

The Power of Memoirs on the Journey Toward Recovery

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People share and listen to stories of illness, trauma, and recovery as a powerful source of healing. Memoirs reflect the intimate, emotional, and personal insights of the wounded storyteller based on their experience of illness and recovery, for sharing with others. Because memoirs are in written form, they also offer the opportunity for readers to learn from them in perpetuity. The present study examines the content of memoirs based on experiences of survivors of stroke, the majority of whom also have aphasia, a stroke-induced communication disorder. Over fifty memoirs of survivors of stroke were assembled for analysis, representing authors from twelve different nationalities, with balanced proportions of male and female authors. A set of representative quotes and content extracted from the memoirs illustrate three main themes. One theme was the threat to one's identity following the traumatic onset of stroke and aphasia, and how one rises to that challenge. A second theme was how to achieve acceptance, including acceptance of one's new life and post-stroke identity. A third theme centered on gratitude for survival and providing lessons for others on how one can cope and recover, as one expression of that gratitude. Findings hold implications for the potential universality of healing themes of identity reformulation, acceptance, and gratitude—across time, cultures, and genders—among survivors of illness and trauma.

Keywords: aphasia; identity; memoirs; recovery; stroke

Health threats, brushes with mortality, and forced interpersonal disconnection are traumas common to all of us as members of the human race. When we look back to recount these events, how are they expressed? Who receives and understands the stories we share about the traumas we have endured and the path that we followed as we sought to recover from them? And what are the words of wisdom that we share, based on our experiences during the journey toward recovery? We as humans both share and listen to stories as a powerful source of healing.

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The first author and her colleagues have examined oral and written accounts of personal experiences of survivors of different types of traumas as a window into the post-traumatic healing process. Survivors of World War II concentration camps from a variety of European cultures expressed stories of their war experiences and the process of healing and forgiveness (Ulatowska, 2013). American Veterans of World War II also recounted stories of their own war experiences, highlighting the collaborative war effort and the healing value of hard work (Ulatowska, Santos, & Walsh, 2018). Survivors of stroke, many of whom were living with an associated communication disorder called *aphasia*, have also shared oral stories of their post-traumatic life journey on the road toward recovery; the narrators in these studies have included representatives of populations of Black Americans, White Americans, Hispanic Americans, Asian Indians, Filipinos, and Poles (Armstrong & Ulatowska, 2007; Ulatowska, 2008). Representation of a range of cultures holds potential to highlight differences between cultures in their voyage through and beyond personal trauma and illness. On the other hand, cross-cultural sampling may also allow us to discern commonalities across cultures that reflect our common humanity during the post-traumatic life journey.

Some post-traumatic stories are expressed verbally or in art, while others are expressed in writing. For the present study, we extend these previous lines of research by the first author and her colleagues on personal narratives as told by survivors of stroke who have aphasia. Likewise, we sample these narratives from a variety of different cultures. However, in this phase of the research, we examine and consider *published written narratives* of members of this population, as opposed to their oral

narratives. This focus on published written narratives of illness potentially captures a unique set of perspectives on personal accounts of illness that may not be otherwise highlighted through oral accounts of illness. As noted by Frank (1995/1997), most published illness stories are *quest narratives* (p. 115). In quest narratives, the interruption of the illness in the author's life is reframed as a "challenge" or an "opening" that requires the person to rise to the occasion, to be "more" than they have been in the past; the purpose of the quest is "becoming one who has risen to that occasion" (p. 128). One expression of this 'rising to the occasion or challenge' may include accounts of the *lessons that one has learned* about how they personally have coped with and managed the experience as they proceed through life. Lessons that one has learned may be expressed either explicitly, e.g., as lists of lessons, or implicitly through descriptions of the actions and activities of the narrator that promoted their post-traumatic growth and recovery.

In the present study, we focus specifically on the potential prominence of quest in written accounts by sampling only those published accounts that represent the literary genre of *memoir*. Memoir as a genre of personal narration focuses on a specific important portion of the author's life. It reflects the writer's intimate, emotional, and personal insights regarding that portion of their life, which they choose to share with others through their writing. That important portion of the life of each author, for the current work, is the traumatic onset of their stroke and the subsequent journey of the author following this life-changing event.

An additional advantage of drawing insights from the body of written personal narratives, as opposed to oral personal narratives, is that the majority of these authors who have survived the trauma of the onset of stroke have also experienced the trauma of the onset of aphasia. Aphasia is a communication disorder, typically caused by stroke, that impairs language functions. Any communication that involves one's language, such as speaking and understanding spoken language, or writing and reading language, may be potentially negatively impacted by aphasia. Although the severity of aphasia may sometimes decrease—with time, spontaneous healing, and rehabilitation—aphasic impairments are often chronic and typically last a lifetime. The fact that these memoirs are in a written modality affords each writer time and opportunity to write, read, revise, and re-write, and thus to tailor expression of their deep reflections. Even more importantly, for the writer with aphasia specifically, it affords the essential window of opportunity to seek out linguistic solutions for expressing one's reflections, despite the presence of a language disorder. The tragic irony is that the trauma of the onset of stroke may be layered with yet another trauma: the trauma of the onset of aphasia. The aphasic trauma may impair even the writing of the memoir itself. As one stroke survivor with aphasia writes, "This does put me in a strange position as the author here. I use language [writing] to describe a lack of it..." (Marks, 2017, p. ix). Thus, when we read these memoirs, we can anticipate that the authors will reflect on both the

trauma of stroke and the trauma of the onset of aphasia in their journey toward recovery.

The healing power of written memoirs which follows the combined trauma of stroke onset and aphasia, written even despite the presence of chronic aphasia, is illustrated in the following excerpt. The importance of this excerpt as a catalyst for the current study cannot be underestimated. It is taken from a memoir that served as the portal for the first author to enter into these lines of research on written expression of survivors of stroke who have aphasia. The memoir was written by a rural East Texan, MD, aged 60, who acquired aphasia following stroke. MD had decided that written language was preferable to oral language for expression of his stories, and his stated desire was to leave a legacy before he died, in the form of a memoir. He died within a year after completing it. Note how he coherently reflects on his life, despite his language difficulties.

I know I was gonna be sick someday. I know it. Maybe it was for dreams I did have...Anyway I did do cripple. Yeah, I did sick, it was my head. Ha. I guess I had it for sixty years, but I had some fun...It is to laugh. I have I am still for fun...It is to laugh. I have I am still for fun because I am still alive... (Armstrong & Ulatowska, 2007, p. 204)

Yet another advantage of memoirs is that they afford the readers the opportunity to receive and process the writings in perpetuity, since they offer the opportunity for the initial read and unlimited subsequent re-reads. As noted by Frank (1995/1997), "(p)eople tell stories not just to work out their own changing identities, but also to guide others who will follow them" (p. 17).

Thus, one of the main functions of memoirs as a literary genre is to share one's reflections and insights with others, as a gift of support in the personal journey of each reader. An issue that is commonly tackled by survivors of stroke who have aphasia is the threat to their *identity*; aphasia has been conceptualized as a form of identity theft (Meyerson & Zuckerman, 2019; Shadden, 2005). One's identity may be shaped through the very process of narration, as noted by Oliver Sacks:

To be ourselves we must have ourselves—possess, if need be, repossess, our life-stories. We must 'recollect' ourselves, recollect the inner drama, the narrative, or ourselves. A man needs such a narrative, a continuous inner narrative, to maintain his identity, his self (Sacks, 1970/1990, p. 111).

As the person grapples with threats to their former identity and the emergence of a new post-traumatic identity with aphasia, wisdom in the form of *acceptance* may emerge. Thus, given the very purpose of memoirs to convey one's reflections and insights to others, themes of identity and acceptance may be anticipated in the memoirs of stroke survivors, conveyed explicitly in the form of lists of lessons to the readership or implicitly in the writer's

account of how they rose to these post-traumatic challenges.

Finally, it is important to remember that stroke as a critical illness represents a brush with one's mortality. A core emotion expressed by authors who survive critical illness is gratitude for survival. Expressions of that gratitude may include a desire to give back to others who are going through the same experience; survivors share the lessons they have learned as a way to smoothen the path for those who have similar experiences in the future.

In summary, the responsibility of the narrator to guide recipients of the narrative may be a core responsibility of all humankind, a responsibility that transcends cultural boundaries, just as the traumatic nature of the onset of stroke and accompanying aphasia may know no cultural boundaries. Among survivors of stroke with aphasia, core themes of *identity*, *acceptance*, and *gratitude* may be anticipated and reflected through memoirs. In the current study, we examine quotes derived from a cross-cultural sample of memoirs of survivors of stroke, to tap into this shared human potential for post-traumatic healing through storytelling.

Method

Sample

Memoirs. Within an assembled set of internationally published accounts of strokes, a set of over 50 accounts have been identified as memoirs to date.¹ A memoir is a written set of personal narratives that reflect on experiences from the author's life. Specifically, the memoirs in the current data set focus on the recovery period after stroke and the onset of aphasia. To qualify for consideration in the present study, each memoir needed to be written or translated into one of the native languages of members of the research team: English, Polish, Italian, or Spanish. Most of the memoirs are in English, and there are five in Polish, five in Italian, and one in Spanish.

Authors. Of the authors of the memoirs, all had survived stroke. The majority of them also had aphasia. Of those whose age could be calculated, the majority were middle-aged. Comparable numbers of male and female authors are represented in the sample. Most authors had achieved a level of education that was relatively high (college degrees, professional degrees), consistent with their status as authors. National affiliations of the authors in the sample include the United States (approximately 20 people); Great Britain, Italy, Poland, Australia, and the Philippines (four to five people each); and India, France, Spain, New Zealand, Russia, and Sweden (each single instances).

Analysis

The analysis description is intended to give the reader a general account of our approach. A reading, discussion, and consensus process was used among the research team members. We identified instances in which the author encountered a challenge and described how they rose to that challenge. More specifically, we examined all memoirs for instances of lessons that the authors had learned about life following the traumatic onset of stroke. Both explicit and implicit expression of learned lessons were considered. These instances were then thematically organized. Key illustrative quotes that exemplified each of these themes were identified.

Findings

Analysis of the memoirs yielded multiple instances of quotes and content that illustrated how the authors rose to post-traumatic challenges. The challenges include threats to identity. Achievements that help them rise to the challenges include acceptance of their new life and identity; and feelings of gratitude for survival, as a motivation to give back to others. Both explicit and implicit expressions of what they learned during their post-traumatic journey were considered. A set of representative quotes and content extracted from the memoirs is provided.

Rising to the Challenge of Shifts in One's Identity

Encouraging words of wisdom from an American stroke survivor with aphasia emphasize that one's identity cannot be stolen:

Our identity is not a static thing. It cannot be taken from us, nor can we throw it away...for those of us lucky enough to be survivors, stroke does not steal our future or who we get to become next (Meyerson & Zuckerman, 2019, p. 225).

Acceptance of shifts in identity is essential following stroke, as noted by one American stroke survivor and neuroscientist with aphasia: "I believe he [Einstein] got it right when he said, 'I must be willing to give up what I am in order to become what I will be'" (Taylor, 2009, p. 185). In parallel, strong adherence to one's core values and cultural identity may also tide one through. Polish writer, Zofia Zinserling, writes of her strong sense of independence—a core cultural value in her native Poland—as a support to her in her post-stroke journey: "My independence, strength in achieving a goal and consistency helped me, and I became an active retired woman" (Zinserling, 2021, p. 2). One Filipino man made a career shift after his stroke to enter the priesthood,

¹ The size of the set of all published works of stroke is augmented regularly, as new works are found, as is the size of the set of memoirs.

reflecting a collectivistic emphasis on faith and in his culture (Anonymous). Many of the writers commented on acceptance of shifts in their identity, and a renewed perspective on what is important in life. For example, an Australian pediatrician and professional author, completed and published a second edition of a book as his final professional gesture, and then he moved away from career activities, commenting: “After everything that I have been through, this edition [of his book] shows a much gentler Christopher Green. I am now aware of what is really important in life, for children, parents, and myself” (Green & Waks, 2008, p. 130). Likewise, the Italian oncology physician and researcher, Gianni Bonnadonna, founded a cancer treatment foundation after his stroke and the onset of aphasia; he commented that finding new ways to continue to help others was the best way to feel alive (Bonnadonna, 2005).

Achieving Acceptance

Acceptance is sometimes expressed as release of control of one’s situation to God and spirituality. For example, Sandra Hiakita, a New Zealand Māori survivor of stroke states, “Only God knows what is up ahead for me, my times are in his hands” (2021, p. 59). Gianni Bonnadonna, the previously mentioned Italian medical researcher, reflects on the support that his faith provides after his stroke. Ruth Codier Resch, an American stroke survivor with aphasia, describes how being in nature and practice of meditation guide her, in her chapter entitled “Road of Survival” (Resch, 2012).

Accepting and rising to the challenge is accomplished in different ways by different authors. For example, Australian native, David Roland, a former forensic psychologist, writes, “My intention is to continue with writing, public speaking, and advocacy for mental-health and disability issues. Oh, and with drinking coffee, playing music, being a father, swimming — and investigating my brain” (Roland, 2015, p. 277). Contacts with doctors, neuroscientists, yoga teachers, musicians, and a Buddhist nun supported him in his journey. For Jill Bolte Taylor, her achievement of this acceptance is built on a sense of optimism, as she writes, “For a successful recovery it was important we focus on my ability, not my disability” (Taylor, 2009, p. 123). Debra Meyerson, an American professor and sociologist, provides optimistic words of advice when she realizes that she will not be returning to work at the university: “Look forward, not back,” “Focus on deeper values” and “Seek opportunities for growth” (Meyerson & Zuckerman, 2019, pp. 44-55).

Some survivors focus on hard work following their stroke. For example, American psychologist and academic, Charles Dahlberg, develops strategies to continue his university teaching (Dahlberg & Jaffe, 1977). As another example, Debra Meyerson works assiduously to write her book, interview other stroke survivors, and establish an advocacy organization for stroke survivors (Meyerson & Zuckerman, 2019). Likewise, Paul West, a

British writer and man of letters, comments on the importance of perseverance in his recovery of his life following the onset of aphasia: “...not wanting to overstep myself but never wanting to go a day without any noticeable improvement in the matrix.” He emphasizes the importance of maintaining hope as he chose to bravely persevere, despite the risk of failure: “Of course, things may not have got better no matter how long you waited, but that is the epic chance you take in almost all of life’s heroic adventures” (West, 2008, p. 155). Others find healing in solitary enjoyment of art and nature (Resch, 2012). Still others, such as the American Jewish grandfather, Donald Weinstein, find joy and healing in time with extended family (Weinstein, 2008).

Many authors address the importance of psychosocial support from those around them, as well. For example, Helen Harlan Wulf, an American sociologist, business-woman and advocate for people who have aphasia writes “Truly, an aphasic need to be surrounded by optimism and confidence and by the compassion which gives him that stabilizing sense of his own worth” (Wulf, 1979, p. 162). Jennifer Gordon comments on the strong impact that words of her doctor had on her in fostering hope for her long-term recovery: “...he told me, ‘We must not underestimate the long-term ability of the human brain to recover.’ And I believed him” (Gordon, 1994, p. 163).

Gratitude and Giving Back

More than one writer comments on their brush with mortality when they had their stroke, which re-focused them on what is important in life. For example, David McCrum, from Great Britain, writes, “I have learned, in short, that I am not immortal (the fantasy of youth) and yet, strangely, in the process I have been renewed in my understanding of family and, finally, of the only thing that really matters: love” (McCrumb, 1999, p. xxiii). The sense of gratitude for survival leads these writers to give back to others, through their memoirs. Kirk Douglas, a stroke survivor and American actor, comments on how he moved past his depression, “I found the one thing that took me out of myself, out of my sadness, out of my fear, and out of my darkness: helping others. It gave me hope and courage” (Douglas, 2002, p. 35). Debra Meyerson, an American university professor and academic, writes “I hoped that by bringing both my own experiences, as well as those from a diverse group of survivors... I could write a book that might support all survivors in some meaningful way” (Meyerson & Zuckerman, 2019, p. 235). This giving back, in gratitude for survival, is an affirmation of life, as noted by Arthur Josephs: “Stroke survivors affirm life when they discover the pleasure of feeling loving concern for others. It begins and ends with survival. Start with making yours meaningful, then take on the world” (Josephs, 1992, p. 117).

Discussion

The healing power of storytelling is a gift to both the writer and the reader, as they move through and past life's trauma. Through these memoirs, these writers are giving of themselves, gifting others with the experiences they recount and the lessons that they have learned in the journey. Several of them comment that they are writing the kind of book for others that they themselves wish they had had access to, at the time of their own stroke.

For many of them, the use of language in these writings is an extra challenge, because they have a language disorder. Many of them are written painstakingly, over a long period of time; post hoc analysis reveals that they typically finish their books several years after the onset of the trauma. One New Zealand Māori native writes her memoir at the end of her life, decades after she survived a stroke as a young mother (Hiakita, 2021). Yet they persevere in passing along the lessons they have learned in their journeys, as a form of wisdom and a testimony. Out of gratitude for survival, they are compelled to give the gift of lessons to others. Out of the millions of people worldwide who survive stroke and live with aphasia, these select few have provided a special gift that will go on giving over time and may give voice to the experiences of others who are on parallel journeys. The authors describe their process of physical, psychological, and emotional healing, a healing not only through telling their stories for themselves but also in knowing their stories would be read by others.

Although these are stories of survival of stroke and recovery following post-stroke trauma, the lessons these authors share may apply to traumas other than stroke and aphasia. Extension of this analysis may reveal how the lessons shared by these authors may apply to survival and recovery following trauma of other illnesses, the trauma of war, or the trauma of the pandemic. There may also be a universality to the lessons that span time, cultures, and gender. We benefit in this analysis from a cross-cultural sample, drawn from a variety of historical eras, with representation of both male and female authors. Many of the authors are at a later life stage when they realize that their remaining time may be limited, so there is an urgency to telling their stories before they die. Themes of identity, acceptance, and gratitude are pervasive across a wide variety of sampled memoirs.

Yet, there may be restrictions on the universality of application. These memoirs, by their very nature, share what may be otherwise private. There may be some cultures untapped by the current study, for which writing of such private affairs would be culturally inappropriate. Also, there may be gender differences in the journey toward recovery, which we plan to investigate. We wonder where other venues for sharing of healing stories, beyond written memoirs, may be found.

The path to recovery is not only one of physical health, but also mental and emotional health and the health that comes from connection with others – the gift of sharing

one's human vulnerability and the healing power of storytelling in all its richness. As noted by Arthur Frank, "The mutual responsibilities of the ill to express and the healthy to hear meet in the recognition that our creativity depends on our frailty" (1991/2002, p. 128).

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