

# Visual Analysis of the Challenges of Care giving in Graphic Pathographies

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## Abstract

*Graphic care giving memoirs facilitate the healing process of caregivers' suffering and struggles in the form of storytelling since the graphic narratives have developed both in sophistication and cultural importance as quoted by Ian Williams, the founder of the dedicated website for medical humanities called [graphicmedicine.org](http://graphicmedicine.org). Amelia Defalco identifies "capaciousness" of graphic format which allows for quick oscillation between the rewards and struggles of care, representing ambiguous, even ambivalent attitudes towards care. The Philosophy of care revolves around the ethical act of responding to the other. The narrator or protagonist of graphic pathographies cares for a variety of family members, friends, strangers and even animals. What is care giving? Why should one take care of others? How family members overcome challenges of care giving and how such narratives are portrayed in graphic memoirs? Is it possible to have informal care giving for terminally ill patients? Addressing such questions and drawing on theories of care giving, this paper by close reading Sarah Leavitt's graphic memoir *Tangles*, analyses the responsibility of the daughter in taking care of her demented mother, who is in dire need of assistance even for carrying out personal hygiene related basic life activities and concurs with theories of care giving.*

**Key Words:** Graphic Medicine, Care giving, Alzheimer, Philosophy and Ethics

## Introduction

"Graphic care giving memoirs facilitate the healing process of caregivers' suffering and struggles in the form of storytelling since the graphic narratives have developed both in sophistication and cultural importance" as quoted by Ian Williams, the founder of the dedicated website for medical humanities called [graphicmedicine.org](http://graphicmedicine.org)(2015). Amelia Defalco identifies "capaciousness"(2016) of graphic format which allows for quick oscillation between the rewards and struggles of care, representing ambiguous, even ambivalent attitudes towards care. The Philosophy of care revolves around the ethical act of responding to the other. The narrator or protagonist of graphic pathographies cares for a variety of family members, friends, strangers and even animals. What is care giving? Why should one take care of others? How family members overcome challenges of care giving and how such narratives are portrayed in graphic memoirs? Is it possible to have informal care giving for terminally ill patients? Addressing such questions and based on theories of care giving, this paper by close reading Sarah Leavitt's graphic memoir *Tangles*, explores caring relationships in relation to different cultural and lyrical perspective of family responsibility in taking care of a family member, who is in dire need of assistance even for carrying out personal hygiene related basic life activities.

What forms do such public "confessions" of private experience take, and what specific symbolic structures are employed in order to convey them? Irrespective of the various motivations that drive the production of graphic pathography, be it sheer exhibitionism or a fervent desire for healthcare reform, it is posited that the works of the artists considered here are all united by the performativity that is deployed through "formulas of pathos" and "acting forms." The performative powers of pathography transpire through the distinct expressive structures that pathographic works employ. It is identified that the primary aesthetic tactics that characterize pathographic performativity as formulas of pathos: rhetorical modalities of the auto/pathographic image that transform embodied pathos into legible symbols (Jurecic,2012,p 67). Levinas philosophy of 'the suffering for the useless suffering of the other, the just suffering in me for unjustifiable suffering of the other, opens suffering of the other, opens suffering to the ethical perspective of the inter-human. The productive power of discursive practices, which extend beyond language, is evident in the assembly of a subject within discourse. Foucault described the discursive production of the subject through power relations as the form of power applies itself to immediate everyday life which categorizes the individual, marks him by his own individuality, attaches him to his own identity, imposes a law of truth on him

which he must recognize and which others have to recognize in him. It is a form of power which makes individuals as subjects. There are two meanings of the word subject: subject to someone else by control and dependence, and tied to his own identity by a conscious self knowledge. Both meanings suggest a form of power which subjugates and makes subject to (Foucault 1982, 781).

#### Literature review

Theorists believe that contemporary trend of care giving graphic narratives include introduction of such narratives as part of medical curriculum, then creating awareness on the students, the importance of humanness in their attitude towards patients. Another contribution of Graphic illustrations aim and enthuse terminally ill patients as well as their care takers to understand the need for coping with illness but also to have challenging tendency in overcoming the suffering. Graphic medical narratives make use of the fragmented layout of comics contained in “boxes of time” (Chute, 2010, p.6). Many illness narratives have positive ending there by making readers understand that there are some lacunae on the part of medical system and also responsibilities involved in care giving function. *Cancer vixen* by Marisa Acocella Marchetto is a live example of thought provoking, philosophical ending in Graphic Memoir. Any disease experience when narrated in visual format, involve readers to focus their attention and decode the original intention of the author in visualizing an event. Thus, the reader of *Billy Me & You* by Nicola Streeten becomes part of Nicola’s grief over the death of her child Billy just at the age of two and half years. Gendering in caring needs serious thinking as most of the narratives visualize or prioritize woman as caregiver exceptions being *Mom’s cancer* by Brian Fies and in *Janet & Me: An Illustrated Story of Love and Loss* by Stan Mack, the male narrator shouldering the burden of caring his live-in friend when she suffers with breast cancer is perfectly visualized. Dana Walrath’s graphic memoir *Aliceheimer’s Alzheimer’s Through the Looking Glass* reconfigures the theory of care giving as Walrath writes that creating this book allowed her not only to process her grief over her mother’s dementia, but also “to remember the magic laughter of that time.”

#### Defining care giving

Care giving is defined by OED as characterized by attention to the needs of others, especially those unable to look after themselves adequately; professionally involved in the provision of health or social care and also attention to the needs of a child, elderly person, invalid etc.

Arthur Kleinman defines care giving as a moral experience. He talks about medical responsibility to offer some kind of care giving and hope for the future when he encountered a young couple who could not start their loved life due to malformed blood vessel in the husband’s brain which burst. He further elaborates on emphatic suggestions for rehabilitation, family counseling and social work assistance. His own experience of being the primary caregiver for his wife, on account of her neurodegeneration disorder, convinced Arthur yet further that care giving has much less to do with doctoring than the general public realizes or the medical professionals are willing to acknowledge. It is for the most part the preserve of families and intimate friends and of the afflicted person herself or himself.

For economists, care giving is a ‘burden’ whereas psychologists talk about coping. Health care researchers describe social resources and healthcare costs, and physicians call it a clinical skill. When it comes to medical humanities, it is a foundational component of moral experience. Hence Kleinmen describes it as “what it is to be a human being’ (1988). The doing, the feeling, the shadings, the symphonic complexity, the inadequacy, the living at every moment and over what can be since a long journey of the incompleteness yet the presence of care giving. In the words of Defalco, “Care implies Obligation and responsibility, Obligation implies inequality, Inequality implies harm therefore care and harm are interrelated.” (2016)

#### Caring through graphic medium

Deflaco opines that comics offer an engaging, powerful and accessible mode of delivery for illness narratives. Comic’s language is, as Hatfield (2005) professes, always characterized by a plurality of messages through which difficult, ambivalent, chaotic or incomprehensible impressions, narratives or visions can be articulated. This genre has become an important tool for the direct and witness experience of healthcare in addition to the articulation of illness narratives through pictorial embodiment of ideas of corporeal self. Healing is as Ian opines, is a relative concept, more to do with making some of things, and achieving an acceptance than eradication and can come through various avenues like autopathography and graphic medicine. Publications and teaching in the growing field of graphic medicine have brought attention to a wide range of perspectives and Myers (2015) has argued that graphic pathographies have helped medical students understand the perspective of the patient, although possibly to the neglect of other perspectives. Although fewer, there are also graphic novel representations of the experiences of health professionals, including the narrative of a GP’s

struggles with his own mental illness and vulnerability in a tightly-resourced and high pressure health system (Williams 2015). The growth of comics scholarship and its interest in medicine brings with it a turn, in the words of Squier, away from ‘an implicit endorsement of the practitioner’s emphasis on medical treatment to a critical incorporation of the caregiver’s or patient’s experiences, including the social determinants of health and wellbeing’ (Squier 2015: 48). It also provides the opportunity to develop narrative and visual literacy relevant not only for ‘students of medicine but for practicing physicians as well’ (Green 2015: 69).

### Figuring caregiver in *Tangles*

*Tangles* is a graphic memoir by Sarah Leavitt, who writes both prose and comics. The memoir was published in 2012 which is widely appreciated by media and Alzheimer Association of different countries and an animated movie is in progress. The New York Times has preferred to narrate it as “A poignant account illustration brings home the daughter’s pain as her once-vibrant, protective parent was transformed by fear and weakness. Brian Fies, the author of Graphic Novel “*Mom’s Cancer*” has commented about *Tangles* in the following lines:-

“Sarah Leavitt uses the medium of comics to tell her story with more economy and power than either words or pictures could muster by themselves. She brings a good eye for the telling detail—the small observations that reveal larger truths – to her memoir of a family in crisis. *Tangles* is the work of a perceptive, creative and honest story teller.”

Interestingly, the publisher has used both the above comments in back cover with images of two unknown characters struggling to climb up the staircase and in another visual, the iron box remain being switched on status and clothes uncared for. The other visuals represent trees in black images to our surprise; the visual of a kitty (cat) appears along with the opinion of John Bayley, author of *Elegy for Iris* (a famous memoir) in the following words.

“An extraordinary moving and vivid account in text and cartoon style pictures of the life and death of an Alzheimer’s patient.”

The front jacket cover symbolically represents the unified bond between mother and daughter, and the other (tight holding someone seeking support) panel portrays the mirror image of Midge presumably after the attack of Alzheimer. Just below the panel of trees, Sarah’s image as engaged in serious preparation of notes and journals is visible. The writer has allotted the next page for stars and the phenomena of world revolving around. The title page symbolically has the undivided portrayal of mother and daughter in a bonding

emotional attachment, the same visual is used in inner pages. In the copyright or publishers page, there appears to be a deviation from routine with the visual of socks, symbolically conveying the importance of objects in this narrative. Sarah has devoted the work to her father Robert and sister Hannah. As Kasthuri observes “mundane objects like socks and a blanket are transformed into a symbolic reminder of her deceased mother, Midge”. (2015)

The mention of her companion Domino in the acknowledgement page brings surprise to the reader who is described as the dearest companion, which explores the sexuality of Sarah, which can’t be concluded at this stage. Next acknowledgement is for the drawing friend Mary and finally there is mention of her mother, who is the “most of all” for Sarah and whom Sarah misses for over. Here the ethical implications of the central relationship between the narrator and her ailing mother explore the repercussions and reverberations of pathological memory loss interestingly in middle age. Many of the claims by ethics of care theorists are based on the premise that caring is essential for identity hence Virginia Held claims “care is probably the most fundamental value” (1995).

In the introduction, Sarah is honestly talking about her really bad memory. Very rarely, the writers begin introduction revealing their weakness. However, Sarah might have preferred to address the readers with her honest admission of her weak memory, where the entire narrative revolves around the issues of memory. Hence the last Para of introduction talks about her piecing together from her memory, notes and sketches (7). She cautions the readers that other people in her family may remember things differently. Sarah declares that she made small notes on scraps of paper right as things were happening, like at the dinner table when her mom started talking to broccoli. Leavitt’s graphic memoir, as Renata Lucena Dalmaso observes “unsettles some traditions of the auto biographical genre by contesting an implied ownership of the truth in her narrative” (2015). The following description keeps the reader aware of her mother’s attachment towards the family.

“My mother loves her family with a fierce and absolute love. Alzheimer’s disease took her away from us and from herself in a cruel, relentless progression of losses. But as she lost her ability to form sentence, and stopped saying our names, and stopped understanding ideas like sister, daughter or husband, she would still cry out with joy when we came into the room”. There is no mention of any pets in the introduction. Interestingly, Sarah instead of describing the family pet, kitty, simply devoted the entire page with the image in camera focused behind kitty. Kitty does not focus on readers; it

seriously looks at the other side, probably taking care of her "human mom" in its own way(8)and Sarah has visualized The Kitty in two pages with thirty one panels conveying the readers the importance of kitty in her family.(65,66) Midge is portrayed as a person frustrated with her illness. "I hate what's happening to me ", Midge utters (42).

The graphic memoir is arranged in different chapters starting with 'Nightmare' giving clue to the reader that it is an involvement of serious characters. Rhetorical performance and arrangement of characters and handwritten format emphatically brings readers in close contact with the writer. The entire book is divided into three parts the first part is further decentralized with titles like Nightmares, sixteen long distance, signs, arrival, sunny Mexico, waiting, language and diagnosis, Sarah Leavitt admitted that both the first two chapters (Nightmares & Sisters) have been included as advised by the Editor, to initiate clarity on topic, increasing intensity of her remembering her mother. Most of the narrations are light, thinly and sketchy. The scenes are arranged episodically and not chronologically. Mother taking care of her daughter is swapped later on, when mother is afflicted with Alzheimer; the role reversal is emotionally narrated. Arrangement of panels resembles "Fun home" and in pages about her relationship with Donimo, Sarah is trying to negotiate or understand her queer trouble. Although trauma resists exact representation, Venkatesan comments, the comics medium induced by basic structure and gutter space grants a mediated authentication which in turn enables the graphic pathographers to revive traumatic moments from the past and reconstitute the disrupted self out of its inherent meaninglessness (2016,p.225)

Regarding family, Sarah portrays the three dimensions of grandfather as a man of taste, intellectual positive and socially conscious, and her grandparents meeting Duke Ellington is symbolically conscious. Mom's attachment with her parents is visualized in the form of the poem reproduced by Sarah. Midge, her mom titled it as orphan and both the parents died of cancer, cautioning the readers that death at an earlier age has been a hereditary phenomena symbolically preparing herself to emotionally face the death of Midge at middle age. Sarah wanted to establish the honesty in her reporting hence produced the original hand written poem of her mother. Comparison of Mom's sister and Sarah & Hannah is well established in panels (To tackle the question that how a memoirist can access the part).Photographs inspired cartoon and material trapping of photographs to authenticate truth value of the narrative is beautifully constructed in pages. Comic medium is exploited with the use of box of razor blade and postal letter, sharing of experience with the original

poem. Care taking as an integral part as an inherent in the family of Sarah is cleverly established in the panels of Sarah's mourning with her sisters, intellectual legacy of Jews as Sarah's family belongs to Jewish however not so religious(44). Superiority of the individuals and ethical obligation are represented without gutter spaces in handwritten borders. In reproducing the handwritten letter/notes of the mother or the "tiny notes"(34) as Leavitt calls them, the narrator not only divulges the personal identity crisis and the loss of linguistic identity but also unveils the degeneration of Midge's cognitive and motor skills.

In an interview with Sarah Lightman, Leavitt declares: "I think the book has allowed me to keep my memories of my mother alive, to keep her close and present. My mum was such an intellectual person, so interested in language, such a good writer. It was terrifying to watch her handwriting and language skills deteriorate until she was unable to write at all" (2014). As Vaidehi Ramanathan observes about Alzheimer patients "Indeed, as we will see, it is precisely because their hold on themselves and language is fast becoming tenuous—and thus too fluid—that the need to fix themselves and loved ones becomes imperative" (2009).

It was such a powerful expression of Midge's overall decline. Leavitt is able to convey the complex and difficult emotions and events in *Tangles*, not only through her careful yet light drawings, but also through a number of visual devices including tracing her mother's increasingly illegible notes to her. Leavitt has been gratified by the positive reaction to the work. She elaborates: "One of my favorite things is meeting people who've not read comics before but who decided to give *Tangles* a chance. Once they finished it, they then went on to read more and more comics. It's like a gateway drug!" As observed by Vaccarella M "Using the theoretical writings of Will Eisner and Scott McCloud, (medical) students were introduced to the constituent elements of comics (e.g., word-image interplay, sequentiality and closure). Special attention was devoted to the additional meaning carried by formal elements: for example, black gutters between panels can intensify the depiction of characters' depression, while an unconventional panel arrangement can either reinforce the theme of social oppression or contribute to a sense of liberation"(2012) graphic pathographies can facilitate humanizing medical education.

Men are in the margin in terms of panels dedicated clearly focus the strength of female relationship. Multiple roles performed by her mother such as an intellectual educator, counselor, stress reliever and loving wife and every relationship is built over a period of time. Secular and non-religious identity, counter cultural attitude-all have been synthesized to

bring the idea of (knowledge) journey in acquiring knowledge, using the metaphor of journey with spiritual involvement. As Venkatesan observes "Although it was possible for Sarah Leavitt to surpass the moments of confusion with virtuous understanding of the filial bond, it often raises the ethical moorings of the care giver" (2015). Mom's journey continued until death even with mobility being restricted because of Alzheimer.

#### Coda

The paper's perspective on care giving in graphic pathographies is firmly grounded in the plain recognition that we are all but "temporarily able-bodied," to borrow a term from disability studies. This research into graphic pathographic performativity details the artwork's function in creating care giving as an "acting form." According to this notion, both the pathographic process and its resulting artworks are endowed with an acting power that has the capacity to restore the subject. It seems likely that, among the multiple and complex reasons for publishing a graphic memoir of suffering, some artists hope that the process will afford some measure of healing and some artists find some therapeutic effect, whether expected or not. (Williams, 2011) In considering pathographic performativity in this light, two elements tied to the performance of recovery surface from the examined

artworks: on the one hand, the displacement of suffering that occurs in the process of auto/pathographic depiction, and on the other, the notion that graphic pathography functions as a survival technique on multiple levels. That recovery and survival should recur as motifs in these visual artworks leads the researcher to propose that performative pathographies manifest a constructive aesthetics of failure, insofar as they draw a productive gesture from the experience of the body's fallibility. *Tangles* with its pulsating words and sparse pictures highlight the transformation of crisis that patients undergo and reconstitute their identity. The basis of care giving begins with the realization and acceptance of the care receiver as another person for mere existence. Care is committed to the flourishing and growth the narrator encounters the alterity of her mother, and the ensuing relationship of dependence and responsibility challenge her own sense of self. Leavitt's graphic memoir conveys the opacity of her mother's dementia, its fragmentation and conflicting emotions, from both sides of the care giving relationship. Graphic somatography, in particular, incorporates productive tensions that reflect the experience of care giving, which is characterized by contradiction and ambivalence, to quote DeFalco.

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