



Journeys into care giving: lessons from Sarah Leavitt's "Tangles: A Story About Alzheimer's, My Mother, and Me"

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Defined in the Blackwell Encyclopedia of Sociology as "an act of providing unpaid assistance and support to family members or acquaintances who have physical, psychological or developmental needs", [1] care giving can be better phrased as the diurnal course of illness, if illness is the "night-side of life". [2 p.3] Put differently, illness and care giving share a complementary relationship. Even though the activities encompassed in the process of care giving can be classified with admirable ease into practical assistance, financial favours, legal advice, emotional/moral solidarity, care giving often baffles both the care giver and the care receiver. In an Arthur Kleinmanian perspective, care giving demands a tincture of humanity, something other than "scientific and technological learning," thus characterizing care giving as "a foundational component of moral experience". [3] When care giving becomes more of an obligation, the carer confronts copious challenges in that the sufferer has to be kept emotionally close to the care giver which metaphorically

expressed is like drawing sword against another person's demons while battling with one's own debilitations. As Kittay maintains: "People do not spring up from the soil like mushrooms. People produce people. People need to be cared for and nurtured throughout their lives by other people, at some turns more urgently and more completely than at other times". [4 p.433] Subscribing, as it were, to these interpretations of care giving as an ethical and moral responsibility rather than as a cursory enterprise, the present paper seeks to examine the multifarious challenges of care giving through close reading of Sarah Leavitt's *Tangles: A Story About Alzheimer's, My Mother, and Me* (hereafter *Tangles*).

Published in 2012 by Skyhorse, *Tangles* is a graphic memoir which recollects a daughter's experience of caring for her mother, Midge, who has Alzheimer's disease. Sarah Leavitt reconstructs her mother's "night side of life" as she also poignantly recounts a family's struggle with Alzheimer's disease. [2 p.3]

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Classified into three basic levels (physical assistance, emotional support and informational aid), care giving addresses the exigencies of a sufferer in handling their daily needs as well as their emotional mayhem. Although institutionalised care giving provides a plausibility of legal and medical assistance, the impact it has on the care receiver is often marginal compared to the personal care received at home. Against this context, Tangles presents, through the prism of family care giving experience, the importance of creating awareness about illness; the ethical challenges of a care giver; and, the effect of care giving on both the carer and the sufferer. Put differently, Tangles, when analysed beyond the realistic depiction of the effects of Alzheimer's disease, is also an elucidation of the significance of care giving and the necessity of sharing those experiences with the world.

"I have Alzheimer's": Creating Awareness about Care Giving

Any disorder in the natural functioning of the human body fosters vulnerability which in turn reinforces the significance of care giving. One of the major challenges identified in care giving is transcending the phase called 'denial of disease' by creating awareness in the patient. In some sense, Tangles is an admonition for care givers to create awareness in the patient about their illness in the initial stage rather than allowing them to struggle with a disease-denial routine. Sarah Leavitt's negotiation with her parents about Midge's illness at the onset of the disease is one such exemplifying attempt. In the chapter titled "Arrival," Sarah Leavitt depicts an irritated and frustrated Midge who stops conversing with those who find her to be sick. Later she comes to terms with her condition and Midge admits with woe that "I have Alzheimer's", [6 p.25] particularly after Sarah Leavitt makes her mother realize her bizarre behavioural changes.

As illustrated in Tangles, the initial challenge of the care giver lies in making the sufferer aware of the necessity of care giving and this involves the patient's acceptance of illness as well as commitment to someone else's care. Midge's initial refusal to accept her illness mirrors the chimerical notion of independence, which Kittay, contextualizing the theoretical literature and political life of

the western industrialised nations, insightfully elaborates thus: "the myth of the independent, unembodied subject—not born, not developing, not ill, not disabled and never growing old—that dominates our thinking". [2 p.445] When occasion arises for Midge to be assisted by her family members such as Rob (her husband), Sarah, and Midge's sisters, she becomes stubborn and refuses to accept care. Midge's occasional altercations with her family on trivial matters, punctuated with words such as "I don't need to go to the doctor!" [6 p.22] and "I hate what's happening to me", [6 p.42] reflects her ardent faith in her own physical and cognitive abilities. Such resistance disrupts the bond between the care giver and the care receiver and further, it also unsettles family members. For instance, Sarah is enraged when Midge says, "But I hate Sarah more"; [6 p.24] Rob is disappointed when he concedes "Oh, she hates everyone right now. Even me sometimes"; [6 p.24] and Hannah's disapproval is evident when she leaves stating thus, "She's driving me crazy! She's just sad or angry all the time". [6 p.19]

"[S]ome basic dignity is lost": The Ethical Challenges of Care Giving

Care giving emanates from the vulnerability of one person and thrives on the humanitarian instincts of another person. Hence a clear comprehension of the patient's medical condition, psychological temperament and physical compulsions are necessary. These inevitable demands include a substantial understanding of the patient beyond the disability; respecting the dignity of the sufferer and his/her rights; and, valuing their personhood and privacy. In spite of its sacrosanct ethos, care giving itself is an epilogue to one's vulnerability, as Sarah Leavitt construes: "You get sick and your body is no longer private. Even if none of your caretakers ever hurts you, some basic dignity is lost". [6 p.111]

One of the major ethical issues in the process of care giving is identity crisis. As decorously asserted by Vaidehi Ramanathan, Alzheimer's is "a state of being abandoned by one's very self". [7 p.76] While it is inevitable for an Alzheimer's patient to lose one's own sense of self, it is a challenging transition for the care giver. For instance, Midge in the chapter titled "Gaps" ruefully remarks thus: "I've

lost all my sweetness”[6 p.71] and “I’m not really much of a person right now”.[6 p.98] However, what is emotionally destroying is when the care recipient owing to their illness fails to respect and acknowledge the carer, thereby risking the care giver’s dignity and morality. Midge, the whip smart, active, energetic, intelligent, quick-witted, Radcliffe-educated and renowned teacher in Canada is transformed into a phantom. Moving around aimlessly and remotely tethered to her past, Midge is a floating signifier without a cause. Starting from the notes in Midge’s journal about her “blankety-blank headaches”,[6 p.34] the readers get to see the gradual deterioration of her hand writing reflecting her loss of uniqueness and identity. Also, Midge’s ability to read, write and speak increasingly becomes vague and ‘blankety.’ Worse still, not only does the patient but the care giver also undergoes an identity crisis and makes significant compromises in such a situation. Thus, Sarah Leavitt who is initially not much attached to her ‘home’ starts visiting Fredericton, a place which she never liked. As if taking care of her mother is not enough, she also has to leave aside her diverse social commitments and personal choices. Together, these dire straits provoke identity crisis, unneeded strain and exhaustion in Sarah Leavitt, the care taker.

“[J]ust enough to bleed”: The Emotional Challenges

A metamorphosis of identity in Midge turns out to be an emotional debacle for herself as well as for her family followed by the encroachment of the disease. Because self determines our uniqueness as human beings, to lose the very core of it is to lose one self. Yet, by accommodating her mood swings, Rob and his family help Midge stabilize her confusion. They accept the disease as well as the new Midge with great sympathetic concerns especially for her likes and dislikes, as is reflected in Rob’s remarks about Midge’s behavioural mutation, “She knows people are talking about her. She can’t stand it”[6 p.23] and also by not reacting to Midge with spite when she bursts out in the Chinese Restaurant saying “Rob, every time I find something that brings me joy, you take it away!”[6 p.71] Equally emotional is the chapter titled “Why are You Depressed?” where Midge fails to recognize Sarah Leavitt, her own daughter while, ironically,

remembering their pet cat Kitty.

“Cut my life into pieces”: Burdens of a Care giver

The physical and psychological strains of the care giver in managing one’s own life while taking care of the sufferer is yet another devastating situation. Patients with neuro degenerative diseases require continued assistance, as much as is needed for a newborn. Diligent presence and unrelenting alertness is an enervating exercise; and, in some instances, under duress the care giver compromises both professional and personal life. In Tangles, Midge’s illness not only creates an existential agony and identity crisis of her own self but also in her care takers. By taking care of Midge, Rob, the Harvard professor transforms from the status of a professor to a full time care taker of his wife. Sarah Leavitt herself finds it difficult at times to accept her mom’s new identity. In one of her recollections in the chapter titled “Arrival,” Sarah Leavitt recollects: “As we headed to my place, I felt like I was running as fast as I could back to my own life, eager for relief”[6 p.26] and elsewhere she acknowledges that she “spent a lot of time doing nothing” but playing with her cat, Oscar.[6 p.117]

Apart from these challenges, care giving can be emotionally gruelling when it involves taking care of another fully developed human being particularly with a neurogenerative condition. The kind of perplexity and mixed feeling which Sarah Leavitt experiences while caring for her mother intimately (such as cleaning her and attending to her bodily needs and ensuring her personal hygiene) is echoed in a series of confessions thus: “Sometimes I felt like the calmest, most capable nurse . . . Other times I thought I might throw up from the smell of urine or shit”[6 p.110] “her breath stank” and “she sweated a lot”[6 p.59] “She just couldn’t recognize. Couldn’t recognize shit, dirt, shame”[6 p.60] “I sang songs to help mom pee”[6 p.90] “She submitted to tooth brushing, nose wiping, hair brushing” and “We did laundry almost every day”.[6 p.110] Although it was possible for Sarah Leavitt to surpass the moments of confusion with a virtuous understanding of their filial bond, it often raises the ethical moorings of the care giver. Neurodegenerative diseases especially

Alzheimer's leave the patient in a state of what the Latin philosophies define as 'tabula rasa,' where the person becomes traceless. In such conditions, the care receivers are less likely to express their gratitude for the care they receive, making the enterprise of care giving a thankless job. This may in turn cause severe psychological distress when the care givers are family members themselves.

"Are you running away from home?": The Dissociation of Relationships

The emotional challenges of care giving also extend from the disruption of the relationship between the care giver and the care receiver to the dissociation of family. With a disease that challenges one's identity, the definitions of human relationships in terms of commitments such as marriage, parenthood, and filial bonds gets blurred. In fact, Midge stops understanding ideas like sister, daughter, and husband. In her introductory note, Sarah Leavitt observes that "Alzheimer's disease tore her [Midge] away from us and from herself in a cruel, relentless progression of losses".[6 p.7] When Sarah Leavitt recollects that Midge "did not know what a daughter was, or a mother",[6 p.115] it depicts the emotional challenges she had to encounter while making peace with the catastrophic past, which in turn makes her feel like cutting herself with a razor or wanting to "drive my car into the oncoming traffic".[6 p.115] While it demoralizes and debilitates Sarah Leavitt, it is yet another ethical as well as emotional challenge for the author as well as for Rob to approach Midge's illness with rationality.

"Tangled but with spots of brightness": The Impact of Care Giving

Depending on the perseverance of the care giver, the impact of care giving could be positive or negative. Even when the care giver might not benefit, care when provided in the right form could create miraculous epochs in the sufferer in that it helps them feel good about themselves and, in some cases, it could even empower them. Through faithful portrayal of Debbie, Midge's elder sister, in the chapter titled, "Grab Your Heart", Sarah Leavitt illustrates how a care taker should not be. Debbie was exasperating and uncaring to the extent that Sarah had to ward her off at one point stating thus: "For the first time in my life, Mom complained to

me about her big sister".[6 p.54] On the other hand, the immediate family never expressed any insouciance to Midge, nor retaliated or rejected her because of her failing faculties or her foul body odours; instead, they treasured every moment with her to the extent of nursing her with good food, cleaning her and her clothes every day and keeping her hygienic and healthy. Midge was never restricted at home in the name of her disease; on the contrary, she was taken for long walks, for vacations and on short trips. Alzheimer's was never a concern for the family but Midge definitely was. In fact, for her convenience they even rearrange the house so that "[t]he downstairs was much easier for Mom to navigate".[6 p.101] Above all, by being empathetic with her frailties rather than expressing mere sympathy, the family returned their "fierce and absolute love" to Midge.[6 p.7] All such gracious acts of love had a definitive impact on Midge—as Sarah Leavitt attests: "In some way she recognized me. My voice and face had some meaning for her".[6 p.115] However, when Midge's condition deteriorates and it becomes increasingly difficult to administer care, then the family as a last resort sends her to Pine Grove, a nearby nursing home. Elsewhere, regretting this action, as it were, in the chapter titled "Up and Down," readers' meet a sullen faced Rob telling Sarah Leavitt that he would "want to keep [Midge] at home as long as possible".[6 p.101]

Care giving provides advantages to the care taker also, when it makes them feel proud about themselves and, at times, when it leads to socializing with people who share the same disability. On the other hand, when the care giver fails to maintain a healthy relationship with the patient it causes negative impact, which might lead to distress, depression and even death. Therefore the care giver also needs to be taken care of in order to create a positive effect on the patient, failing which individuals may choose institutionalised care. This happens in Paco Roca's graphic narrative, *Wrinkles*. Even though promises are made by the hospice authorities in *Wrinkles*—"Overall, we can take better care of your father than if he stayed at home",[7 p.9] it ends with a monotonous, monochromatic dragging of the patient's existence. In fact, one of the inmates in *Wrinkles* in a regretful tone

observes thus—“I feel a little off colour”. [7 p.23]

Coda

In the final analysis, *Tangles*, characterised by sparse and unpolished drawings is a graphic memoir of Alzheimer’s disease and the changes that it has wrought in a family, particularly with the transition of Midge from an educated mother to a mere medical entity. In simple but highly gestural sketches, *Tangles* traces the fine progression of Midge from the onset of the disease to her death. Through the effective portrayal of Midge’s obvious symptoms, Sarah Leavitt makes familiar the complexities of Alzheimer’s disease. At another level, the memoir is a manifesto of a care giver’s challenges, pain and perseverance in making the last years of Midge’s life lighter and easier. Specifically, if

Tangles explicates the metamorphosis of Midge from a wife/mother/sister/teacher to a vegetative existence then it also documents the painful transition of the author from the status of a daughter to a mere care giver. Unlike any other narrative species, graphic memoirs effectively relay the emotional contours of the care giving experience. *Tangles* is an illustrious example in that it succinctly elicits the basics of care giving such as patience, practice and persistence. Sarah Leavitt makes it clear that caregiving is in equal measure tragic, cherishing and transformative especially with an easily fading person. As Rob remarks “sometimes it turns out that everything you thought about how the future would be just isn’t true” and that is where the role of care giver assumes its grace. [6 p.46]

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