The Relationship Between Post-Stroke Depression and Disenfranchised Grief

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Abstract

Disenfranchised grief is grief that occurs when a loss is not socially recognized; this prevents an individual from processing their loss. Disenfranchised grief as a factor in post-stroke depression (PSD) has received minimal attention, although it is common. The purpose of this paper is to examine the relationship between disenfranchised grief and PSD, and the related implications for counselling. A literature review was conducted by searching PsychInfo, Google Scholar and PubMed for relevant research studies. Findings revealed that PSD is a common outcome for stroke survivors and has an impact on long-term recovery, quality of life, and mortality. Post-stroke physical and cognitive disabilities interfere with evaluation and treatment of PSD. The losses that follow a stroke result in feelings of grief that go unrecognized by others and can contribute to PSD. In order to counsel stroke survivors, the counsellor benefits from understanding the relationship between disenfranchised grief and post-stroke depression, and being familiar with therapeutic interventions that accommodate stroke-related disabilities. Further research is needed on predictors and effects of PSD, and on creating effective assessment tools and interventions for treating PSD related to disenfranchised grief.

Keywords: stroke, counselling, post-stroke depression, disenfranchised grief

The Relationship Between Post-Stroke Depression and Disenfranchised Grief

The goal of this study is to gain a better understanding of the relationship between disenfranchised grief and post-stroke depression (PSD) in stroke survivors. Stroke is defined as a disturbance of cerebral function with the apparent cause originating in the vascular system (Coupland et al., 2017). Stroke is the most common serious neurological condition in the world (Starkstein & Hayhow, 2019) and stroke survivors face sudden, unexpected, and permanent changes to their day-to-day functioning, such as paralysis and aphasia (Hughes & Cummings, 2020).

PSD is the most common neuropsychiatric consequence of stroke (White et al., 2014) with a prevalence of about 30% in stroke survivors (Ayerbe et al., 2014; Khedr et al., 2020; Krueger et al., 2015; Saikaley et al., 2018; Vahid-Ansari et al., 2018). The presence of depression can significantly impact stroke recovery (Khedr et al., 2020; Saikaley et al., 2018). The health-related consequences of PSD include increased mortality and disability, poor long-term functional recovery, and reduced quality of life (Ayerbe et al., 2013). However, these depressive symptoms may go unnoticed and untreated in stroke survivors (White et al., 2014) due to physical and cognitive disabilities resulting from the stroke (Krueger et al., 2015).

There are a wide range of negative physical and cognitive outcomes after stroke, ranging from mild weakness to total loss of function (Hughes & Cummings, 2020). Consequently, the stroke survivor may experience losses including loss of identity, independence, body autonomy, and relationships, resulting in feelings of grief (Hughes & Cummings, 2020). However, the post-stroke rehabilitation process primarily focuses on regaining physical and cognitive abilities; rarely is there an acknowledgment of the grief associated with stroke-related disabilities (Hughes & Cummings, 2020).

Grief is a natural reaction to a loss, including the loss felt by stroke survivors who have experienced stroke-related disabilities (Hughes & Cummings, 2020). When there is a lack of acknowledgement of loss, opportunities for stroke survivors to grieve become limited, resulting in disenfranchised grief (Horn et al., 2016). Disenfranchised grief refers to grief that is unacknowledged by social norms or unrecognized by a person's institutions, such as employers or schools, and social networks, such as family, friends and co-workers (Horn et al., 2016). Similarly, ambiguous loss refers to non-death losses that are not clearly understood as grief-producing (Boss & Yeats, 2014). Theories of brain injury and ambiguous loss are primarily focused on the grief of the family system rather than the survivor (Kreutzer et al., 2016). Current practices limit the opportunities for stroke survivors to identify and process grief, but expanding these opportunities has the potential to reduce PSD in stroke survivors (Knight & Gitterman, 2019). Connecting studies of ambiguous loss related to brain injury and studies of disenfranchised grief related to stroke survivors could benefit both areas of research and has the potential to benefit stroke survivors' recovery process.

The effects of stroke on grief and PSD can continue for many years, thus there is a need for long-term and intermittent mental health counselling for stroke survivors (Erikson et al., 2010). Stroke-related disabilities can hinder assessment of PSD and also hinder effective counselling treatment of PSD; greater knowledge and application of counselling interventions for stroke survivors is needed for better outcomes. Disenfranchised grief can continue to plague individuals for many years if it is not acknowledged and processed in some way (Knight & Gitterman, 2019) but current research on disenfranchised grief in stroke survivors is limited. This paper reviews current research on PSD and disenfranchised grief, and offers suggestions for the practice of counselling psychology and areas for further research.

Self-positioning Statement

The origins of my interest in this topic are my personal experiences with depression, feelings of disenfranchised grief, and family members who have experienced a stroke and possibly PSD. All these personal experiences could be a source of bias in my research, therefore I must be clear about my perspective on these subjects and how I will manage my biases.

My mother had a stroke at the age of 86 that resulted in deficits that left her unable to live independently. She had to leave her house of 40 years and move into a single room in a senior's home. She could not maintain her balance and had weakness and lack of control on her right (dominant) side. Most of her previous activities such as baking, golfing, line dancing, and bowling were no longer possible. To an outsider, her physical deficits were not immediately apparent, however, given the fastidious and precise person that she was, small impairments were mortifying to her. For example, a slight paralysis of her mouth meant that food could escape without her awareness. Her cognitive impairments seemed to be manifested in limited emotional reactions, a loss of short-term memory, and limitations in carrying on a conversation. These deficits were not obvious or easy to understand for others and were therefore a topic avoided by those close to her. She was able to play bridge at her previous expert level, which helped to fill her days, however, she gradually appeared to become depressed. She seemed unwilling or unable to accept her situation and adapt to a new type of life, and she often made comments about her unhappiness regarding her impairments. When her health eventually failed she appeared to welcome death as a relief from the prolonged disabilities she experienced in her life post-stroke.

I acknowledge that this description of her experience is my subjective point of view and that my view may not accurately reflect her inner thoughts and feelings, or others' observations.

It was not until after her death, five years after her stroke, that I encountered the concept of disenfranchised grief. This concept seemed to capture a feeling she may have been experiencing in those five years: grief at what she had lost and the lack of opportunity to process that grief while others didn't see it. It was then that I recognized the possible significance of unresolved grief in relation to her mental health and I wondered if she could have lived more happily if she had been able to process her grief. That is the origin of my interest in this research; it sparked my imagination and gave me the possibility of closure on a troubling period of my life.

The concept of disenfranchised grief was a revelation to me not only in the context of my mother's post-stroke life but as a philosophical lens for viewing one's movement through life's stages, in other words, recognizing life as an ongoing series of periods of disenfranchised grief. I presume that very few people achieve all that they hope to or move through life in a smooth series of goals accomplished, and recognizing those defeats can create feelings of grief. When I consider disenfranchised grief in my personal life I think of my experiences of anxiety and depression, and the impact they have had on my pursuit of goals and career interests. This impact can be categorized as grief over time lost, which has been identified as an experience that can bring about disenfranchised grief (Gitterman & Knight, 2019). From a mental health perspective, unprocessed grief may have limited my ability to move forward with a clear self-awareness and acceptance. However, if there were more structured or formal supports for processing disenfranchised grief, perhaps a more positive outcome would result.

I come to this topic with a view of depression as similar to any other life event that reduces productivity and quality of life. I have learned that depression is a common outcome of disenfranchised grief and that depression is also one of the most common mental health problems. My own experience of depression has influenced my desire for the destigmatization of this mental illness and gives me a bias towards research that shares this point of view. The connection between depression and disenfranchised grief seems obvious to me from my experience both with my own depression and my observation of my mother's possible PSD. However, this was my own interpretation of my mother's experience and not a clinical diagnosis. I will keep an open mind to the likelihood that her possible depression was not stroke-related even though it seems likely to me, and subsequently be open to the possibility that PSD is not commonly related to disenfranchised grief in post-stroke individuals.

Like depression, stroke is another very common health challenge. The sudden onset of a stroke is a frightening prospect. To be suddenly and irrevocably changed, with no warning, and thrust into a different identity at a vulnerable stage of life would be a major shock. Again, my understanding and perspective of stroke is directly related to my personal life. In addition to my mother, my father-in-law had a major stroke at age 70 that took away his independence and caused his wife to become a full-time caregiver. In both cases it was the sudden and unheralded occurrence that made the greatest impression on me. Although there are some behaviors that can mitigate the chances of suffering a stroke, many strokes could not have been prevented. Thus, my own experiences with family members and stroke have left a lingering fear. This fear may influence my research regarding the importance that I place on post-stroke mental health care in relation to other areas of study. It may also influence my choice of studies on which to focus and my interpretation of the research towards a definitive connection between depression and stroke.

My personal interest and biases are thus rooted in my own experiences. I feel strongly about the need for greater research about disenfranchised grief after a stroke and its relationship to post-stroke depression and poor quality of life. In pursuing this research, I will remain vigilant to the influence of my experiences and their impact on my objectivity. In much the same way as a counsellor must be aware of countertransference I will try to always be alert to my own emotional connection to the material. The possibility that some of my hypotheses are not valid is something I will consider with an open mind. Perhaps disenfranchised grief is not as prevalent as I predict or perhaps there is no clear way to ascertain its presence; maybe the potential for processing disenfranchised grief is too limited to be effective. Preconceived ideas can affect every stage of writing a literature review, including identifying sources, selecting articles, and evaluating evidence. To mitigate bias, I will begin by creating a structure that sets boundaries on the scope of the review and will structure the review into sections that address specific areas. I will choose articles that both agree and disagree with my hypothesis and include criteria that result in opposing findings. I will evaluate the quality of the studies and their assessment factors equally between those studies that do and do not support my hypothesis. I will maintain vigilance over my interpretation of the data by watching for subjective bias and I will not omit outliers.

Disenfranchised Grief and Stroke Survivors

There is considerable literature on the topic of disenfranchised grief, however little is focused on stroke survivors. To demonstrate, a search for "disenfranchised grief" through the primo ex libris at the University of Calgary library produced studies of numerous subjects considered in connection with disenfranchised grief but only three related to stroke. In studies that examine the topic of ABI and grief, the term ambiguous loss is used rather than disenfranchised grief. When the terms "ambiguous loss" and "stroke" were searched on PsychInfo, Google Scholar and PubMed, no articles were found that contained both search terms. Using the keywords "acquired brain injury" and "grief" resulted in 24 articles, 13 of which dealt with an individual's experience of grief related to their own ABI. The content from these searches was reviewed and synthesized, resulting in the following key themes: (a) PSD as a serious and poorly understood chronic condition in stroke survivors, (b) grief as another common post-stroke condition with correlation to PSD, (c) disenfranchised grief as a specific form of grief common to stroke survivors, and (d) disenfranchised grief and ambiguous loss in the broader category of ABI.

Stroke

Stroke is the most common serious neurological condition in the world and the leading cause of long-term disability (Starkstein & Hayhow, 2019). More than 62,00 strokes occur in Canada each year and that number is projected to rise as the population continues to age (Canadian Institute for Health Information, 2021). Stroke-related mortality has declined in recent decades which has led to an increase in stroke survivors and thus a greater need for post-stroke care and rehabilitation (Krueger et al., 2015; Starkstein & Hayhow, 2019). The effects of a stroke can vary from mild to severe, and many survivors do not fully recover (Krueger et al., 2015). Effects include physical pain, paralysis, aphasia, and a range of cognitive difficulties (Horn et al., 2016). An average of 36% of stroke survivors retain major disabilities five years after the stroke and over 40% require assistance with daily living (Krueger et al., 2015). Furthermore, there is a strong association between stroke survival and psychiatric disorders such as depression (Starkstein & Hayhow, 2019). Although ample research exists on the cognitive and physical outcomes for stroke survivors, there is limited focus on the mental health outcomes (Hughes & Cummings, 2020).

There are several aspects of stroke that contribute to poor mental health in survivors, including the experience of sudden changes in physical and cognitive functioning, and the frequency of a vague prognosis regarding recovery (Bergersen et al., 2010). Mental health outcomes are often overlooked by family and health care professionals because of the priority placed on physical effects and rehabilitation, and further complicated by the common situation of a stroke survivor's reduced ability to express themselves (Horn et al., 2016). These are also factors that may contribute to feelings of grief. This type of unacknowledged or ambiguous loss is referred to as disenfranchised grief (Winokuer & Harris, 2012), and it can lead to chronic depression (Knight & Gitterman, 2019).

Post-Stroke Depression

PSD is categorized as a mood disorder due to another medical condition, specifically, stroke (American Psychiatric Association, 2013). A diagnosis of PSD requires the presence of either loss of interest in previously pleasurable activities or depressed mood, concurrently with two to four other symptoms of depression, for at least two weeks, subsequent to suffering a stroke (Dar et al., 2017). PSD is the most common neuropsychiatric consequence of stroke, with a prevalence of about 30% in stroke survivors; depression is more common among stroke survivors than it is in patients with any other physical illness of a similar level of disability (Ayerbe et al., 2014; Dar et al., 2017; Khedr et al., 2020; Krueger et al., 2015; Saikaley et al., 2018; Starkstein & Hayhow, 2019). In a cross-sectional study assessing for the presence of PSD in 103 stroke survivors, 36.9% of stroke patients had depression compared to 12% of healthy control participants (Khedr et al., 2020). Across a 15-year period of studies, the average prevalence of PSD in stroke survivors was consistently 30% (Ayerbe et al., 2014; Dar et al., 2017; Khedr et al., 2020; Krueger et al., 2015; Saikaley et al., 2018; Starkstein & Hayhow, 2019). However, there are also indications that the prevalence could be higher, given the challenges of assessing depression in stroke survivors (Dar et al., 2017). Overall, these findings highlight the problem of PSD for stroke survivors, and subsequently the need to identify and address PSD.

Depressive disorders are often unrecognized in the general population, and it is particularly complicated to diagnose in stroke survivors (Dar et al., 2017). The diagnosis of PSD is made more complex, and PSD is possibly underreported, due to the presence of cognitive and physical problems resulting from stroke (Dar et al., 2017; Khedr et al., 2020; Starkstein & Hayhow, 2019). These problems include communication impairment due to physical or cognitive disability, lack of self-awareness, and emotional and behavioural disturbances caused by damage to specific areas of the brain (Dar et al., 2017; Khedr et al., 2020; Kouwenhoven et al., 2011). For example, lack of self-awareness resulting from stroke makes it difficult for the stroke survivor to sense their emotional level, which is necessary for interview or scaling assessment tools (Dar et al., 2017). It can also be difficult to differentiate between impairment due to stroke and impairment due to depression, as they can both impact cognition in similar ways (Dar et al., 2017). For example, loss of concentration and impaired learning abilities may be interpreted as a result of the brain injury as well as a psychological reaction (Kouwenhoven et al., 2011).

Diagnosis of PSD requires comprehensive rating scales and interviews by trained professionals. Many screening assessment tools exclude individuals with cognitive or physical impairments who are not capable of carrying out the screening tool (Dar et al., 2017). A major limitation found when using assessment tools for the diagnosis of PSD was the frequent presence of insufficient communication capabilities in stroke survivors suffering from aphasia (Dar et al., 2017). Aphasia is the term given to the impaired communication that can result from a stroke, including difficulty both formulating and comprehending language (Horn et al., 2016); it is present in 20% to 40% of stroke survivors (Dar et al., 2017). Depression screening tools often require the client to have a sufficient level of verbal communication skills to accurately complete the questions (Dar et al., 2017). Screening tools can be modified to better accommodate communication deficits, for example altering the questions or the timing of the interviews, or using visual analog scales, but these modifications decrease the diagnostic accuracy of the tests (Dar et al., 2017).

Researchers must determine how they will approach communication deficits when screening for depression in stroke survivors and many choose to avoid the challenge altogether (Khedr et al., 2020; White et al., 2014). Khedr et al. (2020) acknowledged the challenges of accurately screening for depression when communication difficulties are present and avoided those complications in their study by excluding individuals with communication disabilities. White et al. (2014) also excluded participants with severe language impairment in a prospective cohort study to explore predictors of PSD over a 12-month period. Both studies recognized the exclusion as a limitation to the generalisability of the findings. Similarly, Starkstein and Hayhow (2019) conducted a review of prevalence of PSD as part of a larger review focused on treatment of PSD and found that all studies cited accurate assessment as a key issue for future management of PSD. Taken together, there is ample evidence that accurate assessment of PSD is an area that requires further research and improved application.

The risk for the onset of PSD is present and on-going throughout the year after a stroke (White et al., 2014). Prompted by research that correlated PSD with negative long-term recovery and likelihood of post-stroke mortality, White et al. (2014) explored PSD intermittently over a 12-month period by conducting a prospective cohort study utilizing face-to-face interviews. They found that stroke survivors who do not initially show threshold scores for PSD may meet criteria later on in the year after a stroke. They also found evidence through review that if PSD is not resolved within a year post-stroke it may result in chronic depression; therefore, the on-going possibility of acquiring PSD during the first year post-stroke indicates that it is a critical period for monitoring and implementing interventions (White et al., 2014).

Untreated PSD compromises the long-term health and the cognitive and physical recovery of stroke survivors (White et al., 2014). Considering the high prevalence of PSD in stroke survivors, accurate PSD assessment is a key issue in treating this population, but there are significant challenges due to the cognitive and communication deficits common to the population. Beginning with accurate assessment, early treatment of PSD would be facilitated by better knowledge of the prevalence, time period of onset, and risk factors of PSD (White et al., 2014).

Impact of PSD on Stroke Recovery and Quality of Life

The presence of PSD has a significant impact on stroke recovery and post-stroke quality of life (Blöchl et al., 2018; Khedr et al., 2020; Saikaley et al., 2018). While it can be difficult to differentiate between outcomes of PSD and outcomes of other comorbidities that may accompany stroke, there are clear associations between PSD and disability, impaired functionality, mortality, anxiety, and quality of life (Ayerbe et al., 2013; Blöchl et al., 2018; White et al., 2014). In a systematic literature review of the association between PSD and physical disability, Blöchl et al. (2018) found that while PSD may not impede recovery from physical disability in the short term, PSD may have an independent and negative effect on survivors' long-term functional recovery (Blöchl et al., 2018). PSD also influences the likelihood of post-stroke cardiac events and mortality (Dar et al., 2017; White et al., 2014). Stroke survivors with PSD are 3.5 times more likely to die 10 years after a stroke has occurred, as the presence of PSD aggravates some pre-existing medical conditions like hypertension, cardiovascular illness, diabetes, and COPD (Dar et al., 2017). For example, there is an association between myocardial infarction and PSD, relating to disruption of immune and coagulation mechanisms (Dar et al., 2017). PSD can also lead to death by suicide (Dar et al., 2017). Suicidality decreases motivation for complying with treatment and ultimately results in self-destructive tendencies (Dar et al., 2017). Suicidality is especially prevalent in young adult stroke survivors, and in the first five years after a stroke (Dar et al., 2017), making suicide assessment an important intervention during post-stroke rehabilitation and follow-up in the years after a stroke. The impact of PSD on physical health and mortality indicates a serious need for on-going assessment and treatment, but the impact of PSD on quality of life is equally serious and may be more easily overlooked in post-stroke recovery.

PSD greatly affects stroke survivors' quality of life and well-being; it is correlated with delayed recovery, longer institutional care, failure to return to work, reduced social activities, and low community participation (Dar et al., 2017; Khedr et al., 2020; White et al., 2014). Stroke survivors with PSD have a higher incidence of functional impairment in activities of daily living compared to non-depressed stroke survivors, which then leads to greater social withdrawal and social discontentment with relationships (Dar et al., 2017). Only seven percent of stroke survivors with PSD socialize with friends and relatives compared to 66% of non-depressed stroke survivors (Dar et al., 2017). Quality of life and severity of PSD are interconnected, and each affects the other (Kedhr et al., 2020), which is a key consideration for those treating stroke survivors. Given the prevalence and impact of PSD, defining risk factors is important but there is no clear agreement on the risk factors or populations at risk for PSD (Khedr et al., 2020). The difficulty in finding conclusive predictors may be connected to the number of possible predictors that merit consideration as well as the same challenges that face researchers studying prevalence, namely the impediments of post-stroke disability when conducting assessments.

Risk Factors for PSD

A number of predictors for PSD have been identified but the results are inconsistent (De Ryck et al., 2014). Khedr et al. (2020) found predictors for the development of PSD include smoking, level of post-stroke functional impairments, low educational level, and low socioeconomic status. A systematic review by Ayerbe et al. (2014) identified predictors as post-stroke disability, cognitive impairment, anxiety, and pre-stroke depression. In a prospective cohort study, White et al. (2014) found predictors of PSD to be low community participation and higher disability post-stroke. The one predictor of PSD common to these studies is level of disability or impairment, but each study considered different factors from the outset of their research. In a systematic review, De Ryck et al. (2014) outlined conflicting evidence of risk factors for PSD and concluded that widely varied methodology among the studies was likely responsible for the differences in results. The variable designs of the studies contribute to the variety of predictors that emerged in the findings, which creates a challenge for drawing conclusions about predictors of PSD. As with the study of prevalence, research on predictors of PSD demonstrates considerable challenges, which indicates a need for clinicians to consider a wide scope of possible risk for PSD in stroke survivors.

Grief

Grief is a universal reaction to loss experienced by most individuals at some point in their lives (Coetzer, 2003). Grief can be defined as an individual's affective reaction to a major loss, but what constitutes a major loss is subjective (Coetzer, 2003). On a fundamental level, a major loss can be defined as a reduction in both tangible and intangible resources in which the individual has an emotional investment; thus the changes and challenges that the stroke survivor experiences can clearly be characterized as significant loss (Coetzer, 2003; Hughes & Cummings, 2020). The reaction to grief is recognized as a multidimensional process that evolves over a period of time and that can result in adverse effects on both physical and mental health (Coetzer, 2003). The majority of individuals cope with grief by utilizing both internal and external support resources to eventually reach a permanent adaptation to the loss and a renewed satisfaction in ongoing life (Gonschor, 2020). However, a minority develops protracted grief, sometimes categorized as complicated grief, which is associated with mental health impairments, such as depression, and lowered quality of life (Gonschor, 2020). Grief can continue to plague individuals for many years if it is not acknowledged and processed in some way (Knight & Gitterman, 2019), therefore it is important to understand how grief is experienced by the stroke survivor in the years after a stroke and how a greater awareness of this grief can lead to better interventions for stroke survivors.

Grief After Stroke

Grief and loss are themes in the study of stroke survivors; stroke-related losses have been characterized as a sudden catastrophe (Dar et al., 2017), the intensity of which non-survivors could not imagine (Hughes & Cummings, 2020). Identified stroke-related losses of a subjective nature include the loss of identity, independence, relationships, and confidence (Ayerbe et al., 2014; Bergersen et al., 2010; De Ryck et al., 2014; Hughes & Cummings, 2020; McCurley et al., 2019).

Connections have been made between grief and PSD, but there are challenges in differentiating between PSD and the sadness that often accompanies grief after a major loss (Kouwenhoven et al., 2011). Coetzer (2004), in a review considering self-awareness and grief after brain injury, observed that depression is sometimes considered a basic characteristic of the grief response and that the emotional anguish associated with grief puts an individual at risk for adverse effects on mental health. In a qualitative study of nurses working in a stroke setting, it was found that nurses considered depression in their patients as comparable to grieving, as a natural, normal response to the many losses and fears accompanying post-stroke life (Stroyde, 2019). Dar et al. (2017) suggest that it can be difficult to differentiate between PSD and grief in stroke survivors, noting that stroke can bring about both grief and depressive symptoms. They also observe that grief can be difficult to recognize for stroke survivors who have retained a lack of self-awareness, and do not have insight into their disabilities. Thus, the interconnectedness of post-stroke losses, sadness, grief, and PSD is apparent but not clearly defined.

Holbrook's bereavement model, which is specific to stroke adjustment and which uses patterns related to a conceptualization of four stages of grief, is useful for understanding grief responses in stroke survivors (Alaszewski et al., 2004; Hughes & Cummings, 2020). Holbrook's stages of bereavement are categorized as crisis, treatment, realization of the level of disability, and adjustment to reality (Alaszewski et al., 2004). Each stage carries its own emotional reactions starting with shock and confusion, followed by denial, then anger and despair, and ending with acceptance. Holbrook's model has proven useful to professionals for conceptualizing stroke rehabilitation and facilitating discussion of grief and loss (Alaszewski et al., 2004; Hughes & Cummings, 2020).

In a qualitative, person-centred study using semi-structured interviews and self-report diaries to explore the impact of stroke on the lives of stroke survivors and their professional caregivers, Alaszewski et al. (2004) found that professional caregivers use the bereavement model to conceptualize stroke rehabilitation but survivors do not include bereavement in their own stories of life after a stroke. Rather than generalize their feelings in terms of a common pattern, they tended to speak more about their own specific losses in the context of their personal narratives, such as specific activities they could no longer accomplish and how to make up for that. The bereavement model was used by professionals to create perspective when they felt that the stroke survivors were unrealistic about their goals and had become stuck in their progress towards recovery.

The bereavement model was also found to be useful for families in understanding the grief responses of stroke survivors (Hughes & Cummings, 2020). A cross-sectional study utilizing focus group interviews and discussion with stroke survivors and their spousal caregivers found that, without prompting, loss emerged as a major theme from stroke survivors (Hughes & Cummings, 2020). In this case, the bereavement model was useful for understanding the grief responses of the participants. Generally, these studies identified the value of using the Holbrook grief perspective when looking at stroke recovery and they indicate the need for processing of grief after stroke.

Grief was identified in a grounded theory study of stroke survivors 11-13 years after a stroke, intended to understand the long-term impact of stroke on everyday life (Erikson et al., 2010). The authors found three main themes throughout the years after stroke: analysing loss, trying to reclaim the former life, and trying to find meaning in a different life. One of the participants had utilized professional help to process his grief after the stroke and intermittently throughout the years afterward. He recognized that he was able to adapt to a new reality through the processing of grief, which helped him to understand his new life and move forward. The cumulative effect was that he felt he had become a more thoughtful and empathetic person, demonstrating the possible value for stroke survivors in understanding and processing their stroke-related grief.

Given the personal nature and immensity of the losses suffered in a stroke, grief is an understandable response, yet there are minimal socially recognized ways for acknowledging and processing that grief. Social constructs of bereavement are focused on death-related grief, present in the formal recognition of death through institutions such as funeral homes, and rituals such as funerals, memorials, and burial ceremonies (Doka, 2008). The lack of formal or socially recognized ways to mourn other losses leaves those who suffer, such as stroke survivors, without a way of processing and resolving that grief.

Disenfranchised Grief

The concept of disenfranchised grief begins with the understanding that grief is an experience that is situated and interpreted in a larger social field, not simply as a private emotional process (Bellet et al., 2019; Doka, 1989; Dominguez, 2018). Every aspect of grief is normalized through social rules including which circumstances are considered suitable and acceptable for grieving, the community view of loss, and the way that the greater culture polices the expression and enactment of grief (Bellet et al., 2019; Knight & Gitterman, 2019). These social aspects of grief either validate the loss or inhibit the attempt at making meaning of the loss (Doka, 1989). It is the meaning-making process that is affected by social support; social support allows for better processing of grief and its absence creates a risk of complicated grief (Bellet et al., 2019; Dominguez, 2018). Overall, a sense of validation by others of the attempt to find meaning after a loss plays a major role in a healthy outcome for grief processing (Bellet et al., 2019; Dominguez, 2018; Knight & Gitterman, 2019). A loss unrecognized by a person's social networks or institutions does not provide opportunities for grieving. A lack of social and professional support can result in a chronic state of mourning (Horn et al., 2016).

Disenfranchised grief refers to grief that is unacknowledged by these social norms and thus leaves the grieving individual lacking crucial social support (Bellet et al., 2019; Doka, 1989; Dominguez, 2018; Knight & Gitterman, 2019). The concept of disenfranchised grief originated with a questioning of the limits of the social recognition of grief and mourning in relation to the AIDS epidemic of the 1980s (Dominguez, 2018). Kenneth Doka (1989) presented a paper comparing the grief experienced by heterosexual and homosexual life partners and found that stigma around homosexual relationships resulted in a lack of social support for those grieving the loss of their partners (Dominguez, 2018). Doka found that limiting social recognition of grief to the deaths of family members was initially connected to the need to limit material support, especially from employers. From the perspective of employer support, policies for grief support need to be clearly laid out and limited in scope in order to contain the resources required to maintain that support (Doka, 2008). The limitations that are initially used to contain employer support are subsequently ingrained as limitations to social support, meaning disenfranchisement for those losses that fall outside the limitations (Doka, 2008). Disenfranchised grief has been organized into several categories: relationships that are not recognized, losses that are not socially validated, a griever excluded by being defined as not capable, the circumstances of the death, and the style of grieving (Doka, 2008).

The current body of literature is largely made up of examples and narrative accounts of specific types of disenfranchised grief (Dominguez, 2018). A search for disenfranchised grief produced results related to a variety of subjects but only one investigation of disenfranchised grief related to stroke (Horn et al., 2016). There are several subject categories with more than one journal article; the most numerous subjects are pet death, pregnancy losses, health care workers, and suicide-related topics. Other study subjects related to disenfranchised grief include parent-child issues, SUD-related death, figures in popular culture, gender change, same sex partner death, transnational deaths, COVID-19, HIV, and military deaths. This literature search confirms that disenfranchised grief has been explored more in terms of circumstances than the experience (Dominguez, 2018).

Disenfranchised grief is a distinct form of grief that is manifested in a variety of symptoms (Dominguez, 2018). A phenomenological qualitative study of movement therapists who worked with clients experiencing disenfranchised grief resulted in descriptions of it that included overwhelming, complex, disconnecting, and pervasive (Dominguez, 2018). The effects of disenfranchised grief included intensified emotional and behavioural reactions, an inability to make use of comfort sources, the inability to engage in or access mourning rituals, and social isolation. Individuals who internalized the disenfranchisement and felt conflicted about their grief reacted with self-blame. Emotions were found to be expressed externally, in aggressive or impulsive forms, or internally as isolation, depression and withdrawal. Self-destructive behaviour was sometimes the result. The complex nature of disenfranchised grief resulted in distinct experiences for each individual sufferer.

Disenfranchised Grief and Stroke

Two of Doka's categories may be relevant to a stroke survivor's experience of disenfranchised grief: the possibility of losses that are not socially validated and a griever excluded by being defined as not capable (2008). A non-death loss in the form of disability, such as that found in a stroke survivor, is seldom socially acknowledged, and a stroke survivor who appears incapable of grieving due to disability is also deprived of the opportunity to grieve

(Knight & Gitterman, 2018). For example, as many as 70% of aphasia victims experience deep feelings of social and psychological losses, and support for their sense of loss is made more complicated by their impaired ability to express themselves (Horn et al., 2016). Thus, the condition of post-stroke aphasia presents several factors that illustrate elements of disenfranchised grief theory.

Aphasia

As noted previously, a consistent challenge facing both researchers and clinicians who study and work with stroke survivors is the common post-stroke effect of aphasia. Aphasia has been defined as a language disorder that dramatically affects talking and understanding, as well as the ability to write and read, which masks the individual's inherent competence (Taubner et al., 2020). Taubner et al. (2020) conducted a multimethod qualitative study involving nine participants, in which data from online observations was triangulated with interview data. Their aim was to investigate self-identity construction in persons living with post-stroke aphasia in a digitalised society. They noted participants' feelings of grief related to the loss of their pre-stroke identities, including feelings of anger at the loss of their old self, feelings of panic upon awakening and being different than before the stroke, and describing their pre-stroke self as being dead. Other participants spoke of initially thinking they would recover but gradually realizing they had a disability; one individual acknowledged a period of three years before she accepted that she would not recover.

Another salient observation in relation to categories of disenfranchised grief was the participants' experiences of being treated as absent or incapable by the clinicians who were treating them, even after they had demonstrated that they could understand and comply with instructions (Taubner et al., 2020). This experience of dismissal is related to the experience of being viewed as incapable of grieving, identified by Doka (2008) as a potential situation for the experience of disenfranchised grief. These examples indicate the role that aphasia may have in the experience of PSD and disenfranchised grief.

Another situation experienced by stroke survivors, similar to being treated as incapable, is the stroke survivor's solicitations for counselling going unnoticed during the rehabilitation period immediately after a stroke (Simmons-Mackie & Damico, 2011). For example, although counselling is within the scope of practice for speech language pathologists (SLPs), it is most often intentionally avoided, thereby missing a counselling opportunity and possibly increasing the stroke survivor's emotional distress (Simmons-Mackie & Damico, 2011). Simmons-Mackie and Damico (2011) conducted an ethnographic microanalysis of SLPs in aphasia treatment sessions in order to identify and describe strategies that are associated with counselling opportunities that are avoided by SLPs. They found that a variety of strategies were utilized to divert talk away from potential counselling interactions, even though SLPs have unique skills in understanding people with aphasia. They concluded that SLPs' avoidance of providing emotional support to stroke survivors was likely because of enculturated and habituated behaviours within the profession. Here once again, is a situation wherein the stroke survivor's losses are not acknowledged, creating another situation for the possible formation of disenfranchised grief.

Aphasia and Disenfranchised Grief

Horn et al. (2016) conducted a single-case study designed with the goal of helping counsellors to understand grief and loss experienced by persons with aphasia. They used a qualitative phenomenological case study method in order to understand the problem in depth, engaging a participant they believed would effectively provide insight into the experience (Horn et al., 2016). The patient, Lynn, was highly educated, had been successful in her career, and had previously juggled many responsibilities at home and at work. After her stroke, she suffered from aphasia and struggled to communicate but still had some language ability. She could no longer fully participate in daily life, as even the most mundane tasks were now a challenge to perform.

The researchers conducted semi-structured videotaped interviews using open-ended questions that were provided to Lynn beforehand. The transcribed interviews were rigorously analyzed by each member of the research team, resulting in the identification of five themes that described Lynn's experience: adapting to a new reality, and questioning identity, existence, normality, and feelings. Also identified was an overarching theme of disenfranchised grief. Lynn described experiencing many layers of loss, including her self, her identity, and even her existence, as others did not seem to understand her new self (Horn et al., 2016). She could not define herself and it seemed that other people did not acknowledge her current self. Lynn felt that she reexperienced her loss of identity every day when she woke up and initially forgot about her change. Lynn experienced strong emotions but was unable to express them or have them understood by others. These losses were deep and permanent yet there was no social validation, as categorized in disenfranchised grief theory (Doka, 2008; Dominguez, 2018). Lynn's losses had no public rite or ritual to enact, no avenue for public expression with which to validate them, and no opportunity for grieving that was recognized by her social networks or institutions (Doka, 2008; Dominguez, 2018).

Lynn's altered physical abilities may have placed her in another category pertaining to disenfranchised grief theory, that of a griever who is excluded from grieving due to being considered incapable of experiencing grief (Doka, 2008). In spite of her interior cognitive and emotional capabilities, her limited ability to communicate caused others to not consider that she may be able to experience grief over her losses (Horn et al., 2016). This lack of consideration from others may have resulted in internalized disenfranchisement, conflicted feelings, and even greater isolation (Dominguez, 2018). It can be concluded that stroke survivors would benefit from the recognition of disenfranchised grief, and from the normalizing of their responses to the losses they have suffered (Horn et al., 2016).

Disenfranchised Grief, Ambiguous Loss, and Acquired Brain Injury

Disenfranchised grief and its relation to PSD has not been widely researched, however acquired brain injury (ABI) and its relation to ambiguous loss investigates similar themes. Stroke as a medical term falls into the broader category of ABI (Brain Injury Association of America, 2021). ABI refers to any injury to the brain that is not hereditary, degenerative, congenital, or caused through birth trauma (Brain Injury Association of America, 2021). The causes of ABI include disease, tumors, poisoning, lack of oxygen, shock, seizure, and stroke (Brain Injury Association of America, 2021). ABI is the leading cause of death and disability in the United States and frequently results in permanent loss of physical abilities as well as cognitive deficits including slowed processing speed, impaired memory, and poor self-awareness (Kreutzer et al., 2016). Ambiguous loss is related to disenfranchised grief in that both refer to losses that are not socially recognized and are therefore difficult to mourn (Kreutzer et al., 2016). Although ambiguous loss is closely connected to the concept of disenfranchised grief, the research on ambiguous loss explores different populations, focused on the experiences of friends and loved ones rather than on the ABI survivor. Still, there are many parallels and it seems productive to examine the two separate lines of research in relation to each other in order to understand their similarities and differences and to consider if it would be beneficial to consolidate them going forward.

Ambiguous loss in the context of ABI refers to the common experience of loss for the loved ones of an ABI survivor (Kreutzer et al., 2016). The theory of ambiguous loss was developed in the 1970s to describe the experience of the non-death loss of a loved one's psychological or physical presence (Boss & Yeats, 2014; Flores, 2021). A physical presence but psychological absence is commonly found in an ABI survivor (Boss & Yeats, 2014). The person may appear to be the same as before even though they have changed in their capabilities, personality, and/or emotions (Boss & Yeats, 2014). The loss is not clear, is not socially validated, and therefore there is no closure with which to process the loss (Boss & Yeats, 2014; Flores, 2021; Kreutzer et al., 2016).

There are a wide range of outcomes from ABIs, and even mild injuries can result in deficits in attention, memory, concentration, and emotional regulation (Kreutzer et al., 2016). According to ambiguous loss theory, mild cognitive disability is often subtle, as is often the case with stroke effects, so that the survivor may present as unimpaired on the surface (Kreutzer et al., 2016). This can make it difficult for other people to see or understand the impairment, which in turn makes it difficult for others to empathize with the survivor (Kreutzer et al., 2016). The lack of understanding from others tends to make the survivor uncomfortable, causing them to subsequently retreat from social interaction and leading to greater social isolation for the injured person (Karpa et al., 2020). This dwindling of social support is mirrored in the healthcare system, which tends to reduce available resources after the acute care stage (Karpa et al., 2020). This pattern of diminishing support parallels findings in PSD research that emphasises the need for long-term and on-going assessment and support (White et al., 2014).

In contrast to disenfranchised grief theory, which is focused on the injured individual, ambiguous loss theory is primarily focused on the ABI survivor's family and friends, although there is substantial overlap between the two theories, as both encompass losses that may be unnoticed by the casual observer (Coetzer, 2003). Ambiguous loss studies consider family and friends' sense of loss when their loved one changes (Knight & Gitterman, 2018). It is notable that the ambiguous loss literature points out that there is little support in place for the family as the support is focused on the individual (Karpa et al., 2020). In contrast, research on stroke survivors refers to the lack of support in place for the stroke survivor to mourn their own losses (Horn et al., 2016). Thus, there appears to be a significant absence of support for both the families and the stroke survivors, when seen from the separate perspectives of each group.

Further mapping of their similarities and differences is out of the scope of this project but it could be helpful to create a consolidated theory of grief and loss for both ABI survivors and their loved ones. By combining these two perspectives a broader, more comprehensive understanding of the mental health concerns that arise from ABIs could be formulated for both the affected individual and their loved ones and caregivers. Applicable aspects of a general theory could then be applied to more specific situations such as stroke, and treatment approaches could be developed according to theoretical guidelines.

The high prevalence and harmful effects of PSD indicate the need for attention to this common outcome for stroke survivors. Impacts on long-term functioning, quality of life and mortality make it an important focus for clinicians and counsellors working with stroke survivors. Physical limitations resulting from the effects of stroke, such as aphasia, not only make it difficult to assess for the presence of PSD, they also present challenges in its treatment. As well, the significant losses resulting from stroke-related physical and cognitive disabilities inevitably result in a grief reaction in many stroke survivors. This grief is often poorly understood or unacknowledged during the stroke recovery process, resulting in disenfranchised grief, which can contribute to PSD and prevent effective mental health treatment. The topic of grief has been found helpful for professionals working with stroke survivors and their families, and disenfranchised grief provides a useful lens through which to view and treat the stroke survivor's experience of unacknowledged loss and its relationship to PSD.

Implications for Counselling

Experiencing a stroke, and the associated social, physical, and psychological consequences of its aftermath, is often devastating (Coetzer, 2004). Physical rehabilitation offers a stroke survivor the chance to recover and adapt to their new situation (Hole, 2014), but psychosocial needs that accompany the process of recovery are equally important; psychological difficulties such as PSD can negatively affect long-term outcome and quality of life to a dramatic degree (Coetzer, 2004). There are multiple factors for counsellors to consider when working with stroke survivors during their recovery process, notably the possible presence of PSD related to feelings of grief and loss, in relation to difficulties with self-awareness and communication, lack of social support, experience of stigma, challenges with identity, and the complexity of the recovery process (Hole, 2014; Horn et al., 2016). Stroke survivors may also have their own ideas about recovery and rehabilitation that are associated with their expectations and hopes for the outcome and timeline (Alaszewski et al., 2004; Hole, 2014). Assessing and treating PSD, understanding its relationship with grief, and concurrently remaining cognizant and educated about other post-stroke losses, presents a significant but important challenge to a counsellor.

In order to design effective therapeutic interventions, the counsellor should have a strong understanding of potential long-term outcomes of stroke and how those outcomes relate to self-awareness and grief (Coetzer, 2004). Stroke survivors often feel uncertain of their abilities and this uncertainty can be exacerbated if rehabilitation professionals, including counsellors, inadvertently perpetuate that uncertainty by under- or over-estimating the client's understanding and abilities (Hole, 2014). Therefore, the timing and sequence of interventions may need to be calibrated to the individual's level of emotional distress and level of self-awareness (Coetzer, 2004). The extent of loss in brain injury can be hard for the survivor to comprehend as the very faculties required for such understanding can be impaired (Coetzer, 2004; Hole, 2014). Impaired self-awareness is often characterized by a lack of perceiving or understanding changes in the self, which can also result in frustration for the counsellor (Coetzer, 2004). The process of comprehending changes is likely to change over time and the process of grieving while trying to understand brain injury losses is a complex process that is not well understood (Coetzer, 2004). It is difficult for others to understand the experience of reduced self-awareness, yet for effective rehabilitation it becomes important for the counsellor to consider the ways that impaired self-awareness influences and interacts with grief, and how these factors can be considered in relation to counselling approaches (Coetzer, 2004).

Grief as a Response to a Stroke

Grief is a likely response to the significant losses that accompany a stroke (Coetzer, 2004). The process of grieving is individual in nature, however a common theme is the need to discover meaning coupled with a resultant emotional outcome (Coetzer, 2004). The psychosocial transition theory of grief processing is applicable for the stroke survivor as its focus is on reconstructing the view of the self (Coetzer, 2004). Viewed through the psychosocial transition theory, gaining understanding of a loss is often associated with initial reduction in grief, while a longer-term positive result comes from finding growth through the loss (Coetzer, 2004). The factor of impaired self-awareness may create a barrier to understanding a loss, so it is important that a counsellor helps the stroke survivor toward greater awareness concurrently with the grieving process (Coetzer, 2004). Denial and confusion regarding post-stroke impairments also present challenges in moving through a grieving process (Hughes & Cummings, 2020).

Holbrook's bereavement model, which is specific to stroke adjustment, and which conceptualizes the four stages as crisis, treatment, realization of the level of disability, and adjustment to reality, is useful for counsellors as a foundation for understanding grief responses in stroke survivors, as each stage is accompanied by emotional reactions (Hughes & Cummings, 2020). The use of this model can be helpful but can also be rejected or denied by the stroke survivor. In particular, the state of acceptance and positivity described in stage four is not easy to achieve in cases where a stroke survivor faces little chance of full recovery after the initial rehabilitation period (Hughes & Cummings, 2020).

The counsellor can be more effective if they understand the pain of unacknowledged or misunderstood grief, and the resulting experience of disenfranchised grief. The losses that follow a stroke are often not socially recognized as they can be difficult to perceive and/or don't fit into an easily defined category of loss. Stroke survivors also may not be considered capable of grieving if their stroke-related impairments limit their cognitive or communicative abilities (Horn et al., 2016). Counsellor awareness of disenfranchised grief allows for its acknowledgment and expression (Horn et al., 2016).

Social Support

Following a significant loss, timely social support is one of the best determinants of positive mental health outcomes (Gonschor, 2020; Logan et al, 2017). Stroke survivors' experience of social support during their recovery affects their ability to recover a feeling of autonomy and a sense of self (Hole, 2014). Social support can come from professionals as well as family and friends, and can take many forms (Hole, 2014). There are four different dimensions of social support: emotional, esteem, tangible, and information (Hole, 2014). It is important that there is at least one dimension included in stroke rehabilitation and the counsellor should consider matching the support to the patient's situation (Hole, 2014). For instance, emotional support may be best in the crisis situation immediately following a diagnosis but during a transition period of change, information and resources may be more useful (Hole, 2014). Increased family support is also beneficial for increasing autonomy, well-being, and self-esteem (Hole, 2014). While there are many possible complications for the grieving process, social support is a factor that can be identified and modified after it has initially been absent and therefore can be assessed by the counsellor at any point after the initial loss (Logan et al, 2017).

The provision of social support is a function of the social rules of grieving, including who should grieve, when, where, how, for how long, and for whom (Mortell, 2016). There is also an interplay of variables relating to the factors of the bereaved, the loss, and the potential supporter that accounts for the inconsistency of support sometimes received by bereaved persons (Logan et al, 2017). In order for social support to be effective there must be a recognition of the need for support, a capable and willing supporter, and a perception of helpfulness by the receiver; those suffering from grief often do not receive the type or amount of social support that they need because one or more of these elements is not available (Logan et al., 2017). Thus, the counsellor needs to be cognizant of the social rules of grieving as well as the elements that are necessary for effective social support, in order to assess each client's situation on an on-going basis.

In order for a need for support to be recognized it is necessary that the stroke survivor understands their situation and its relationship to possible feelings of grief (Horn et al., 2016). Thus, the counsellor's role includes assisting with the recognition that grief may exist (Horn et al., 2016). Capable and willing supporters may be found in family and friends, but they may also need to be educated on the possible presence of grief and the concept of disenfranchised grief (Horn et al., 2016). Grief is often uncomfortable for others so the counsellor may also need to facilitate responses and assist with lowering the level of discomfort (Hole, 2014). Finally, the counsellor must be sensitive to the approaches that might be most helpful in relation to the stroke survivor's individual response to grief and emotional needs (Hole, 2014).

Public stigma, defined as social groups endorsing stereotypes about another group and acting against that group, is another factor that affects social support and thus should be considered in relation to the disenfranchised grief of the stroke survivor (Gonschor, 2020). The negative cognitive and affective evaluations that arise from stigma can result in social avoidance and withholding of help (Gonschor, 2020). Individuals with ongoing disenfranchised grief experience more perceived negative social responses due to stigma, and social groups experience more social discomfort toward the stigmatized individuals (Gonschor, 2020). Furthermore, self-stigma often follows social stigma, as the stigmatized individual internalizes the public stigma and begins to believe that they are of less value (Gonschor, 2020). Stigma can also have a negative impact on the likelihood of seeking professional counselling (Gonschor, 2020). The counsellor needs to be aware of the potential for feelings of stigma in the stroke survivor and how those feelings may inhibit expression of emotions or even seeking help. Counselling may need to address feelings of shame related to stigma and to the discomfort that others may show because of social stigma.

Identity

The changes brought on by a stroke can challenge an individual's ability to engage in their previous activities, thus removing professional and other important identities (Hole, 2014; Martin-Saez & James, 2019). The evolution of identity is a key theme when constructing counselling interventions for stroke survivors, as an individual's identity is an essential aspect of perceived recovery (Hole, 2014). Identity is influenced by, and evolves throughout, stroke recovery, therefore, identity requires ongoing attention (Hole, 2014). Individual identity encompasses factors such as comorbidities and age as well as hobbies and activities that the individual enjoyed prior to their brain injury (Hole, 2014). It is important that these factors are considered and acknowledged in the counselling process. Specific needs arising from an individual's experience with identity should be prioritised rather than approaching this aspect of counselling in a formulaic manner (Foster et al., 2014). An individual recovery model allows the stroke survivor to participate in their own recovery path by combining their knowledge of themselves and their life experiences with professional advice and opinions throughout the counselling process (Hole, 2014).

Occupational identity is part of the general construct of self-identity and the loss of occupational identity is closely connected to a sense of a devalued self (Martin-Saez & James, 2019). The stronger the feeling of occupational identity loss, the greater the perception of decreased self-worth (Martin-Saez & James, 2019). This is likely impacted by Western cultural norms wherein one's identity is closely linked to their line of work (Martin-Saez & James, 2019). Counsellors should aim to understand an individual's occupational re-construction process and support stroke survivors in re-inventing themselves over an extended period (Martin-Saez & James, 2019).

Psychosocial needs of the client must be considered in order to support their transition in identity (Coetzer, 2004). The desire for reintegration to their previous social world is a strong source of motivation in the rehabilitation process but adjustment to a different identity first requires recognition of a new self (Hole, 2014). Adapting to a new identity is a difficult process and the individual must be encouraged and supported when they are attempting to evolve their new identity following the initial rehabilitation process (Hole, 2014). The counsellor must consider the importance of listening and indicating that the client has been heard when the stroke survivor expresses loss, uncertainty, hope and aspirations (Hole, 2014). Following this it is beneficial to use questions to offer alternative views and possibilities in a negotiation with the client rather than directing them (Hole, 2014). The counsellor thus recognizes the individual's need to regain a sense of self-sufficiency and control so that they can rebuild their life following a stroke.

Communication Challenges

Disabilities that are common to stroke survivors can be impediments to both speaking and understanding language (Foster et al., 2014). When an individual is limited in their ability to communicate their needs they are at risk of receiving inadequate or inappropriate health care services (Foster et al., 2014). In fact, patients with communication barriers are six times more likely to experience an unfavorable event in the hospital (Foster et al., 2014). Improved communication plays a crucial role in the stroke survivor's ability to relay their health care needs and participate in their own care, and results in a greater sense of independence and control for the stroke survivor (Foster et al., 2014). Communication disabilities must be taken into consideration from the beginning of treatment and the counsellor may need to work closely with SLPs in order to ascertain the specific limitations and how they may affect the counselling process (Horn et al., 2016).

As previously discussed, aphasia is a communication-related disability that is a frequent outcome of stroke. Unfortunately, at the crucial first stages of care, service to people with acute post-stroke aphasia in an acute care hospital setting has been found to be inconsistent with best practices, including attention to emotional needs (Foster et al., 2014; Simmons-Mackie & Damico, 2011). Counsellors need to be aware that SLPs are key personnel addressing aphasia in the post-stroke population but that they often miss or avoid opportunities to address clients' emotional needs (Horn et al., 2016; Simmons-Mackie & Damico, 2011). Understanding the factors that influence the SLP in providing care can be instructive in improving other psychological care for stroke survivors (Foster et al., 2014).

Limited Resources and Working Collaboratively

Although the importance of psychological expertise in post-stroke care has been recognized (Stroyde, 2019), there is often a limited amount of counselling resources available for treating the psychological needs of stroke survivors, which can result in health care workers from other disciplines, such as SLPs, physical therapists, occupational therapists, social workers, and nurses, taking on some of that responsibility (Foster et al., 2014; Stroyde, 2019). A systematic review exploring the practices of multi-disciplinary health care workers (MDHCWs) in post-stroke care settings across multiple countries found concerns of lack of resources, and insufficient staffing and time, to meet the psychological needs of the stroke survivors (Stroyde, 2019). Professional boundaries related to psychological care was a common theme, suggesting that MDHCWs in post-stroke care settings can be unsure of when it is appropriate for them to address the psychological needs of the stroke survivor. When MDHCWs were clearer about their role there was still hesitancy regarding their own competency in addressing psychological needs. There were also challenges stemming from institutional policies and goals, as well as models learned in training; for example, occupational therapists followed more holistic models compared to the medical models with which nurses were trained (Stroyde, 2019).

While there is uncertainty among MDHCWs about addressing the psychological needs of stroke survivors, there is still a general awareness of the presence and the significance of those needs (Stroyde, 2019). Counselling psychologists can take a leadership role in the area of treating psychological needs by providing consistent supervision, consultation, and collaboration for MDHCW colleagues within a post-stroke care setting. With sufficient support, MDHCW's confidence and clarity about what role they can have in treating the psychological needs of stroke survivors would result in better care for the psychological needs of stroke survivors (Stroyde, 2019).

Taken together, there are numerous implications for counsellors to consider when treating stroke survivors. There is a possibility for PSD to appear throughout both short-term and long-term post-stroke recovery, which makes PSD assessment an on-going factor. There also needs to be an on-going awareness of the way that losses are being understood and the resulting grief that may occur, as the reality of the stroke survivors' situation becomes more apparent to them. Social support is crucial for the grieving process after stroke and must be considered in relation to changes in identity for the stroke survivor, as well as possible stigma. Impaired self-awareness and communication can inhibit the ability for the stroke survivor both to comprehend and to communicate their feelings of grief and loss, placing a greater onus on the counsellor to facilitate that understanding, as well as collaborating with and supporting MDHCWs in addressing the psychological needs of the stroke survivor. Overall, the post-stroke recovery process is complex and the counsellor plays a critical role, as mental health recovery cannot be separated from other areas of recovery.

Next Steps for Research

A better understanding of stroke survivors' individual experiences would result in higher quality services and more efficient processes in a safer environment (Hole, 2014). In particular, there is value in learning more about patients' subjective experiences after a stroke that can contribute to feelings of grief, including experiences of diminished physical capabilities, struggles to comprehend their situation, changed relationships with loved ones, adapting to new surroundings, the rehabilitation process, changes in personal identity, and social isolation (Hole, 2014; Horn et al., 2016). Measuring health outcomes using surveys with predetermined and standardised questions is frequently aligned with the health care professional's agenda rather than the patient's or their caregivers', and prevents understanding of an individual's personal experience (Hole, 2014). Stroke can have a unique impact on each survivor and subsequently a tailored approach is required for the recovery process (Coetzer, 2004). Qualitative research is increasingly being seen as valuable for understanding the psychosocial experiences that result from stroke in order to inform practice and policy within healthcare (Hole, 2014).

While there is a need for further research in all areas of stroke recovery, data on PSD are insufficient and inconclusive (Ayerbe et al., 2013; Blöchl et al., 2018; Dar et al., 2017; Starkstein et al., 2019; Vahid-Ansari et al., 2018). PSD has a negative impact on the functional recovery, mortality, and quality of life of stroke survivors, therefore it is essential that it be diagnosed and treated appropriately (Dar et al.,2017). Areas identified for further research on PSD include predictors, outcomes, prevalence at different time-points, timepoints of recovery, recurrence patterns, preventive interventions, associations with other health outcomes, impact on physical disability and quality of life (Ayerbe et al., 2013; Blöchl et al., 2018; Krueger et al., 2015; Starkstein et al., 2019; Vahid-Ansari et al., 2018). The prevalence and impact of PSD makes accurate assessment a key issue; presently there are no universally acceptable assessment tools for evaluating PSD (Dar et al., 2017). Stroke-related impairments such as cognitive disability, reduced self-awareness, and aphasia contribute to challenges in assessing stroke survivors for PSD (Dar et al., 2017). Further research is required to design an accurate assessment of PSD for stroke survivors with these impairments. Currently there are a variety of predictors of PSD that have been identified but there is no conclusive agreement except that it is a result of multiple factors, with disability the one predictor commonly identified (Dar et al., 2017). The wide variety of risk factors that are considered contributes to variability in study design. Further research that considers a full scope of possible risk factors, including feelings of grief, is vital.

Presently, disenfranchised grief is not well understood in relation to stroke survivors (Horn et al., 2016). Feelings of disenfranchised grief can begin immediately after stroke, when the focus is on physical rehabilitation with little time spent on helping the stroke survivor understand, mourn, and come to terms with the losses that have been incurred (Horn et al., 2016). Disenfranchised grief can result in prolonged grief reactions, which contribute to poor mental health in stroke survivors (Horn et al., 2016). Research must go beyond cataloguing the many types of losses that are disenfranchised and extend to studies that can provide a basis from which to assess the variety of ways that disenfranchised grief is expressed, the process, and the outcomes. (Doka, 2008).

There is insufficient understanding of how stroke survivors experience post-stroke losses, such as identity loss (Horn et al., 2016), and how counsellors can help them to express and process their losses. As well, inconsistent or unsupportive actions and the breakdown of social networks may become a secondary loss that complicates the primary loss (Logan et al., 2017). Lack of recognition and processing of their losses can result in a prolonged grief response a stroke survivor. A greater understanding by counsellors of post-stroke losses in the context of disenfranchised grief would improve counselling outcomes; individual case studies may be the most effective route for gaining an in-depth understanding (Horn et al., 2016).

Social support for grief has received limited research, meaning that there is a lack of understanding of the mechanisms behind both the perceptions of those suffering from losses and the intention to support them (Logan et al, 2017; White et al., 2014). Social support is important in the recovery process for those experiencing less-recognized losses, such as stroke survivors (Logan et al., 2017), who often do not receive the type or amount of social support that they need when recovering from their losses (White et al., 2014). Quantitative research will help to create a picture of how and why social support is given and under what circumstances it is unacknowledged or curtailed. The question may be formulated in terms of what factors help people recognize and respond to others' distress, as these factors are complex and not well understood (Logan et al., 2017).

The specific challenges faced by stroke survivors with communication difficulties who are experiencing grief are currently not well understood or accounted for (Foster et al., 2014, Horn et al., 2016). The role of SLPs in counselling stroke survivors is ambiguous and results in a gap between the emotional needs of the stroke survivor and the treatment that is available to them during post-stroke aphasia rehabilitation (Logan et al., 2017). Rather than compartmentalizing the various rehabilitation treatments it may be preferable for the client to be provided with combined care, but this requires research comparing the experiences of SLPs, other rehabilitation clinicians, and counsellors (Foster et al., 2014, Horn et al., 2016). Future research should consider ways that the professions could collaborate in the early days of post-stroke recovery in order to improve client care. Future research could also investigate the strategies that clinicians from different specializations have found most effective in working with stroke survivors in order to create a common base of interventions from which to choose. This might also have broader implications for other populations who face similar challenges in areas of communication and disenfranchised grief.

There are currently two separate streams of research focusing on, respectively, the experience of ambiguous loss for loved ones of ABI survivors and the experiences of disenfranchised grief for survivors of stroke. There is potential gain in combining the studies of ambiguous loss and disenfranchised grief in relation to ABI. There is some overlap, but the separate bodies of research could expand understanding in both areas. For example, research on the effect of ambiguous loss on the family of ABI survivors could be expanded to encompass the reciprocal effects on the survivor. Individual case studies are needed that seek to understand both perspectives.

Recommendations for Practice

Education and Awareness

For counsellors working with stroke survivors and their loved ones, there are multiple factors to consider, beginning with the physiological effects of a stroke and the complexity of stroke recovery (Foster et al., 2014). Counsellors working with stroke survivors can be educated about the physical and mental effects of the stroke on each client in order to then assess their psychological needs. The client, their family members, and their caregivers should also be informed of the stroke effects on the stroke survivor; the counsellor can begin with psycho-education about brain injuries and their effects. Assessment tools can be used to provide feedback to clients, which can help them to understand the cerebral changes that have resulted from their stroke (Coetzer, 2004).

There is often a lack of self-awareness in the stroke survivor, brought on by cognitive effects of the stroke, that prevents the client from being able to comprehend the changes they have undergone (Coetzer, 2004). Depending on the level of self-awareness, it may be necessary to educate the client about problems of self-awareness in order to facilitate an understanding of their challenges. Self-awareness is seen as the first stage for intervention and precedes the stage of acceptance (Coetzer, 2004). Increased self-awareness may in turn result in emotional relief and better comprehension of the effects of their stroke, however, the potential for increased emotional problems, including depression, may follow an increase in awareness (Coetzer, 2004). Acceptance may be difficult for the stroke survivor as they will need to stop mourning their losses and to make meaning of them (Coetzer, 2004).

Disenfranchised Grief

Empathic support should follow when disenfranchised grief has been identified in a client (Mortell, 2015). Through active listening and assessment, the counsellor can help a client break down the who, where, what, and why of their disenfranchised grief. They may assist the stroke survivor in analyzing the factors that might inhibit their expression of grief, for example inquiring about where in the system there exists a failure of empathy or who contributes to an empathic disconnect (Mortell, 2015). Questions regarding which aspect of a client's loss or reactions feel disenfranchised and at what point in the time period the disenfranchisement was felt can illuminate a shared understanding between the client and the counsellor (Mortell, 2015).

Self-Conversation

Grief is a complex experience, and the stroke survivor may have many confounding perspectives and thoughts when dealing with grief. Having a conversation with different aspects of themselves can provide a more focused awareness of their feelings and thoughts. (Mortell, 2015). With this in mind, the Gestalt empty chair technique may be a helpful intervention for allowing the stroke survivor to articulate their isolated or suppressed selves and to create a dialogue among them (Mortell, 2015). The empty chair dialogue can also be used to build a bridge between suppressed elements of the self and the loss narrative (Mortell, 2015). The counsellor can facilitate these dialogues and assist in creating an integrated narrative or map of the stroke survivor's selves in relation to loss.

Expressive Arts

When traditional communication is difficult due to aphasia, expressive arts are suggested as a helpful strategy for counsellors to employ for clients with disenfranchised grief to communicate their feelings (Horn et al., 2016). Having a visual reference point in the form of an artistic medium facilitates understanding of the many losses that are felt, including those that are not assumed or expected (Horn et al., 2016). For example, a client may create a collage of losses from words and pictures representing the losses the client has experienced (Horn et al., 2016). Clients may need assistance in gathering images, cutting and pasting, or in creating a virtual collage online (Horn et al., 2016). When the collage is finished it can be used as a reference point for processing and acknowledging their losses, even if only within the counselling relationship (Horn et al., 2016).

Another expressive approach is the creation of a visual life story PowerPoint using clients' photos, accompanied by their thoughts and feelings, as a tool for giving voice to their previous and current identities (Horn et al., 2016). Other tools for non-verbal expression include sand trays, colour, musical playlists, and memory scrapbooks (Horn et al., 2016). The counsellor needs to learn the client's abilities and interests in order to best choose an appropriate method (Horn et al., 2016). Utilizing expressive therapy approaches allows stroke survivors with physical or cognitive communication challenges to convey feelings of disenfranchised grief that may help with the processing of that grief.

Ritual

Rituals can help a bereaved person work through integrating loss with continued living and can solidify the experience of loss as something real (Mortell, 2015). For example, a funeral creates an event in time and space that identifies and characterizes a loss and is usually accompanied by some type of artifact. Disenfranchised loss, such as that experienced by the stroke survivor, is often surrounded by shame and secrecy, so a ritual is not usually socially sanctioned, yet the lack of public support and acknowledgement that ritual provides can make it more difficult to process a loss (Mortell, 2015). The importance of ritual is therefore a valuable subject to address when responding to disenfranchised grief in a stroke survivor. Alternative or belated rituals can be useful interventions for those who feel excluded from mourning their loss (Doka, 1989). The client should be involved in the process of designing the ritual and be aided in processing their feelings afterwards (Mortell, 2015; Doka, 1989). For example, a stroke survivor may wish to acknowledge the loss of some aspect of their identity by performing a symbolic action in a performative way (Horn et al., 2016). One individual chose to clash cymbals because she felt invisible after her stroke whereas before she was someone who commanded attention (Horn et al., 2016). There are no limitations on the possible types of rituals that can be performed; it is a collaborative process between the counsellor and the stroke survivor.

Support Groups

The concept of oppression can be a useful analogy to that of disenfranchised grief (Mortell, 2015). Oppression can similarly lead to alienation from one's culture, social support, and personal identity. It can also inhibit a person's ability to take part in certain cultural activities such as rituals that can help in the healing process after a loss (Mortell, 2015). Grieving can be seen as an act of liberation when disenfranchised grief is viewed as a form of oppression; individuals can find freedom in giving themselves permission to grieve in spite of social invalidation (Mortell, 2015). Bringing oppressed people together, in this case grieving stroke survivors, to share similar experiences can help facilitate psychological healing and may help break the feeling of isolation that can come with oppression. Support groups that connect a client to others with similar losses can therefore help those who are experiencing disenfranchised grief. (Mortell, 2015).

Participation in a support group may help prevent individuals from moving into the despair, shame and self-hatred that can grow when one is part of a disenfranchised group (Mortell, 2015). Facilitation of emotional expression, exploration of the impact of grief on their lives, and validation of their losses can all be facilitated by a group leader who is educated in the grief process (Mortell, 2015). Relationships can develop within a group; listening and providing suggestions for others can also increase feelings of self-esteem (Mortell, 2015). Online communities of stroke survivors, initiated by a counsellor, can also play a vital role in group support (Bellet et al., 2018). The goal of the support group is to validate, educate and encourage emotional expression (Mortell, 2015).

Role Concept and Collaborative Care

Role concept for counsellors should be considered in shaping practices for working with stroke survivors as well as with MDHCWs in a post-stroke care setting (Foster et al., 2014; Simmons-Mackie & Damico, 2011; Stroyde, 2019). Role concept is both personally and socially mediated, influenced both by the counsellor's personal clinical experiences and by cultural expectations of the role (Foster et al., 2014; Stroyde, 2019). Work culture is the medium through which the clinician's understanding of work attitudes, practices, and behaviour is shaped and learned, and it plays a significant role in forming role identity (Foster et al., 2014). A feeling of solidarity with others in the same or a similar role can act as an inspiration for implementing change in intervention models, but it can also influence the perpetuation of poor practices by limiting the possibilities of the professional role (Foster et al., 2014). The counselling psychologist needs to take responsibility for ensuring that their skill level is adequate even if there is an unspoken laxity for this area of practice in the counselling culture. For instance, if attrition of skill level in treating the psychological needs of persons with aphasia is accepted within the professional culture of counsellors, there may be implicit permission for the individual to allow their skill level to decline (Foster et al., 2014).

Counsellors can take a stand against complacency and identify cultural and educational prejudices about stroke treatment in relation to communication, grief and stigma, and construct a strategy for incorporating new knowledge as it becomes available (Foster et al., 2014). The counselling psychologist can also play a leadership role with MDHCWs, who are more often called on early in the recovery process (Stroyde, 2019). Providing training to improve their psychological skills and knowledge, as well as consistent support and consultation, will benefit the patient’s psychological recovery needs as well as the MDHCWs' sense of confidence in their healthcare roles (Stroyde, 2019).

Reflexive Self-Statement

This research has proven both painful and valuable for my own grief process since my mother's death in December 2019. Because she suffered from stroke-related disabilities, this research has consistently kept her memory in the forefront of my mind. Sometimes the memories were unwelcome, as they brought forth emotions that made it difficult to focus on the work of research and writing. It has given me greater understanding of what my mother may have been experiencing in the last five years of her life, but it has also brought feelings of regret and guilt. It is hard to have this knowledge now when it is too late to help her, and I can only speculate on how I might have attained a better understanding of what she was going through. I wish that she had received better care through her recovery process, especially in the area of emotional care. Beyond a prescription for anti-depressants there was little recognition of her emotional needs and no acknowledgment of the potential for disenfranchised grief.

I am aware that my inclination is to see a strong connection between PSD and disenfranchised grief, therefore I have tried to question my responses to research that did not confirm my assumptions. A key point in that regard is the lack of evidence linking PSD to reduced recovery in the short term. I was challenged to accept that research but the results seemed conclusive, and I accepted it even as it conflicted with my hypothesis. I feel strongly that this line of research is crucial for a better outcome for stroke survivors. I still must concede that I may have been unable to completely override my bias in ways of which I was not aware.

The concept of disenfranchised grief has also been a revelation to me in relation to many other aspects of life, first as a concept that can be integrated into my conceptualization of my own life and also as a concept that can be useful to me in my role as a counsellor. I have since utilized the concept of disenfranchised grief when counselling two separate clients. They were grieving losses related to, respectively, a death from substance use disorder and the estrangement of grown children. In both cases the clients' grief carried elements of disenfranchisement; merely recognizing that factor was helpful for their therapeutic process.

Several other of these research concepts have piqued my intellectual curiosity. The expansion of the concept of disenfranchised grief to encompass concepts of oppression in relation to power and social sanction opens further avenues of understanding in other areas of mental health. The power of social forces to determine the validity or importance of an identified group may be under-recognized but it is evident in the way that public concern and subsequently public dollars are allotted.

Stigma related to mental health challenges is something I feel strongly about and the discussion of stigma surrounding post-stroke depression and disenfranchised grief also opened further considerations for me. It brought up questions of power once again and the irony of closed social groups in the culture of professional practice. In my own professional counselling education, I have observed attitudes that perpetuate stigma towards certain areas of mental illness. This is where those attitudes are learned and endorsed, which means they will likely be continued in the professional working culture.

This research has also validated my mother's negative experiences with the post-stroke rehabilitation process during which I observed systemic challenges in relation to clinicians' weak expertise and prioritizing of physical disability over emotional needs. There was also a lack of incorporating the client's knowledge of self. For instance, in the case of testing of cognitive weakness that does not take into account the pre-stroke identity, I was reminded of an assessment that was not individualized, as recommended in the research literature. Another familiar situation that came up in the research was seeing the client as their disability rather than as a person. The general theme of creating an individual approach geared to the specific needs of each client, which was present through much of the research literature, reminded me of the superficial and formulaic approach that I witnessed throughout my mother's rehabilitation process.

Overall, this has been a fulfilling line of research to pursue as it expanded my knowledge and understanding of important areas related to counselling that I will be able to apply professionally. As well, it has helped me to better conceive of and process my own grief from past experiences.

Conclusion

With stroke the leading cause of long-term disability in the world, the likelihood of stroke highest in an older population, and a growing percentage of seniors in Canada's population (Starkstein & Hayhow, 2019), further research on stroke-related topics is of on-going importance. PSD is a common outcome for stroke survivors, with a 30% prevalence, yet there is no clearly effective approach for evaluating, treating, or resolving it (Ayerbe et al., 2014; Khedr et al., 2020; Krueger et al., 2015; Saikaley et al., 2018, Vahid-Ansari et al., 2018). The presence of PSD has a significant long-term impact on stroke recovery, quality of life, and mortality but it is often missed as it is difficult to diagnose in stroke survivors due to stroke-related disabilities and cognitive deficits (Dar et al., 2017; White et al., 2014). Therefore, assessment for PSD requires individualized approaches and experienced clinicians but often those resources are not available (Dar et al., 2017).

The onset of PSD is related to the abrupt and unforeseen physical and cognitive changes that often accompany a stroke (Hughes & Cummings, 2020). These changes often result in feelings of loss and grief that are rarely attended to during the post-stroke rehabilitation period, which focuses primarily on physical and cognitive function (Hughes & Cummings, 2020). Lack of acknowledgment of grief and loss results in disenfranchised grief and creates an inability to process and resolve feelings of grief (Doka, 1989; Horn et al., 2016; Knight & Gitterman, 2019). Thus, the sudden changes resulting from a stroke, coupled with a disenfranchisement of the grief feelings that follow those changes, often produce PSD in stroke survivors (Horn et al., 2016). Disenfranchised grief is best understood as an outcome of social rules that govern our grieving processes and our ability to make meaning of our grief ((Doka, 1989). In order for the stroke survivor to process their grief it must first be recognized and then be given an outlet for mourning (Horn et al., 2016). A bereavement model can be useful for understanding post-stroke grief responses (Hughes & Cummings, 2020). It is also useful to look at the broader category of ABI and its relation to ambiguous loss from the perspectives of the loved ones and caregivers (Karpa et al., 2020). Research on ABI and ambiguous loss is separate from that of stroke survivors and disenfranchised grief, but it would be helpful going forward to consolidate the two streams of research in order to create a broader theoretical approach that combines the experiences of both the survivor, and their family and friends. Further research is needed in many other areas related to PSD and disenfranchised grief.

The implications for counselling are numerous. Factors to consider include the prevalence of PSD and its impact on post-stroke life, the difficulties of assessing PSD, the possibility of disenfranchised grief as a source of PSD, and the consideration of a bereavement model for counselling PSD. The comparison of professional roles between the SLP and the counsellor produce important considerations for a general approach to counselling stroke survivors. Suggestions for effective interventions include those related to self-identity, increased social support, psycho education and expressive arts. These are not thoroughly researched but merit much more investigation. By understanding more about these factors, researchers and clinicians can more effectively develop interventions and successfully treat those suffering from PSD related to disenfranchised grief.

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