



Autobiographical accounts of living with dementia: Life story narration as self-care

Valerie Keller, Malte Völk*

University of Zurich, Department of Social Anthropology and Cultural Studies, Affolternstrasse 56, 8050 Zurich, Switzerland

ARTICLE INFO

Keywords:

Age
Dementia
Biography
Self-care
Diaries
Narrative interviews
Agency

ABSTRACT

Based on statements from people with dementia on the positive impact of reflecting on one's own biography, this study examines the ways in which life story narration can help those affected make sense of a disrupted present and a fragmented life characterised by forgetfulness. In this paper we analyse both oral and written accounts of everyday life as told by people living with dementia. In doing so we apply a heuristic based on the notion of key (auto)biographical strands in order to make clear how the individuals in question link their current experience of dementia with previous experiences and thereby revise the way they see themselves. Whether this occurs in an erratic, associative manner or in a more structured and connected fashion, there are varied ways in which people with dementia come to an emotional and cognitive appreciation of their life. The main aim of the analysis is not to establish biographical accuracy but rather to identify elements of self-care: a creative act of appropriating one's own life story, and the communicative presentation of a self-image.

Introduction

While the challenges posed to society by dementia in general are the subject of broad discussion and often presented in the media, this can hardly be said of the people affected themselves. People with dementia – barring important exceptions¹ – are hardly present, heard or visible at all. Biomedical reports on the various shortcomings of people affected by dementia as well as economic scenarios portraying the burden on contemporary society (Grebe, 2019) are the dominant framing. It is primarily nursing or medical professionals and family members who 'represent' people with dementia. Despite the concept of personhood, which has been established in social science discourses on dementia since the 1990s and sees personhood created in "relations and through social being" (Kitwood, 1997), people with dementia continue to be portrayed in media discourses through narratives of loss, absence and regression, that is, as people who increasingly lose their personality and eventually end up as "empty shells" (Grebe, 2015). In perceptions like these, being human is linked to the possession of certain cognitive abilities, leading to the idea that as dementia progresses, those affected increasingly dissolve into nothingness (Fuchs, 2010). In addition, as Schweda and Jongmsa (2018) critically note, metaphorical comparisons

with children are common, fundamentally questioning whether people with dementia are able to make decisions, to maintain maturity, or indeed even to possess citizenship (Brannelly, 2016). In the current context of a crisis in care provision and the stigma associated with dementia, anecdotal evidence suggests that there is a widespread lack of time, patience and openness to listen to or include people with dementia.

Until the late 1980s, most research on dementia focused on facilitating care work. It was not until 1990 that Tom Kitwood's seminal person-centred approach led to a remarkable change: the emphasis was no longer on dealing with an illness, but on the person, whose dignity and integrity should be preserved (Kitwood, 1990; Kitwood & Bredin, 1992a). This recognition of the person with dementia led to a deeper understanding of those affected. Following the path taken by Kitwood and Bredin, scientific studies incorporated the voices of people with dementia as data material, notably Malcom Goldsmith's book *Hearing the Voice of People with Dementia* (1996), which shows that people with dementia have their own voice, that this voice can be heard, and that this voice needs to be integrated into the discourse about dementia (Goldsmith, 1996). Among the many important scientific studies following Kitwood's person-centred approach, those we can build on the

* Corresponding author.

E-mail addresses: valerie.keller@uzh.ch (V. Keller), malte.voelk@uzh.ch (M. Völk).

¹ Publicly visible are and have been, above all, the pioneering Dementia Advocacy and Support Network International (DASNI, active since 2000), dementia activists such as Helga Rohra (Germany), Christine Bryden (Australia), Richard Taylor (USA) or spokespeople from PROMENZ (Austria).

most for our own analysis are studies emphasising particularly the individual narratives of people experiencing dementia: Barnett (2000), Beard (2004, 2016); Beard, Knauss, and Moyer (2009), Stechl (2006), Bartlett and O'Connor (2007), O'Connor, Phinney, and Hulko (2010), Tanner (2012) and Lange (2018). While dementia itself is attracting greater attention in many societies, more disciplinary fields are providing important and highly differentiated insights into the phenomenon. In Social Anthropology, for example, the voices of people with dementia have been explored and presented in a way that includes multiple dimensions of associations, fears and intertwined factual situations (Eilat, 2023) – an approach which recalls previous studies combining Psychiatry and Social Anthropology (Kleinman, 1988).

Furthermore, the concept of citizenship has been introduced into the academic discourse on dementia, and efforts have been made to advance society's recognition of the agency of people with dementia. Accordingly, the status of "person" (to counter assumptions of the loss of personality in dementia) has been criticised as being apolitical, as it would not improve the life situation of people with dementia, either in terms of their social or their political engagement (cf. Bartlett & O'Connor, 2007; Branelly, 2004, 2007). The aim of discussing the relationship between people with dementia and society is to make their civil, political and social rights visible, and to this end explicit research on the agency of people with dementia has been called for (cf. Innes, 2009, p. 156).

According to McParland, Kelly, and Innes (2017), the subsequent shift in academics' perspective to the agency of people with dementia has given rise to a discourse in social science research that provides a voice for all those people with dementia who speak of social inclusion and positive life experiences. A more positive approach to dementia has been created by challenging the previously predominant portrayals of dementia as being nothing but a tragedy and augmenting them with examples of cognitive rehabilitation, coping strategies, and self-management by people with dementia. However, this discourse, they argue, must be called into question, as the effort to normalise dementia bears the risk of excluding the most vulnerable: people with advanced dementia who do not embody the image of 'successful' ageing would thus continue to "live in the shadows" (McParland et al., 2017, p. 264). The authors criticise the notion, implied by this discourse, that people with dementia are valuable because they can still actively contribute to society. This, they argue, excludes all those who no longer engage in activities seen as 'productive' (2017, pp. 259–264). McParland et al. therefore call for an alternative concept of a good life with dementia, one that is not measured by 'normality' and 'productivity'. The concept they seek should exclude neither difficulty and pain nor joy and freedom in living with dementia; it should acknowledge the fearful as well as the joyful aspects and thus enable a discourse on dementia that reduces the risk of marginalisation and social exclusion (2017, p. 265).

Building on the vast body of research on the subjective experience of dementia outlined above, we conducted interviews with individuals affected, participated in self-help groups and analysed the diaries of people living with dementia. Informed by important theories, we have learned from our research that narrative interviews as well as the practice of writing a diary can become opportunities for self-care. Based on first-person documents and narrative interviews with people with dementia, the present study will examine how people facing dementia-related challenges revise their self-image, how they establish contexts of meaning within their life and, on this basis, develop opportunities for active participation in life. The concept of self-care – a concept Michel Foucault borrows from writings of classical antiquity and uses to locate, empower, and disengage the modern subject from social and religious power structures (cf. Foucault, 1986) – will be used as a heuristic lens to make the agency of people with dementia explicit without neglecting the relational aspects of agency. The term *self-care* serves to make explicit that the self is not 'lost' in dementia, as the prior literature discussed above demonstrated, but can constantly be revised and maintained by others and by those affected themselves.

The opportunity to reflect about oneself, to describe one's current

situation and to connect it with previous biographical strands can be of great importance for personhood, especially when living with dementia since abilities, goals and meanings in life that were long taken for granted can suddenly break down, leaving the person affected deeply insecure (Keller, 2022; cf. also Kitwood & Bredin, 1992b, p. 285, who examined the notion of a "self that is shattered in dementia"). As reported in prior literature, being invited to speak – or feeling inspired to write – about oneself and one's situation provides an opportunity to bolster one's own self-image, to revise it and develop it further. Taking our experience from the data collection as a starting point, in this paper we discuss what autobiographical self-reflection has to offer in terms of potential benefits and possibilities in living with dementia. This leads us to the following main research questions: As memories fade and prospects for the future seem limited, how do people with dementia speak or write about their own life? To what extent can looking back on one's life be understood as a form of self-care and perhaps even be used as a resource to establish a sense of self?

The following section on the theoretical background of life story narration, including ideas about why it is helpful to include diaries when studying first-person accounts spoken by people with dementia, helps us derive the narratological concept of key narrative strands, which is also applied to the oral interviews. The section that then follows presents the empirical material on which we draw, and describes our methodological approach. Then, in the main, analytical part of our study, we proceed in two steps: first, we present and compare specific examples in which a person's account of their life becomes confused, more associative and is not clearly ordered – which can be interpreted in terms of a liberating dynamic. The second step details examples in which the autobiographical account is used in exactly the opposite way, namely, to shape the course of a life into a structure that offers reassurance. It becomes apparent that diaries and similar documents can play an important role in this.

Life story narration: the role of factual intentions

Conceptualising biographical disruptions, care and narratives as being intertwined is an enduring idea, especially in Medical Anthropology (cf. Kenyon & Randall, 2015). With his focus on medical practice and professional care, Arthur Kleinman (1988) made a powerful plea to expand "the language of molecules and drugs to include the language of experience and meanings" (266). In *Illness Narratives*, he identifies the importance of the "web of meaning that links illness experience to life world" and to "certain critical points in the life course" (Kleinman, 1988, p. 32). With regard to this biographical aspect, Kleinman discovered from his empirical studies that while illness is often perceived as a disruption, it need not necessarily be a purely negative one, but can also be "an occasion for growth, a point of departure for something deeper" (p.144).

The model of regarding sudden and chronic illness as a "disruptive event" that bears the gravity of a "biographical disruption" (Bury, 1982) had been introduced prior to Kleinman's work. However, with the advent of more extensive qualitative research on individual biographical circumstances and experiences, the counter-notion of illness embedded in a "biographical flow" (Faircloth, Boylstein, Rittman, Young, & Gubrium, 2004) became more influential. The findings we present in this paper can be seen to resemble this structure of a biographical disruption versus a biographical flow.² Nonetheless, our focus is more on *autobiographical* accounts and the narratological interpretation of heterogeneously documented life stories originating from people specifically living with dementia. We do not wish to define normative concepts like 'illness' but refer instead to self-perceived experiences of

² A similar approach could be found in Arthur W. Franks Wounded Storyteller with his typology of "The Restitution Narrative," "The Chaos Narrative" and "The Quest Narrative" (cf. Frank, 2013, pp. 75–136).

disruption.

First-person accounts of life stories generally follow a “plot,” understood in Paul Ricœur’s definition as “the intelligible whole that governs a succession of events in any story” (Ricœur, 1981, p. 167). Narrated forms of selfhood like these seem to constitute particularly authentic empirical material, providing insights that would be hard to gain otherwise. From an ethnographical, sociological and historical point of view, though, it has long been questioned how reliable such accounts can possibly be, given that the individuals’ “plots” cannot exist in a sterile, laboratory-like environment, but are necessarily influenced by subsequent experiences, changing and fading memories, social interactions and other – often fictional – stories that may constitute a blurred line between fictional and factual stories (cf. Schwalm, 2014).

Autobiographical accounts are nevertheless seen as important means to strengthen the agency especially – although certainly not exclusively – of people in vulnerable situations such as those living with dementia (cf. Stanley, 2013). These narratological presuppositions, while not claiming to cover the entire range of theories on selfhood in general, can be summed up in the distinction between two different research foci concerning the “narrated self” (Peacock & Holland, 1993): The research either stresses the question of what lies behind the narrated story and thus attempts to reconstruct the life events, current situation and identity of a narrating person – or else it stresses the question of the story’s composition and thus attempts to reconstruct and interpret the structure of the story. Peacock and Holland coined the terms “‘life-focused’ approach” and “‘story-focused’ approach” to describe this distinction (pp. 368–370). In a heuristic pattern designed to provide a framework in which to present our own research, one could assume that ageing studies looking at the experience and identity of people living with dementia and working with empirical material predominantly tend towards a life-focused approach – reconstructing the life behind the stories. This approach is very much part of a development that sees more and more “Autobiographical Accounts of the Alzheimer Experience” (Gruener, 2022, p. 79) receiving attention and getting published, not only for academic research purposes (cf. Benbow & Kingston, 2016) but also because more generally “the genre of autobiographical medical narratives enjoys a rapidly growing international readership” (Gruener, 2022, p. 79). This demonstrates that the need to make the voices of people with dementia heard is increasingly getting noticed – and should be analysed in a broad and differentiated way. Apart from research on works of fiction, the story-focused approach typically appears in traditions based on formalism or structuralism. Anthropological research operating in this area sometimes “traces formal narrative conventions drawn from folk tradition that are manifest in life stories” (Peacock & Holland, 1993, p. 370; cf. Stahl, 1977). The theoretical linchpin of the present paper lies in the idea of a heuristic back-and-forth movement. While maintaining a life-focused approach, we analyse the first-person accounts of people living with dementia using a story-focused approach, before returning to the question of possible results for a better understanding of personhood and identity regarding the narrating individuals.

In this regard, two factors are especially important for the present context: the communicative, dialogical function of diaries – which in some cases is highlighted quite deliberately – and the attempt to shape one’s own biography as a meaningful story that makes sense and into which the changes brought on by dementia are woven retrospectively. In terms of a narratology rooted in cultural anthropology, these phenomena can be viewed according to the concept of key strands of autobiographical storytelling (*Leitlinien des lebensgeschichtlichen Erzählens*), as introduced into German-language narratology by Lehmann (2007), pp. 43–58). Taking Wilhelm Dilthey’s *Lebensphilosophie* (philosophy of life) as his point of departure, Lehmann adopts the latter’s understanding of human living as an act of “individual self-creation [...], which repeats itself in the course of giving an account of oneself” (Lehmann, 1983, p. 24).

While autobiographical storytelling is framed in terms of hermeneutic interpretation and understood as fashioning a self on the basis of

individual accomplishments, it nonetheless cannot be devoid of “societal experiences” (p. 26) and cultural patterns. The product of this influence is the “key strands” which make up a “cohesive life story [...] in general” (p. 19). These key strands provide a structure that enables a person’s life story to be pieced together into a meaningful whole while also making it easier to recount. At any rate, there are always numerous key strands (internally rigorous to varying degrees) operating simultaneously and in parallel to one another. Adaptations and new versions of a given self-image are thus also possible within this conception. The recurring structures that are based on general cultural narrative patterns make it easier to understand and recount one’s own life in a coherent manner, which may prove especially helpful for people affected by dementia.

We want to use this concept of key strands to look at the autobiographical dimension of diary writing, as it makes it easier to connect the latter to oral interview accounts. In doing so, we observe two tendencies: one is that there are autobiographical recollections which appear to emancipate themselves from precisely such commonplace patterns in a veritable drive towards liberation. The second tendency is one in which the person’s own life story is repeatedly told and written down and appears increasingly as an unbroken, cohesive, and internally rigorous set of events. Both ways of dealing with the impacts of dementia can be regarded as an emancipatory form of self-appropriation of one’s life story that combines the perception of a “biographical disruption” (Bury, 1982) with that of a reassuring “biographical flow” (Faircloth et al., 2004), which also could be called “biographical reinforcement” (Carricaburu & Pierret, 1995).

Material and methodology

Research including the voice of people with dementia has largely focused on oral narratives, which may take several different forms and can be actively elicited in conversation or in an interview. In contrast to this, written forms of reflection on life by people with dementia are comparatively rare. They often arise in cooperation with relatives and professionals – whether in the context of publication projects for a broader public or as part of therapeutic writing projects involving support from gerontologists (Freadman & Bain, 2016; Van Wijngaarden, Alma, & The, 2019). We aim to contribute to this area of research with a unique combination of heterogeneous sources that leads to a multi-method approach, bringing oral and written narratives of people with dementia together in targeting the phenomenon of personal agency experienced through life writing and oral narrating with dementia.

Based on oral and written sources, we conduct a qualitative analysis of content, guided by the cultural anthropology approach of the life writing school (Smith & Watson, 2017). We also draw on the German-language tradition of structuralist narratology (Lehmann, 2007; Meyer, 2014), as it links a concept of intentionality with the act of reflecting on one’s life and represents the story-focused approach. This is relevant and helpful when analysing first-person accounts given by people with dementia: the intention in question is to tell the story of one’s own life within the parameters of culturally established and readily reproducible “key strands” (Lehmann, 1983, p. 19). Here, the analytical focus lies on the emotional reality of experience rather than on any loyalty to dates, facts or chronology. Adopting this methodological approach to autobiographical storytelling (which ultimately derives from Wilhelm Dilthey’s theory of hermeneutics) is helpful in gaining a deeper understanding of the narratives of people with dementia, as we shall show. The major advantage of this methodical approach is that it encourages ongoing reflection on the interplay between orality and writing as well as remembering and forgetting, which also characterises the sources examined here (Gu, 2018; Gudmundsdottir, 2017).

Our study is based partly on data from conversations and interviews conducted in the context of participant observation, and partly on written records such as diaries, letters, notes, and more. What the different sets of material have in common – and what connects them to

the theoretical background outlined above – is that they were largely not created for the purpose of researching life story narration. They have also not been created in a guided, therapeutical setting, like it is practiced in life review therapy or reminiscence therapy (cf. Cuevas, Davidson, Mejilla, & Rodney, 2020; Daniels, Boehnlein, & McCallion, 2015). Although the oral interviews *as a whole* were indeed conducted for research dealing with everyday dementia-related challenges, we concentrate here on those parts of these oral accounts that digress freely from issues connected to living with dementia and provide insight into the person's life story in a much broader sense. These quite different sets of material are nevertheless strongly connected with each other: we draw on both oral and written sources, in some cases originating from the same person. Looking at such different sources in parallel enables us to cover longer periods of time and to trace certain developments in the lives of those concerned, paving a way for the juxtaposition between a life- and a story-focused approach.

The interviews and participant observations from which the data for the present study originate took place as part of the project *Self-care in the Face of Dementia. In the Horizon of Spiritual Care and Cultural Science* conducted at the University of Zurich/Switzerland between 2018 and 2021. One of the authors met regularly with four different self-help and self-advocacy groups of people living with dementia in Switzerland and Austria over a period of two years. In total, 42 group meetings were attended and recorded in writing. Additionally, through contacts gained via these groups, a total of 17 interviews were conducted with people affected by dementia. The people interviewed are between 51 and 85 years old, white, German-speaking, have different social and biographical backgrounds, and have been living with the diagnosis of 'dementia' for between a few months and fourteen years. They were at an early stage of their dementia when the data was collected; they did not experience any advanced dementia-related impairment and were all able to give their informed consent (Hellström, Nolan, Nordenfeldt, & Lundh, 2007, p. 611; Hopf, 2004, p. 591) to participate in the study. The introductory request to tell the interviewer "how everything transpired with their dementia" was followed by conversations ranging from 45 min to 3 h. Every interview was conducted at a location of the interviewee's choice – including a restaurant, a living room, a park bench or even on a walk – and was recorded acoustically using a mobile phone to maintain a relaxed atmosphere.

Regarding the written records, some of these were documents made available to us by the study participants. The initiative to do so came from the participants themselves, based on their wish to be understood and seen as individuals with stories worth being told, read, and listened to. Other written records came from collections and archives that hold a broad and thematically non-specific range of first-person documents from German-speaking countries.³ Concerning the latter, we concentrate here on one diary that is particularly striking – while the others, which are not analysed in this paper, similarly confirm the patterns we identify and have been presented elsewhere from different angles (Völk, 2017, 2021b). None of these documents were written for the purpose of being analysed, and neither were they generated in collaboration with researchers or professional writers. The daily diaries, in particular, contain information about living with dementia merely by chance.

Important projects with a broad impact, such as the *Dutch Dementia Diaries Project*,⁴ take the occurrence of dementia symptoms as an initial opportunity to produce and collect autobiographical accounts (oral, written and video-filmed). Such accounts are well established and recognised in dementia studies. Less noticed are, however, written

documents in archives and collections as well as documents that are part of an estate left (or prepared) by people with dementia who have given over their written accounts to research – but only subsequently, after they had been produced for their own sake. We believe that including written accounts like these – as well as life stories digressing from interviews – in dementia studies, and analysing them using a heuristic story-focused approach, can contribute towards efforts to better understand people living with dementia and hopefully, further strengthen their voices.

The detailed analysis of the data outlined above integrates approaches from grounded theory (Strauss & Corbin, 1990) as well as narrative analysis (Lucius-Hoene & Deppermann, 2002) and frame analysis (Goffman, 1976). Applying the method of open coding by grounded theory (Böhm, 2004 p. 476), a method that aims to recognise important elements in the material and form them into thematic groups, helped us to identify different forms of self-representation and self-expression in the material. Given our analytical focus based on the theoretical linchpin outlined above, we have not organised the findings in terms of fact and fiction but rather according to different forms of expressing emotional reality and self-perception while living with dementia. Narrative analysis and frame analysis were then applied to examine more closely how people with dementia use autobiographical storytelling as a form of narrative self-care: how they integrate their dementia into their biography and how they understand and view their current situation. The analysis was carried out as follows: First, the written records and the transcripts of the oral statements were each analysed individually by one author respectively. Then, the different forms of narrated self-understanding and self-expression could be identified, compared and linked with one another.

Following the ethical research principle of "non-harming" (Hopf, 2004, p. 594), the names of the participants speaking are anonymised. The names of people who explicitly expressed their wish to appear with their real names are an exception to this. The reason for this is their conviction that dementia is nothing to be ashamed of. The request of the people to appear with their correct name shows their emancipatory desire to defy the stigma of dementia. We complied with this request not only to support them in their conviction, but also because the people in question have already presented themselves to the public elsewhere as living with dementia, for example, in the form of dementia activism or as representatives of a public working group of people with dementia. Thus, revealing their names in this study does not expose them to any disadvantages or dangers that they do not already willingly face in their daily lives.

Analysis

Autobiography as liberation

Findings from diary studies have indicated that, despite their exclusionary facade, diary-like documents are generally communicative in character (cf. Steinitz, 1997, 2011; Smith & Watson, 2001, p. 67; Gerhalter, 2020; Völk, 2021a). This seems to be the case especially with written accounts produced in the context of dementia. There is often an interplay between a person's oral account and what they put down in writing, while both can be seen in the context of care and self-care. Noting down one's own thoughts, experiences, and recollections on paper provides a sense of structure and reassurance (as is often articulated by individuals concerned) while at the same time one is free to appropriate the traditional elements of diary writing in a new way. The course of events becomes muddled, details are forgotten or are related in a new way, causal connections are dropped or newly added. This freedom applies especially to the chronological course of events. Whereas the main purpose of a diary – given its origins as a means of documentation – is based on chronological structure, with each entry marked by a specific date (Dusini, 2005), diary writers affected by dementia often create their own chronology. Diarists who are confronted

³ Specifically, the women's estates collection (*Sammlung Frauennachlässe*) at Vienna University's Institute of History, the Collection of Biographical Records (*Dokumentation lebensgeschichtlicher Aufzeichnungen*) at Vienna University's Department of Economic and Social History, and the German Diary Archive at Emmendingen.

⁴ <https://dementiadiaries.org/>. Cf. van Wijngaarden et al., 2019.

with the first symptoms of dementia use the characteristic features of diary writing in a very specific way. It is the freedom inherent in this genre that allows the diarist to write in an uninhibited manner, even as forgetfulness increases.

One example shall be discussed here in more depth: the diary of Irma Maier [pseudonym] (b. 1927).⁵ In 2015, the institution mentioned in the footnote below, supported by the Austrian government and in collaboration with other academic institutions, had widely publicised a call for private diaries and notes concerning private care in general, the title of the call being “Who cares? – prospects for cultures of care.” The goal was to further augment their collection of such documents. Mrs. Maier had responded to that call, given that by that time she was taking care of her husband, who had previously suffered a stroke. She sent in some diaries and notes and also had personal contact with Mr. Müller (see footnote below). In the following years, up to 2021, she sent in old diaries, various notes, and calendars from time to time. In one of her last notes, she mentions that her doctor has diagnosed her with dementia and that she is moving into a nursing home. Based on this knowledge, the factual information contained in the following is taken solely from the diary itself and is integrated as such into the analysis.

At one point, Mrs. Maier writes down a detailed description of an event – in which her dementia first manifested – as if it occurred over a period of years. It happened in 2009, so she states, yet the description is written beneath the heading “Christmas 2012” and begins with these words: “It is now August 15th 2015” (9). The concept of a chronologically sequential diary is deconstructed by Mrs. Maier on a different level as well: due to her dementia she keeps several diaries in parallel, as becomes clear in an entry from the year 2020: “Today, on 17.5.2020, I came across the book again by chance. I was so surprised. I am so forgetful, I couldn’t remember I had it at all. I’ve long since started another diary!” (41) At another point she even seems to play with the chronological structure of diary keeping by writing in the space for the date above one entry: “Undated thoughts (sometime or other)” (16). This free appropriation of biographical chronology may encourage the person to re-view their own life story from a new and different perspective. In June 2021, in one of her parallel diaries, Mrs. Maier describes the following phenomenon, which correlates with a further intensification of her dementia symptoms: “I’ve recently been learning much more about my generation and the way life was back then than I myself experienced at the time. I was never really aware of the lead crystal” (45).

As a young woman, Mrs. Maier often had to clear away the dirty crockery in her parents’ house when they had visitors. Her father had a good job at a management level in a shoe factory, so the family was relatively well situated in terms of social status and hosted their many guests accordingly. Their daughter only participated in this to the extent that she was to clear away the dirty crockery afterwards. Now, she recalls the glasses – the “lead crystal” – out of which the guests sipped their fine alcoholic drinks. She noticed back then “that most of the little brandy glasses had a little left in them and you could just reach it with your tongue ... and it tasted fantastic!” (46) Her mother soon caught on, however, and tried to put a stop to this subversive behaviour – “but sometimes I was quicker” (46). What Mrs. Maier remembers, then, is that she had found a gap in the system that had given her a certain sense of secretly being a part of events, even if she was otherwise largely excluded from social life. This recollection in turn prompts her to remember and reflect upon events that followed during her life with a greater focus on her own needs – for example, when considering how her marriage came about, and also a previous relationship to another man –

whom she describes as her “dream husband” (56) – that didn’t work out.

Here, it is material culture that prompts a different way of looking at one’s own life story. Starting from this re-stimulated memory of lead crystal glasses, a memory of her biography unfolds, which in this context firmly establishes a new emphasis that had clearly been neglected previously: the question as to how she felt in certain phases of her life and to what extent her own needs were considered. The afore-mentioned glasses open up this perspective because they are associated with a budding feeling of pleasure and independence. A new, previously unremarked key autobiographical strand becomes apparent. Mrs. Maier’s parallel diaries provide a vivid illustration of the phenomenon described by Lehmann’s concept of parallel key autobiographical strands that are present in varying degrees of distinctness: they demonstrate the principle that facilitates such parallelism, namely, that nothing determines which events and thoughts will be accorded the greatest significance. Instead, a measure of contingency constantly hovers between the lines. The recollection recounted here is one of the “vague, blurred key strands” that are often hidden and exist in parallel in the memory, and which “largely serve to enable self-reflection” (Lehmann, 1983, p. 24). All this is prompted by the situation of being confronted by the onset of dementia. Making use of a broadly apprehended allegory, Mrs. Maier writes with a hint of melancholy about how she sees herself: she is, she says, “like an old (not even precious) thing kept in a display cabinet” (22), like a glass you have to treat carefully so that it doesn’t develop a “crack” (22). This view of her own life, articulated as if contemplating a separate object that functions as a “souvenir of a lovely time when all was well” (22), neatly sums up the great importance of looking back upon one’s life – especially as Mrs. Maier imagines herself to be a decorative, albeit not especially precious, glass, this reference pre-empting her recollection of the lead crystal glasses. There is surely also a felt sense of self-alienation associated with this image, which presumably has to do with the increasing impact of dementia. The situation is clearly frightening to her, and yet it also provides a prompt for re-appropriating her own life story. This narrative and reflexive re-appropriation can be understood as a form of self-care. Evoked by an intensive observation of an object’s materiality, the emotions tied to previous experiences can blend with the present moment. This associative practice can help formulate a current state of being and self-image. For a brief moment, a vague key strand comes to the fore: Something holds her back from trying to fulfil her needs. But the associative link to the past also triggers a sense of resilience: “...and I’m still alive” (39), as 92-year-old Mrs. Maier states with some surprise.

“Undated thoughts (sometime or other)” – the title of Mrs. Maier’s diary entry – points to a mode of perceiving oneself and the world that is also addressed in oral accounts given by people with dementia. The title indicates that, at the time of writing the diary entry, she does not locate her lifeworld within the conventional date/time structure but rather is in the process of liberating herself from this otherwise strict rule of temporality: her thoughts are “undated.”

The experience of no longer having to adhere to a temporal order is one shared also by Mrs. Marquez⁶ [pseudonym]. In an interview, Mrs. Marquez speaks of her relationship to time having become “somewhat less coordinated” since living with dementia: “[t]hat lengths of time [can] somehow change subjectively” so that certain things she wanted to do “drift out of your mental field of vision” and she suddenly finds herself having spent hours moving a small box from one position to another. Similarly, Mrs. Gulyn⁷ reports how, strolling through the area where she had lived and studied years ago, she “got a bit stuck in the past” and, as a result, missed the bus that would have taken her to her destination. Rather like Maurice Merleau-Ponty’s “nows,” a person with

⁵ Diary of Irma Maier [pseudonym], Collection of Biographical Records (*Dokumentation lebensgeschichtlicher Aufzeichnungen*) at Vienna University’s Department of Economic and Social History. We wish to thank Günter Müller from this institution for providing us with this document and ample background information.

⁶ Interview with Maria Marquez on September 6, 2018 and on May 7, 2019, in Vienna.

⁷ Interview with Beatrix Gulyn on September 5, 2018 and on May 8, 2019, in Vienna.

dementia may find that their relation to their lifeworld becomes temporarily detached from a time-structuring perspective. According to Merleau-Ponty, time is “not a real process” and nor is it an “actual sequence I have merely to register. It arises out of *my* relationship to things. [...] What is past or future to me is, in the world, present” (Merleau-Ponty, 1965, p. 468).

At times, people living with dementia manage to escape from a learned temporal regime and to change their subjective perception of time – they can stretch time or ‘freeze’ it, and in doing so lose sight of things they had intended to do. When, as Mrs. Marquez explains in an interview, she had “intended to cook something” and then “comes across a book,” it is perfectly possible that she will forget the cooking entirely and become engrossed in the book. However, she does not consider it a lapse to spontaneously become engrossed in something else and thus diverted from what she had actually planned to do. Rather, she sees in it a newfound ability acquired through living with dementia, namely, allowing herself to be “distracted.” In any case, she says, she mainly forgets those things that “have probably never really interested me.” Living with dementia opens up the possibility to no longer structure available time according to a logic of efficiency. Allowing oneself to become distracted – to get stuck in the past and to freeze in time – is a way of resisting “chrononormativity” (Freeman, 2010, p. 3), a use of time that orients the human body towards maximum productivity. This makes it possible to perceive one’s spatial and material surroundings in a new way – to allow oneself to be spontaneously “distracted,” perhaps indeed by reflecting on one’s life in new ways. A certain interaction with something that crops up in the field of perception can then be drawn out or repeated for as long as the experience of the moment demands, enabling new impressions and observations to arise within the person’s lifeworld. This is also apparent in Mrs. Maier’s “undated” diary entry, when she recounts that now, for the first time in her life, she can perceive the gleaming lead crystal “properly.” She begins to relate to an object through her senses, re-lives past experiences, and connects them at an emotional level to her present experience.

As discussed above, this diary entry is followed by a metaphorical consideration of her life with dementia. Her comments could be construed to mean that, even now, she feels separated from society around her, which she can observe but in which she cannot fully participate. Such an interpretation of Mrs. Maier’s diary entry displays similarities – both in terms of content and metaphor – with oral statements made by others with dementia. Mrs. Gulyn, for example, relates that the various courses of medicine and the safety measures that are part of living with dementia give her the feeling of living under a bell jar. All she wants, though, is to be allowed to die and to engage with the process itself. After all, she says, the “wilting process” (as she describes physical ageing) is only natural – in nature, an entire season is devoted to it. Mrs. Pototschnigg⁸ agrees with this plea to be allowed to live through the physical degenerative processes in a life-affirming way: she wants “leaving this world to be an intensive experience,” and does not regard it “as anything really terrible.”

People with dementia tend to portray the opportunity to experience the process of physical “wilting” intensively as being the opposite of what they describe metaphorically as living behind glass. As the interviews make clear, one possible way of living in a life-affirming way as one ages with dementia is to do as described above: not to view one’s lifeworld as being constructed by time, but rather to live fully in the body, independent of temporal constructions – to have “undated thoughts” (see above). This is viewed as adding a new quality to and enhancing one’s life because it is no longer geared towards deadlines, as if subject to a “guillotine,” but rather enables one to do things in a more sensory, playful way. Although Mrs. Gulyn concedes that she also needs “fixed appointments at times like these” in order to remain at least somewhat anchored in a shared understanding of time, she also enjoys

“living without a clock [...] in every minute possible.” Thus, it is possible for people with dementia, by means of lived-body interaction with a given lifeworld, to enter into a relationship with their surroundings that is independent of time and simultaneously sense-based. In this way, they can re-live past events, re-interpret them from a present-day perspective, and when communicating this interpretation to others, indicate how they view their own situation.

Instead of holding a chronological view of how their present situation came about, people with dementia emphasise key narrative strands of their autobiography in emotional and allegorical comparisons to episodes in the past, thereby creating a self that can also be linked to the concept of experience ‘sedimented’ in the lived body. In this way, incorporating previously less heeded or more hidden biographical elements can – despite their fragile form and associative relation to the present – lead to a liberating experience, one that also provides some stability by virtue of having been gained by actively appropriating one’s own life narrative.

Autobiography as a reassuring structure

The second major trend in the narratives examined here consists in consciously and coherently embedding the current situation with dementia in a contemplation of one’s past. To illustrate the potential of these narratives, in the following we offer an insight into the conversations conducted with two comparatively younger female interviewees, in each of which a form of narrative self-care emerges clearly. Both of them also entrusted us with diaries and notes about their situation and expressed the hope that these could help generate a better understanding of dementia. First, we highlight the case of 56-year-old Mrs. Schwager,⁹ who is confronted with a diagnosis of Alzheimer’s “out of the blue” and uses the practice of narration to weave her current sense of self as someone living with dementia back into a meaningful biographical flow. Second, we contrast this case with the narration of Mrs. Freiberg, who had to go to great lengths until finally receiving an explanation for her forgetfulness and frames the hard-won receipt of the diagnosis as a success story, albeit one that is leading into new challenges in her daily life, one of them being the task of finding a (narrative) framework for her situation that makes sense in terms of the way she sees herself.

Case 1. Mrs. Schwager.

In the interview, Mrs. Schwager says that she had “always been conscientious.” This is a characteristic, then, that has long influenced her image of herself and performs a stabilising function in her view of herself (Goffman, 1982). This does indeed help her as she deals with the initial symptoms of dementia, which can disrupt a person’s view of themselves considerably. When demands that previously could be dealt with easily and had long been an ordinary part of everyday life suddenly and for no apparent reason can no longer be mastered properly, this can greatly unsettle a person’s self-perception (cf. Keller, 2022, pp. 35–101). This is even more the case for Mrs. Schwager as she describes herself as someone who was “always able to stand the pace” even in “tough” situations. She then says of the initial signs of dementia in her job as a qualified care worker: “I didn’t even know what direction the room was in that I wanted to go to [...] and I no longer knew the name of my colleague.” This is why she decided to go and see a doctor: “I was very conscientious, and at some point I said to myself: if you carry on like this, something will happen, you can’t do that, can you? [...] ‘Cause I was dealing with patients and I can’t put patients in danger, can I?” When Mrs. Schwager finds herself in a situation in which she becomes uncertain of herself but is able to refer to a characteristic that remains unchanged even in the context of dementia, she is able to remain proactive while at the same time accepting that she must give up her job.

⁹ Interview with Rita Schwager, on August 17, 2018, in Immensee, Switzerland.

⁸ Interview with Angela Pototschnigg, on September 4, 2018, in Vienna.

Upon receiving the diagnosis, she decides to leave her profession and takes a job at the same place as a cleaner.

Mrs. Schwager also associates a further development of her identity with the key autobiographical strand of living her life conscientiously. When she received payments from her invalidity insurance, this prohibited her by law from continuing to work. As a result, she had to give up her job as a cleaner and was not able to find any meaningful substitute for it, there being “not a single structure you fit into [anymore].” In her view, this situation is the result of a false idea of people with dementia: “Somehow they’ve forgotten that it might be a need people have. ‘Cause they just don’t trust an Alzheimer’s patient per se with anything and it doesn’t occur to them that maybe they’d still like to do something.” With this realisation in mind, she begins to speak out for people with dementia and their needs. She may be living with dementia herself, but she can still speak, which is why she “[feels] a bit duty-bound to speak out about it – for those [...] who can’t express themselves anymore.” It is very important, she feels, that people with dementia begin to speak out, because only they are in a position to convey to other people what it means to live with dementia. Her conscientious self with dementia – as becomes apparent in her narrative – has begun to take an activist stance; she has set up a self-help group of her own, writes articles, takes part in panel debates, and gives interviews for various magazines. Being a voice for people with dementia is her new job, she says.

In relation to narratives that make sense of chaotic upheavals in one’s life, Jill Yamasaki and Barbara F. Sharf speak of narrative sense-making. According to them, illness, violence, or trauma can disrupt the notion of continuity in one’s life, splitting it into a time before and a time after. By means of narratives about earlier experiences, the present can again be presented in a positive, and meaningful way as well as a guideline for the future can be developed (cf. Yamasaki & Sharf, 2011, pp. 14–15). Connecting her life with dementia with her time as a stress-resistant, qualified care worker in the form of a biographical narrative, Mrs. Schwager frames her activist self using the key narrative strand of living life conscientiously as a meaningful development of her identity. The fact that she had always been “conscientious”, that life had “never been a bed of roses” for her, and that she had “always had to struggle” helps her to weave a pattern that flows continuously throughout her life.

Mrs. Schwager uses the interview situation in part to reinforce her new self-image and to incorporate it into a *biographical flow* (Faircloth et al., 2004) that feels right, and in part also to negotiate the task that lends her life new meaning: the interview itself becomes a site of activism in which she tries to raise awareness of the daily “insanity” she experiences and the state of exhaustion associated with it. To this purpose, she uses a narrative strategy in which she makes an ally of her conversation partner. Anticipating this person’s perspective on “normal” behaviour, she herself adopts this perspective and laughs about her own shortcomings. Her humorous narrative about herself and her insane experiences living with dementia thus becomes an awareness-raising session and fulfils Mrs. Schwager’s need to minimise stigmatisation and to convey how people with dementia see their everyday life: “I think [...] it’s fantastic that people like you, who actually have nothing to do with it otherwise, are taking an interest. Giving us a voice. Really giving us a voice!” Her account highlights the importance of narrative self-care while at the same time illustrating two of its key functions: firstly, establishing a consistent and meaningful idea of the self, and secondly, avoiding stigmatisation in positioning oneself within a normality.

However, not in every case does the oral narrative allow her voice to be heard. There are people, she says, who don’t want to hear her: “The people who are still healthy don’t want to know anything about people with Alzheimer’s.” This is why Mrs. Schwager uses a form of communication that is not dependent upon direct conversation: she puts her experiences with dementia into a box. The “Alzheimer’s box”, as she calls it, is her very personal collection of what it is like for her to live with Alzheimer’s and what she considers to be right and proper when dealing with it. Anyone who wants to can read what she has written, and

perhaps begin to get an understanding of how she has felt, what she has thought, and what it has meant for her to live with Alzheimer’s. As a response to the difficulties of communicating her situation to others, Mrs. Schwager has made a kind of time capsule that can be opened and investigated as soon as anyone wants to engage with the contents. With this, she has found a way of practising narrative self-care detached from her physical presence, for the latter could potentially trigger fears or inhibitions that would stand in the way of the narrations’ purpose.

Upon opening this time capsule belonging to Mrs. Schwager (who has since died), one comes across a heterogeneous collection of numerous documents of various kinds – from doctors’ referrals to newspaper articles. Here we find the key biographical elements from the oral interviews in written form – whether it be private emails, correspondence with hospitals and state agencies, or notes and diary-like, dated writings. The integration of her dementia in a biographical and family-related context can be found, for example, in a handwritten piece that can be read as an act of self-reassurance. “Who am I?” Mrs. Schwager asks in this document. Her answer contains not just dates and facts from her biography; she also names two aunts who are living with Alzheimer’s and her father, who “has full-blown dementia and is in a care home.” By referring to her family history, Mrs. Schwager situates herself within a key autobiographical strand that is intergenerational: she is carrying forward what her ancestors had brought into the world. Against this backdrop, her situation seems less like a sudden tragedy and more like an inevitable consequence of her genetic heritage – a narrative that relieves her from feelings of personal failure and integrates her life story into a coherent flow that extends beyond her life span.

As she writes things down and thereby shapes her experience in language more consciously, Mrs. Schwager links biographical self-appropriation with strategies of dealing with the changes brought on by dementia in her everyday life. She further develops a form of self-care, resisting the loss of control by explicitly using “language as a means of control.” She apparently also attempts this act of taking control when dealing with fictional literature: when reading novels, for example, she makes a “list of figures with pers. characteristics, names etc.” This (as Mrs. Schwager herself said in an interview) is obviously a method for cognition training designed to maintain and improve one’s linguistic capabilities. Furthermore, she systematically plans her escape route in tricky conversational situations when “interruptions in speech, stammering” occur: “Don’t know what I want to say [...] don’t get agitated, stay calm, talk in spite of it.”

In her written accounts, Mrs. Schwager also wrote down definitions of things and concepts that were clearly important for her. One gets the impression that this is how she wants to get a grip on things that are confusing or that elude her in her situation. Whereas in the examples contained in the previous section, the autobiographers gave themselves over to free association, allowed themselves to be carried away by colourful lead crystal glasses, like Mrs. Maier and Mrs. Pototschnigg, Mrs. Schwager attempts to render such things comprehensible and controllable again and to use “language as a means of control” to do so. She notes down the following definitions, for example:

“**Kaleidoscope** seeing lovely shapes that keep changing.

Lots of different, changing things are often described metaphorically as a kaleidoscope.”

And similarly:

“**Labyrinth** a complex system of paths with intersections and dead-ends. The visitor (looking for the right path) doesn’t reach the centre or the exit via the direct route and often does so only after much effort.”

To get her bearings amid the labyrinthine changes in her perception of her world and her kaleidoscopically displaced experiences brought about by dementia, Mrs. Schwager records important strategies, correlations, and explanations in writing, and thus forms the key narrative strands of her biography out of a coherent biographical flow. These strands then feed into her self-image as an activist and into her open, self-confident approach to her challenging situation. To be sure, she loses track of many things due to the changes brought on by dementia:

“time has somehow disappeared,” is how Mrs. Schwager sums it up. And yet the time capsule re-materialises this dissipated time, making it controllable by transporting the past from her own life into the future.

Case 2. Mrs. Freiberg.

We now turn to look at forms of narrative self-care expressed by Brigitte Freiberg¹⁰ [pseudonym], contrasting them with those observed in the interview with Mrs. Schwager. Like Mrs. Schwager, 66-year-old Mrs. Freiberg begins her account with an early image of herself, which she has no longer been able to maintain since the first signs of dementia appeared. She had “actually been very independent,” had been able to get things done and had gone far in her working life thanks to her “down-to-earth intelligence,” which had always helped her achieve her aims – until it suddenly no longer did. Suddenly, work had become too much for her, upon which Mrs. Freiberg embarked on an exhausting search to get herself correctly diagnosed. Once again, her practical intelligence enabled her to achieve her goal and thus confirmed her old familiar self-image:

“On April 30th Doctor A. said to me: ‘Mrs Freiberg, you have early-stage Alzheimer’s.’ And my sister was there too, and after the memory clinic we went to the *Beachhouse* by lake M., drank some Prosecco, the second day we spent a bit, well, **normal**, and on the third day I lay in bed for 24 hours and practically bawled the whole time.”

After celebrating her success, Mrs. Freiberg spends a day, as she says, in a sort of in-between state before beginning to realise what she now faces. The day spent beneath her bedcovers suggests an element of fear and an inability to cope, but she also mentions that this moment is short-lived. Being a “Leo” (as she describes herself by referring to astrology), she doesn’t give up that quickly. At this point, it becomes clear, as in the example with Mrs. Schwager, how ways of seeing oneself that remain intact when living with dementia can be helpful in stabilising fragile aspects of a person’s relation to themselves. To help her accept her situation, in her interview, Mrs. Freiberg makes use of the narrative technique of comparison. She begins to judge her own vulnerability and mortality – characteristics which have come much more to the fore in her life since being diagnosed with Alzheimer’s – as a normal and basic human fact of life (cf. Rentsch, 1992, p. 297), doing so by telling stories about other people who have nearly died (several times) or have actually died.

In November 2017, while still being treated for burnout but already feeling “strangely forgetful,” Mrs. Freiberg writes in her diary notebook¹¹ during a stay at the clinic: “What have I experienced during my life [...] write down what was good / bad.” This wish to take stock and establish a clear sense of her inner life – she alludes to a positive/negative ratio of “5:1” – is typical of diary writers. In Mrs. Freiberg’s case, it is obviously prompted by the onset of dementia. She will not carry through with the idea in this way, but it is possible to discern from her diaries and similar documents going back to her youth how she uses biographically significant elements of her self-image in a similar way over the course of time in order to define a clear position that gives her a sense of security, also presenting them later in narrative interviews in the same way. This relates, for example, to the key autobiographical strand according to which she had never been “brainy” but did at least possess practical “down-to-earth intelligence.”

In the interview, she presented and reflected on this self-image trenchantly and in an almost refined, cultivated way. Mrs. Freiberg emphasises that she completed her vocational training with flying colours and even achieved the “best mark in the whole of Switzerland” – a

narrative presumably used frequently as a defence against the widespread assumption that vocational qualifications are less demanding than academic ones. This pattern can also be found in her earlier diaries. Looking back in 2016, for example, she writes that as a girl she had deliberately decided against going to a *Gymnasium* (a school form with a more academic curriculum) because she knew she would probably get poor marks, whereas she expected to get good marks by choosing an educational path via the *Realschule* (less academic curriculum) and vocational training. Indeed, on the last day of school, as a 17-year-old at the *Realschule*, she lists in her teenage diary the marks on her final report and comments: “so I can be content, and wonder how my first report from the apprenticeship turns out” (29th March 1981). The pattern continues during her apprenticeship: she copes better with the practical aspects, her difficulties being more in the sphere of cognitive understanding. When she finally attains her qualification, she is very satisfied with the good mark she has achieved – even if she does not yet describe it as a major national achievement or highlight it particularly. In the end, however, it is out of this and other experiences that the key autobiographical narrative strand emerges which she expresses in the interviews: this practical intelligence has helped her “fight” to get the diagnosis, a way of putting it that cushions the blow, as she at least used her capacity for self-determination to reach this point.

This is the way she integrates dementia into her image of herself, an observation suggested additionally by the fact that over a period of decades prior to this point, she dealt with other symptoms in a similar way. She frequently undergoes treatment for depression and burnout and always seeks to understand her symptoms within the context of her life history, which is clearly helpful to her. For a long time, there is no mention of dementia symptoms, even though she occasionally notes that she has grown “strangely forgetful,” or that “at the moment the memory business isn’t very good.” This long-rehearsed practice of lifelong reflection eventually encourages her to explore more and more determinedly the changes brought on by dementia and to see them in the context of her capacity for self-expression through language and storytelling. For example, during a stay in a burnout clinic where she struggles against a diagnosis that increasingly feels wrong, she observes: “The words burn up before they are spoken.” Given these self-observations, she develops a narrative, biographical way of taking stock of her life about key autobiographical strands.

As the dementia advances progressively, the act of collecting papers and other first-person documents takes on more and more of a communicative function, as Mrs. Freiberg herself explains. She eventually hands over her collection to the researcher with the explicit hope that her materialised life story may continue to be made available to others even when she herself is no longer able to express herself in language. As Mrs. Freiberg said, this will help people to better understand “how Alzheimer’s works.” As with Mrs. Schwager’s time capsule, here too the actual completion of the autobiographical communicative act occurs only when others have read the documents and papers.

Both Mrs. Schwager and Mrs. Freiberg, use the opportunity to speak about what it is like to live with dementia as a chance to reflect in detail about themselves, to engage deliberately with their own situation, and to portray themselves by means of an autobiographical narrative. They derive the self-image thus developed or bolstered from their own biography, making sense of their life in terms of overarching contexts, and then immediately establish the structures of meaning they have thus carved out. The point of doing so is not so much to establish biographical facts or a clear-cut distinction between a correct or incorrect representation of their life story as to set emphases and to choose to make emotional sense of past experiences so that they can be put to rest.

Concluding reflections

The offer of an interview that entails considering oneself and one’s own life seemed to meet with an existing need: it was not unusual for a single interview to last over two hours, generally coming to a halt when

¹⁰ Interview with Brigitte Freiberg, on October 23, 2018, in Freiburg, Switzerland.

¹¹ Personal diaries and notebooks of Brigitte Freiberg, personally made available for research purposes.

the person being interviewed became tired and brought the conversation to a close. At the end, many expressed gratitude for the interview, including 85-year-old Mr. Reiter [pseudonym], whose remarks of gratitude were captured on the sound recording: "I have had one of the most interesting and lovely times of my life, being able to have this conversation with you." Others drew attention at this point to the fact that they would be happy to give a second interview, which largely did happen. Among them was former physician Mrs. Guly, who had been living with Alzheimer's for 14 years. In the interview she states: "I'm incredibly grateful to you, because you've given me a nudge, [...] that was like psychotherapy. [...] I dealt with myself! In that respect I must say thank you, dear – dear – [name of the author]! (*laughs heartily*) Do you understand? [...] And that opens up a nice view of the future."¹² Participating in the study was a form of self-care for Mrs. Guly and enabled her to develop a personal perspective on her future which she views as "beautiful."

If people with dementia are given the time and space to reflect on themselves – if they are listened to carefully – narrative agency (cf. Innes, 2009) comes to the fore. Regarding our initial research questions – "As memories fade and prospects for the future seem limited, how do people with dementia speak or write about their own life? To what extent can looking back on one's life be understood as a form of self-care and perhaps even used as a resource to establish a sense of self?" – this paper has mapped out how people with dementia use autobiographical narratives to negotiate their current situation and self-image. Having the intention of recognising people with dementia as citizens (Brannelly, 2016), we listened carefully to their voices and have drawn on their autobiographical narratives to reveal different forms of self-care: First and foremost, they can be read as a practice of resilience that helps the person to live with an uncertain and fear-inducing situation. A key part of this is the act of nurturing one's own self-image: using narratives that weave the present situation with dementia into a broader biographical flow, it becomes possible to establish a *self with dementia*. This kind of self-image is not reduced to the role of patient (cf. Keller, 2024), but rather is interwoven with long-held perceptions of oneself. Depending on which key strands come to the fore in this process, either old goals can be pursued – or new meaning generated. On the basis of a self-image with dementia that signifies a further development of previous currents of life, future prospects can be created that not only describe a continuous reduction of cognitive abilities, but are permeated by structures of meaning. Furthermore, narrative accounts of one's own situation can serve as a means of control by capturing thoughts about oneself and others in writing and catering them in a diary or an Alzheimer's box. Narrative self-care can then be understood as a practice that establishes security and stability within a world that has become unstable, fractured or uncertain. Against the backdrop of the constant possibility of forgetting previously developed strategies for dealing with forgetfulness, writing them down and storing them safely could be seen as a material externalisation and a way of securing precarious knowledge.

In addition, however, there is another form of narrative self-care that has little to do with establishing continuity and stability. Instead of creating a chronological biographical flow, temporal structures are neglected and biographical episodes – sometimes from a time long past – are connected to the present. Detaching themselves from socially shared conventions regarding time, some people with dementia talk of a sensual immersion in past episodes of one's own life. In an erratic and associative manner, they may draw comparisons between past intense experiences and the present moment, which then helps them to reactivate their bodily self-awareness and to emotionally reinterpret the present situation. Here, indeed, it could even be argued that it is the commonly-held assumption of life being characterised by continuity that makes a break in the biographical flow traumatic in the first place. With regard to the deliberate practice of detaching oneself from

temporal structures, it could be assumed that if more space were given to all that is fragile and incomplete in life, a sudden and big change would not necessarily have to be experienced as a traumatising event. To assert that there is continuity in life would then involve the possibility of connecting different fragments of life and integrating them into a meaningful whole – a strategy which seems to emerge when living with dementia.

Written documents and oral interviews, when taken together, make it especially clear that the act of engaging with one's own biography constitutes a process of active self-appropriation of one's life story; it is a creative process in which techniques of narration enable life stories to be re-configured as a means of self-care. This process does not exclude the pain or difficulties a life with dementia can entail – but it can help those affected to cope with it in decisive, intentional and sometimes even joyful ways (cf. McParland et al., 2017). According to Foucault (Foucault, 1986), caring for oneself – an ethical practice of freedom – occurs in the context of relationships: it is made possible by relationships, developed within relationships, and affects relationships. The communicative form of narrative self-care also displays a relational character. This version of oneself portrayed to others – be it in the form of diary entries, collected documents or an oral telling of one's own life situation – enters into dialogue with a counterpart who may either accept and corroborate this representation or else reject it and render it non-viable.

Although engaging with one's own biography can be read as self-care in anyone's life – whether with or without dementia – it becomes increasingly important in those moments when memories fade and the contexts of meanings come adrift. Yet it is precisely at these times that the opportunity to tell one's own life story rarely occurs. This is not only due to difficulties in verbal and written expression, and cannot be explained solely by memory lapses. It also seems to be closely related to the way dementia is conceptualised in society, where the ability of people with dementia to narrate their own life story and the various possibilities for doing so go largely unheeded (cf. Grebe, 2015; Keller, 2024). This article has shown that the ability to narrate one's own life and self does not suddenly disappear with the onset of dementia. However, life story narration conducted by people with dementia may take on new forms that adhere less closely to chronological sequence and are not always about creating a sense of completeness. It should be stressed here that such forms of self-expression can only be fully satisfying for the narrator if the listener or reader refrains from judging parts of the story as true or false, or from seeing only the symptoms of an illness in an elliptical or (for them) improbable narrative. The people in the individual's immediate environment can thus play an important role in maintaining the personality that presents itself. When a counterpart accepts and confirms the self-image constructed by a person with dementia, the latter's understanding of themselves can be conveyed and maintained intersubjectively. Indeed, according to Kitwood & Bredin (1992b, pp. 274–275), personhood – the status of being a person – cannot be regarded independently of the social environment that enables a human being to achieve this status in the first place, by recognising and thus affirming it. Against this backdrop, autobiographical narrative practices engaged in by people living with dementia are to be understood, among other things, as a means of comprehending one's own sense of oneself, putting it into a communicative form, negotiating it in relationships and, not least, participating thus in a social world as a person with a cognitive and emotional, lived-body understanding of themselves. Whether the episodes narrated occurred or not is relevant only to the extent that the other person can reject the portrayal if it appears to them to be too implausible. If we assume, however, that fictional autobiographical narratives are an art form that gives expression to a person's emotional, lived-body experiences and can clarify their own ethical and moral attitudes and horizons of meaning, then the issue of the truth of such narratives recedes into the background.

As our research questions are hermeneutical, revolving around issues of "how" and "to what extent," the points we have made in this paper –

¹² Interview with Mrs. Guly, on May 18, 2019, in Vienna.

especially in the theoretical parts – are not all exclusively valid in relation to dementia. The characteristic features, as well as the positive and even therapeutic effects of keeping diaries, for example, are well documented. However, diary research in general derives its findings from texts that have been produced by people who have not been affected by dementia. This gave us the opportunity to look at our own material as dementia-specific – also because some of the diarists started writing long – in one case decades – before the first symptoms started showing, so that changes in the way they wrote about their life could be clearly traced. In a similar vein, concepts like the individual self emerging from language (cf. Taylor, 2016) or every narrative's inevitable and dialectical gap between factual and fictional aspects (cf. Koschorke, 2017), are not specifically linked to dementia. These concepts and deliberations do, however, arise and show distinctively in connection with dementia-related narration, which led us to derive from our material a certain urgency and specific handling of aspects like these. In addition, we would regard it as a valuable contribution to a more progressive approach to dementia if autobiographical accounts by the people affected were regarded not merely as objects of research, but rather included in discourses such as those mentioned above.

Funding

Third party funding was provided by Porticus Foundation (The Netherlands). The funding source had no involvement in the collection, analysis and interpretation of data; in the writing of the report and in the decision to submit the article for publication.

CRedit authorship contribution statement

Valerie Keller: Writing – review & editing, Writing – original draft, Validation, Supervision, Software, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Malte Völk:** Writing – review & editing, Writing – original draft, Validation, Supervision, Software, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization.

Declaration of competing interest

None.

Data availability

The data that has been used is confidential.

References

- Barnett, E. (2000). *Including the person with dementia in designing and delivering care: 'I need be me!'*. London: Jessica Kingsley Publishers.
- Bartlett, R., & O'Connor, D. (2007). From personhood to citizenship: Broadening the lens for dementia practice and research. *Journal of Aging Studies*, 21(2), 107–118. <https://doi.org/10.1016/j.jaging.2006.09.002>
- Beard, R. L. (2004). In their voices: Identity preservation and experiences of Alzheimer's disease. *Journal of Aging Studies*, 18(4), 415–428. <https://doi.org/10.1016/j.jaging.2004.06.005>
- Beard, R. L. (2016). *Living with Alzheimer's. Managing memory loss, identity, and illness*. New York: New York University Press. <https://doi.org/10.1111/1467-9566.12498>
- Beard, R. L., Knauss, J., & Moyer, D. (2009). Managing disability and enjoying life: How we reframe dementia through personal narratives. *Journal of Aging Studies*, 23(4), 227–235. <https://doi.org/10.1016/j.jaging.2008.01.002>
- Benbow, S. M., & Kingston, P. (2016). 'Talking about my experiences... at times disturbing yet positive': Producing narratives with people living with dementia. *Dementia*, 15(5), 1034–1052. <https://doi.org/10.1177/14713012145518>
- Brannelly, T. (2004). *Citizenship and Care for People with dementia: Summary research paper*. Birmingham.
- Brannelly, T. (2007). Citizenship and care for people with dementia: Values and approaches. In S. Balloch, & M. Hill (Eds.), *Care, community and citizenship: Research and practice in a changing policy context* (pp. 89–101). Bristol: Bristol University Press.
- Brannelly, T. (2016). Citizenship and people living with dementia: A case for the ethics of care. *Dementia*, 15(3), 304–314. <https://doi.org/10.1177/1471301216639463>
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness*, 4(2), 167–182. <https://doi.org/10.1111/1467-9566.ep11339939>
- Carriacaburu, D., & Pierret, J. (1995). From biographical disruption to biographical reinforcement: The case of HIV-positive men. *Sociology of Health & Illness*, 17(1), 65–88. <https://doi.org/10.1111/1467-9566.ep10934486>
- Cuevas, P. E., Davidson, P. M., Mejilla, J. L., & Rodney, T. W. (2020). Reminiscence therapy for older adults with Alzheimer's disease: A literature review. *International Journal of Mental Health Nursing*, 29(3), 364–371. <https://doi.org/10.1111/inm.12692>
- Daniels, L. R., Boehnlein, J., & McCallion, P. (2015). Aging, depression, and wisdom: A pilot study of life-review intervention and PTSD treatment with two groups of Vietnam veterans. *Journal of Gerontological Social Work*, 58(4), 420–436. <https://doi.org/10.1080/01634372.2015.1013657>
- Dusini, A. (2005). *Tagebuch. Möglichkeiten einer Gattung*. Munich: Fink.
- Eilat, S. (2023). The shadow of dementia: Listening to undecidability in ethnographic interviews with persons suspecting possible dementia. *Journal of Aging Studies*, 66. <https://doi.org/10.1016/j.jaging.2023.101156>
- Faircloth, C. A., Boylstein, C., Rittman, M., Young, M. E., & Gubrium, J. (2004). Sudden illness and biographical flow in narratives of stroke recovery. *Sociology of Health & Illness*, 26(2), 242–261. <https://doi.org/10.1111/j.1467-9566.2004.00388.x>
- Foucault, M. (1986). *Die Sorge um sich*. In *Sexualität und Wahrheit 3*. Frankfurt a.M.: Suhrkamp.
- Frank, A. W. (2013). *The wounded storyteller. Body, illness, and ethics*. Chicago and London: The University of Chicago Press.
- Freadman, R., & Bain, P. (2016). Life writing and dementia care: A project to assist those 'with dementia' to tell their stories. *Life Writing*, 13(1), 105–126. <https://doi.org/10.1080/14484528.2016.1130533>
- Freeman, E. (2010). *Time binds: Queer temporalities, queer histories*. Durham, NC: Duke University Press.
- Fuchs, T. (2010). Das Leibgedächtnis in der Demenz. In A. Kruse (Ed.), *Lebensqualität bei Demenz?* (pp. 231–242). Heidelberg: Akademische Verlagsgesellschaft AKA.
- Gerhalter, L. (2020). Überraschend kommunikativ. Geheimnisse und andere Funktionen von Tagebüchern von Jugendlichen in der ersten Hälfte des 20. Jahrhunderts. *Medien & Zeit. Kommunikation in Vergangenheit und Gegenwart*, 35(4), 18–29.
- Goffman, E. (1976). *Frame analysis: An essay on the organization of experience*. Cambridge: Harvard Univ. Press.
- Goffman, E. (1982). *Das Individuum im öffentlichen Austausch. Mikrostudien zur öffentlichen Ordnung*. Frankfurt a.M.: Suhrkamp.
- Goldsmith, M. (1996). *Hearing the voice of people with dementia. Opportunities and obstacles*. London/Bristol/Pennsylvania: Jessica Kingsley Publishers.
- Grebe, H. (2015). Die Wiederbelebung der leeren Hülle. Zur metaphorischen Konstruktion von Demenz in potenzialorientierten Kontexten. *Zeitschrift für Volkskunde*, 112(2), 236–256.
- Grebe, H. (2019). *Demenz in Medien, Zivilgesellschaft und Familie. Deutungen und Behandlungsansätze*. Wiesbaden: Springer VS.
- Gruener, P. (2022). *Beyond the great forgetting. Narrative resistance in American literature on early-onset Alzheimer's disease*. Berlin: J.B. Metzler.
- Gu, Y. (2018). Narrative, life writing, and healing: The therapeutic functions of storytelling. *Neohelicon: Acta Comparationis Litterarum Universarum*, 45(2), 479–489.
- Gudmundsdottir, G. (2017). *Representations of forgetting in life writing and fiction*. London: Palgrave Macmillan.
- Hellström, I., Nolan, M., Nordenfeldt, L., & Lundh, U. (2007). Ethical and methodological issues in interviewing persons with dementia. *Nursing Ethics*, 14(5), 608–619. <https://doi.org/10.1177/096973300708020>
- Hopf, C. (2004). Forschungsethik und qualitative Forschung. In U. Flick, E. Kardorff, & I. Steinke (Eds.), *Qualitative Forschung. Ein Handbuch* (pp. 589–600). Reinbek: Rowohlt.
- Innes, A. (2009). *Dementia studies. A social science perspective*. Los Angeles, CA: SAGE.
- Keller, V. (2022). *Selbstsorge im Leben mit Demenz. Potenziale einer relationalen Praxis*. Bielefeld: transcript.
- Keller, V. (2024). Children of old age? Infantilisation of people living with dementia. In A. Wanka, T. Freuel-Funke, S. Andresen, & F. Oswald (Eds.), *Linking ages. A dialogue between childhood and ageing research* (pp. 276–287). London: Routledge. <https://doi.org/10.4324/9781003429340>
- Kenyon, G., & Randall, W. L. (2015). Editorial introduction to special issue on 'narrative care'. *Journal of Aging Studies*, 34, 143–145. <https://doi.org/10.1016/j.jaging.2015.02.012>
- Kitwood, T. (1990). The dialectics of dementia: With particular reference to Alzheimer's disease. *Ageing and Society*, 10(2) (177–19).
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Maidenhead: Open University Press.
- Kitwood, T., & Bredin, K. (1992a). *Person to person: Guide to the Care of those with Failing Mental Powers*. Loughton: Gale Center Publications.
- Kitwood, T., & Bredin, K. (1992b). Towards a theory of dementia care. Personhood and well-being. *Ageing and Society*, 12(3), 269–287. <https://doi.org/10.1017/S0144686X0000502X>
- Kleinman, A. (1988). *The illness narratives: Suffering, healing, and the human condition*. New York, NY: Basic Books.
- Koschorke, A. (2017). *Wahrheit und Erfindung. Grundzüge einer Allgemeinen Erzähltheorie*. Frankfurt a.M.: Fischer.
- Lange, R. (2018). *Soziale Vernetzung als Ressource für Menschen mit Demenz. Gruppeninterviews mit Betroffenen auf der Grundlage der dokumentarischen Methode*. Wiesbaden: Springer.
- Lehmann, A. (1983). *Erzählstruktur und Lebenslauf. Autobiographische Untersuchungen*. Frankfurt a.M., New York: Campus.

- Lehmann, A. (2007). *Reden über Erfahrung: kulturwissenschaftliche Bewusstseinsanalyse des Erzählens*. Berlin: Reimer.
- Lucius-Hoene, G., & Deppermann, A. (2002). *Rekonstruktion Narrativer Identität*. Wiesbaden: Springer.
- McParland, P., Kelly, F., & Innes, A. (2017). Dichotomising dementia: Is there another way? *Sociology of Health & Illness*, 39(2), 258–269. <https://doi.org/10.1111/1467-9566.12438>
- Merleau-Ponty, M. (1965). *Phänomenologie der Wahrnehmung*. Berlin: Walter de Gruyter.
- Meyer, S. (2014). Was heißt Erzählen? Die Narrationsanalyse als hermeneutische Methode in der Europäischen Ethnologie. *Zeitschrift für Volkskunde*, 110(2), 243–267.
- O'Connor, D., Phinney, A., & Hulko, W. (2010). Dementia at the intersections: A unique case study exploring social location. *Journal of Aging Studies*, 24(1), 30–39. <https://doi.org/10.1016/j.jaging.2008.08.001>
- Peacock, J. L., & Holland, D. C. (1993). The narrated self. *Life stories in process*. *Ethos*, 21(4), 367–383.
- Rentsch, T. (1992). Philosophische Anthropologie und Ethik der späten Lebenszeit. In P. B. Baltes, & J. Mittelstrass (Eds.), *Zukunft des Alterns und gesellschaftliche Entwicklung* (pp. 283–304). Berlin/New York: Walter de Gruyter.
- Ricœur, P. (1981). *Hermeneutics and the human sciences: Essays on language, action and interpretation*. Cambridge, UK: Cambridge University Press.
- Schwalm, H. (2014). Autobiography. In P. Hühn, et al. (Eds.), *Handbook of narratology* (pp. 14–29). Berlin/Boston: Walter de Gruyter.
- Schweda, M., & Jongma, K. (2018). Rückkehr in die Kindheit oder Tod bei lebendigem Leib? Ethische Aspekte der Altersdemenz in der Perspektive des Lebensverlaufs. *Zeitschrift für Praktische Philosophie*, 5(1), 181–205. <https://doi.org/10.22613/zfpp/5.1.8>
- Smith, S., & Watson, J. (Eds.). (2001). *Reading autobiography: A guide for interpreting life narratives*. Minneapolis, MN: University of Minnesota Publishing.
- Smith, S., & Watson, J. (2017). *Life writing in the long run: A Smith & Watson Autobiography Studies Reader*. Ann Arbor, MI: Michigan Publishing.
- Stahl, S. K. D. (1977). The Oral personal narrative in its general context. *Fabula*, 18, 18–39.
- Stanley, D. (2013). *Autobiographical accounts of early-onset Alzheimer's disease: Obituaries of the living dead?* Ottawa, ON: University of Ottawa Research. <http://hdl.handle.net/10393/30173>.
- Stechl, E. (2006). *Subjektive Wahrnehmung und Bewältigung der Demenz im Frühstadium. Eine qualitative Interviewstudie mit Betroffenen und ihren Angehörigen*. Berlin: Verlag Dr. Köster.
- Steinitz, R. A. (1997). *Shared secrets and torn pages: Diaries and journals in Nineteenth-century British society and literature*. Berkeley, CA.
- Steinitz, R. A. (2011). *Time, space, and gender in the nineteenth-century British diary*. London: Palgrave Macmillan.
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Thousand Oaks, CA: SAGE.
- Tanner, D. (2012). Co-research with older people with dementia: Experience and reflections. *Journal of Mental Health*, 21(3), 296–306. <https://doi.org/10.3109/09638237.2011.651658>
- Taylor, C. (2016). *The language animal: The full shape of the human linguistic capacity*. Cambridge, MA: Harvard University Press.
- Van Wijngaarden, E., Alma, M., & The, A.-M. (2019). 'The eyes of others' are what really matters: The experience of living with dementia from an insider perspective. *PLoS One*, 14(4), Article e0214724.
- Völk, M. (2017). "Wenn sie die Augen schloss, fing sie an zu denken." *Demenz in Biographie, Chronik und Tagebuch*. BIOS. *Zeitschrift für Biographieforschung, Oral History und Lebensverlaufsanalysen*. 28 pp. 102–118.
- Völk, M. (2021a). "Sie sagte zu mir 'du weißt sehr viel'." Zum kommunikativen Charakter lebensgeschichtlicher Selbstzeugnisse. *Österreichische Zeitschrift für Volkskunde*, 124(2), 243–270.
- Völk, M. (2021b). "Was haben wir doch für ein reiches Leben gehabt!" Tagebücher und Autobiographien als Mittel der Selbstsorge bei Demenz. In S. Peng-Keller, & H.-P. Zimmermann (Eds.), *Selbstsorge bei Demenz. Alltag, Würde, Spiritualität* (pp. 251–266). Frankfurt/New York: Campus.
- Yamasaki, J., & Sharf, B. (2011). Opting out while fitting in: How residents make sense of assisted living and cope with community life. *Journal of Aging Studies*, 25(1), 13–21. <https://doi.org/10.1016/j.jaging.2010.08.005>