



Article

Improving Dementia Home Caregiving and Restructuring the Dementia Narrative Through Creating a Graphic Memoir and Engaging in a Psychoanalytic Narrative Research Method

Carol Nash

History of Medicine Program, Department of Psychiatry, Temerty Faculty of Medicine, University of Toronto, Toronto, ON M5S 1A1, Canada; carol.nash@utoronto.ca

Abstract: Informal dementia home caregiving is viewed negatively by society and can result in caregiver depression and anxiety from burnout, potentially compromising caregiving. Caregiver creation of a graphic memoir may help to mitigate the negative dementia narrative while engaging in it, and a psychoanalytic narratology method may reduce experienced depression and anxiety associated with burnout. This investigation examines writing, illustrating, and publishing a graphic memoir by one informal dementia home caregiver. As the mother of the illustrator and the editor and publisher of this graphic memoir, I provide the perspective of this investigation based on communications with the author and illustrator. My historical analysis, in which the author participated, represents psychoanalytic narrative research, serving as the historical method. The effects of writing, illustrating, and publishing the graphic memoir were able to reduce the informal dementia home caregivers' symptoms during the entire process and extend the effect of this endeavor until the death of the mother. Engaging in the psychoanalytic narrative research process was additionally effective in this regard. The outcomes demonstrate the viability of writing and illustrating a publishable graphic memoir for other informal dementia home caregivers and the possibility of it and the narrative research method to help decrease their depression and anxiety regarding burnout.

Keywords: dementia; informal home caregiving; depression; anxiety; burnout; graphic memoir; psychoanalytic narrative research; historical method



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1. Introduction

1.1. Overview

The intention of this report is to assist dementia home caregivers who strive to enhance the positive narrative surrounding dementia home caregiving and reduce their burnout from this caregiving. The method includes a presentation of two means to accomplish this. The first is by providing detailed information regarding the 2015/16 creation of one graphic memoir related to informal dementia home caregiving that helped its author reduce her burnout through working with an illustrator and a publisher (me) to have this work available at North America's largest psychiatric bookstore. This account is from my perspective as the publisher following discussions with the graphic memoir author. The second is by presenting a narrative method engaged with the author years later in 2023/24 to reconstruct what was meaningful to her regarding the process of writing, illustrating, and printing the graphic memoir, again offering a method to reduce her depression and anxiety concerning her role as an informal dementia home caregiver. The introduction pertains to several topics; the method section describes the two means, offering perspective. These include information on informal dementia home caregiving, burnout, non-pharmaceutical interventions, and graphic memoirs. The aims of the study are next section.

1.2. Informal Dementia Home Caregiving

Informal dementia home caregiving is viewed negatively by the public [1], such that caregivers of persons with dementia may be uniquely aware of public stigma regarding dementia home caregiving [2]. This care requires a long-term commitment, usually lasting between 10 and 20 years [3], and acceptance and commitment by the caregiver to be sustained [4]. Acceptance and commitment provide the basis for intervention therapy for these dementia caregivers [5]. Therapy, when sought by informal dementia home caregivers, regards the depression and anxiety they can experience from continuous engagement in their caregiving role [6] brought on by stress [7], equaling burnout [8,9]. The suggestion is that psychological inflexibility is the cause of this stress, leading to the depression and anxiety demonstrated by burnout in these informal dementia home caregivers [10,11]. However, as the behavior of the person under care can be increasingly unpredictable and aggressive toward the caregiver [12], factors that expand and complicate the burden of informal dementia home caregivers [13,14], these escalating changes may provide an additional reason for these reported depression and anxiety symptoms [15,16], representing caregiver burnout [17]. Concomitantly, this may lead to compromised care for the demented family member [13,18].

For informal dementia home caregiving to be effective in its extended time commitment, it is imperative to reduce the public stigma regarding it by creating positive narratives [19]. In contrast, negative depictions further the social stigma [20]. Creating positive views on informal dementia home caregiving is accomplished by narratives where these caregivers are presented as visible and are acknowledged for their work by those who are empathetic to their situation [21], and publication furthers these views [22].

1.3. Burnout

Burnout is a work-related syndrome characterized by emotional exhaustion, feelings of cynicism, and reduced personal accomplishment [23], which was first recognized in 1974 [24]. Although a recent review of the literature has noted no conclusive overlap between burnout and either depression or anxiety, indicating that they are distinctly robust constructs [23], in their burnout resulting from the constant and increasingly difficult care they provide, informal dementia home caregivers also experience depression and anxiety. Depression involves a degree of anhedonia, impaired concentration and memory, and anergia [25]. These are also evident in burnout [26]. Compromised self-esteem, another factor of depression, is not usually found in burnout [26]. However, for informal dementia home caregivers, compromised self-esteem can result [27], indicating that this burnout is a unique form [8], although some of these caregivers may demonstrate an increase in self-esteem from the effectiveness of their caregiving [28]. Anxiety is feelings of tension and worry, demonstrating physical symptoms like palpitations [29]. Levels of guilt and rumination associated with financial strain in caring for the demented family member often bring on this anxiety in informal dementia home caregivers [30].

1.4. Non-Pharmaceutical Interventions

In perhaps the most extensive review of the literature on non-pharmaceutical interventions intended to reduce depression and anxiety in informal dementia home caregivers to date [3], several conclusions are drawn. (1) Most intervention programs last for four months or less, well below the number of years caregivers can expect to care for their relative experiencing dementia, and the effectiveness of these programs wanes with time. (2) Intervention programs require tailoring to the individual circumstances of the caregiving relationship for them to be effective. (3) Mindfulness activities are the interventions that improve caregiver acceptance and commitment to caregiving.

Another review notes that only psychoeducation can significantly reduce anxiety [31]. Yet anxiety reduction is not the focus of most interventions [32], and 49.7% of caregivers never use a psychosocial intervention—of those who do, there is a 31.8% dropout rate—still, this is below the 50% dropout rate for other interventions regarding this group [33].

The two reviews did not identify any publications that examined the physical well-being of the caregiver. Yet, an intervention improving caregiver subjective and objective physical health is seen as necessary by the first review, as physical ill health from extended caregiving is a primary reason for abandoning informal dementia home caregiving [3]. Based on the results of these two reviews, in total, if an intervention program is to be effective in reducing the depression and anxiety associated with burnout in informal dementia home caregivers, the intervention must include five aspects. (1) Be relatively long-lasting, (2) be tailored to the circumstances of the caregiving relationship, (3) be mindfulness-based, (4) provide psychosocial assistance, and (5) contain a component that attends to the physical health of the caregiver.

Concerning dementia home caregiving, “long-term” pertains to an effective intervention under changes in symptomology or the caregiving relationship—considered to represent a minimum six-month period [34]. Although the need for a long-term intervention in reducing the depression and anxiety accompanying burnout in informal dementia home caregiving is well-recognized [3], research concerning “long-term” in such caregiving focuses on transferring family members experiencing dementia to long-term facilities, rather than long-lasting interventions to help with caregiver burnout; of note, this research is not current [35–37]. Researchers may feel reluctant to investigate the long-term effects of interventions resulting from the minimal outcomes recorded, although improvement is identified as possible and should be attempted [38]. In doing so, any long-term intervention must anticipate that the burden on the home caregiver will increase with time [39].

Several factors are relevant when considering whether the intervention tailors the relationship between the person experiencing dementia and the dementia home caregiver. These include respect for the dyad and the dyad members as individuals [40]. A 2017 systematic review of the topic of the caregiving dyad [41] stressed that a successful intervention requires that the relationship between the relative experiencing dementia and the informal home caregiver remain intact and supported by the intervention. The authors of this study found that this is a problem as most interventions do not consider the importance of maintaining this relationship. By 2021, researchers had noted that the number of publications regarding support for the dyad had increased [40]; however, these authors stress that many publications continue their lack of consideration in maintaining this caregiving relationship. One recent article focuses on enriching the relationship [42], finding that enrichment in the relationship depends on communication support and skill-building.

Mindfulness is well-cited as elusive and difficult to capture in studies [43]. Its definition in psychological research is an awareness of accepting stressful thoughts and feelings to facilitate an engaged identification and exploration of adaptive responses [44]. Nevertheless, studies often limit the definition to non-judgmental present awareness of physical, emotional, and mental states without consideration of the adapted response as the purpose [45]. In this regard, for an intervention to be mindful, it must encourage the dementia home caregiver to accept these aspects of themselves, their relative experiencing dementia, and the dyad relationship in a manner that promotes an identification of adaptive responses. Mindfulness training focuses on attentional control of internal conditions [46], representing monitoring practiced during episodes of depression and anxiety [47]. A systematic review identified that participation in mindfulness-based practices enhances multiple mediators with the potential to improve anxiety and depression in a range of health and mental health populations [29]. Concerning mindfulness-based practices, another recent systematic review considered several factors aiming to reduce depression and anxiety: stress reduction, cognitive therapy, meditation training to improve mental unification, and the development of core processes [48]. What is lacking from these mindfulness interventions regarding informal dementia home caregiving is the added dimension of encouraging mindfulness in creating adaptive responses to the evolving dementia dyad concerning the relationship and the two members as individuals. As such, in informal dementia home caregiving, standard mindfulness-based interventions limited to accepting physical, emotional, and mental states may lack effectiveness regarding the broader task of initiating the identification of

adaptive responses. The need for creative solutions supporting the mindfulness of informal dementia home caregivers results, with multicomponent miscellaneous interventions found to be most effective [3].

The meaning of psychosocial assistance for informal dementia home caregivers varies by country [49]; yet, the assistance being comprehensive and systematic, enabling informal caregivers to maintain their commitment to caregiving with a work-life balance, is constant [50]. Included in this is attending to the physical health of the informal dementia home caregiver [33]. Physical activity creates physical health, defined in 1985 as “any bodily movement produced by skeletal muscles that results in energy expenditure” [51]—a definition recently expanded to recognize that physical activity is inherently cerebral and depends on a cognitive and emotional aspect [52]. In other words, for physical activity to promote health, it needs to involve more than energy expenditure. It must also connect with the thoughts and emotions of the informal dementia home caregiver in being freely chosen. Other components of physical activity employed to define it as physically healthy are that it is inherently social, spatially situated, and political [52]. In this way, the experience must be enjoyed and connected with all significant aspects of the informal dementia home caregiver for physical activity provided through psychosocial assistance to promote physical health.

1.5. Graphic Memoirs

Graphic memoirs are autobiographical narratives on mental illness expressed through comics [53]. A graphic memoir arises as part of narrative medicine, first recognized by Charon and Montello as a distinct form of research in 2002 with their edited collection, *Stories Matter: The Role of Narrative in Medical Ethics* [54]. A subsequent book, published in 2006 by Charon, *Narrative Medicine: Honoring the Stories of Illness* [55], offered a deeper understanding of the bioethical importance of narrative research and recognized the increasing acceptance and use of narrative. In 2015, Czerwiec and Williams produced the *Graphic Medicine Manifesto* with four other narrative researchers from various backgrounds in healthcare—Squier, Green (the same Green who is part of the account of creating the graphic memoir to follow), Myers, and Smith [56]. The purpose of calling their collaborative work a graphic medicine manifesto was to acknowledge that graphic medicine represents multiple subjects with valid and potentially conflicting points of view and experiences [56] (p. 2). Recent academic work in graphic medicine has concentrated on the alternative realities of dementia [57].

What makes graphic medicine attractive to readers and increasingly popular is the accessibility of the text and the engagement possible in following the story with comic illustrations [58]—this level of accessibility and engagement was more comparable with professional text or medical manuals regarding specific conditions and extending to public health more generally as of recently [59]. Graphic memoirs permit participation in the personal story about the ailment based on lived experiences [53], enhancing the empathy of clinicians for their patients [60] by encouraging patients to put their illness into their own words [61].

An informal dementia home caregiver creating a graphic memoir is not new. *Special Exits* of 2010, written by Joyce Farmer [62], concerns more than the negative aspects of the experience [63]. Sarah Leavitt’s 2011 graphic memoir, *Tangles: A Story about Alzheimer’s, My Mother, and Me* [64], is considered by the public and Alzheimer’s associations in various countries as a sensitive and honest depiction of this form of dementia [65]. Since its publication, writing a graphic memoir has increasingly become a means by which caregivers can conceptualize their experiences regarding dementia [66]. The use of graphic memoirs regarding informal dementia home caregiving includes reinterpreting the narrative of neurological decline causing a loss of self, with various graphic memoirs presenting alternative views of the self [67]. Re-examining the lived experiences of these caregivers from being undervalued and disregarded is also relevant to the purpose of graphic memoirs [68], such that a laudable creative practice represents care [69]. Regarding 2016 works like Dana Walrath’s *Aliceheimer’s: Alzheimer’s Through the Looking Glass* [70] and *Wrinkles* by

Paco Roca [71], graphic memoirs, sought to restore the personhood of demented family members [57], taking their perspective and presuming their competence [63].

It was in 2015 during this fertile period of graphic memoir creation related to informal dementia home caregiving that Liza Futerman undertook writing a graphic memoir as the appropriate medium to recount an episode between herself and her mother. The purpose was to reconceptualize her mother's condition creatively to reduce Liza's depression and anxiety resulting from burnout as an informal dementia home caregiver. The outcome was the 2016 publication *Keeper of the Clouds*, illustrated by Evi Tampold [72] and published through Tampold Publishing—a company Evi's mother (me) started to publish her daughter's work. Furthermore, by Futerman creating and publishing a graphic memoir, the necessary ingredients of an effective burnout intervention were evident—the experience was relatively long-lasting, the writing of the memoir and working together with the illustrator and publisher were mindfulness-based and provided psychosocial assistance, and the graphic memoir connected Futerman's thoughts and emotions as an informal dementia home caregiver in being freely chosen, inherently social, spatially situated, and political, as such, making the activity physically healthy.

1.6. Study Aims

This study examines the process Futerman underwent in creating, illustrating, and publishing her graphic memoir from my perspective as her publisher to provide insights into what ways creating this graphic memoir improved the narrative regarding the social stigma of informal dementia home caregiving and reduced Futerman's burnout by decreasing her depression and anxiety as an intervention. Both the writing of the graphic novel and engaging in a similar psychoanalytic narratology process to the one to be presented also act as examples for other informal dementia home caregivers to similarly create graphic memoirs and structure their thinking regarding the process to reduce their burnout and simultaneously improve the care they can give to their family members experiencing dementia, which is performed through reaffirming their acceptance and commitment. This study is the first to examine the creation of a graphic memoir using psychoanalytic narrative research as the historical method for this type of investigation.

2. Materials and Methods

The method to gather the materials for this study is a unique narrative research process developed by me (comparable to recent narrative research directions [73,74]) that examines varying perspectives of Futerman's constructed story to make her experience understandable [75] to the extent that other informal dementia home caregivers can use this examination in creating their graphic memoir and to structure their thinking process regarding its creation. In this way, data are examined as stories regarding the relationship of Futerman's actions to their occurrence in a social context [76] from my perspective as her publisher. An examination of Futerman's data as stories is a history taking in the psychoanalytic narratology tradition, noted by Fludernik [77] as a form of narrative research originated in the mid-1980s with works by Brooks [78] and Chambers and Godzich [79] to investigate concealed aspects of the data to portray an individual's history [80] by creating a structure to the thinking process. Narratology is a recognized humanities discipline studying the practices, principles, and logic of narrative [81], continuing its relevance to current authors as "chrononarratology" [82] and narrativity concerning historical theory [83], recognizing history and narrative methodologies as interdisciplinary [84]. Although it has a history stretching back to the 1980s, significant contemporary work continues using the method of psychoanalytic narratology [85–88]. I employ it in previous publications [89–93] and develop Futerman's story regarding her graphic memoir into a narrative with a particular point of view in response to questions posed regarding the experience of creating her graphic memoir.

2.1. Pivotal Points

In seeking to investigate the concealed aspects of the process of Futerman writing the graphic memoir, collaborating with Tampold to illustrate it, and working with me to publish and organize the printing and selling of the graphic memoir, the manner of conducting this investigation is by focusing on pivotal points. Here, pivotal means that the graphic memoir development took a different course at that point [94,95], permitting openness to the unexpected in narrative research [96]. Therefore, to select these points, the conversation with Futerman determined when one aspect of the process began and ended. Deciding the beginning and end of the pivotal points is relevant to aiding a participant in reducing their burnout because it places the creation of (in this case) the graphic memoir into a story, with chapters of the story represented by the pivotal points. Structuring thoughts about creating a graphic memoir into a story is relevant based on the ability of this process of writing one's experiences to reduce anxiety and depression [97]. In this regard, experiences become memorable and meaningful because their subjective value evolves from developing objective coherence [98]. Following identifying the pivotal points is the structured questioning method. The questions range from the most objective and specific to those subjective and more general by following a set order of question-asking—when, where, who, what, how, and why. This technique has value because the perspective developed represents the beliefs [99] Futerman held in making her choices during the creation of her graphic memoir in collaboration with her illustrator and publisher, so what guided these choices is revealed from relationships among the data regarding the pivotal points. The conclusions arise from a qualitative interpretation of the results [100] in response to the posed questions, similar to the method presented by Brooks [78].

2.2. The Narrative Process

For the “when” questions, the materials gathered are the recorded dates. Answers to the “where” questions come from identifying place names where events occurred. “Who” questions provide answers concerning those who participated in the pivotal points of the informal dementia home caregiver. The information to answer “what” questions offers the narrative story concerning prior world knowledge organized as a representation of the information [73]. “How” questions list the details of the process regarding the creation of the graphic memoir. Unique to the process undertaken here is that, in asking these ordered questions, why Futerman undertook to make the decisions she did in collaboration with her illustrator and me (as publisher) is gathered by interpreting the connections among all six of the types of questions asked.

A significant component of this method is that question answers (providing the materials for this study) concern only the particular question asked at any time. For example, although answering a “when” question could include information on where an event occurred, who was there, what happened, how the event came about, and why it occurred, these additional points are addressed only under the relevant section heading. As such, answers to “when” questions are under “when” only, those of “where” questions under “where”, and so on. The purpose is to classify the information clearly to make it easier to identify and permit the development of relevant comparisons.

2.3. The Role of the Facilitator

Positive results regarding a reduction in depression and anxiety associated with burnout using this question-asking process are achievable by a self-directed memoir writer who has become acquainted with the process, as self-direction is found able to reduce depression and anxiety regarding burnout. The intention of presenting the details to follow in the results is to provide the structure of this process for those who can self-direct. However, there is a relative inability to self-direct during burnout [101]. Those most likely to be able to self-direct through a narrative research process are optimistic and possess emotional intelligence and resilience [102]. For those unable to approach this process alone, the role of an empathetic and supportive facilitator in a private group is imperative.

Futerman related my importance in facilitating this process for her in such a group in a 7 November 2024 text to me, as follows: “trying to answer questions in the order of when, where, who, what, how, and why was usually overwhelming and demanding in a way that added more stress to the system at first. I think that what was at play back then was a deep seated trauma that was dormant before and the questions triggered it in ways that were not manageable for me. I think that this was the reason that most of the time, instead of answering the questions I’d write intuitively as if it was a stream of consciousness kind of writing. And what was helpful in the group was having you as a facilitator and feeling a sense of belonging”.

Facilitation, by providing this sense of belonging, was the necessary ingredient in working with this memoir writer to complete this process and produce the following results. A consequence of the necessity of the facilitator in this process is that these results are provided reliably from my perspective as the facilitator. The advice for memoir writers looking to achieve the benefit of this second means for reducing their depression and anxiety related to their burnout, beyond creating the graphic memoir, is to consider whether they can self-direct the narrative process or find it more helpful working with a trusted and empathetic support person.

3. Results

The results are collected from the following sources, representing the following materials: the published graphic memoir [74] (see Figure 1), PsychNews, the weekly newsletter of the Department of Psychiatry, University of Toronto [103], continuous email correspondence between the informal dementia home caregiver and the publisher since 27 November 2015 through this author’s University of Toronto email address, email correspondence between the publisher and the printers, C J Graphics, during the final month of the creation of the graphic memoir, using the publisher’s parent company email address, and email correspondence with Caversham Booksellers during the month when the books were delivered to the bookstore using the email address associated with Tampold Publishing, an article in a peer-reviewed journal [104], a published interview in a peer-reviewed journal [105], the private Facebook group with Futerman initiating the psychoanalytic narratology method starting 18 October 2023, and text messages between this author and Futerman 11–15 May to confirm details of the process. Google Maps provided the calculation of all distances.

The accomplishment of this examination is the structuring of the process of creating the graphic memoir into a story, with “chapters” represented by pivotal points in the narrative of the graphic memoir construction developed in collaboration with Futerman through a psychoanalytic narratology process described in the methods section.

In consultation with Futerman regarding when significant events began and ended, six pivotal points were identified and numbered concerning the graphic memoir:

1. Writing the memoir;
2. Memoir author meeting the illustrator and the publisher;
3. Memoir author explaining the graphic memoir to the illustrator and publisher;
4. Collaborative process of creating the illustrations;
5. Editing the graphic memoir;
6. Publishing the graphic memoir.

The following six tables present these pivotal points concerning when and where they took place, those involved, what happened, how they happened, and the reason for the occurrence. Through questions asked concerning these six pivotal points, reconstruction of the narrative of the informal dementia home caregiver can occur to reduce the memoir author’s burnout as a caregiver, attending to her depression and anxiety.

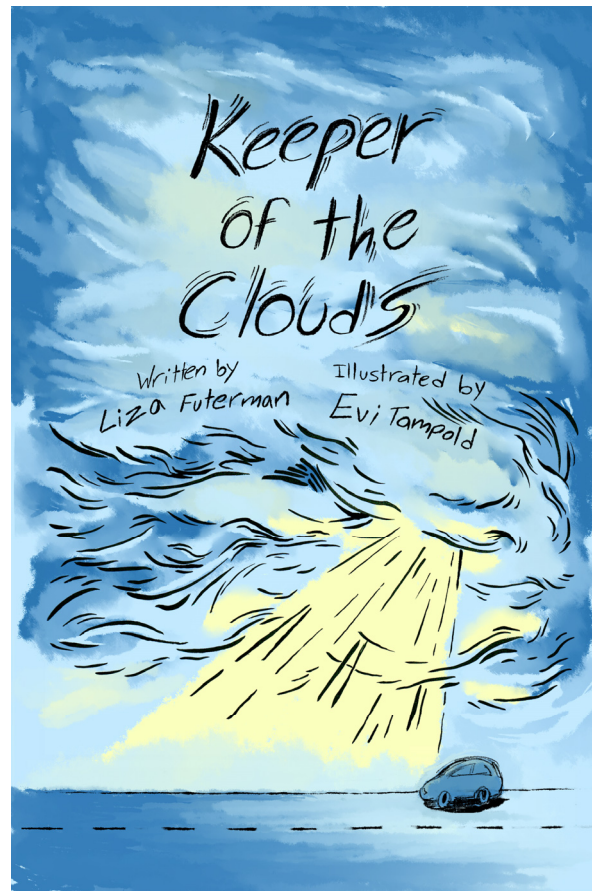


Figure 1. Cover of *Keeper of the Clouds* [72] published by Tampold Publishing, a company owned and operated by me, the author of this article.

3.1. *When the Pivotal Points Occurred*

The initial memoir writing date, until it was available for purchase, represented eleven months. Sunday 15 November 2015 marked the beginning of writing the memoir, two days before the 60th birthday of the mother of the informal dementia home caregiver [105]. Serendipitously, the writer of the memoir, the future illustrator of it, and I, its future publisher, met three days later, on Wednesday 18 November 2015 [106]. We met again on Wednesday 9 December 2015 to discuss collaboration [107]. The graphic memoir collaboration began in January 2016 and lasted until June 2016 [105]. The editing of the memoir between the memoir writer, illustrator, and me, as the publisher, was between June 2016 and August 2016 [108,109]. As the publisher, I organized book printing in September 2016 [110] and the book selling from 30 September to 19 October 2016 [111] (see Table 1).

Table 1. Numbered pivotal point and the date it occurred.

#	Date
1	Sunday 15 November 2015
2	Wednesday 18 November 2015
3	Wednesday 9 December 2015
4	January 2016–June 2016
5	June 2016–August 2019
6	19–29 September 2016/30 September–19 October 2016

3.2. Where the Pivotal Points Occurred

Primarily, pivotal points related to the graphic memoir creation occurred at the apartment of the memoir author, 603-26 St. Joseph Street in Toronto [112]—a 14-min walk east of Massey College, 4 Devonshire Place, Toronto, where the collaborators first met. Most communication occurred by email during the editing of the graphic memoir. The printer was C J Graphics, at 134 Park Lawn Road, an 18-min drive west of the parent company of Tampold Publishing, 87 Avenue Road. The location of Caversham Booksellers, the seller of the graphic memoir, is 98 Harbord St., a 20-min walk west from the apartment of the memoir author (see Table 2).

Table 2. Numbered pivotal point and location it occurred.

#	Location
1	26 St. Joseph Street. Apt. 603., Toronto
2	Upper Library, Massey College, 4 Devonshire Place, Toronto
3	26 St. Joseph Street. Apt. 603., Toronto
4	26 St. Joseph Street. Apt. 603., Toronto
5	Internet
6	C J Graphics, 134 Park Lawn Rd. Toronto/Tampold Publishing parent company, 87 Avenue Rd., Toronto/Caversham Booksellers, 98 Harbord St., Toronto

3.3. Who Was Involved in the Pivotal Points

A direct inspiration for Futerman to write her memoir was her rereading of *Tangles: A Story About Alzheimer's My Mother and Me* by Sarah Leavitt [64] just before beginning her writing [103]. Involved in discussing the possibility of Evi Tampold illustrating *Keeper of the Clouds* as a graphic memoir were Futerman, Tampold, and me (Nash) while waiting in line at a book signing for Green [105]. The former three discussed what would be involved in the collaboration after Tampold agreed to create the illustrations, and I consented to edit and publish the work through Tampold Publishing [105]. Once work began on the graphic memoir, Futerman and Tampold met regularly [105]. Editing the graphic memoir concerned discussions between Futerman and Tampold [105] and later, those with me [108]. To print the graphic memoir, I contacted Dort [110]. He assigned the printing to Medan [110]. Following printing and delivery, I communicated with Adelaars for book sales [111] (see Table 3).

Table 3. Numbered pivotal point and who was involved.

#	Who Was Involved
1	Sarah Leavitt, rereading <i>Tangles: A Story About Alzheimer's, My Mother and Me</i>
2	Liza Futerman, Evi Tampold, Carol Nash PnD, Mike Green MD
3	Liza Futerman, Evi Tampold, Carol Nash
4	Liza Futerman, Evi Tampold
5	Liza Futerman, Evi Tampold, Carol Nash
6	Boris Medan/Brian Dort, CJ Graphics Carol Nash/ Joe Adelaars. Caversham Booksellers

3.4. What Occurred in the Pivotal Points

Creating the graphic memoir represented writing a testimony of 'a day in a life' regarding the graphic memoir author as an informal dementia home caregiver of her mother experiencing dementia [105]. At the first meeting of the graphic memoir author, illustrator, and me, the publisher, we looked at the previously created graphic memoir of the illustrator, *The Hallway Closet* (see Figure 2) [113], brought to the book signing to show to the guest

panelist as a well-known author regarding graphic medicine publications [56,114–116]. The collaboration offers occurred, leading to its result [105]. A significant moment during the collaboration was the consideration by the graphic memoir author and the illustrator of what was to be the expression of time. The decision was that it should represent an empty signifier in the illustration (see Figure 3) [105]. Once complete, the graphic memoir author and illustrator concentrated on finding the proper facial expression to express less anger (see Figure 4a,b) [117]. With printing initiated by me, errors found by the printer in the text and page setup required correction [110]. Printing of the book resulted in delivery to the parent company of the publishing company [110] and, following discussions between the bookseller and me [111], subsequent delivery to the bookstore for immediate sale on consignment (see Table 4).

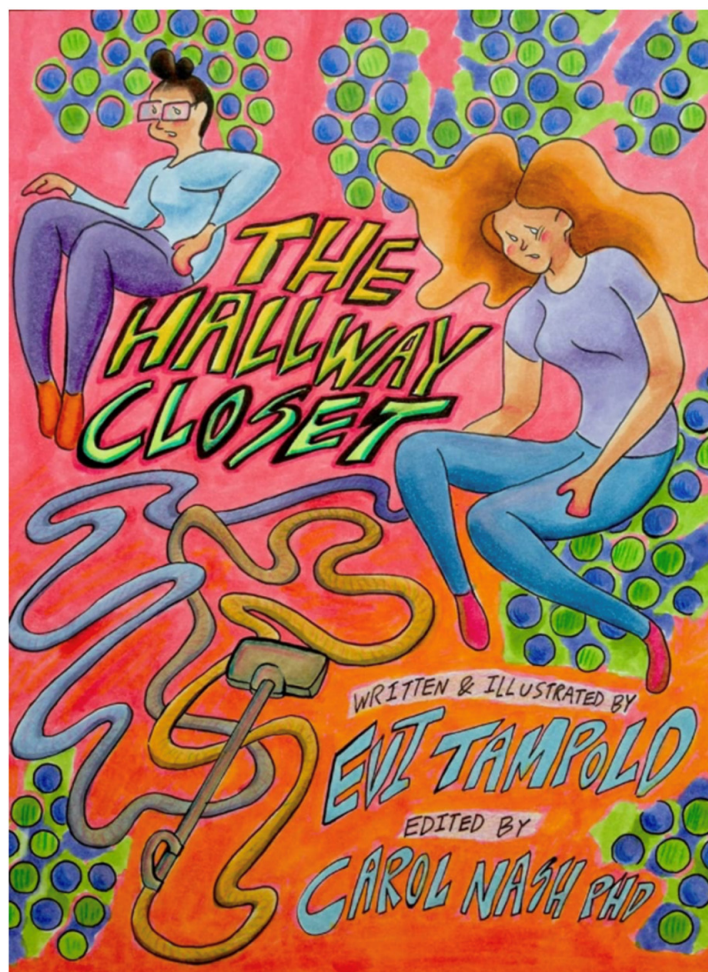


Figure 2. Cover of *The Hallway Closet* [113] published by Tampold Publishing, a company owned and operated by me, the author of this article.

Table 4. Numbered pivotal point and what it affected.

#	What Was the Pivotal Point
1	Writing a testimony of ‘a day in a life’
2	Discussing <i>The Hallway Closet</i>
3	Offer of collaboration
4	Expressing time as an empty signifier in the illustration
5	Changing expression on page 3 to not show anger/errors found
6	Book is printing, delivered, and transported to the bookstore



Figure 3. Bottom half of page 5 of *Keeper of the Clouds* [72] published by Tampold Publishing, a company owned and operated by me, the author of this article.



Figure 4. (a,b) Bottom half of the original page 3 of *Keeper of the Clouds* is on the left, and the final version of the bottom of page 3 (published by Tampold Publishing, a company owned and operated by me, the author of this article), is on the right [72].

3.5. How the Pivotal Points Occurred

The graphic memoir was written in one sitting, taking four to five hours to complete [105], using a stream of consciousness [118] or somatic writing [119]. By attending the Comics and Healthcare Panel [103], the graphic memoir author, illustrator, and I, the publisher, were able to meet in the book signing line [105]. The offer of a homecooked meal began discussions regarding the graphic memoir [105]. During the creative collaboration, the most memorable point was the extended discussion between the author and the

illustrator regarding the philosophical implications of time [105]. Editing of the graphic memoir depended on collaborator discussions [105]. Similarly, discussions at the print shop between me and the printer determined the additional editing [110]. The final printing, delivery to me [110], and transport to the bookseller [111] were completed through continuous email contact, often more than once a day (see Table 5).

Table 5. Numbered pivotal point and how it happened.

#	How It Happened
1	4 or 5 h of stream of consciousness or somatic writing
2	Attended the Comics and Healthcare Panel
3	Home cooked meal
4	After a long discussion about the philosophical implications of time
5	In discussion between author and illustrator/publisher and printer
6	Continuous email contact

3.6. Why the Pivotal Points Occurred

The writing of *Keeper of the Clouds* was to express and communicate grief, gratitude, and joy regarding the 60th birthday of the mother of the graphic memoir author [105]. Attendance was possible at the Comics and Healthcare Panel as the Illustrator in Residence in the Faculty of Medicine, University of Toronto [114,116], organized the event [103]. The informal dementia home caregiver (memoir author) was interested in attending this event as a fan of graphic medicine memoirs and finding a way for her story to reach as many people as possible [105]. The author of the memoir focused on the meaning of time conveyed in her memoir because the images and words combination required a powerful effect [105]. The facial expression required alteration because the graphic memoir author considered the picture too harsh [105]. Changes were made to the book during printing because of identified errors and the requirements for printing by the printing company [110]. The accomplishment of printing, delivery to me, and transportation to the bookseller resulted because the graphic memoir author is an advocate for culture change regarding dementia care, and she considered that having her book available for purchase would be an effective way to encourage this culture change [105] (see Table 6).

Table 6. Numbered pivotal point and why it happened.

#	Why It Happened
1	Express and communicate grief, gratitude, and joy at mother's 60th birthday
2	Organized by Illustrator In Residence, Faculty of Medicine
3	Fan graphic medicine memoirs/wanted to have her story reach the most people possible
4	Combination of images and words required a powerful effect
5	Facial expression considered too harsh/errors and the requirements for printing
6	Advocate for culture change in dementia care by purchasing the book

4. Discussion

The discussion has five parts. The first examines in what way writing and publishing *Keeper of the Clouds* met the intention of the memoir author to reconstruct the narrative regarding informal dementia home caregiving and, concomitantly, in what way it meets the five requirements for a successful intervention to reduce the burnout of the memoir author by decreasing depression and anxiety. Psychoanalytic narrative research is appraised in the second part as the historical method to examine the six pivotal points of creating the graphic memoir related to its author from my perspective as its publisher and to provide an

additional means for reducing informal dementia home caregiving. Next are the limitations of this study. Offered then are future publishing directions for *Keeper of the Clouds*. Finally, consideration is to future research directions.

4.1. Meeting the Intention and the Five Requirements

The intention of Futerman in writing her memoir was to improve the narrative associated with informal dementia home caregiving, taking the focus away from the negative aspects depicted in popular culture [20] and presenting a moment between the mother experiencing dementia and the daughter relating the story. It is one where the daughter sees the poetic semblance of what her mother says when referring to a bird on a wire as the keeper of the clouds. Futerman uses the graphic memoir as a vehicle to present all the problems associated with informal dementia home caregiving but, at the same time, demonstrates that the relationship has times that can make the caregiver feel that the commitment is worthwhile by helping the caregiver become more flexible in appreciating and accepting the relationship—both are necessary ingredients to reducing burnout in informal dementia home caregivers [4,5,120,121]. A unique ingredient in *Keeper of the Clouds* not studied in previous research on graphic memoirs is the value that comes from retelling the story of a poignant moment between the relative experiencing dementia and the caregiver to another family member participating in providing home caregiving. This importance of social support in reconsidering the narrative associated with dementia home caregiving cannot be overlooked [19].

The first of the five requirements for an intervention to successfully reduce the depression and anxiety that accompanies burnout in informal dementia home caregiving is that the intervention be long-term. Although most interventions regarding these home caregivers are four months or less [3], writing, illustrating, and publishing *Keeper of the Clouds* involved 11 months. Furthermore, although not the focus of this study, the book has continued to be relevant to its author in her ability to recount the story to other informal dementia home caregivers [105].

Secondly, the importance of keeping the dyad together in tailoring the intervention to the relationship, recognized in a 2017 systematic review [41], has been stressed in a recent publication [42]. Writing, illustrating, and publishing *Keeper of the Clouds* enhanced the relationship between mother and daughter by bringing joy to both and simultaneously strengthened the relationship between Futerman and her father as mutual home caregivers when she retold the story of what had happened between her and her mother that day at the dinner table (see Figure 5).

As a stream-of-consciousness piece [118] created by engaging in somatic writing [119], the writing of the graphic memoir was mindfulness-based—the third requirement to meet for a successful intervention to reduce the depression and anxiety associated with burnout from informal dementia home caregiving [29]. An activity requiring deep conversations between the memoir author and illustrator, “mindfulness in the classroom” [122], is a name provided about the importance of this type of deep listening. A study has found that using picture books in the classroom is a means to develop these deep conversations, creating this type of mindfulness [123] and reflecting the value of graphic memoirs. Thus, the mindfulness inherent in publishing this graphic memoir can extend beyond those involved to the readers of *Keeper of the Clouds* in helping to reduce their burnout associated with informal dementia home caregiving.

Acceptance and Commitment Therapy is recognized as the gold standard for successful interventions concerning these caregivers in providing psychosocial assistance [5]. It is notable that improvement in acceptance and commitment does not demand formal therapy [124]. Each stage of creating *Keeper of the Clouds*—the writing, illustrating, and publishing of the graphic memoir—was considered by Futerman to enhance her commitment to the informal home caregiving of her mother and reaffirm her acceptance of what she experienced in this regard in bringing together her mother’s story as a complete and positive narrative [105].

Later that evening, at the kitchen table at my parents' home, I tell mom and dad about mom's poetic interjection on the way to the doctor's office.



Figure 5. The bottom half of page 12 of *Keeper of the Clouds* [61]—a publication of Tampold Publishing, a company owned and operated by me, the author of this article.

For any physical activity to promote physical health, the thoughts and emotions of the informal dementia home caregiver must be involved through being freely chosen, inherently social, spatially situated, and political [52]. Futerman did not use exercise [125] as a physical activity; however, creating the graphic novel meets the criteria of a physical activity promoting physical health in every way. Writing, illustrating, and publishing the graphic memoir were each freely chosen, connecting Futerman's thoughts and emotions regarding her informal dementia home caregiving. Collaborating with Tampold and me (Nash) to illustrate and publish the graphic memoir made the activities inherently social. Furthermore, as most activities occurred in Futerman's home or proximity, it was spatially situated. Finally, this graphic memoir intends to reconstruct the narrative regarding information about dementia home caregiving. Thus, this work was envisioned and enacted as political to promote a more positive narrative regarding dementia home caregiving.

From Futerman's perspective, the writing, illustrating, and publishing of *Keeper of the Clouds* significantly reduced her depression and anxiety concerning the burnout she experienced as an informal dementia home caregiver until the time of her mother's death. A 6 November 2024 text to me offers the insight of Futerman. "This was the first time I acknowledged that one of the feelings that I was repressing during the caregiving period was sadness. I was afraid to feel sad during that time, however, the writing and the time given for reflection granted me with the opportunity to acknowledge the sadness and sit with it for the first time in many years. I think it was then that I started my journey of healing the caregiver's trauma and attending to my burnout (not yet naming it this way)". The points discussed above offer the reasons for this result in creating *Keeper of the Clouds*.

4.2. *Psychoanalytic Narrative Research as the Historical Method*

According to Brooks, when describing psychoanalytic narrative research, “the relation of teller to listener is inherently part of the structure and the meaning of any narrative text, since such a text (like any text) exists only insofar as it is transmitted, insofar as it becomes part of a process of exchange” [78]. From this perspective, I am, as the publisher of the graphic memoir, fundamental to this historical method. Psychoanalytic narratology is the historical research that recognizes and depends on this privileged position regarding the story. To create the graphic memoir, the participants in the historical account were each dependent on the publisher. Thus, I needed to act with appropriate professionalism and empathy to ensure the continuation of the graphic memoir process and develop a meaningful account. In this way, the graphic memoir represents a more specific example of narrative memoir as “a genre that resembles the psychoanalytical clinical case construction, in as much as it considers the subjective and political dimensions that pervade the unconscious processes” [80].

In providing the historical account, as the graphic memoir publisher, I use a process for “the making of an intelligible, consistent and unbroken narrative” [78]—a method of psychoanalytic narrative research developed by the author in 2015 specifically to help health researchers experiencing burnout reenergize their relationship to their work through responding to a series of questions from those that are most objective to those increasingly more subjective. This type of method has been found to be successful in decreasing depression and anxiety because of the structure it provides to memory [98]. The result is to produce a coherent narrative providing the relationship of the researchers to their work regarding their burnout, one that coincides with being “about plots and plotting, about how stories come to be ordered in significant form, and also about our desire and need for such orderings” [126]. The results of this method have been presented in various publications by this author over the last few years [89–93]. What differs between the previously published narrative research process undertaken over 28 weekly sessions and the psychoanalytic narrative research undertaken in this work is the importance of pivotal points to the account [94,96] representing the “chapters” of the narrative. It is because the focus is on pivotal points in contrast to a focus on the questions asked that the narrative has inherently increasing order over the stream-of-consciousness accounts that participants provide in the health narratives research groups that have provided the content of the past publications. As stated by Chambers, “. . . meaning is precisely the perception of a relationship between discourse and its context (however difficult it may be, in purely formal terms, to distinguish one from the other)” [79]. In using pivotal points, the when, where, who, what, how, and why questions asked have a clear and distinct focus, becoming self-evident.

Six pivotal points were identified. There were six and not five, seven, or any other number because, at the six points identified, the making of the graphic memoir took a different direction when considering the intention and the requirements for lessening the burnout of the graphic memoir author. This change in direction equates them to the narrative chapters in constructing the graphic memoir. Thus, although the perspective that provides this account is mine as the publisher, the story is told regarding the graphic memoir author, explaining why, even though printing and organizing the sale of the graphic memoir included distinct pivotal points to the publisher, the grouping is relevant to the graphic memoir author. Futerman’s intention and the requirements for lessening her burnout represented a combination of getting her graphic memoir to the public—Futerman’s only interest regarding these aspects. Concerning the illustrations and the editing, each was over an extended period, yet there was a selection of only one pivotal point for mention. In the case of the collaboration in developing the illustrations, that point was the creation of the drawing related to time. Regarding the editing process, it was with a reconsideration of the illustration of Futerman’s facial expression. In both cases, the decisions made to produce these drawings created a change in direction in the graphic memoir in a way that was influential to realizing Futerman’s intention and concerning

confronting her burnout—representing the fundamental reasons why six pivotal points were the optimal number to select for this psychoanalytic narrative research.

A reason for using psychoanalytic narratology for this study is to recount the narrative involved in creating the graphic memoir to help reduce burnout in the informal dementia caregiver. Futerman was undecided regarding her future when this author initially discussed writing a manuscript regarding the process of publishing *Keeper of the Clouds*. After participating in the final question-asking regarding this narrative process, Futerman applied for a grant to research mixed-abilities dance as a therapeutic form in rehabilitating trauma and non-apparent disabilities through a palliative model, which she successfully received. In a 13 June 2024 message to the author, Futerman expressed how happy she was to receive this grant as it was a small step in integrating people with apparent disabilities into programs accommodating individuals with non-apparent disabilities [127]. Futerman was thankful for the opportunity to discuss the relevance of the graphic memoir with me as this discussion using psychoanalytic narratology was able to put the process of writing the graphic memoir into perspective to the extent that she felt reenergized to creatively refresh her work in improving the narrative regarding informal dementia home caregiving from a new and more inclusive perspective.

As the second means for reducing the depression and anxiety associated with burnout from dementia home caregiving, using this particular version of psychoanalytic narratology must be compared with the five requirements for a successful intervention. It must be the following. (1) Long-term; (2) tailored to keep the dyad together; (3) mindfulness-based; (4) a means providing psychosocial assistance; and (5) freely chosen, inherently social, spatially situated, and political.

Determining the pivotal points and asking questions of Futerman extended over six months—the agreed standard for a successful intervention [34]. However, the reason for developing the structure and answering these questions is that these results are available to Futerman at any time. The 6 November 2024 text to me provides additional insight by Futerman. “Of course it was not a singular event but a series of events that led to the realization I should go back to the feeling body. This is the genesis of how I arrived into the sphere of mixed abilities contact improvisation and somatic learning and arts practices”. In this way, it is an intervention with no end date—one to which she can always return.

Regarding keeping the dyad together, when Futerman underwent this narrative process, it was after the death of her mother. Nevertheless, in determining what was valuable to her in this narrative process concerning the creation of *Keeper of the Clouds*, Futerman was able to experience a sense of closure that would have been unavailable to her without the intervention. Engaging in this process was mindfulness-based and permitted acceptance of what happened to her mother, as well as reenergizing Futerman’s commitment to reducing the negative narrative of dementia home caregiving. Finally, the choice of intervention was free and inherently social. As Futerman and I no longer live on the same continent, the possibility to conduct this intervention over the Internet permitted it to be spatially situated, and, in reinvigorating Futerman’s academic and practical work in this area, it was political. As such, the second intervention process meets these five requirements of a successful intervention.

4.3. Limitations

The first limitation of this study is the incomplete record of what transpired among the memoir author, illustrator, and me, as the publisher, as much of the collaboration was in person. Also missing is a comprehensive record of conversations between me and the printer and between me and the bookseller, as in-person and telephone conversations completed many printing and selling instructions. This study might have included a more extensive account otherwise.

The second limitation is that this account concerns the period of writing, illustrating, and publishing the graphic memoir; it does not include the period immediately before—describing the event between Futerman and her mother that is related in *Keeper of the*

Clouds—or after, regarding the sales of the book, conferences attended by Futerman promoting the book, or other ways that the public has since come to know about the graphic memoir—including its sale in other book stores. As such, the full impact of the graphic memoir on reconstructing the narrative regarding informal dementia home caregiving and aiding the burnout of this informal dementia home caregiver is lacking. The reason for keeping this study within the boundaries of its writing, illustration, and publication is that this research intends to demonstrate that any informal dementia home caregiver can help to change the narrative regarding informal dementia home caregiving and successfully attend to the depression and anxiety that accompanies their burnout by writing a similar graphic memoir. The other details of this particular graphic memoir are both personal to the memoir author and depend on the connections she had made in the academic world. These circumstances are not available to others who might want to create a graphic memoir, nor are they necessary to know to engage successfully in the writing, illustrating, or publishing of their work. Therefore, they are left unmentioned. However, in not providing information on these other aspects of Futerman reducing her burnout, there is a reason for considering that the process of moving the written manuscript into an illustrated and published work and engaging in the narrative process years later individually reduced both Futerman's depression and anxiety related to her burnout. As such, these two means are available to other dementia home caregivers following the method presented here.

Another limitation regards the extent to which the informal dementia home caregiver can positively change the narrative regarding dementia if the efforts to make a change have the possibility of further reinforcing temporal normality. To this extent, one of the aspects of *Keeper of the Clouds* that Futerman and Tampold felt was most compelling in indicating how Futerman's mother experienced time was having each of her eyes reflect a digital clock that is no longer functioning. Although superimposing "00:00" across each open eye of the mother was intended to mean that her dementia entailed that she was no longer seeing time as others do, by using a defective representation of a standard clock—rather than creating some other way of indicating that the mother had her own experience of time—it means that the perspective on the mother's understanding of time still originates from the norm. Though meant to highlight the mother's individuality regarding her view of time, this artistic choice of a digital clock possibly further stigmatizes people with dementia in the unique way they experience time. It may be that to be effective in changing the narrative regarding dementia, graphic memoirs must be written in a non-linear sequence, abandoning the usual focus on time, as does Walrath's graphic memoir [70].

In choosing to study the creation of a graphic memoir to reduce the depression and anxiety associated with burnout in the informal dementia home caregiver by using psychoanalytic narratology, this author has not used other available methods. Significant work in disability studies and dementia studies regarding narrative and graphic memoirs remains unconsidered. A conference paper, *Nothing About Us Without Us: Investigating the Role of Critical Disability Studies in HCI* [128], was instigated from the perspective of graphic memoirs by one of the leading proponents of comics and medicine, Susan Squire [129]. The works of Venkatesan and colleagues have been cited [53,57,66,68,69], representing a developing oeuvre concerning a deepening understanding of the relationship a graphic memoir can have in depicting and narrating dementia. Beyond graphic memoirs, Anne Basting has concentrated on the creative process of memoir development by those experiencing dementia writing in association with their informal dementia caregivers [130]. The author judged psychoanalytic narratology to be most effective in presenting what is entailed in writing, illustrating, and publishing a graphic memoir so that others may attempt the same while simultaneously providing a method to help its author reduce burnout. These are purposes that together cannot be met by other methods.

The final limitation is that, though helpful, creating a graphic memoir cannot be considered a panacea for either changing the narrative regarding informal dementia home caregiving or reducing the depression and anxiety resulting in burnout from such care. Liza Futerman is perhaps the best example of an informal dementia home caregiver who

can create a positive narrative regarding this care and reduce her depression and anxiety, resulting in burnout, by creating a graphic memoir. Still, when her mother's condition deteriorated ten months after the publishing of *Keeper of the Clouds*, Futerman self-reflects, "On the surface, I was abled-bodied, young and capable. But the anxiety attacks and the depression episodes made my thoughts foggy and my memory a blur. I could no longer read or write, nor could I have an intellectual conversation, I was burned out and constantly overwhelmed and I couldn't keep my affairs in order. Ironically, as I was fighting the stigma against people living with dementia, the stigma on mental health issues was very pertinent in my mind, which prevented me from seeking help for a long time" [105]. Ultimately, when her mother died as a result of her Alzheimer's in early 2021 [131] at the age of 65, Futerman became unsure of the personal value of her book. Still, she also stated that the graphic memoir was more significant than its meaning to her personally: "In one way, I had dealt with all the emotions. Also, I sort of had to distance myself from everything as I did it. I wanted it to work as a narrative, I didn't want it to be a personal confession that would not help other people... As time passed, I realised there was a cathartic element to it, though. Perhaps it is no more than feeling as though there was sense to it all, a narrative, even if one I imposed on it" [105]. With the help of the process of psychoanalytic narratology presented in this report, Futerman could regain her perspective and happily reestablish her connection to improving the narrative of informal dementia home caregiving. In other words, this type of historical method may be helpful to others who, after creating a graphic memoir, lose their focus as informal dementia home caregivers as a result of the deteriorated condition of their loved one.

4.4. Future Directions in Publishing the Graphic Memoir

Keeper of the Clouds was published in 2016 [110] and reprinted in 2019 [132] by Tampold Publishing. Since then, the memoir author has received the files for the graphic memoir and is responsible for any further publication. Futerman will now determine in what way she wants to continue to make her graphic memoir available to the public. The purpose is to meet her intention of increasing the positivity associated with informal dementia home caregiving. The hope is to provide an additional opportunity to decrease her depression and anxiety that relates to burnout in this capacity by meeting the five requirements for a successful intervention in this regard. There are two directions that Futerman might pursue in meeting these objectives. The first is to create her own publishing company to publish the graphic memoir. The second is to make the graphic memoir into a zine.

The 1989 seminal work on starting a publishing house is the creation of Bloomsbury Publishing in London [133]. In describing the relevant features of the process, the author highlights the pivotal points and answers when, where, who, what, how, and why questions about them, like the outlined process of assessing the publication of *Keeper of the Clouds*. The author of the 1989 work explains that attending to the answers to each of these questions at specific pivotal points is imperative to creating a successful publishing enterprise. Bloomsbury Publishing is a large internationally-known publishing house. However, if Futerman creates her own publishing company to produce *Keeper of the Clouds*, it need not require such an investment of time, energy, and capital. A 2004 book on creating your own publishing house informs readers that, by using a home computer and printer, anyone can start their own profitable publishing house [134], including registering an International Standard Book Number (ISBN) [135] for each publication. A 2004 review relates that the book "could save much grief and money for technical communicators considering publishing their own books" [136].

In contrast, if Futerman does not want to invest in developing a publishing house to republish *Keeper of the Clouds*, a zine may meet the intention and serve as an intervention for burnout reduction. Zines are low-budget self-published non-profit print publications originating from fan works that serve as significant communication means for various subcultures. They are a mainstay of a personally empowering creative movement to express personal and political narratives [137]. Zines represent a community archive to "strengthen

marginalized voices in the dominant culture through community-building and political resistance” [138]. In providing this DIY anti-mainstream positioning, ethos, and aesthetic, zines present an intimacy and an intensity unavailable through traditional publishing houses [139]. Questioning whether producing a zine would provide a similar level of serious consideration provided to *Keeper of Clouds* as a publication through a publisher, a 2020 study noted that between 1990 and 2018, scholarly interest in zines increased steadily by 1700%, with scholarship being provided most consistently in the fields of Library Science, Education, Feminist Studies, and Media Studies, concluding that “zines are influential and worthy objects of study, not just as a form of print media, but as educational and pedagogical tools in the classroom, as evidence of activism, political movements, third-wave feminism, cultural critiques, cultural movements, and much more” [140].

4.5. Future Research Directions

Research regarding the effect of producing a graphic memoir on decreasing burnout in informal dementia home caregivers is in its infancy. Most recently, the introduction in a more general book on caregiving in fiction, film, and memoir mentions graphic memoirs but does not develop the theme [141] (p. 6). Although a 2016 publication examines many of the graphic memoirs published by that time regarding the role of the caregiver, the focus is not on their effect in reducing caregiver burnout [142]. The most relevant work investigating burnout in dementia home caregivers is a master’s thesis that looks at the role of art therapy—it does not consider graphic memoirs [143]. In this regard, the opportunities to research this area are extensive. Furthermore, using psychoanalytic narrative research as the historical method to conduct the investigation would build upon this work. Research such as determining if the findings replicate these results would be valuable.

Beyond the negative discourse about home caregiving, future research would be valuable regarding enhanced coping methods and additional public discussion regarding the humorous and poignant aspects of caring for someone who sometimes wonders who you are or considers that pigeons are cloud keepers. Research on the broader visibility of dementia, its human dimensions, and the support and well-being of caregivers in creative forms is as valuable as improving the negative discourses concerning home care. Part of this future research must include the effect of engaging with graphic memoirs to help decrease depression and anxiety in readers experiencing trauma. There is little recent research in peer-reviewed journals on this topic; however, what is available points to the relevance and significance of graphic memoirs in this regard [144–146].

5. Conclusions

Informal dementia home caregiving requires acceptance and commitment. To sustain these, the narrative related to caregiving needs positive reconstruction and a means of reducing the associated depression and anxiety of the caregiver that can come from burnout. For their success, interventions must have the following qualities. (1) Relatively long-lasting, (2) tailored to the circumstances of the caregiving relationship, (3) mindfulness-based, (4) providing psychosocial assistance, and (5) containing a component that attends to the physical health of the caregiver. One intervention that improves the narrative regarding informal dementia home caregiving and meets these five criteria is writing and illustrating a publishable graphic memoir by the informal dementia home caregiver. The assessment included how six pivotal points in writing, illustration, and publishing the graphic memoir were affected using a unique version of psychoanalytic narrative research as the historical method. Then, engaging in this historical method offered another opportunity for the informal dementia home caregiver to reduce burnout.

For the informal dementia caregiver of this study, the publication of a physical book was the result. Although published by a publisher, this is not imperative to meet the intention and result in a successful intervention. One option is for the graphic memoir author to develop a personal publishing house. Another alternative is to publish the graphic memoir as a non-profit zine. The chosen option should promote a positive reconstruction

of informal dementia home caregiving that meets all the requirements of a successful intervention while maintaining quality care for the relative experiencing dementia.

Future research in this area could compare the difference between the success of published graphic memoirs to zines in improving the narrative of informal dementia home caregiving and reducing the depression and anxiety resulting from burnout. Making use of the research method of psychoanalytic narrative research to question graphic memoir authors about their experiences provides another avenue for study to determine if this historical method consistently reduces the depression and anxiety of informal dementia home caregivers that characterizes their burnout. Additionally, research on improving the negative discourse regarding informal dementia home caregiving can take an indirect approach by focusing on the positive aspects of support and well-being of caregivers in creative forms.

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