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*Article*

# Graphic Memoir Creation for Reconstructing the Dementia Narrative While Reducing Depression and Anxiety Associated Burnout in Informal Dementia Home Caregiving

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**Abstract:** Informal dementia home caregiving is viewed negatively and can result in caregiver depression and anxiety from burnout, potentially compromising caregiving. Solutions are unclear, as caregiving relationships are unique—caregiver creation of a graphic memoir may help to mitigate the negative dementia narrative and reduce experienced burnout. This investigation examines the writing of a graphic memoir by one informal dementia home caregiver, created with the help of a cartoon illustrator and a publisher who edited, printed, and made the graphic memoir available at the psychiatric bookstore considered the largest in North America. Mother of the illustrator and the editor and publisher of this graphic memoir, this author provides the perspective taken in this investigation. The analysis, developed by this author, represents psychoanalytic narrative research, serving as the historical method. Aided by email threads between the publisher/caregiver, publisher/printer, and publisher/bookseller, and a published interview with the dementia caregiver are answers to how writing, illustrating, and publishing the graphic memoir affected the caregiver's narrative reconstruction and burnout. Providing an example for other informal dementia home caregivers similarly to write and illustrate a publishable graphic memoir for their positive narrative reconstruction and to help decrease their depression and anxiety from burnout is the aim.

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

## 1. Introduction

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 10-20 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 towards 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 acknowledged for their work by those who are empathetic to their situation [21], and these views are advanced by their publication [22].

Burnout is a work-related syndrome characterized by emotional exhaustion, feelings of cynicism, and reduced personal accomplishment [23], first recognized in 1974 [24]. Although a recent review of the literature has concluded that there is 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. These are also evident in burnout. Compromised self-esteem, another factor of depression, is not usually found in burnout [25]. However, for informal dementia home caregivers, compromised self-esteem can result [26], 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 [27]. Anxiety is feelings of tension and worry, demonstrating physical symptoms like palpitations [28]. 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 [29].

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 identified as improving caregiver acceptance and commitment to caregiving. Another review notes that only psychoeducation can significantly reduce anxiety [30]. Yet anxiety reduction is not the focus of most interventions [31], 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 [32]. 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]. 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 the following—(1) be relatively long-lasting, (2) tailored to the circumstances of the caregiving relationship, (3) mindfulness-based, (4) provide psychosocial assistance, and (5) contain a component that attends to the physical health of the caregiver.

Graphic memoirs are autobiographical narratives on mental illness expressed through comics [49]. An informal dementia home caregiver creating a graphic memoir is not new. *Special Exits* of 2010, written by Joyce Farmer [50], concerns more than the negative aspects of the experience [51]. Sarah Leavitt's 2011 graphic memoir, *Tangles: A Story about Alzheimer's, My Mother, and Me* [52], is considered by the public and Alzheimer's associations in various countries as a sensitive and honest depiction of this form of dementia [53]. Since its publication, writing a graphic memoir has increasingly become a means by which caregivers can conceptualize their experiences regarding dementia [54]. 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 [55]. Re-examining the lived experiences of these caregivers from being undervalued and disregarded is also relevant to the purpose of graphic memoirs [56], such that care is depicted as a laudable creative practice [57]. For 2016 works like Dana Walrath's *Aliceheimer's: Alzheimer's Through the Looking Glass* [58] and *Wrinkles* by Paco Roca [59], graphic memoir seeks to restore the personhood of demented family members [60], taking their perspective and presuming their competence [51].

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 [61] and published through Tampold Publishing—a company started by Evi's mother (the author of this article) 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.

This study examines the process Futerman underwent in creating, illustrating, and publishing her graphic memoir from the perspective of her publisher to provide insights into in 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. It also acts as an example for other informal dementia home caregivers to similarly create graphic memoirs to reduce their burnout and simultaneously improve the care they can give to their family members experiencing dementia—done 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 the author (comparable to recent narrative research directions [62,63]) that examines varying perspectives of Futerman's constructed story to make her experience understandable [64] to the extent that other informal dementia home caregivers can use this examination to create their graphic memoir. In this way, data are examined as stories regarding the relationship of Futerman's actions to their occurrence in a social context [65] from the perspective of her publisher. An examination of Futerman's data as stories is a history taking in the psychoanalytic narratology tradition, noted by Fludernik [66] as a form of narrative research originated in the mid-1980s with works by Brooks [67] and Chambers and Godzich [68] to investigate concealed aspects of the data to portray an individual's history [69]. Narratology is a recognized humanities discipline studying the practices, principles, and logic of narrative [70], continuing its relevance to current authors as “chrononarratology” [71] and narrativity concerning historical theory [72], recognizing history and narrative methodologies as interdisciplinary [73]. The author employs the method in previous publications [74–78] and develops Futerman's story regarding her graphic memoir into a narrative with a particular point of view in response to questions posed regarding her graphic memoir. These range from those that are the most objective and specific to those that are subjective and more general by following a set order of question-asking—when, where, who, what, how, and why—concerning six identified pivotal points regarding the creation of the graphic memoir, where “pivotal” means that the graphic memoir development took a different course at the specific point [79]. This technique has value because the perspective developed represents the beliefs [80] 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 collection of data. The conclusions arise from a qualitative interpretation of the results [81] in response to the posed questions, similar to the method presented by Brooks [67].

### 2.1. The Narrative Process

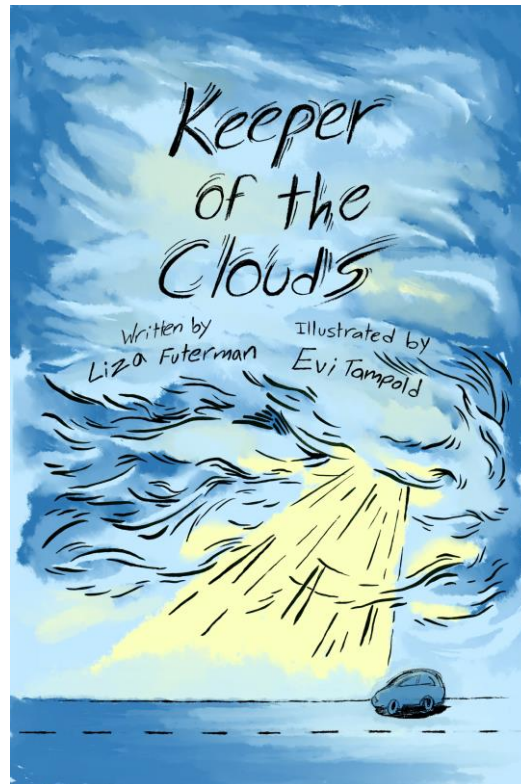
For the “when” questions, the materials gathered are the recorded dates. Answers to the “where” questions come from identifying place names where events occurred. “Who” questions



provide answers concerning those who participated in the pivotal points of the informal dementia home caregiver. The information to answer “what” questions provides the narrative story concerning prior world knowledge organized as an extensive representation of the information [62]. “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 publisher is gathered by interpreting the connections among all six of the types of questions asked.

Collected from the following sources are the materials: the published graphic memoir [61] (see Figure 1), PsychNews, the weekly newsletter of the Department of Psychiatry, University of Toronto [82], 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 [83], a published interview in a peer-reviewed journal [84], and text messages between this author and Futerman 11-15 May 2024 to confirm details of the process. Google Maps provided the calculation of all distances.

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.



**Figure 1.** Cover of *Keeper of the Clouds* [61] published by Tampold Publishing, a company owned and operated by the author of this article.

### 3. Results

Six pivotal points are identified and numbered regarding the creation of the graphic memoir in positively reconstructing the narrative of informal dementia home caregiving and reducing the memoir author's burnout as a caregiver through attending to her depression and anxiety:

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 six tables to follow present these pivotal points concerning when and where they took place, those involved, what happened, how they happened, and the reason for the occurrence. In narratology, pivotal points cause the creative direction of the graphic memoir to change because of the occurrence [85], permitting openness to the unexpected in narrative research [86].

### 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 [84]. Serendipitously, the writer of the memoir, the future illustrator of it, and its future publisher met three days later, on Wednesday, 18 November 2015 [87]. The three met again on Wednesday, 9 December 2015, to discuss collaboration [88]. The graphic memoir collaboration began in January 2016 and lasted until June 2016 [84]. The editing of the memoir between memoir writer, illustrator, and publisher was between June 2016 and August 2016 [89,90]. The publisher organized book printing in September 2016 [91] and the book selling from 30 September to 19 October 2016 [92] (see Table 1).

**Table 1.** Numbered pivotal point and 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 [93]—a 14-minute 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-minute 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-minute 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
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3.3. Who Was Involved in the Pivotal Points

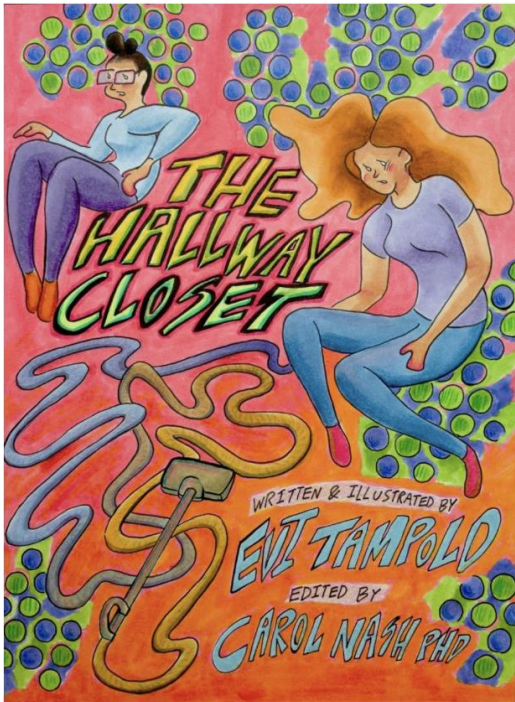
A direct inspiration for Futerman to write her memoir was her rereading of *Tangles: A Story About Alzheimer’s My Mother and Me* by Sarah Leavitt [52] just before beginning her writing [84]. Involved in discussing the possibility of Evi Tampold illustrating *Keeper of the Clouds* as a graphic memoir were Futerman, Tampold, and Nash while waiting in line at a book signing for Green [84]. The former three discussed what would be involved in the collaboration after Tampold agreed to create the illustrations and Nash to edit and publish the work through Tampold Publishing [84]. Once work began on the graphic memoir, Futerman and Tampold met regularly [84]. Editing the graphic memoir concerned discussions between Futerman and Tampold [84], and later those with Nash [89]. To print the graphic memoir, Nash contacted Dort [91]. He assigned the printing to Medan [91]. Printed and delivered, Nash was in communication with Adelaars for book sales [92] (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 [84]. At the first meeting of the graphic memoir author, illustrator, and publisher, the three looked at the previously-created graphic memoir of the illustrator, *The Hallway Closet* (see Figure 2) [94], brought to the book signing to show to the guest panelist as a well-known author of regarding graphic medicine publications [95–98]. The collaboration offers occurred, leading to its result [84]. 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) [84]. Once complete, the graphic memoir author and illustrator concentrated on finding the proper facial expression to express less anger (see Figure 4a and Figure 4b) [99]. With printing initiated by the publisher, errors found by the printer in the text and page setup required correction [91]. Printing of the book resulted in delivery to the publisher’s parent company [91] and, following discussions between the bookseller and publisher [92], subsequent delivery to the bookstore for immediate sale on consignment (see Table 4).



**Figure 2.** Cover of *The Hallway Closet* [94] published by Tampold Publishing, a company owned and operated by the author of this article.



**Figure 3.** Bottom half of page 5 of *Keeper of the Clouds* [61] published by Tampold Publishing, a company owned and operated by 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 the author of this article), is on the right [61].

**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

3.5. How the Pivotal Points Occurred

The graphic memoir was written in one sitting, taking four to five hours to complete [84], using a stream of consciousness [100] or somatic writing [101]. By attending the Comics and Healthcare Panel [82], the graphic memoir author, illustrator, and publisher were able to meet in the book signing line [84]. The offer of a homecooked meal began discussions regarding the graphic memoir [84]. During the creative collaboration, the most memorable point was the extended discussion between the author and the illustrator regarding the philosophical implications of time [84]. Editing of the graphic memoir depended on collaborator discussions [84]. Similarly, discussions at the printer between the publisher and printer determined the additional editing [91]. The final printing, delivery to the publisher [91] and transport to the bookseller [92] 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 hours 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 60<sup>th</sup> birthday of the mother of the graphic memoir author [84]. Attendance was possible at the Comics and Healthcare Panel as Prof. Shelly Wall, Illustrator in Residence in the Faculty of Medicine, University of Toronto [95,98], organized the event [82]. The informal dementia home caregiver was interested in attending this event as a fan of graphic medicine memoirs and to find a way for her story to reach as many people as possible [84]. 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 [84]. The expression required alteration because the graphic memoir author considered the picture too harsh [84]. Changes were made to the book during printing because of identified errors and the requirements for printing by the printing company [91]. The accomplishment of printing, delivery to the publisher, 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 [84] (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 Prof. Shelly Wall, (Illustrator In Residence, Faculty of Medicine)
3	fan graphic medicine memoirs / wanted to have 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 considers the five ingredients for success in reducing informal dementia home caregiving. The second 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, meets the five requirements for a successful intervention to reduce the burnout of the memoir author by decreasing depression and anxiety. The third part appraises using psychoanalytic narrative research as the historical method to examine the six pivotal points of creating the graphic memoir related to its author from the perspective of its publisher. Next are the limitations of this study. Finally, offered are future publishing directions for *Keeper of the Clouds*.

##### 4.1. Five Ingredients of Successful Interventions

The following examines the research regarding the five recognized ingredients necessary for a successful reduction in depression and anxiety resulting from burnout in informal dementia home caregivers.

##### 4.1.1. Long-term

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—furthermore, this research is not current [33–35]. 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 [36]. In doing so, any long-term intervention must anticipate that the burden on the home caregiver will increase with time [37].

##### 4.1.2. Tailored

A 2017 systematic review of the topic of the caregiving dyad [38] 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 don't consider the importance of maintaining this relationship. By 2021, researchers had noted that the number of publications regarding support for the dyad had increased [39]; 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 [40], finding that enrichment in the relationship depends on communication support and skill-building.

#### 4.1.3. Mindfulness-based

Mindfulness training focuses on attentional control of internal conditions [41]—representing monitoring practiced during episodes of depression and anxiety [42]. 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 [28]. Concerning the range of 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 [43]. A psychoeducational component suggestion to reduce or prevent depressive symptoms is the practice of stretching or aerobic activity for 30-45 minutes daily. Also effective is developing nonreactive and nonjudgmental awareness of present experiences with additional acceptance skills of openness and equanimity and not permitting mind-wandering. The stress of participants decreases with these practices [43].

#### 4.1.4. Psychosocial Assistance

The professionally provided psychosocial intervention producing a reduction in depression and anxiety regarding burnout in informal dementia home caregivers is Acceptance and Commitment Therapy [4,5]. What is crucial to the success of this therapy is that the caregivers accept the changing symptoms of their demented family member and that they fully commit to their role as caregivers through developing psychological flexibility skills [44]. Consequently, flexibility skills development is the basis for acceptance and commitment and, as such, is fundamental to the effectiveness of psychosocial support [45]. A change that develops psychological flexibility skills is likely to result in the informal dementia home caregiver becoming accepting and committed to their role as a caregiver—such a change need not require professional Acceptance and Commitment Therapy [46].

#### 4.1.5. Physical Health

Attending to the physical health of the informal dementia home caregiver can take a variety of forms. Physical activity creates physical health, defined in 1985 as “any bodily movement produced by skeletal muscles that results in energy expenditure” [47]—a definition recently expanded to recognize that physical activity is inherently cerebral and depends on a cognitive and emotional aspect [48]. 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 argued to define it as physically healthy are that it is inherently social, spatially situated, and political [48]. In this way, the experience must be enjoyed and connected with all significant aspects of the informal dementia home caregiver for physical activity to promote physical health.

### 4.2. *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, demonstrate 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 necessary ingredients to reducing burnout in informal dementia home caregivers [4,5,44,45]. 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. Where most interventions regarding these home caregivers are four months or less [3], writing, illustrating, and publishing *Keeper of the Clouds* involved eleven 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 [84].

Secondly, the importance of keeping the dyad together in tailoring the intervention to the relationship, recognized in a 2017 systematic review [38], has been stressed in a recent publication [40]. 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).

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.** Bottom half of page 12 of *Keeper of the Clouds* [61] published by Tampold Publishing, a company owned and operated by the author of this article.



As a stream-of-consciousness piece [100] created by engaging in somatic writing [101], 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 [28]. An activity requiring deep conversations between the memoir author and illustrator, “mindfulness in the classroom” [102], 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 [103]. 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 information dementia home caregiving.

Acceptance and Commitment Therapy is recognized as the gold standard for successful interventions concerning these caregivers [5]. Noted is that improvement in acceptance and commitment does not demand formal therapy [46]. 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 [84].

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 [48]. Futerman did not use exercise [104] 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 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.

#### 4.3. 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” [67]. From this perspective, this author, as the publisher of the graphic memoir, is 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, the publisher needed to act with appropriate professionalism and empathy to ensure the continuation of the graphic memoir process and to 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, inasmuch as it considers the subjective and political dimensions that pervade the unconscious processes” [69].

In providing the historical account, this author, as the graphic memoir publisher, uses a process for “the making of an intelligible, consistent and unbroken narrative” [67]—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. 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” [105]. The results of this method have been presented in various publications by this author over the last few years [74–78]. 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 [85,86]. 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)” [68]. In using pivotal points, the when, where, who, what, how, and why questions asked have a clear and distinct focus, becoming self-evident.

Identified were six pivotal points. 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. Thus, although the perspective that provides this account is that of 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 considers the graphic memoir author. The reason is, regarding her intention and the requirements for lessening her burnout, they represented a combination of getting her graphic memoir to the public—Futerman’s only concern regarding these aspects. Regarding developing 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 reconsidering the illustration of Futerman’s mouth. In both cases, the decisions made to produce these drawings created a change of 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.

Regarding each of the six questions asked, identified in using the author-devised narrative process to assess the writing, illustrating, and publishing of *Keeper of the Clouds* are the following. The entire process was eleven months, with the bulk of that time devoted to the collaboration between Futerman and Tampold in creating and editing the illustrations, brought to light by the answers to the when questions. As became evident from the where question answers, creating this graphic memoir was centered around Futerman’s home, suggesting that closeness to her home was relevant to the successful culmination of this work. Who question answers reveal that the creation of this graphic memoir depended on Futerman’s recent rereading of Sarah Leavitt’s graphic memoir on her informal dementia home caregiving. These answers also demonstrate that few people were involved in creating this work. One group—Futerman, Tampold, and Nash—operated similarly to a family unit. The other groups were either academics or professionals. The academics were experts in graphic medicine, while the professionals were the representatives of the printing company and the bookseller. What question answers provide a deeper understanding of the relevance to the pivotal points for Futerman in this process. The process is replicable from answers to how questions. They provide information to accomplish a similar result in producing a graphic memoir on this topic. Finally, why question answers offer the motive of Futerman regarding the pivotal points, acting as the culmination of the psychoanalytic narrative research.

#### 4.4. Limitations

The first limitation of this study is the incomplete record of what transpired among the memoir author, illustrator, and publisher, as much of the collaboration was in person. Also missing is a comprehensive record of conversations between the publisher and printer and between the publisher and 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, and publishing of their work. Therefore, they are left unmentioned.

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 Futerma 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*, Futerma 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" [84]. Ultimately, when her mother died as a result of her Alzheimer's in early 2021 [106] at the age of sixty-five, Futerma 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" [84].

#### 4.5. Future Directions in Publishing the Graphic Memoir

*Keeper of the Clouds* was published in 2016 [91] and reprinted in 2019 [107] by Tampold Publishing. Since then, the author has received the files for the graphic memoir and is currently responsible for any further publication of the graphic memoir. Futerma 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 Futerma 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 regarding the creation of Bloomsbury Publishing in London [108]. 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 Futerma 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, using a home computer and

printer, anyone can start their own profitable publishing house [109], including registering an International Standard Book Number (ISBN) [110] for each publication. A 2004 review relates that the book “could save much grief and money for technical communicators considering publishing their own books” [111].

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 [112]. Zines represent a community archive that works to “strengthen marginalized voices in the dominant culture through community-building and political resistance” [113]. In providing this DIY anti-mainstream positioning, ethos, and aesthetic, zines present an intimacy and an intensity unavailable through traditional publishing houses [114]. 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” [115].

## 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. 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 of 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.

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