomenon is the “central ideas in the data” (Strauss & Corbin, p.101). The researcher would then explore the concepts that become the “building blocks of theory” (Strauss & Corbin, p.101). So in this case, the research might note that these creatures known as dogs, have specific parts such as ears, tails, noses, and legs. The categories are “the concepts that stand for the phenomenon” (Strauss & Corbin, p.101).

To continue with the subject of dogs, the ears for example might be pointed or floppy. Then other properties of the animal’s ears might provide “characteristics of a category” (Strauss & Corbin, p.101) such as the pointed ears might be furry, woolly, or hairless. The dimensions, are the “range along which general properties of a category vary” (Strauss & Corbin, p.101). In this case, the furry ears might be fine or coarse in nature. Subcategories are “concepts that pertain to a category, giving it further clarification and specification” (Strauss & Corbin, p.101). Again referring to this case, the colour of the furry ears might be white, black, brown, or taffy colour. Each and every detail forms a new part of

our understanding of what dogs are like. Each detail provides a richer description of the one before, thus building on the previous description.

In analyzing the data from this research, it was my hope that the participant's voices, when heard together in this manner, would provide the reader with a richer description of the participants lived experiences.

Chapter 4

Qualitative Analysis

In this chapter, I discuss the qualitative data, based upon the three focus groups. These groups, with 37 participants in total, were held in different locations around the Waterloo Region and explored three specific questions. Please see appendix 3 for a copy of these questions.

Each of the sessions was recorded and transcribed by the principle investigator. Then, I created a set of open codes and the axial coding that arose out of that and, finally, the selective codes. The story or metaphor that has risen like a phoenix for many of these individuals appears to tell the story in a different way than what I had initially thought. The metaphor was grounded in the story these individuals told.

Initially there were many, many open codes and I began to wonder whether I would be able to identify the phenomena, concept, category, properties and sub-categories (Strauss & Corbin, 1998, p.101). However, a story began to emerge. The phenomenon I gleaned were God, resiliency, stigma, diagnosis, self-concept, isolation and loss.

Strauss and Corbin (1998) describe grounded theory as “theory that was derived from data, systematically gathered and analyzed through the research process”(p.12). The grounded theory arising from this set of research data, illustrates clearly that when individuals receive a medical diagnosis, whether it is a physical health or mental health issue, it appears to have an impact on their

sense of well-being and how they view themselves as people; for many it appears to create barriers in their ability to worship within their faith communities.

One significant finding was how participants identified themselves at the time of volunteering to participate in the focus groups. Each of the individuals had completed one of the quantitative surveys and had phoned or connected directly with me to convey their interest in participating in a focus group. Of the 37 volunteers, 35 indicated when asked, that their diagnosis was a physical health issue. Two individuals indicated they experienced a mental health issue. However, while conducting the focus groups there appeared to be a significant amount of trust that was built not only among the group participants but also with the investigator. By the end of the three focus groups, 35 individuals had acknowledged that their diagnoses also included a significant mental health issue. There were only 2 individuals with strictly physical health issues in the group.

When I speak of significant mental health issues, I am using as my criteria the five diagnoses recognized by the Province of Ontario for a disability pension. These are, schizophrenia, bi-polar disorder, depression, paranoia and head injury. In two out of three focus groups I had individuals who experienced significant head trauma that at times made it a little difficult to glean their experiences; however, their stories emerged along with those of the rest of the participants. The story or metaphor that has risen like a phoenix for many of these individuals appears to tell the story in a different way than what I had initially thought. The metaphor was grounded in the story these individuals told.

God

The strongest story that arose out of the ashes of most people's experiences was that they had a strong relationship with God but not with a faith community. For these individuals prayer was the primary coping strategy used by all three focus group participants. It was their relationship directly with God that was crucial in their lives. The participants noted:

- "In God's eyes I'm not different."
- "He doesn't treat you any different, He loves you no matter what."
- "My mom always used to say, if you pray, just pray, you will receive it, but you have to pray."
- "Well, I talk to God a lot, but when I talk to God, I just say "Thank you very much for forgiving me, I thank Him."
- "Because God's there no matter what. Even when you don't think He's there at that present second, but He is. He watches over you and He guides you to what you need."

God, when viewed as a coping strategy or as a resource is viewed as having a positive impact. Participants reported:

- "Yes, my faith gives me hope. Keeps me level."
- "I do pray but I don't go and get involved in church or anything."

- “It helps to pray.”

For others, God is viewed as providing a sense of comfort.

- “About 19 years ago I was diagnosed with depression which I have had to learn to live with. But I think God teaches us so much through all these things that happen to us and through the crisis in our life or through learning to live with a chronic disease.”
- “At least there’s somebody out there who cares and is there to watch over you.”

When God is viewed as being in control one participant reported:

- “I had been diagnosed with lymphoma and the doctor needed to do a lung biopsy. My son-in-law’s sister prayed with me the night before my biopsy and she prayed that God would reveal himself to me as a shepherd. So before I went to the hospital, I opened my Bible and the Lord showed me something to help me. He was my shepherd here to help me. So here I am lying down on the operating table and thinking they are going to cut my throat and I thought no, I’m in God’s hands. Where else could I be that would be better than that.”

Other individuals indicated that their ability to trust God was very important for them, particularly because they felt they had been let down by others throughout their lifetime:

- “You don’t want a relationship with somebody you can’t trust. But that doesn’t happen with God. You can trust him.”

- “I do believe in God. I believe in Jesus. I’m not really a church-goer. I do go on special occasions but I don’t go all the time. But I talk to God in my mind. I talk to him a lot because I know He’s there.”

For other individuals, God provided a sense of hope and being cared for, particularly when their situation was feeling hopeless. They observed:

- “If you want something, ask God to give it to you. And if you ask God for something, you will receive it. My Mom used to say if you pray, just pray, you will receive it, but you have to pray.”
- “Even though I was facing surgery, this was fine whether I woke up or whether I didn’t wake up. I was fine.”
- “Now my hope does come from God, but you can use these doctors and people around me to help me get from here to here.”

Still other individuals indicated that there was comfort for them in knowing that God is the one in control and that God is an active part of their lives:

- “I’m a lucky man in many ways. I’m a Christian and my firm belief is that I’m not in charge, God is and he knows all about my body and what it can and can’t do, that’s for Him to do.”
- “He watches over you and He guards and guides you to do what you need.”

Others found themselves expressing this affirmation of the relationship they had with God in the form of thankfulness:

- “When I talk to God, I just say “Thank you very much for listening to me.”
- “I was raised Catholic but I am a born again Christian. In my car is a medal and every time I get in my car and I happen to look up and I say ‘thank you God for taking care of me.’”

Almost every individual (34/37) who participated in the focus groups reported having been harmed by members of a church or faith community in the past resulting in the church being unhelpful. However, not only was the church viewed as being unhelpful, the church appeared to be an unsafe place for them to disclose they had a significant mental health issue. Almost all told of having been asked to leave a church because of their mental health issue. Time and again they reported that when they disclosed their mental health issue they were forced to leave and move on. Interestingly, participants in the focus group held in the community based setting indicated they will no longer share that they have a significant mental health issue with their church, pastor/priest or faith community. When asked to elaborate on this decision, a variety of responses ensued:

- “Not a chance will I ever again talk about depression at church.”
- “Church people say that you shouldn’t have that problem if you are a strong person. If you are a strong Christian and that if you are right with God. Then I’m hearing people say I’m reluctant to talk about the fact that I have depression. That spread a blanket over the whole issue of depression.”

- “But one thing I heard that made me fear telling people I had depression, I was talking to another pastor’s wife and she was talking about someone in her church who was depressed and she said ‘wouldn’t it be awful to think that your personality came out of a bottle?’”
- “I had my son when I was 17. I had to go to a doctor’s appointment when he was a few months old, so I asked my pastor if they could watch him. When I came back he said he wanted me to either give the child up or get in front of the church and withdraw my membership. I just never went back to church.”
- “When I would go to church and if I get up and leave before it’s over and the person standing in the back said to me ‘oh you’re escaping’. That stung my heart because I was having anxiety and I needed to leave.”
- “I haven’t let myself get involved in a faith community for 30 years.”

People reported that those within the church just do not appear to understand and are ignorant about the issues involving mental health. They stated:

- “I find I’m a little reticent to talk to people about my mental health issues. I work at a Christian institution and I don’t think I would share that information there. They might be accepting but I’ve also seen what has happened in the past when someone has disclosed their mental health issues. I don’t want that.”

- “You know when people ask you ‘how are you’, they really don’t want to listen. They just want you to say fine and go on. Sometimes you are so tired of saying that, that you are saucy.”
- “What I always do in that case when somebody asks how are you doing, if I feel okay, I say ‘Oh okay’. Or if I’m feeling bad I will say ‘Oh, I’m struggling’ or ‘I guess just the same as everybody else. And that’s the end of it.’”
- “I have found that in some ways, people who are depressed are afraid to talk about it at church. Christians will think this is a spiritual problem and that if they were only right with God they wouldn’t be depressed.”
- “Being vulnerable and talking about your mental health issue is a real risk.”
- “People in general don’t know enough about mental illness. Like I had church people who I was really, really close to, 15 years ago now. I was friends with a lady who had troubles with her heart and with that she got depression. And she said she never realized that people had such a struggle. And I mean, in all those years that she spent time with me, did she have blinders on?”

However, even with story after story of hurtful encounters, these tremendously resilient individuals had chosen to not abandon their faith. They noted:

- “But I think that God teaches us so much through all these things that happen to us and through the crises of our lives or through learning to live with a chronic disease.”

- “I believe in God and I believe in Jesus. I’m not really a church goer but I talk to God all the time in my mind.”
- “I just keep myself at a distance. I do pray but I don’t go and get involved in church or anything.”
- “I haven’t let myself get involved in a faith community for thirty years but my faith is very important to me.”

Even though these participants had experienced some unfortunate exchanges with others within a church context, none of the negative factors came from their relationship with God. It appears that it was people who had let them down, not God. As their relationship with God was able to remain strong, their faith in God enhanced their resiliency and determination to keep moving ahead.

Resilience

The second theme that participants articulated as being important was that of resilience. Individuals appeared to be able to pick up the “gems” and “jewels” out of their learning and move on. It appeared to me that the theme of rising above the diagnosis itself was a metaphor that kept repeating itself. They reported:

- “This diagnosis is “not who I am. It’s how I think. It’s just a facet of who I am.”
- “I have it but it doesn’t have me.”

The above positive statement became her positive affirmation that kept her going, according to the participant. She reported that it kept her from becoming

the diagnosis or allowing others to turn her into the diagnosis. Another individual reported:

- “I don’t look at myself as somebody with [a diagnosis], I’m a writer.”

For some individuals, medication appeared to make a substantial difference that aided with their ability to get their feet under them again. One participant reported:

- Before medication “I told my doctor I felt like I can’t see over the fence, I am behind this fence and I can’t get over it. So you know you need help and you know you need to do something about it but I just couldn’t pull it out of myself to do it.”

The third aspect of resilience was how well the individual appeared to be coping and the reasons why they thought this way. Individuals who were coping well reported finding healthy ways to deal with the changes they had experienced. Integrating who they saw themselves as and being determined to rise above the illness, proved to be helpful strategies. Participants shared:

- “I also have had trouble with anxiety for many years and it probably has always been there, but I didn’t pay any attention to it. I just thought I was hyper.”
- “So it changed how I feel about myself. I can look at myself and go okay, I am behaving this way, but that’s not who I am. It’s how I think. It’s just a facet of who I am. It gave me the ability to say okay, what can I do now? How can I handle this?”

- “The illness is part of me. So it was better that I looked at it that way rather than as two separate things.”
- “If I separate the illness out, the illness became a bad thing. But if I took it the other way, it’s all part of the package. It’s who I am.”
- “I’m a writer, not a disease.”
- “I am trying to get there. Thinking positively. So, I turn the music on and do something different.”
- “I’m not stupid, my brain is just wired different from other people.”
- “I’m being more optimistic. I’ve changed my way of thinking. I’m not going to let my diagnosis limit me. I’m still going to do what I want to do.”
- “I have my illness but my illness doesn’t have me.”

Resilience is the determination to find a new sense of normal, to learn and to grow from the experiences without allowing the obstacle or barrier to destroy you. These participants have found unique ways to express themselves, understand and act in ways that declared to themselves and those around them, their determination to not allow the diagnosis to take over their life.

Stigma

The third theme that arose for many people was the issue of stigma, which was broken down further into physical health, mental health and quality of life

issues. Individuals reported that there were some benefits to knowing their diagnosis, including access to specialized services. They stated:

- “Just knowing that ‘it’s not all in my head’ made a big difference.”
- “It was good because then I could do my own research on the internet and educate myself.”
- “I was on the computer trying to find out about my diagnosis myself. I have other problems solved too.”
- “Knowing what was wrong was helpful. There we had something to work on. The doctors were able to help.”
- “Then after my diagnosis in 1993 I went into a rehab hospital for a month. The thing that helped me most was the first 5 minutes when I learned I didn’t have any problems compared to others.”
- “Well one way would be when I was in this program Focus for Change. It was supposed to help you figure out what career you wanted to get into and give you a foot in the door.”
- “There are 60 of us in Waterloo Region, so now I know I’m not alone. We have a support group that I can attend.”

However, there were also some negative outcomes. The visible effects of the diagnosis caused many embarrassing moments. They noted:

- “It was only when I used the words that I am socially unacceptable at home or abroad that I got some results.”
- “I was told that because of the diagnosis, that if I wanted to be looking at this college course, I was going to be needing to take medication, even though it had side effects.”
- “With my diagnosis, people don’t want to have anything to do with you.”

The invisible issues also attracted attention in a negative way, resulting in the individual not being able to access the resources she believed she required. Another individual reported experiencing a lack of understanding of the issues she was facing which left her feeling like no one cared about her. They observed:

- “I had questioned whether I could access some of the special needs department in the college. Apparently those programs are only available to those who are paying for their education in a college program. My EI course didn’t count.”
- “Nobody cares. That’s the whole issue here is that nobody cares about nothing.”

Within this second theme of stigma, mental health also played a significant role. One individual expressed a positive outcome of having been diagnosed with a mental health issue that she was then able to access services she might not have been able to access. Participants noted:

- “Doctors, doctors. I see a psychiatrist doctor and he keeps me going.”
- “The diagnosis was helpful because you research it and then you understand it.”

- “CMHA helped me with that job. I learned to stock the shelves and I was used to that kind of work. But I learned that there.”

However, again, negative results appear to be the more frequent experience of individuals. Individuals reported that they lost part of themselves behind the label or diagnosis and that the diagnosis actually worked against them in a number of different situations:

- “But the anxiety attacks, they definitely take a part of you. You get a complex opening your mouth, you are not sure whether you are going to have an attack.”
- “I think it depends on how noticeable the physical disability might be. For example, something like cancer, people know about and there’s a lot of sympathy and tolerance. Whereas something like depression, people know little about. It’s something I think is taboo to talk about so people often keep the opinion that you are lazy or unmotivated.”
- “I think my diagnosis worked against me. I was going to get custody of an older girl and it was a definite through F & CS that she would come here. Then they decided to look at my file one more time and they decided that my health didn’t warrant having her.”

For individuals who did not appear to be coping well, inadequate housing and unhealthy relationships appeared to play a role in their lack of coping.

Participants observed:

- “They have a lack of understanding. I’d say $\frac{3}{4}$ of them at work know my situation and $\frac{3}{4}$ of them hate me because of my situation and where I’m living right now.”
- “Okay, people generally look at you in certain ways. Does this look like things are going well? (Referring to living in the shelter)”
- “But if they don’t like me or the fact that I am in this position, I can’t change that. I’ve been having troubles with a lot of people around this place.”
- “For about 5 or 6 years I’ve been telling my landlord that there’s bats, mice and birds in there. Finally they went in and they took out all of the nests.”

While stigma with its many oppressive layers had the ability to get participants down and keep them down, it also has had some beneficial outcomes for the individuals who were able to access the services they required. However, for the most part though, the negative outcomes were the ones that caught attention as a result of the nature of the diagnosis.

Diagnosis

The fourth theme that arose from the focus groups was that of the diagnosis itself. Again both physical and mental health diagnoses were found to be helpful for individuals even though they resulted in changes in their every day life. Participants noted:

- “When it’s acute, when my hands are swollen, it limits what I can do, and you know, I find it limits walking as well.”
- “Everyday it was on my mind, in everything I did or maybe didn’t do. Like for instance they say you shouldn’t over-exert yourself. So I’d be thinking, if I got invited to go out after work with my friends, and if I had a really busy day at work, I would think, should I really be doing this? You know, it was kind of impacting my life in that respect.”
- “I feel now that I have come to the point where it almost doesn’t bother me anymore. When I get in my car, I just relax and I think, ‘all right, you just do whatever you need to do. I’m not going to let you bother me’. Just having that kind of outlook and thoughts and things like that have really, really helped me feel better about myself because I am more optimistic and I can see the better things in life and I view myself as, it’s just something I have. I’ll deal with it and just live my life the best that I can. You know, I’ll maybe change a little, a couple of things here and there along the way to make it better for my future. It started out negative at first but its turned out to make me a more confident person which is great.”
- “I was a lay preacher and I haven’t done any preaching since then because I can’t stand up.”
- “I told the doctor I was tired all the time. Now I know why.”

- “Well it has had an impact because there are a lot of things I can’t do, but there are a lot of things I can do.”

Individuals reported that knowing what their mental health diagnosis was also helpful for them. Everything from being able to research and understand it to the diagnosis providing a sense of hope and a shift in their own sense of self became helpful for them. Participants observed:

- “The diagnosis was very helpful. You research it and then you understand it.”
- “The diagnosis definitely provided me with a sense of hope. Part of my journey there is as a Christian. I should be able to get my hope from God, so I must really be a failure if I can’t get over this with His help. But now I know differently.”
- “When I was diagnosed with depression a number of years ago and I was put on medication. I felt this is who I really am, after I got on medication. I’m not what I thought I was.”
- “Then, I knew that it’s not all in my head.”
- “I came to realize that the illness is part of me.”

On the other hand though, there was also a down side to having a physical diagnosis. Individuals reported that as a result of the illnesses, there were changes they experienced in everyday life that they had not counted on. Changes such as routines, limitations due to movement, activities and travel were reported to be problematic. Participants noted:

- “It’s one of those diseases that goes down by plateaus. You can do things and then you can’t do that anymore. You can do less and less but the disease itself won’t kill you.”
- “So, I had to take the pills and sit down. You have to sit for a half hour and you can’t lie down or walk or stuff.”
- “We have a support group. My frustration is that they have their meetings in the afternoon but I can’t attend because that’s when I have to sleep.”
- “In the beginning, I was thinking, ‘now I can’t do everything I want to do. Now I can’t go on trips because if I have to walk a lot I’m going to be really tired and that’s going to cause a relapse.’”
- “I can’t fly. I have limited travel. I’m a Nova Scotian and I can’t go back. I can’t travel. That really bothers me a great deal because you can take the Nova Scotian out of Nova Scotia but you can’t take the Nova Scotia out of him.”

Issues related to travel were common both for individuals with physical health issues as well as mental health issues. Individuals with mental health diagnoses also reported experiencing unhelpful shifts in how they saw themselves. Participants recognized:

- “It would be nice to be able to travel. I find that very limiting. If there’s anything that makes me feel at all depressed, it’s that.”

- “With anxiety, it’s like I don’t even know who I am. Its so constant for a little over a year that, that’s all I’m doing, is just doing the same old, same old boring old thing just in case I have an attack.”
- “I always thought I was a strong person. But I don’t feel that anymore.”
- “Even if you are on vacation, it sometimes limits you and you can’t go.”

Participants were able to recognize the need for changes in their every day life both positively and negatively. They reported that things that they were unable to do or accomplish could at times feel overwhelming; however, individuals appeared to be able to recognize these limitations and rise above them. However, the one consistent draw back was that of limitations on their ability to travel which created a distance between themselves and others.

Isolation

The fifth theme that was presented was that of isolation. Participants reported feeling shunned by family, friends, and others, which then resulted in a great deal of loneliness. They said:

- “They don’t care about anyone else. I asked them if one of them might come and see me, but no. I’ve got no relationships. I’ve got no relationships with my father, with my sister, with my nephew. So, I don’t have any relationship with my family.”
- “Well you try to talk to friends and they say to stay away from her and everything

else. There's nobody."

- "That's how I feel for me because I didn't even share Christmas this year with my family. I didn't share a lot of Christmases with my own family. Even when my Mom drove a lot, I couldn't go home."
- "Nineteen years this year that I couldn't go home for Christmas. That must mean something. You know in your heart how it is. You just keep on going and going and hoping."
- "Some days I think that the day is never going to end. Or I just want to go to bed and then that's it. Like lately, that's how I felt. But my family's not around to know that so they don't see that. They just tell me to go to the hospital if you feel that way. I can't be going to the hospital."
- "Other people don't want to have anything to do with you."
- "Then you're like shunned by everybody and you can't participate, even in worshipping."
- "It would affect everybody if I were diagnosed with a mental illness. If you take depression, that's a mental illness and I was diagnosed when I went to the United States last year. I was depressed and I was diagnosed and it affected everybody."
- "I don't have very many friends but at least I have some and they help me as well. Not all of them discriminate against me because of my situation. And that's what I need."

- “But, it’s kind of hard for me because no one’s ever there for me.”

The pain of isolation appeared to sear into the hearts of the participants, particularly those who did not appear to be coping as well as others. The shunning by friends and others in the community had an impact; however, it appeared that the shunning by family created the greatest pain for individuals. This pain appeared to invade all parts of their being and their interaction with others.

Self-concept

The sixth theme was that of self-concept. Some individuals reported seeing themselves in a positive light where both physical health issues and mental health issues were concerned. Strategies for coping well and demonstrating their resiliency as well as being seen as the same as everyone else in God’s eyes appeared to be helpful for these individuals. Participants observed:

- “At the beginning, it made me feel like I was very little. I had a very little sense of self. I thought this was going to be my life so I was going to have to live my life around the disease. I was largely skeptical and pessimistic about a lot of things. I would honestly say it’s a blessing in disguise really, but in a way where I have been becoming a more optimistic person. I try to enjoy the little things in life.”
- “It was kind of impacting my life in that respect. I’ve learned a little bit over the past year to do the things I want to do but still not over exert myself.”

- “It really helped me re-evaluate different things in my life. Now I’m thinking is this reasonable to be doing and do I have to do this?”
- “I can see things that I would do before that I didn’t recognize, like if the table wasn’t cleared after supper I would go ‘nobody likes me’. Now, when I look at it, I go ‘what a bunch of lazy people in my house!’”

One individual discussed her positive experiences within a small group at church.

- “I have a very supportive small group in my church. I don’t talk a lot about my diagnosis at church. I’ll just stay away because most people at church don’t understand. That’s why I am part of a small group. And that’s where I can just spill my guts whenever I want to. They’re very helpful and supportive. In the small group that I’m in, there’s four couples in it and each couple has somehow been affected by depression.”

However, a number of individuals reported negative feelings with regard to self-concept when the diagnosis was a physical health issue. Many reported feeling weak as a person, questioned why this was happening to them and acknowledging a loss of their dreams in this process. They reported:

- “It really made me feel like, why me? Great, I had to be the one that got this. It made me feel weak as an individual. Everyday it was on my mind, of course, in everything I did or maybe didn’t do.”
- “It has limited my dreams. I want to live by the ocean, what am I doing here?”

- “It certainly changed any further schooling that I was choosing.”
- “I haven’t lost any dreams, its just sort of more stuff than I expected to lose.”

Participants also reported experiencing negative feelings towards the concept they held of themselves with regard to their mental health issues.

Participants reported feeling that others thought they were lazy, they reported questioning the value of their life, that they were being punished and that a mental health identification created barriers to employment particularly with the concept they held of themselves and portrayed to a potential employer. They noted:

- “Maybe in my eyes I feel like I should be, I wish I could do more, or be more productive.”
- Whereas something like depression, people know little about. It’s something I think is taboo to talk about so people often keep the opinion that you are lazy or unmotivated.”
- “I look at it all in one and I keep saying, ‘what’s the sense in living?’”
- “I find it much harder to physically be there for my children because I am so depressed. I find that for them to be where they are is better for them than for them to be with me and watch me go through my horrible life I’m going through every day. I’m up and then I’m down.”
- “I’m always looking for a job. I’ve been looking for a job since the last couple of weeks. I’ve been looking all over. I tried Walmart and they’re just taking down

names. They've been taking down names for over 20 weeks. They've got a lot of names. Through CMHA I just had a job, to stock shelves. I used to do that kind of work. I learned that."

Both physical health and mental health issues had a negative impact for participants. For some, it was the barriers that were created regarding employment and others it was the view held by others that they were lazy. However, there were individuals who reported being able to adopt a new understanding of themselves in light of the illness. For these individuals doing what they were able to do and being optimistic all positively impacted their sense of self. There appeared to be a direct, positive correlation between individuals who were able to maintain an optimistic vantage point and the degree to which their losses appeared to be manageable.

Loss

The seventh and final theme that participants reported experiencing was that of loss. Individuals reported that because their diagnosis impacted on their ability to parent and have their children or foster children with them. Some participants indicated that there were a variety of reasons they no longer had custody of their children. For some, it was their own choice, while others had had their children placed in the care of Family and Children's Services. As a result of these losses, individuals reported experiencing a loss of goals, a loss of dreams and a loss of a sense of future. In situations where it was their own choice for the

children to not be with them, they reported feeling put down by others and a loss of contact with the children:

- “I was going to get custody of an older girl and it was a definite through Family and Children’s services that she would come here. Then they decided to look at my file one more time and they decided that my health didn’t warrant having her. She used to live in the building and I have known her since she was born and she used to come on weekends or whatever but because of my health, they stopped it.”
- Now that her children were gone one participant reported “I don’t feel I have any goals anymore.”
- “I love my children, but this is the best thing I ever did for them. I don’t have them with me. I know that. I see them, but I don’t see them very often. Of course you try to see them. I have an invitation. But I don’t see my daughter very often. I don’t see her. I see my one son once a week. I see my other son once in a while because his father has custody of him.”
- “We went to court and he got sole custody and I got visitation. I find it very depressing cause I don’t have them to keep me supported. It’s hard.”
- “I got all the way through, but what do I have to show for it? Everything I get is taken away from me. Like everything gets taken away that I shouldn’t have. Like that’s just not right.”

The losses that these individuals experienced were at times overwhelming. The loss of their children, goals, dreams and a sense of future stung. Yet these participants did not allow the losses to hold them back. They were finding ways around the pain. Ways to once again take charge of their lives.

Consequently, like a phoenix rising up out of the ashes, so the story of these participants also arose and took flight. The themes of God, resiliency, stigma, diagnosis, self-concept, isolation and loss formed the structure of their experiences. It was their courage to speak up and allow their voices to be heard that hopefully will precipitate changes in how those of us around them will respond in the future. There can be no healing without justice and justice requires courage. This is the type of courage shown by the participants in these focus groups.

Chapter 5

Quantitative Analysis

One thousand surveys were distributed throughout Waterloo Region with 360 completed and usable surveys returned to the principle investigator. It was my intention to analyze the differences in responses of those individuals with a physical health issue, a mental health issue or both and determine what impact the mental health diagnosis had on how people viewed themselves, their quality of life and their relationship with God and a faith community.

Through the surveys, 37 individuals volunteered to participate in the focus groups with 35 indicating they experienced a physical health issue only, leaving 2 individuals who identified as having a significant mental health issue. However, as trust was built in the group and with the principle investigator before the end of the group session, 35 participants indicated they actually experienced both a physical health and mental health issue with only 2 individuals reporting they experienced only a physical health. Individuals reported feeling unsafe with originally disclosing their mental health issue, and, consequently, only reported the physical health issue.

While 360 completed surveys were returned, 195 individuals or 54% of the participants failed to identify on their survey whether they experienced a mental health issue, a physical health issue or both mental health and physical health issue. My intention had been to compare the experiences of people with a physical diagnosis and people who had a mental health diagnosis, but only 16 people reported having a mental health diagnosis, and 132 people reported having

a physical health diagnosis. Fourteen people reported having both, and one person reported having neither. As a result, I am unable to analyze the remaining data because the sample sizes in the groups I was interested in were too small. While this is a very frustrating situation, it once more reaffirms what had been stated by focus group participants: that disclosing one has a significant mental health issue is too risky, even on an anonymous survey. Consequently, there is no quantitative data analysis to be included in this report.

Chapter 6

Theological Reflection

In this research, nearly all the focus group participants (35 out of 37) reported it felt unsafe for them to disclose a significant mental health issue within their faith community, almost all related having been asked to leave a faith community as a result of a previous disclosure regarding a mental health issue, and as a result, many stated that they no longer allowed themselves to participate in worship or a faith community. However, almost all participants reported experiencing a personal relationship with God or Jesus and utilizing prayer as their primary coping mechanism.

In this chapter I will be exploring the theological issues arising from the research. To reflect theologically, we need to identify the themes of our experiences and bring those themes together with the teachings of our faith tradition so that we are able to create some sense of meaning for ourselves, as we are meaning-making people. Reflecting theologically then requires that we put our new experiences into a context that perhaps is drastically different than our previous experiences. Killen and de Beer (1994) noted that the process of bringing together our experiences and our faith tradition can bring about new insights, new understandings that then are able to bring about changes in behaviour and perceptions (p. 51).

Theological reflection is the discipline of exploring our individual and corporate experience in conversation with the wisdom of a religious heritage. The conversation is a genuine dialogue that seeks to hear from

our own beliefs, actions and perspectives, as well as from those of the tradition. It respects the integrity of both. Theological reflection therefore may confirm, challenge, clarify, and expand how we understand our own experience and how we understand the religious tradition. The outcome is new truth and meaning for living (Killen & de Beer, 1994, p.51).

The method of theological reflection that I have utilized in this chapter rises from the “standpoint of exploration” (Killen & de Beer, 1994, p.50) where I have allowed my own Christian heritage to impact on my new understanding of the relationship between faith and participant’s experiences.

In the following reflection, I will be addressing five areas arising from this work. These areas are:

- Genesis 1:26 – 27 – Created in God’s image
- Exodus 3:14 – “I am that I am”
- God as disabled
- The perceived correlation between disability and sin
- The plight of Hagar.

Genesis 1:26 – 27 records this account: “Then God said ‘Let us make man in our image, according to our likeness ... So God created man in his own image, in the image of God He created him; male and female he created them”.

Here the author of Genesis acknowledges the plurality of God the creator. “The narrative presents God as calling on the heavenly court, or the other two members of the Trinity, to centre all attention on this event” (Pfeiffer, 1962, p.55)

as God decides to create man and woman in their image. By incorporating all aspects of the Godhead in the decision to create humankind in their likeness, people have been created with presence, form and spirit just as the Godhead. Both likeness and image have been incorporated into our being.

But what is the difference between image and likeness as referred to in Genesis 1:26? Micks (1982) noted that image was “not lost in the Fall, but the likeness was. According to this perspective, the image was essentially our capacity for rational thought, whereas likeness was righteousness” (p.5).

But in the story of creation, humankind reflected both aspects of “God-likeness” at the moment of creation. So, when scriptural accounts identify the fact that all of us are created in God’s image at birth, does that then convey to individuals with disabilities, particularly those with disabilities acquired later in life, that they are no longer “in God’s image”? According to the participants in this study, they believed “in God’s eyes I’m not different”. Not only did they not see themselves as different from God, but they argued God also “doesn’t treat you any different. He loves you no matter what”. Karl Barth pointed out that being made in the image of God “affirms our individuality – my God-given right to be me and your God-given right to be you. It frees us from all cultural stereotyping” (as cited in Micks, 1982, p.20).

So, if in fact Barth is right and we are freed from our culture’s limited understanding of stereotypes, perhaps we can also be freed from our limited understanding of what it means to be “perfect”. How we define being “perfect” will be different for each of us. Whether the individual has a disability of some

form is really not the issue. The essence of God within a person is what creates perfection and being created in God's image, not some outward facet of their being.

Next, the author of Exodus 3:14 acknowledges the conversation between Moses and God at Horeb, also known as the Mountain of God. Here Moses asks God whom he should tell the people sent him. God replies for Moses to tell them "I am who I am" according to the New King James Version. Here, "I am" represents "a name indicating rather the unsearchableness of God rather than the mere existence as commonly supposed (Archer, 1964, 114). Archer (1964) goes on to explain that "I am that I am" is the Hebrew *'ehyeh 'aser 'ehyeh*, which means "to become or to be". The verb *hayah* never expresses the ontological existence, but the concept of "happen, become, entering into a new condition or state or relationship" (Archer, 114). What God is advocating for Moses to say in essence is that He is who He is becoming, indicating an on going process of change.

This then presents a very different image of God, if in fact God is growing and changing on an ongoing basis in the same way we are growing and changing. Does that then mean that being created in God's every changing image is what our change is all about, or does it leave the door open to other possibilities and interpretations of just what does God "look" like? Is it possible that God just might be a big black woman whose motherly nature and love is just what we need in that moment? Or a tiny, oriental man whose wisdom is characterized in the few delicately chosen and measured words he conveys to us. Perhaps God's

image is what we need it to be in order to fill a void in our own life -- whether that is male or female, white, oriental, Hispanic or black it does not make a difference to the essence of who God is for each person. Ultimately, does it even matter what we call God? The limitations of the English language appear to be the problem, not the ontological presence of the being known as God.

Is it possible then, that God is also disabled? In the parable recorded of the Great Judgement (Matthew 25:31-46 King James Version) Cooper (1993) notes that God is seen as poor, hungry, naked, sick, imprisoned and that whatever we have done to individuals who are also poor, hungry, naked, sick or imprisoned, we have done unto God.

So if God can “be” all of these situations, Cooper (1993) asks the question why God cannot be disabled too? “God could not be God without suffering because those who do not experience the suffering of the ‘suffering other’ do not understand the reality of the other” (Cooper, 1993, 65). Consequently, if God is disabled, then God would be able to experience the world in the same ways as those who experience physical health and mental health challenges do.

This concept of God as disabled may seem offensive to some people; however, I wonder if it would be any more offensive than Jesus eating with sinners or tax collectors? For that matter, how different would it be than Jesus being seen as poor to the rich young ruler, or naked to those who were finely dressed? If God is a God who meets us where we are at, does He not also meet us in our illnesses?

For centuries there has been a perceived correlation between illness and sin. During Biblical times the belief was that illness was a result of sin (Luke 5:18-26, Matthew 9:2-7, John 5: 1-14, John 9:1-12 King James Version). In John 9:1-12, we find the disciples asking Jesus who was responsible for a young man's blindness, whether it was his own sin or the sins of his father and mother. There appeared to be a belief system in place that attributed disease to an individual's actions or possession by evil spirits. But Jesus answered them saying "neither had this man sinned, nor his parents; but that the works of God should be made manifest in him". There was no one to be blamed for sinful behaviour but in essence this family ought to be welcomed into the community of faith, just as others are welcomed in.

However, creating a welcoming environment requires more than adding ramps, elevators or widening doorways. It also requires changes within the attitudes and hearts of people, the ways we interact with those who are perceived to be different from us, and the language we use in relation to individuals with differing abilities.

Merrick (1993) draws together several authors who provide a common theme of providing *hesed* to those around us. "*Hesed* is an all-encompassing love that knows no barriers and no limits; it is compassion and loyalty beyond what we are able to comprehend" (Blair, 1993, 24). This experience of *hesed* is demonstrated time and again through Jesus' interactions with the people who were seen as undesirable.

The Samaritan woman, the tax collectors, the ritually unclean, and the dead were all to be avoided; yet these were the very people Jesus interacted with, healed, and ate with. His overwhelming and all-encompassing love did not stop where social customs of the day would have had him stop. Jesus spoke the language of inclusion. He befriended the friendless.

Hoekema (1986) stated that

Human beings reflect God, who exists not as a solitary being but as a being in fellowship – a fellowship that is described at a later stage of divine revelation as that between the Father, the Son and the Holy Spirit. From the fact that God blessed human beings and gave them a mandate (v.28) we may infer that humans also resemble God in that they are persons, responsible beings” (Hoekema, 14).

God, portrayed as the trinity, is a being in relationship with all aspects of the Father, Son and Holy Spirit. There is no hierarchy within the relationship, only community and interaction as a growing, living, changing being not a being alone and experiencing isolation or dominance from others. However, it is inclusion and lack of understanding by their faith communities that individuals with significant mental health issues report lacking. One participant reported “they don’t care about anyone else. I asked them if one of them might come and see me, but no. I’ve got no relationships”. Still others indicated “other people don’t want to have anything to do with you” and “then you’re like shunned by everybody and you can’t participate, even in worshipping”.

One Gallup study that was commissioned by Group Publishing reported that people with close friendships in their church reported feeling very satisfied with their congregation, were less likely to leave their place of worship, and were more likely to have a strong friendship with God. Of those highly satisfied members, 77% report having eaten a meal with fellow congregants over the past year. Mealtimes fellowship appears to be strongly correlated with high levels of congregational satisfaction. Individuals who have a best friend at church are 21% more likely to report attending services at least once a week. Connecting socially is vital for all of us, including those who face physical health and mental health issues. Inclusion is essential.

Based upon this research, individuals who do not experience being included in the community report feeling isolated and lonely. “They don’t care about anyone else. I asked them if one of them might come and see me, but no. I’ve got no relationships”. Others who face disabilities die emotionally from the language used in interactions with them. How we speak about someone or the language we use about an illness can have devastating effects for that person. Language impacts on how we interact with our world. I believe that we need to be aware of how our language may stigmatize someone else. Vanier (1998) noted that people tend to want to view themselves as being at the top of a pyramid and down on those individuals who are different from them. These may be individuals who for a variety of reasons face challenges. However, even with challenges, we can use language that reflects positive attributes, not negative

ones. Language can open up conversations and relationships or it can shut them down, creating barriers and isolation.

According to Micks (1982) language is the hallmark of our being human, which is a social being (Micks, 1982, p. 32). George Steiner in his book *After Babel* believes that the “basic function of language is to help us hide from one another. Language conceals and internalizes more, perhaps than it conveys outwardly. Social classes, racial ghettos speak at rather than to each other” (Micks, 1982, p. 38).

While language is intended to be the tool to relay information between people with clarity and in the simplest format, it does not always happen. Communication between individuals can be hampered as a result of filters such as previous interactions, culture, tone, rate of speech, volume, knowledge, and life experience. Unfortunately, it appears that even within the church, individuals tend to speak at rather than to each other with not really understanding what the other person intended. One participant reported:

- “people in general don’t know enough about mental illness. Like I had church people who I was really, really close to 15 years ago now. I was friends with a lady who had troubles with her heart and with that she got depression. And she said she never realized that people had such a struggle. And I mean, in all those years that she spent time with me, did she have blinders on?”

This participant reported feeling she had not really been heard or understood, even after all that time being in the relationship with this close friend.

Not being understood and not having power in their lives is a common theme for many people. Such was the plight of Hagar. According to Weems (1988) “because she was a slave, Hagar was powerless” (Weems, 1988, p.10). Sarai owned her and any children she might ever have. “To a slave, life without a mistress is inconceivable. Hagar’s body was free but her mind remained in bonds. What Sarai thought of Hagar had become what Hagar thought of herself: she was property” (Weems, 1988, p.13). Hagar was mistreated by her mistress Sarai, treated poorly by her child’s father, and dismissed by the rest of the community.

Individuals with a significant mental health issue also begin to believe about themselves what others around them believe to be true. Research has shown that people do internalize negative perceptions when dealing with mental health issues (Link et al., 1987, Link & Phelan, 2001; Corrigan, 1998, 2004; Holmes & River, 1998) and that being labelled mentally ill can lead to lower levels of self-esteem (Link, Strueing, Neese-Todd, Asmussen & Phelan, 2001). Consequently, a person may decide not to become involved in social activities in order to avoid the stigma. One participant reported “I haven’t let myself get involved in a faith community for thirty years but my faith is very important to me” and another indicated “I just keep myself at a distance. I do pray but I don’t go and get involved in church or anything”. Inclusion and social justice have not been their experience of the church.

Social justice was also an issue for Hagar. Even though Abram had a legal obligation to pay Hagar “one mina (60 shekels) of silver” (Baker, 1992,

p.89) according to the Cod of Ur-Nammu, he “rose up early in the morning, and took bread and a bottle of water, and gave it to Hagar, putting it on her shoulder and the child, and sent her away” (Genesis 21:14 King James Version). He did not fulfill his legal obligations to her and the community did not appear to hold him accountable to her or his first-born child. Hagar and Ishmael became the cast offs of the primitive society.

But God’s back was not turned on them. While the rest of the community allowed this injustice to happen, God did not. God hears Ishmael’s cry. God’s messenger calls to Hagar and tells her that God has heard the boy’s cry and reminds her that Ishmael is to become a great nation (Genesis 21: 17-18 King James Version). Then God open’s Hagar’s eyes and she sees a well of water from which they drink and fill their skin. God is with Ishmael as he grows up in the wilderness and becomes an expert archer” (Ogden Bellis, 2007, p. 63).

Williams (1993) notes that when Hagar refers to Ishmael, she calls him her child but when God refers to him, God calls him a youth which reminded him of his strength and potential. God is able to see the potential that each one of us has been given.

Winter (1991) notes that both times Hagar fled to the wilderness, God’s messenger comforted her and intervened to save her life, assuring her that her son Ishmael would become a mighty nation. God had not forgotten the promise made to either one of them, just as God does not forget the promises to those on the fringes today.

Just as Hagar and Ishmael were told to leave their community, many of the participants have also experienced being asked to leave their faith communities.

One participant reported:

- “I had my son when I was 17. I had to go to a doctor’s appointment when he was a few months old, so I asked my pastor if they could watch him. When I came back he said he wanted me to either give the child up or get in front of the church and withdraw my membership. I just never went back to church.”

Another reported:

- “church people say that you shouldn’t have that problem if you are a strong person. If you are a strong Christian and that if you are right with God. Then I’m hearing people say I’m reluctant to talk about the fact that I have depression. That spread a blanket over the whole issue of depression.”

Still another person reported

- “one thing I heard that made me fear telling people I had depression, I was talking to another pastor’s wife and she was talking about someone in her church who was depressed and she said ‘wouldn’t it be awful to think that your personality came out of a bottle?’”

Almost all of the participants in the three focus groups reported having been asked to leave a faith community they were a part of as a result of disclosing

a significant mental health issue. They had become the fringe of their community.

“God is the God of those deserted in the wilderness, of those on the fringes” (Niditch, 1987, p. 65). In fact, God’s love and concern for Hagar and Ishmael was reinforced by providing her a prominent role in both the Hebrew scripture and the Qu’ran. “Hagar is the first person in the Bible who is visited by a divine messenger. She is the only biblical character who dares to name God. She is the first woman who receives a divine promise of descendants” (Ogden Bellis, 2007, p. 64). Everyone around her had treated Hagar poorly but God had not forgotten her. Their spiritual communities appear to have treated the participants in this research poorly also, but God has not forgotten them either. Many participants reported not being involved in a spiritual community but stated that they have maintained a strong relationship with God. The strength of their faith has grown out of an intimate prayer life and trusting relationship with God. These participants have found a new way of making meaning by bringing together their lived experiences and their faith in and relationship with God.

We, as the Christian community, also have challenges ahead of us as we move forward forging a new understanding of what it means to belong to a body of believers, some of whom may experience a significant mental health issue. To be a community that does indeed welcome everyone, will require us to change how we assign meaning to our interactions. As Killen and de Beer note:

Our habitual meaning-making processes do not want to be upset by new knowledge or insight. Change is uncomfortable. If we learn something

new from the Christian heritage, we may have to revise our interpretive frameworks or our positions and learn new ways of making meaning and of behaving. Similarly, our experience may help us to see new truths or depth in the tradition that again will require us to change our theological positions (p.64).

It will require us to come to a different relationship with God and others. Just as Hagar was able to name God in spite of her lived experience, so too have the participants been able to name God and develop a deep relationship of faith.

It is the depth of this relationship that participants reported helped them cope, particularly when the isolation became overwhelming for them. The finer details of the ontological nature of God did not appear to matter to individuals; however, the relationship did matter. Being created in God's image who was defined as the great "I am" has played a significant part in people's lives. Whether God is disabled or whether there is a perceived correlation between disability and sin did not appear to matter to the research participants. But issues of inclusion and exclusion mattered greatly to people. Their experiences paralleled that of Hagar. Their stories were "Hagar stories" and their plight of rejection, abandonment and isolation was her plight. May we choose to become more compassionate people, honouring the differences between all of us whether able-bodied vs. disabled, mentally well vs. mentally ill, or physically healthy vs. unwell individuals.

Chapter 7

Discussion

This chapter will discuss the general findings, important aspects of this research, the points that are consistent and inconsistent with what I expected to find, the practical implications, strengths and limitations of the research, implications for future research and a logo representing a welcoming and affirming community.

General Findings

Seven primary themes rose out of the qualitative data. These themes were God, resilience, stigma, diagnosis, isolation, self-concept and loss. Participants reported having a strong relationship with God, but not with a faith community. Prayer was found to be the primary coping strategy participants used. “Church” was found to be unhelpful because participants believed that those within the church do not appear to understand mental health issues; indeed a majority of participants reported having been asked to leave a church when they disclosed their mental health issue. People had let them down but God had been there for them.

Resilience was also found to be important as participants reported learning to pan for the “gems” and “jewels” and move forward to carve out a new normal for their lives. Participants reported being determined to rise above their illnesses and not allow themselves to become their diagnoses.

Participants reported that stigma created significant barriers for them. These barriers resulted from a lack of knowledge and awareness from those around the participants and the participant's experience of feeling ostracized and excluded as an outcome of the barriers.

Diagnosis was found to be both helpful and unhelpful for individuals. Participants reported their diagnosis was helpful for treatment in that it embodied a sense of hope for them. They reported the diagnosis was unhelpful because of the limitations that were then placed on them regarding travel, due to international health registries, which then created an additional sense of distance between themselves and others by not being able to visit face to face with loved ones. Participants also reported struggling with the unanticipated changes to their daily routines as a result of the diagnosis.

Isolation was the next significant finding. Participants reported being shunned by family, friends, and others, which resulted in loneliness. One participant stated, "No one is ever there for me". While individuals reported being shunned by friends and others, being shunned by family created the greatest pain for them.

Self-concept was found to be a complex category. Participants reported seeing themselves in a positive light when both physical health and mental health issues arose. Individuals reported learning to be more optimistic, positive, and determined to rise above their circumstances. Participants also reported negative experiences related to self-concept. These negative experiences were linked with feelings of being weak, not good enough, and lazy, and to a loss of dreams.

Interestingly, participants reported that barriers were created when they experienced both physical health and mental health issues. There appeared to be a direct, positive correlation between individuals who were able to maintain an optimistic vantage point and the degree to which their losses appeared to be manageable. These participants reported making choices that were positive for them, despite their limitations. “At the beginning, it made me feel like I was very little. I had a very little sense of self. I thought this was going to be my life so I was going to have to live my life around the disease. I was largely sceptical and pessimistic about a lot of things. I would honestly say it’s a blessing in disguise really, but in a way where I have been becoming a more optimistic person. I try to enjoy the little things in life.”

Loss was the final area of reported significance. Participants reported that losses around children, goals, dreams, and the future were the ones that presented the most difficulty for them. Participants noted when they thought about their goals, their dreams and a future without their children the pain was overwhelming.

Important Findings

The categories that appear to result in the most significant findings from this research are God, stigma, and isolation. While individuals report having maintained a strong relationship with God, most of the participants did not find the church to be a safe place for them to disclose their mental health issue. Stigma appeared to play such a significant role that the majority of participants, 54% failed to disclose whether or not they had a mental health issue, even on an

anonymous survey. The pain created by isolation from family created the greatest amount of pain, even over and above the isolation from friends and from community.

Consistent and Inconsistent Findings From What I Had Anticipated

At the beginning of this research, I had anticipated finding numerous differences between participants with physical health issues and participants with significant mental health issues. I believed I would find that individuals with significant mental health issues would avoid receiving treatment to avoid letting other people know of their illness, which would be consistent with the findings by Andrew et al. (2001). What I expected was partially true, in that individuals went to great lengths to avoid others knowing of their diagnosis; however, based upon these participants, individuals did not appear to avoid treatment, and in fact appeared to welcome treatment in order to regain their sense of stability and identity. I had not anticipated this outcome.

I had also anticipated that individuals with a significant mental health issue would exhibit lower levels of self-esteem as a result of their diagnosis, which would be consistent with the findings of Link, Strueing, Neese-Todd, Asmussen & Phelan, 2001; however, this was not consistent across the participants in the focus groups. A majority of participants reported feeling quite good about themselves, what they were able to accomplish and what they had done with their lives. Participants repeatedly emphasized they were not their

“diagnosis” but were a writer, a secretary, a professional person, a mother, or someone who had done something with their lives that they believed was important to them.

Rabin, Rosser & Butler (1993) and Blaxter (1987) found that the label or diagnosis that an individual was assigned as an experimental variable impacted how the participants in research viewed the person’s abilities. These research participants reported negative attitudes towards individuals with significant mental health issues. I had anticipated that I would discover that individuals would want to avoid the negative label in order to lessen the stigma they experienced; but I did not discover this. What I did discover was a welcoming attitude towards a diagnosis so that individuals could then research it, check it out on the Internet, and talk with other health professionals in order to have a better understanding of what they were already experiencing. Individuals did not appear to be denying the diagnosis itself but appeared to be quite thirsty for knowledge about their illness. Perhaps access to the Internet has shifted how people perceive their illness when they are able to make informed decisions based upon their own research and perhaps feel less isolated and alone.

Bibby (2005) reported that 82% of individuals reported believing in God or a Higher Power. I had anticipated that there would be a difference between how participants differed in their beliefs about the existence of God and how participants with a physical health issue and a mental health issue perceived or relied upon God as a source of strength. I expected that participants with a physical health issue would have a greater reliance on God than participants with

a mental health issue. However, participants with mental health issues reported utilizing God as their source of strength and prayer as their primary coping mechanism.

I had not anticipated that even with an anonymous survey, participants would not feel safe enough to disclose a mental health issue. I had anticipated that the anonymity would encourage participants to feel free enough to accurately report their diagnoses without fear of stigma or reprisal. However, 35 out of 37 participants in the focus group who reported experiencing a physical health issue, reported not feeling safe enough to be honest about their mental health issue based upon their past experiences with other people knowing their diagnosis, is a significant finding.

Practical Implications

This research clearly indicates that churches have a significant amount of work to do in order for individuals with significant mental health issues to feel safe enough to participate without fear of stigma, shunning, or being asked to leave. Creating a welcoming community or *hesed* will take more than posting an “All Welcome” sign out the front. Educating a faith community about mental health issues is no different from educating about domestic violence, sexual abuse, or patriarchy. It must be an all-encompassing approach involving everyone in the congregation or parish. When individuals have a lack of knowledge, fear frequently takes over. This is where a clear and systematic approach can be helpful.

Sermons need to include biblical references on inclusion, mental health concerns and concrete, factual information. Sermon illustrations that normalize mental health issues are plentiful. Depression, bi-polar disorder, schizophrenia, and other mental health issues are not foreign illnesses to Christians in spite of their faith.

The learning needs to continue from pre-school through to adult Sunday School and the curriculum could start with simple truths about:

1. Befriending those who are different from you as Christ befriended those on the fringes. In fact, noting that everyone else is different from you and I can reduce the fear some may experience.
2. Loving people as they are in the same way Christ loved people as they were.
3. Addressing challenges that others encounter, even as individuals age their abilities will be different.

Provide an educational program, perhaps 4 – 6 weeks in length addressing what is and is not mental illness. Dispel the myths created by the media, including in particular the perceived correlation between violence and mental illness. Also include a component on pharmacology and the impact of medication on individuals experiencing significant mental health issues. Inviting someone with a significant mental health issue, a family member, psychiatrist and a mental health profession can also add to the learning experience. Pastors, ushers, elders, and deacons may also benefit from specialized training on pastoral

care issues that may arise while visiting with individuals or as the individuals arrive for a worship service.

Youth groups, mid-week activities, women's ministries and men's groups within the church would also benefit from education and coaching around welcoming individuals who may have different life experiences and what support might look like to someone with a mental health issue. Seniors also need to learn the current truth about mental illness, rather than holding onto misconceptions and potentially outdated beliefs.

This research clearly indicates a need for education within our churches. This is a need that can be easily met resulting in individuals feeling a welcoming presence in their faith communities.

Limitations and Strengths of this Research

While this investigation has provided valuable information, there are a number of significant limitations on this research. First, it is not representative of all people who have experienced a significant mental health issue. While attempts were made to sample a broad spectrum of participants, the results are only applicable to those in the Waterloo Region who had the opportunity to participate and chose to do so.

Second, the issues could be related to the gender of the participants. Again, every effort was made to encourage both genders to participate; however, there was an over representation of female respondents both in the quantitative (142 or 39.4% males, 217 or 60.3% females, and 1 or .3% no response) as well as the qualitative (2 or 5.4% males and 35 or 94.6% female) groups.

Third, I did not have access to individuals hospitalized as a result of a significant mental health issue. If I had included hospitalized individuals it may have resulted in participants feeling freer to report their experiences with a mental health issue. However, I had wanted participants to be feeling somewhat stable and not in a state of crisis when they participated.

Finally, the sample sizes of the focus groups were appropriate; however, including more focus groups thus a greater number of participants would have been helpful.

The strengths of this investigation were also numerous and worthy of being noted. First, participants included all adult age groups and in approximately equal proportions. While no children were included in this research, other age groups had the opportunity to participate.

Second, there was a broad base of response locations with access to the general population in community-based settings. Participants learned of the research from such places as community centres, pharmacies, doctor's offices, churches, a mosque, a temple, senior's centres, service clubs, a Bible college and seminary, the Mood Disorder Association of Ontario, Community Access Centres for Mental Health, shelters for the homeless and second stage housing settings.

Third, the multi-faith aspect provided insight into people's diverse experiences. Individuals from the Hindu, Muslim, Jewish and Christian faith traditions participated in this research, providing a rich tapestry of experiences. Mental health issues are not limited to one faith tradition or another. Illness knows no boundaries where faith is an issue.

Finally, the general population had the opportunity to participate in this research whether or not they chose to exercise this opportunity or not is a different issue.

Future Research

In the future, I hope this research will act as a springboard for additional research in the area of mental health issues and the church. There are things I would do differently in the future to reduce the problematic areas I encountered. The following are the areas I would change.

First, I would code all the return addresses in such a way to determine where the participant came in contact with the research. This code then would identify the location that the response was received from.

Second, I would advertise for participants in the local newspaper or on the community news channel on television in order to have access to a greater number of participants with a broader cross section of people.

Third, if I asked whether someone had a physical health issue or a mental health issue, I would immediately follow it with the question "If you left the above question blank, could you please indicate why you chose not to answer that question." I would attempt to glean a better understanding of people's experiences with disclosing a mental health issue.

Finally, I would work specifically with physicians, psychiatrists, or hospital-based treatment facilities in order to have a more representative sample of individuals with mental health issues. Perhaps if I began with people who had been hospitalized as a result of their mental health issue, people might be more

willing to disclose their experiences. I had initially wanted participants to be experiencing some stability in their lives and not in a state of crises; however, I wonder if this then reduced the likelihood of disclosing the mental health issue. Another option would be to visit outpatient treatment facilities and talk with people about the study rather than just leaving the surveys. People might be more trusting if they had the opportunity to meet me and have their questions answered.

Symbol

During the public presentation of my research findings, one of the attendees inquired whether I had considered creating a symbol that churches or community groups could display if they were a welcoming community for people with significant mental health issues. This symbol could be used similarly to the blue and white wheelchair signs that represent wheelchair accessibility for the physically challenged except that this symbol would represent an informed and tolerant community of people with significant mental health issues.

At the time I had not considered it; however, since that presentation I have created such a symbol. The following description describes what it would look like.

It would have seven layers in a Friendship knot with each layer representing the seven significant areas of God, stigma, resiliency, diagnosis, isolation, self-concept, and loss. Next the three semi-circles would represent individuals with physical health issues, individuals with mental health issues, and individuals with both physical and mental health issues. In the centre of friendship knot would be the cross rising out of it. Please see appendix 4 for an

illustration of the symbol. For faith communities that are not Christian, the friendship knot itself would be used without the cross.

Faith communities that have chosen to systematically educate, preach, train, teach, and reach their congregants about issues of mental health, could then display the symbol if they choose to change their style of interacting with those with differing abilities and giftedness.

It is perplexing to me why mental health resources that are readily available to the faith communities are not being used. Many denominations have special interest groups that make these resources available; yet, somehow it does not appear to have made a difference in the church's response to individuals with significant mental health issues.

Chapter 8

Conclusion

This research set out to determine if there was a difference in the impact a physical health diagnosis vs. a mental health diagnosis had on an individual's sense of well-being, their identity, their relationship with God, and their ability to use their faith community as a source of support.

When quality of life issues arise for people diagnosed with a physical health or mental health issue, service providers encourage individuals to explore their natural supports and reach out to previously helpful resources, like their faith communities. However one main question remains. Does the label or diagnosis itself create barriers that appear to prevent individuals from accessing these resources? For some individuals, having received a diagnosis appears to be beneficial in that it appears to put their mind at ease and they stop worrying about the symptoms and it may open many other opportunities for support within their community.

However, for others receiving a diagnosis or a diagnostic label does not appear to be a consolation. Anecdotally individuals with a diagnosis appear to report feeling "less than" those without a diagnosis or label. But, how we interact with individuals with or without a diagnosis will impact on their sense of who they are as a person of worth. People are not labels. "Each individual living

human document has an integrity of his or her own that calls for understanding and interpreting not categorization and stereotyping” (Gerkin, 1984, 38).

If we believe that people are indeed not a label, then why do some people continue to refer to diagnosed individuals by their diagnosis? Since when is a diagnostic thread in someone’s tapestry of their life all there is to their *being*? Is that “schizophrenic” not also someone’s son/daughter, parent or grandparent potentially neighbour, friend, confidante? Are they not more than just that one thread? I believe this is one area of our lives where we need to develop a great deal of intolerance. Perhaps we need to become absolutely intolerant of language that puts someone else down or pigeonholes them and as such then limits their potential of life opportunities. Language impacts on how we interact with our world and with the vital role it has played in history.

This research explored the impact diagnostic labels had on participants, their sense of well-being, their relationship with God, and their ability to use faith as a resource. Stigma associated with a significant mental health issue was cited as the primary reason individuals reported not feeling safe enough to disclose their diagnosis prior to the focus groups. The quantitative analysis revealed that 54% of the participants responding to an anonymous questionnaire failed to indicate the status of their health issue, whether physical or mental health. Participants reported a strong relationship with God but not with a faith community. They also indicated that the type of diagnoses had an impact on their sense of well-being and identity.

While faith communities have intended to be welcoming environments, people with mental health issues have not always experienced them that way. Preaching on stigma and mental illness issues, educating congregants, and reducing the barriers that create the “us and them” feeling can go a long way in changing how individuals with mental health issues experience the faith community. Much work still needs to be done to create environments where all individuals genuinely feel welcome and valued. This is a goal that is within our reach.

Appendix 1
WILFRID LAURIER UNIVERSITY
INFORMED CONSENT STATEMENT

An exploration of the relationship between health issues, self-concept
and spiritual resources.

Researcher: Janice Dinsmore-Czechowsky
Advisor: Dr. Tom O'Connor

You are invited to participate in the following research study. The purpose of this study is to explore the relationship between health issues, self-concept and spiritual resources. The researcher is a Candidate in the Doctor of Ministry program at Waterloo Lutheran Seminary at Wilfrid Laurier University.

Information

Individuals are invited to participate in one of two ways:

1. By completing one of the 9 page surveys which will require approximately 10 - 15 minutes to complete.

2. By participating in a focus group, which will require approximately 1 - 1.5 hours. These focus groups allow individuals to express their experiences with health issues and the impact these issues may have on their life. These groups will be audio tape recorded and the tapes will be destroyed at the end of this research project.

This study will run for the months of November and December, 2004 and January, 2005.

Risks

There does not appear to be any risks involved in either completing the surveys or participating in the focus groups.

Benefits

Participants may however benefit from participating in this research and allowing their perspective to be heard and noted. Participants may also benefit from participating as a group with other individuals in a social setting.

Participant's initials

Confidentiality

Individuals are invited to participate and no identifying information will be released in the publication of this research. Participation in the survey portion of this research is anonymous. However, all participants of the focus groups will hear what each other has to say; consequently, confidentiality will be encouraged but cannot be guaranteed by the researcher. It is anticipated that there will be 5-8 individuals in each focus group. There will be between 600 - 1000 individuals participating in the survey. While direct quotations may be used in the final research, no identifying features or characteristics of participants will be used.

Participation

Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from this study at any time without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study before data collection is completed, your data will be destroyed or returned to you. You have the right to omit any questions you choose.

Contact

If you have questions at any time about the study or the procedures, or if you experience any adverse effects as a result of participating in this study, you may contact the researcher, Janice Dinsmore-Czechowsky, through Waterloo Lutheran Seminary office at 884-0710 ext3234. This project has been reviewed and approved by the University Research Ethics Board. If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Dr. Bill Marr, Chair, University Research Ethics Board, Wilfrid Laurier University, (519) 884-0710 extension 2468.

Feedback and Publication

Results of the research will be included in a doctoral thesis written by the researcher and will be available on or about June 1st, 2005. Participants are welcome to contact the researcher through Waterloo Lutheran Seminary after that date.

Consent

I have read and understood the above information. I agree to participate in this study. By returning this survey to the attached envelope, I will take this as your permission to include your information in the data.

Participant's signature _____ Date

Investigator's signature _____ Date

Appendix 2

SURVEY

The following survey is a research project to explore the relationship between health issues, self-concept and community resources. Please feel free to complete the following survey and drop your completed survey into the brown envelope attached to the introduction sheet.

SECTION A

In this section, please circle the answer that fits best for you.

Do you have 1 or more significant health issues? Yes No

2. If so, what are they?

3. Have you received a formal diagnosis from your physician or medical specialist? Yes No

4. If yes, for which diagnosis?

5. Do you consider yourself a member of a spiritual community with people you interact with on a regular basis? Yes No

6. How long did it take for you to receive a diagnosis?

Hours Days Weeks Months Years

14. Lately, my sense of connection to my spiritual community has become stronger.

1	2	3	4	5	6	7	8	9	10
strongly				no				strongly	not
disagree				impact				agree	applicable

15. I get a strong sense of support from my friends.

	1	2	3	4	5	6	7	8	9
strongly					no				strongly
disagree					impact				agree

16. I feel I am unconditionally accepted for who I am by my family.

	1	2	3	4	5	6	7	8	9
strongly					no				strongly
disagree					impact				agree

17. I am confident that I have as much access to community services as I need.

	1	2	3	4	5	6	7	8	9
strongly					no				strongly
disagree					impact				agree

18. The strength of my spiritual or religious faith has always been about the same throughout my life.

1	2	3	4	5	6	7	8	9	10
strongly				no			strongly	not	
disagree				impact			agree	applicable	

19. On the whole, my quality of life is excellent.

	1	2	3	4	5	6	7	8	9
strongly					no				strongly
disagree					impact				agree

20. If my doctor has prescribed medications, I will take them as prescribed.

	1	2	3	4	5	6	7	8	9
strongly					no				strongly
disagree					impact				agree

21. My friends think of me as a very capable person.

	1	2	3	4	5	6	7	8	9
strongly					no				strongly
disagree					impact				agree

22. Other people's reactions to me have a significant impact on me in how I view my own capabilities.

1	2	3	4	5	6	7	8	9
strongly disagree				no impact				strongly agree

23. I feel there are barriers between me and my concept of God or a Higher Power.

1	2	3	4	5	6	7	8	9	10
strongly disagree				no impact			strongly agree	not applicable	

24. On the whole, my quality of life has gone down hill during my life.

1	2	3	4	5	6	7	8	9
strongly disagree				no impact				strongly agree

25. I have a strong religious faith.

1	2	3	4	5	6	7	8	9	10
strongly disagree				no impact				strongly agree	not applicable

26. I feel that there are no barriers for me in my ability to participate in my faith

community or spiritual practices.									
1	2	3	4	5	6	7	8	9	10
strongly disagree				no impact				strongly agree	not applicable

27. If I have agreed to attend a medical appointment, I will be sure to go.

1	2	3	4	5	6	7	8	9
strongly disagree				no impact				strongly agree

28. The strength of my spiritual/religious faith has decreased throughout my life.

1	2	3	4	5	6	7	8	9	10
strongly disagree				no impact				strongly agree	not applicable

29. On the whole, my quality of life is rather poor.

1	2	3	4	5	6	7	8	9
strongly disagree				no impact				strongly agree

30. My family think of me as a very capable person.
 1 2 3 4 5 6 7 8 9
 strongly no strongly
 disagree impact agree
31. I get a strong sense of support from my spiritual community.
 1 2 3 4 5 6 7 8 9 10
 strongly no strongly not
 disagree impact agree applicable
32. I feel I am unconditionally accepted for who I am by my friends.
 1 2 3 4 5 6 7 8 9
 strongly no strongly
 disagree impact agree
33. I believe that my life is worthwhile.
 1 2 3 4 5 6 7 8 9
 strongly no strongly
 disagree impact agree
34. Lately, mysense of connection to my spiritual community has become weaker.
 1 2 3 4 5 6 7 8 9 10
 strongly no strongly not
 disagree impact agree applicable
35. Lately, I have been feeling alienated by my family.
 1 2 3 4 5 6 7 8 9
 strongly no strongly
 disagree impact agree
36. I believe that my life has a purpose.
 1 2 3 4 5 6 7 8 9
 strongly no strongly
 disagree impact agree
37. My sense of self-worth as a person has always been pretty good.
 1 2 3 4 5 6 7 8 9
 strongly no strongly
 disagree impact agree
38. My sense of connection to my spiritual community has not changed.
 1 2 3 4 5 6 7 8 9
 strongly no strongly
 disagree impact agree

46. Do you receive medical care from:

Physician	Walk-In Clinic
Specialist	Psychiatrist
Community Based clinic	Hospital

47. How old are you?

Under 20	21-30	31-40
41-50	51-60	61-70
71 -80	Over 80	

48. Are you male or female?

Male	Female
------	--------

49. What is your marital status?

Single	Married	Separated/Divorced
Widow/Widower	Common Law	

50. Where do you live?

House	Apartment	Townhouse
Shelter	With Friends	Hotel/Motel
Trailer	Other	

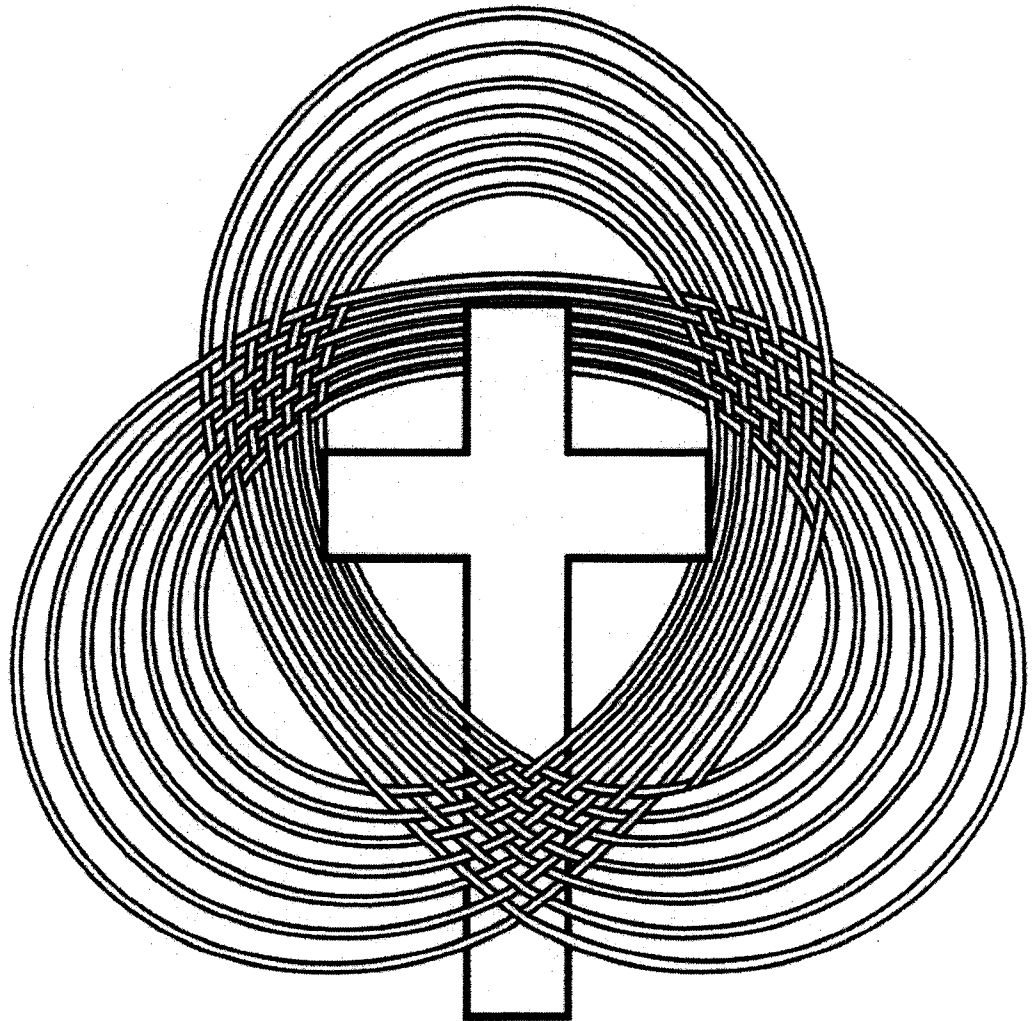
Thank you for your willingness to participate in this important piece of research.

Appendix 3

Qualitative Questions

1. How has your diagnosis impacted your sense of well-being?
2. How, or has your diagnosis put limits on, or does it impact on your sense of who you are as a person of worth and a person of value?
3. Has your diagnosis impacted your ability to use your faith or spirituality? Has it limited your ability to worship, to share with people in your community?

Appendix 4



References

- Abramczyk, L.W. (1981). The counseling function of pastors: A study in practice and preparation. *Journal of Psychology and Theology*, 9, 257-265.
- Anderson, D. & Worthen, D. (1997). Exploring a fourth dimension: spirituality as a resource for the couple therapist. *Journal of Marital and Family Therapy*, 23, 3 - 12.
- Andrews, G., Issakidis, C., Carter, G. (2001). Shortfall in mental health service utilization. *British Journal of Psychiatry*, 179, 417-425.
- Ames, R. (1983). Help seeking and achievement orientation: Perspectives from attribution theory. In B. M. DePaulo, A. Nadler & J. D. Fisher (Eds.), *New Directions in Helping: Vol. 2, Helpseeking*, p. 165-196. San Diego, CA: Academic Press.
- Archer, G.L. (1964). *A survey of Old Testament introduction*. Moody Press, Chicago.
- Atkins, C. (2005). The failure of formal rights in the clinic: A critique of bioethics. *Ethics & Medicine*. Vol. 21, No. 3, 139-162.
- Baker, J. (1992). *Women's Rights in Old Testament Times*. Signature Books, Salt Lake City, Utah.
- Baker, R. (1948). The social psychology of physical disability. *Journal of Social Issues* (1948), 34.
- Benner, D.G. (1992). *Strategic pastoral counseling: A short-term structure model*. Baker House, Grand Rapids, Michigan.
- Bergen, A.E. & Jensen, J.P. (1990). Religiosity of psychotherapists: A national survey. *Psychotherapy*, 27 (1), 3-7.

- Bibby, R.W. (2005). *Why bother with organized religion? The views of insiders, marginals and outsiders.* reginaldbibby.com
- Bibby, R.W. (2007). *Atheism in Canada.* University of Lethbridge, Project Anada Press
Release #7, August 2, 2007.
- Blaine, B. (2000). *The psychology of diversity: Perceiving and experiencing social difference.* Mountain View, CA: Mayfield.
- Blair, W., Davidson, D.(1993). In L.H. Merrick (Ed.) *And show steadfast love: A theological look at grace, hospitality, disabilities and the church.* Presbyterian Publishing House, Louisville, Kentucky.
- Blaxter, M. (1987). Evidence on inequality in health from a national survey. *Lancet.* 1987, ii 30-3.
- Blumer, H. (1986). *Symbolic Interactionism: Perspective and method.* Prentice-Hall, Inc., Englewood Cliffs, New Jersey.
- Cooper, B. (1993). The disabled God. In L.H. Merrick (Ed.) *And show steadfast love: A theological look at grace, hospitality, disabilities and the church.* Presbyterian Publishing House, Louisville, Kentucky.
- Corrigan, P., (1998). The impact of stigma on severe mental illness. *Cognitive and Behavioural Practice, 5,* 201-222.
- Corrigan, P., (2004). How stigma interferes with mental health care. *American Psychologist, 59,* 614-625.
- Corrigan, P. (2004). The social rejection of former mental patients: Understanding why labels matter. *American Journal of Sociology.* Chicago Press, Chicago.
- Corrigan, P., Matthews, A. (2003). Stigma and disclosure: Implications for coming out

- of the closet. *Journal of Mental Health*, 12, 235-248.
- Corrigan, P., Penn, D. (1999). Lessons from social psychology on discrediting psychiatric stigma, *American Psychologist*, 54, 765-776.
- Corrigan, P., Watson, A., Gracia, G., Slopen, N., Rasinski, K., Hall, L. (2005). Newspaper stories as measures of structural stigma. *Psychiatric Services* 56:551-556, American Psychiatric Association.
- Cutting, M. (1999, August). Impediments to religious participation by mental health service recipients. Poster session presented at the annual meeting of the American Psychological Association, Boston, MA.
- Cutting, M., Grosch, W.N. & Browning, J. (2007). Psychiatrists and religious belief. *Psychiatric Services*, American Psychiatric Association, 58, November.
- Erk, R.R. (2004). *Counseling treatment for children and adolescents with DSM-IV-TR disorders*. Pearson, Merrill, Prentice-Hall, Upper Saddle River, New Jersey.
- Eschleman, J.R. (1988). *The family*. 5th edition, Allyn and Bacon Inc. Boston.
- Eschleman, J.R. & Wilson, S.J. (2001). *The family*. 3rd Canadian Edition, Pearson Education Canada Inc., Toronto.
- Fitchett, G., Burton, L.A. & Sivan, A.B. (1997). The religious needs and resources of psychiatric inpatients. *The Journal of Nervous and Mental Disease*, 185, 320-326.
- Fogg, S., Weaver, A., Flannelly, K., Handzo, G. (2004). An analysis of referrals to chaplains in a community hospital in New York over a seven year period. *The Journal of Pastoral Care and Counselling*, Fall, Vol. 58, No. 3, 225-235.

- Furman, L.D., Chandy, J.M. (1994). Religion and spirituality: A long neglected cultural component of rural social work practice. *Human Services in the Rural Environment*, 17, (3/4), 21-26.
- Gagne, C. (2005). Recovery from mental illness. *Family Therapy Magazine*, Vol. 4, No. 3.
- Gallup, G.J. & Castelli, J. (1989). *The people's religion: American faith in the 90's*. New York, Macmillan.
- Gallup, G.G. & Newport, F. (1990). The funds, friends, and faith of happy people. *American Psychologist*.
- Gassert, R.G. & Hall, B.H. (1964). *Psychiatry & Religious Faith*. Viking Press, New York.
- Gerbner, G., Gross, L., Morgan, M., Signorielli, N. (1980). The mainstreaming of America: Violence Profile No. 11. *Journal of Communication*.
- Gerkin, C.V. (1984). *The living human document*, Nashville, Tennessee: Abingdon Press.
- Gilbert, M.G. (1981). Characteristics of pastors related to pastor counseling and referral. *Journal of Pastoral Counseling*, 16, 30-38.
- Goffman, E.(1946). *Thesis statement for the Master's Degree in Sociology*, University of Chicago.
- Goffman, E. (1963). *Stigma - Notes on the management of spoiled identity*. Prentice Hall Inc., Englewood Cliffs, N.J.

- Hodge, D.R. (2000). Spiritual Ecomaps: A new diagrammatic tool for assessing marital and family spirituality. *Journal of Marital and Family Therapy*, Vol. 26, No. 2, 217-228.
- Hoekema, A.A. (1986). *Created in God's image*. Wm. Eerdman's Publishing Company, Grand Rapids, Michigan.
- Holmes, E.P., River, L.P. (1998). Individual strategies for coping with the stigma of severe mental illness, *Cognitive and Behavioural Practice*, 5, 231-239.
- Ingram, B.L. & Lowe, D. (1989). Counseling activities and referral practices of rabbis. *Journal of Psychology and Judaism*. 13, 133-148.
- Killen, P., De Beer, J. (1994). *The art of theological reflection*. Crossroad, New York.
- Kirkwood, A., Hudnall-Stamm, B. (2006). A social marketing approach to challenging stigma. *Professional Psychology: Research and Practice*, Vol. 37, No. 5, 472-476.
- Lau, G.K. & Steele, R. (1990). An empirical study of the pastoral mental health involvement model. *Journal of Psychology and Theology*, 18, 261-269.
- Leavey, G., Loewenthal, K., King, M. (2007). Challenges to sanctuary: The clergy as a resource for mental health care in the community. *Social Science & Medicine*, 65, 548-559.
- Lederer, R. (1991). *The miracle of language*. Simon & Schuster Inc., New York.
- Lefley, H.P. (1989). Family burden and family stigma in major mental illness. *American Psychologist*, March, Vol. 44, No. 3, p. 556-560.

- Link, B; Cullen, F.T. (1990). The labelling theory of mental disorder: A review of the evidence. *Research in Community Mental Health*, Vol. 6, ed. James R. Greenley. Greenwich, CT: JAI Press, 1990.
- Link, B., Cullen, F.T., Frank, J. & Woznick, J.F. (1987). The social rejection of former mental patients: understanding why labels matter. *American Journal of Sociology*, 92, no. 6 (May, 1987): pages 1461-1500
- Link, B., Mirotznik, J., & Cullen, F.T. (1991). The effectiveness of stigma coping orientations: can negative consequences of mental illness labelling be avoided? *Journal of Health and Social Behaviour*, 32, no. 3 (Sept, 1991): 302-320.
- Link, B.G., Phelan, J.C. (2001). Conceptualizing Stigma. *Annual Reviews in Sociology*. August, Vol. 27, 363-385.
- Link, B.G., Strueing, E.L., Neese-Todd, S., Asmussen, S., Phelan, J.C. (2001). Stigma as a barrier to recovery: The consequences of stigma for the self-esteem of people with mental illnesses. *Psychiatric Services*, 52, 1621-1626.
- Lowe, D.W. (1986). Counseling activities and referral practices of ministers. *Journal of Psychology and Christianity*, 5, 22-29.
- McCubbin, H.I., McCubbin, M.A., Thompson, A.I., Han, S.Y., & Allen, C.T. (1997). Families under stress: what makes them resilient. *Journal of Family and Consumer Sciences*, 89 (3), 2-12.
- Menninger, K.A. (1938). The Cinderella of medicine. *New York State Journal of Medicine*, June 15, 1938.
- Merrick, L. Ed. (1993). *And show steadfast love*. Presbyterian Publishing House, Louisville, Kentucky.

- Merrick, L. Ed. (1993). *And show steadfast love*. Presbyterian Publishing House, Louisville, Kentucky.
- Micks, M.H. (1982). *Our search for identity: humanity in the image of God*. Fortress Press, Philadelphia.
- Miller, W.R. (1985). Motivation for treatment: A review with special emphasis on alcoholism. *Psychological Bulletin*, 98, 84-107.
- Mollica, R.C., Streets, F.J., Boscarino, J. & Redlich, F.C. (1986). A community study of formal pastoral counseling activities of the clergy. *American Journal of Psychiatry*, 143, 323-328.
- Niditch, S. (1987). *Underdogs and Tricksters: A prelude in Biblical folklore*. Harper & Row, San Francisco.
- Ogden Bellis, A. (2007). *Helpmates, harlots and heroes - Women's stories in the Hebrew Bible*.
- Pattison, E., Lapins, N., & Doerr, H. (1973). Faith healing. *The Journal of Nervous and Mental Disease*, 157, 397-409.
- Philo, G., Secker, J. Platt, S., Henderson, L., McLaughlin, G., Burnside, J. (1994). The impact of the mass media on public images of mental illness" Media content and audience belief. *Health Education Journal*, Vol. 53, No. 3, 271-281.
- Prest, L.A., & Keller, J.F. (1993). Spirituality and family therapy: Spiritual beliefs, myths and metaphors. *Journal of Marital and Family Therapy*, Vol. 19, No. 2, 137-148.
- Privette, G., Quackenbos, S. & Bundrick, C.M. (1994). Preferences for religious and nonreligious counseling and psychotherapy. *Psychological Reports*, 75, 539-546.

August.

Riesman, D. (1951). Some observations concerning marginality. *Phylon*. Second Quarter.

Roof, W.C. (1999). *Spiritual market place: Baby boomers and the remaking of American religion*. Princeton University Press, Princeton, New Jersey.

Ross, R.J. (1993). Future of pastoral counseling: Legal and financial concerns. In J. McHolland (Ed). *The future of pastoral counselling: whom, how and for what do we train*. American Association for Pastoral Counselors, Fairfax, VA, 113-118.

Rubington, E. & Weinberg, M.S. (1987). *Deviance, the interactionist perspective: text and readings in the sociology of deviance*. MacMillan, New York.

Ruppert, P.P., & Rogers, M.L. (1985). Needs assessment in the development of a clergy consultation service. *Journal of Psychology and Theology*, 13, 50-60.

Statistical Manual of Mental Disorders, Text Revision (DSM-IV-TR). American Psychiatric Association, Washington, D.C., USA, 2000.

Scheff, T.J. (1984). *Being mentally ill: A sociological theory*, 2nd edition, Aldine Publishing Company, New York.

Stark, R. (1971). Psychopathology and religious commitment. *Review of Religious Research*, 12, 165-175.

Strauss, A.L. & Corbin, J.M. (1990). *Basics of qualitative research: grounded theory, procedures and techniques*. Sage Publications, Newbury Park, California.

Tausig, M., Michello, J., Subedi, S. (1999). *A sociology of mental illness*. Prentice Hall, New Jersey.

- Trice, P., Bjorck, J.P., (2006). Pentecostal perspectives on causes and cures of depression. *Professional Psychology: Research and Practice*, Vol. 37, No. 3, 283-294.
- Vanier, J., (1998). *Becoming Human, CBC Massey Lecture Series*, House of Anansi Press Ltd., Toronto, ON
- Veroff, J., Kulka, R.A. & Douvan, E. (1981). *Mental health in America: Patterns of help-seeking from 1957 - 1976*. Basic Books, New York.
- Vining, J. & Decker, E. (Eds.). (1996). *Soul care: A Pentecostal-Charismatic perspective*. Cummings & Hathaway, East Rockaway, New York.
- Virkler, H.A. (1979). Counseling demands, procedures, and preparation of parish ministers: A descriptive study. *Journal of Psychology and Theology*, 7, 271 - 280.
- Vogel, D., Wade, N., Haake, S. (2006). Measuring the self-stigma associated with seeking psychological help. *Journal of Counselling Psychology*. Vol.53, No.3, 325-337.
- Wahl, O. (1995). *Media Madness: Public images of mental illness*. Rutgers University Press, New Brunswick, New Jersey.
- Wahl, O. (1999). Mental health consumers' experience of stigma. *Schizophrenia Bulletin*, 25, 467-478.
- Walsh, F. (1998). Beliefs, spirituality, and transcendence. In M. McGoldrick (Ed.) *Revisoning family therapy: Race, culture and transcendence in clinical practice*. New York: Guilford, p. 62-77.

- Wasman, M., Corradi, R.B. & Clemens, N.A. (1979). In depth continuing education for clergy in mental health: Ten years of a large-scale program. *Pastoral Psychology* 27, 251-259.
- Weaver, A., Flannelly, K. , Koenig, H., & Smith, F. (2004). A review of research on chaplains and community based clergy in the *Journal of the American Medical Association, Lancet* and the *New England Journal of Medicine: 1998-2000. Journal of Pastoral Care and Counselling*, Winter, 2004, Vol. 58, No. 4.
- Weaver, A.J., Koenig, H.G., Larson, B.D.(1997). Marriage and family therapists and the clergy: A need for clinical collaboration, training and research. *Journal of Marital and Family Therapy*, Vol. 23, No. 1, 13-25.
- Weems, R. (1988). *Just a sister away*. Lura Media, San Diego, California.
- Wig, N. (1997). Stigma against mental illness. *Indian Journal of Psychiatry*, 39, p.187-189.
- Williams, M.E. (1993). *The storyteller's companion to the Bible*. Abingdon Press, Nashville.
- Wink, P., Dillon, M. (2003). Religiousness, spirituality & psychosocial functioning in late adulthood: Findings from a longitudinal study. *Psychology and Aging*, Vol. 18, No. 4, 916-924.
- Wink, W. (1995). "Normalcy" as a disease: facing disabilities. *Church and Society*, (May/June), 85 No. 5, 10-17.
- Winter, M. (1991). *Woman Wisdom: A feminist lectionary and psalter. Women of the Hebrew Scriptures*. Crossroads, New York.

Wright, P.G. (1984). The counseling activities and referral practices of Canadian clergy in British Columbia. *Journal of psychology and Theology*, 12, 294-304.

Wuthnow, R. (1998). *After heaven: Spirituality in America since the 1950's*. University of California Press, Berkley.

Wylie, W.E. (1984). Health counseling competencies needed by the minister. *Journal of Religion and Health* 23, 237-249.