

Illness Narratives: The Carer Memoir

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In 1998, actor Michael J. Fox announced that he was suffering from Parkinson's disease. Fox also went on to write two memoirs that included details of his experience with the illness. When Fox opened up about his diagnosis, he became the public face of Parkinson's. I'm glad he did because when my husband, Steve, was diagnosed with Parkinson's disease in 2001, Fox became my point of reference. As we struggled with this devastating diagnosis and an uncertain future, Fox became a symbol of hope – not only because of his dedication to finding a cure, but also because he was proof that it was possible to cope with Parkinson's and continue living a worthwhile life. His dialogue with the public enabled fellow sufferers to be more open about their own experiences. It also educated and informed people all over the world. Fox gave Parkinson's a profile that helped raise awareness of the disease.

Fox's admission reflects a trend that has been evolving over recent decades – that of sharing personal experiences of illness through narrative. Memoirs about illness, or pathographies as they are also known, are part of a rapidly growing field. Some are written by the patient, others by a close family member. I fall into the latter category. I am now Steve's carer and I am writing a memoir about our shared experience with his illness.

Parkinson's disease is a progressive and degenerative neurological condition. I originally turned to carer memoirs because I wanted to know how other patients and their families coped with this type of life-changing illness. I found that reading these stories also helped reduce the isolation of the carer experience. With a view to writing my own carer memoir, and of studying the genre, I began reading these texts more closely. The creative process would reflect my individual experience – a highly subjective perspective influenced by my role as wife and carer. But in order to craft my narrative and present an engaging and meaningful story, I would also need an objective approach. I began examining the literary techniques authors use – specifically how narrative structure, figurative language and mode of enunciation convey the illness experience. Although my reading of these texts includes narratives by patients, my focus is on carer memoirs and the particular issues faced by writing about a sick loved one.

Bearing Witness

Carer memoirs are a hybrid form that bridges autobiography and biography. In these texts the lines between the genres are blurred because the focus keeps shifting between the biographical account of the patient's illness, and the writer's response of bearing witness to a loved one's suffering. Anne Hunsaker Hawkins suggests that carer memoirs “override the conventional boundaries of self and other or biographer and subject” because unlike traditional biographies written from a “disinterested perspective”, these works stem from close family relationships (3). John Wiltshire also claims that “accounts by relatives and bystanders are [even] richer” than accounts by patients because “the narrative is as much about the self that is implicated, or discovered through the history of the other, as it is about the other person, the patient” (410).

However, the ethical dimension of writing about a sick loved one is a primary concern for carers and this issue is particularly significant if the patient is suffering from cognitive loss. While the carer may readily expose his/her own strengths and weaknesses, the vulnerability of the patient means that sensitive handling of private matters is required. Although carer narratives are almost always based on loving and respectful relationships, the possibility that an author may appropriate the patient's story for personal gain needs consideration. As Lisa Diedrich points out, “The relationship between caregiver and the person cared for is often hierarchal and dichotomous” (116).

Yet overwhelmingly these stories pay tribute to the patient while providing a telling account of the burden placed on carers. Arthur Kleinman states that there is, as yet, no medical or sociological theory of caregiving mainly because “caregiving is largely an affair of family, friends, and the sick or disabled themselves” (596). Indeed, there has been little recognition of the impact of serious illness on family carers. Carer stories are needed to fill in the gaps and deficiencies that currently exist in this area of study. I hope that my creative work will contribute to a subject that clearly needs more attention.

The close relationship between patient and carer lies at the core of carer memoirs. In fact, as much attention is often directed towards this bond as is given to the facts of the illness. As Lucy Bregman and Sara Thiermann point out, “What interests the readers is not the medical details of the illness, but the struggle of human beings to suffer it, including how their relationships are transformed or renewed by the struggle” (107). John Wiltshire also suggests that illness narratives, “give as much, if not more, attention to a sick person’s relatives; they are about illness within its familial and marital setting, and often about that family’s or care-giver’s acquaintance with grief” (409).

Narrative and Identity

Why do people write about their illness experiences? Why write about pain and suffering, grief and loss? Arthur Frank argues that ill people “need to become storytellers in order to recover the voices that illness and its treatment often take away”(xii). Serious illness or the demands of the carer role disrupts lives and narrative is one way of restoring coherence and making sense of the whole experience. Serious illness, especially chronic illness, also disrupts a person’s sense of self. Lars Christer Hydén says that “Chronic illness alters the relationship between the patient’s body, self, and surrounding world” (51). As Bregman and Thiermann also add, “The experience of extended caretaking is as isolating and disrupting to one’s sense of normality as being sick can be” (64).

Cheryl Mattingly and Linda Garro say that “Narrative is a fundamental human way of giving meaning to experience” (1). This statement resonates with my own experience as carer. Through my creative work, I have been able to revisit events, dissect them, compartmentalise them, structure them, and develop a greater understanding of them. Illness often compromises autonomy and choice, but writing is a way of regaining control, of feeling empowered. Initially I feared that reliving difficult and distressing times would negatively affect the writing experience. Instead, I have found that writing creatively is a positive process that validates and highlights this significant time in my life.

Why do people read illness narratives? What can be gained from reading stories that discuss confronting and depressing themes? Illness narratives are beneficial to patients and their families because they share knowledge and experience. These narratives are relevant to the wider community as well because they help raise awareness and foster a greater understanding of what it means to live with serious illness. Illness narratives are also an important resource to healthcare professionals. Rita Charon, who has written extensively on the field of narrative medicine, says:

Teachers of literature, novelists, storytellers, and patients who have written about their illnesses have become collaborators at our medical centres in teaching health professionals the skills needed to listen to narratives of illness, to understand what they mean, to attain rich and accurate interpretations of these stories, and to grasp the plights of patients in all their complexity (3).

Narrative Form

Frank classifies illness texts into three types: restitution, chaos and quest narratives. He suggests that most illness narratives fall into one or more of these categories and that many are in fact a combination of all three (76). Illness stories tend to follow general storylines and plots.

1. The restitution narrative. "The plot of the restitution has the same basic storyline: 'yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again'" (Frank 77).
2. The chaos narrative. "Chaos is the opposite of restitution: its plot imagines life never getting any better" (Frank 97).
3. The quest narrative. "Illness is the occasion of a journey that becomes a quest" (Frank 115).

I want to suggest a refinement of Frank's typology that takes into account, not just the narrative mode, but also the character of the illness represented. It is useful to note how these narratives differ, what sets them apart and how the terms of the illness affect the portrayal of the experience.

Acute illnesses (cancer, for example) often follow the restitution or quest plots. The patient becomes ill and receives treatment but recovery or remission is commonly achieved. Chronic illnesses such as neurological disorders, however, may include elements of both chaos and quest narratives because of the profound life changes that these illnesses incur. These are usually long term conditions with little hope of improvement or recovery. My own memoir falls into this category.

The narrative forms of illness memoirs are as diverse as the illnesses they represent. Some illness memoirs follow a chronological order, starting with diagnosis, while others lurch between past and present, positing images of the once healthy person against the suffering patient. According to Diedrich, "The narrative itself and the practice of writing may give form to the experience of illness, but it is often a form that confounds linear structure with a clearly marked beginning, middle, and end" (117). One problem facing authors is how to shape the illness story so that it reflects the turmoil and uncertainty of the experience, and yet is expressed in a coherent way. Laurence J. Kirmayer states that "In acute illness, narratives are often fragmentary or underdeveloped; where narratives are most coherent they also may be formulaic and distant from sufferers' experience" (153).

I am interested in this aspect of writing about illness because my own creative work is in its formative stage. The sections I have written remain unconnected and I am seeking a shape and structure that is logical and consistent, yet still expresses the disorder and devastation of the illness experience. Kathlyn Conway suggests that writers who capture the chaotic experience "are struggling with language and form to communicate what often feels formless and overwhelming" (105). The challenge for writers is to reveal these confronting episodes without alienating the reader.

The effective use of language is critical to the representation of illness. However, the primary difficulty is finding suitable language to adequately express what is often inexpressible. Jens Brockmeier says that there is a limited scope of language when compared to "reach of experience" (19). Leigh Gilmore asks "Can language be found for this experience that will not obscure or deform it? Will a listener emerge who will hear it?" (132)." One way of conveying the illness experience is through the use of metaphor. One widely used example is the "military" metaphor, frequently used in cancer narratives. The "battle" metaphor is particularly appropriate because cancer is seen as "an alien intruder or invading enemy" and the ill person is expected to assume a "warrior" role and "fight" for survival (Hawkins 66).

Metaphor can also provide structure to a story. In *The Young Widow's Book of Home Improvement*, for example, Virginia Lloyd uses metaphor to write about her husband's illness, his death from cancer and her recovery from this devastating loss. In the aftermath of John's death, Lloyd undertakes the much-needed renovation of her damp-ridden home. The transformation of her home has a metaphorical parallel with her own struggle to make a new life. Lloyd writes, "As the months passed, and my house slowly turned from sodden sponge to dried and aerated edifice, the

broader parallels between home and self inevitably emerged”(262). Ultimately, the drying out of her home becomes a metaphor for Lloyd’s journey through the healing process. As Lloyd acknowledges “Without the metaphor to guide my path – without the governing idea that helped give me a structure – I don’t think I could have imagined, let alone written my story” (6).

The following is a short excerpt from my own memoir. Steve and I met through ballet and ballet has been an important part of our life together so it is appropriate to include a scene from our dancing days.

We stand on a darkened stage, the curtain closed. The audience is hushed and waiting in anticipation. I hear the strains of the overture and Ludwig Minkus’s *Don Quixote* fills the theatre with its magnificence. The music builds and my heart flutters with nervousness and excitement. With a few last minute adjustments to my costume, I stand en pointe, feeling the tips of my toes pressing into the familiar hardness of my ballet shoes. My partner and I prepare for a supported pirouette, a series of turns effortlessly achieved as the male dancer supports the ballerina in multiple spins. I feel his hands at my waist, turning me, straightening me when I threaten to go off-balance, pulling me upright. We try again and this time it is perfect. We move together with ease, synchronicity and poise.

It is almost time for the curtain to open. We assume our starting position. We stand together, he behind me, our feet in fifth position, arms in bras bas. It is a simple pose that belies the difficulty of the pas de deux we are about to perform. I will balance precariously on tip toe and glide across the stage. He will leap and soar, his masculinity evident in every jump. He will lift me with ease and I will feel safe in his arms. It is a perfect partnership, this blend of grace and strength.

The curtain opens and the spotlight finds us. I am dressed in a simple red tutu, a rose pinned behind my ear. He is resplendent in black tights and bolero, white shirt, and red cummerbund. We are alone, together, in a halo of light, about to enter a glorious world of movement and music. The magic begins...

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He is lying in bed. He can’t roll over or sit up by himself so I roll him onto his stomach and swing his legs off the bed. Now he is kneeling on the floor with his hands on the edge of the mattress. Slowly he pushes himself up onto one foot, then the other. I help him by lifting him under the armpit until finally he is perched on the edge of the bed.

His eyes are closed. It’s not because he’s asleep. He can’t open them because the muscles around his eyes don’t always function. A string of saliva spills from his mouth and wets his T shirt. I give him tissues and he slowly dabs his mouth but more saliva escapes. It has been building through the night. Last night he woke choking with spit. The sheets and pillow case were saturated with slime.

I offer him a drink of water. I lift the glass to his lips and if he is able to swallow, I give him his first pill for the day. Sometimes it sits in his mouth and he can’t get it down. When that happens the saliva turns orange as the tablet starts dissolving. Once the tablet is swallowed, we work on getting his eyes open. I prise top from lower lid with my fingers and often this is enough to trigger their opening. Sometimes standing up will also trigger the opening response. Other times we just have to sit and wait until the medication has taken effect.

I help him to his feet. He is stooped, eyes fluttering. He looks unsteady, so I hold his arm. When I suggest we start moving his feet won’t work. They stick to the floor though his body wants to

move. Suddenly, he steps forward quickly, as though about to fall. Then he shuffles to the bedroom door pausing at the threshold. I tell him to step through and with a bigger stride he is through the doorway. We turn and I guide him down the hallway, my arm in his. The day has begun...

When Steve was diagnosed with Parkinson's disease, I never imagined that I would one day be writing about our shared experience with this debilitating disorder. In the early years I was kept busy adjusting to his illness and the many changes it brought to our family. Then, as his illness progressed and he required more help, I began seeking support and solace from memoirs written by other carers. Reading these stories made me realise how universal the experience of illness is and how we, as a culture, respond to life-threatening and life-altering diseases. Whether it affects ourselves or someone we love critical illness changes the way we perceive ourselves and our place in the world.

Nancy Mairs states that most works about illness "have an accidental basis: one simply does not set out to have melanoma" (or cancer, or Alzheimer's...) but when affected by illness, writers "start to scribble" (xi). Bregman and Thiermann suggest that most illness narratives are written by professional writers who are "used to examining private feelings and [are] intensely curious about [their] own experiences" (107). However, as they also acknowledge, even "amateur" authors have "a sense of mission about the importance of their story for others" (107).

My own creative work is evolving from events and scenes that demand to be told. My story is individual yet common to carers worldwide. There is a place for autobiographical works about illness, for the patients who suffer, for the caregivers who offer support, and for the readers who learn from them. As James Goodwin states:

Autobiography can wholly immerse the reader in the experience and thought of another person. It can activate the reader to self-reflection and create a deep recognition of shared humanity. Autobiography is able to affect the reader in this manner because the experience it recounts is at once unique and universal. The genre contributes directly to the wealth of shared experience that comprises human existence (23).

Illness is a fact of life. We all know someone affected by serious illness and hear the stories that emanate from the illness experience. Narratives about illness have the capacity to touch people because they tap into the dramas and celebrations of life and validate these experiences. These stories are powerful because they display human vulnerability and resilience in the face of adversity. The strength of these narratives does not lie in commercial success or literary acclaim but in the gift of sharing the intensely private experience of illness with a reader who will listen.

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