Poetry and dementia: Imagining and shaping more just futures

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Introduction

In 2015, I interviewed the established Dutch poet Leo Herberghs (1924-2019) about the ways in which he experienced creativity in the final stage of his career. Herberghs was 91 years old at the time and lived with his wife in their home in the South of the Netherlands. While I was initiating contact with the poet, some of his colleagues wondered if he would agree to an interview given that his health was declining. They cautiously implied that they worried about his cognitive abilities. When I subsequently met the couple at their place, in passing, Herberghs's wife Ciska mentioned the poet's forgetfulness and suggested she sat in on the interview for his comfort. Herberghs himself never used the word "forgetful" during my visit except when his wife subtly referred to it. He did, however, ask me whether there were many poets living with dementia. He was also adamant that, without Ciska's help, he would have to relocate to a care facility immediately. Re-reading the interview transcript today, I realize that the pace of this interview was significantly slower when compared to the conversations with the other poets in my study on experiences of late-life creativity (Swinnen 2018) and that Herberghs had not provided lengthy answers to my questions. Moreover, he often repeated certain statements and phrasings. Still, the author and I engaged in a meaningful exchange on his working routines, his motives for writing poetry, his position in the literary field and his literary legacy.

Herberghs noticed that his poems had become shorter and more impression-like in recent years, possibly due to "a lack of breath" (his words).[1] He had also spent more time on editing and ordering his earlier work than on creating new work. Nevertheless, Herberghs strongly emphasised the continuity in his career and called his life "an existence in words, written words". He felt surrounded by people who helped him sustain this preferred "existence in words" – for instance, Bert van Melick who read and commented on his writings – even

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[1] All translations from Dutch to English in this chapter are mine.

though Herberghs was becoming increasingly vulnerable. In Herberghs's view, age in terms of life experiences had little effect on the nature of his poetry: "When I write poetry, I am a 10-year-old child. I believe that [age] does not play a role in poetry. You may come to a more profound insight [as you age] but that does not result in new poetry, I believe". He even went so far as to pose the rhetorical question that "maybe one has to be 'demented' to write good poems". Herberghs was not only able to continue his literary practice in an adjusted form in the context of his private home at the end of his life, but he also remained visible in the literary field as a professional poet through the instalment of the Leo Herberghs' prize in 2014 to recognise poetic talent.

Interestingly, for Herberghs, poetry and forgetfulness/dementia were not a contradiction in terms. This may be surprising at first because the illness often comes with word-finding and comprehension problems and poetry is regarded the most semantically dense and difficult literary genre. In this chapter, I will argue that, perhaps counterintuitively, the aesthetic and pragmatic affordances of poetry enable people who live with dementia to express themselves. That is, if they find themselves in a context that is open to their contributions. If not, the stigma of dementia is almost impossible to overcome for them, which results in the silencing of their creativity and personhood. I will demonstrate this by means of two further case studies related to the Flemish poet Hugo Claus and to two participatory literary activities, the Alzheimer's Poetry Project and Shared Reading. Before presenting and analysing these case studies, I will introduce my theoretical approach.

Theoretical approach: Dementia as a disability

Since the 2010 project "Beyond Autonomy and Language", awarded in the ZonMw funding scheme Disability Studies in the Netherlands, I have conceptualised Alzheimer's disease and related dementias (from now on referred to as dementia) as a disability together with my Maastricht colleagues Ruud Hendriks, Annette Hendrikx, and Ike Kamphof (2016). In recent years, this approach has gained momentum (e.g. Shakespeare, Zeilig and Mittler 2019) not in the least because it helps us understand dementia as a social justice issue rather than as just a dreadful illness in need of a cure. In her book *Feminist Queer Crip* (2013), Alison Kafer differentiates between the medical/individual model of disease and the political/relational model, a distinction that I find helpful in rethinking dementia as a disability.

The medical/individual conceptualisation of dementia is predominant both within health care and among the general public. Following this model, dementia is considered a disease of the brain that implies a progressive decline in cognition and difficulties in functioning. Dementia is understood to signify a loss of personhood and self which makes it almost unthinkable that one could have a full, meaningful and dignified life with the illness – an assumption that Kafer calls ableist (2013: 3). This concept of dementia has resulted in the stigmatisation and Othering of people living with dementia (Hughes, Louw and Sabat 2006). Dementia conceptualised as a purely medical and individual affliction has established a hierarchical binary between *us*, neurotypical people, and *them*, neurodiverse people who have failed to comply to the neoliberal idea of ageing successfully, i.e. independently and in good health. Consequently, the affects that come with a dementia diagnosis include fear (of losing one's self and one's dignity), shame (about becoming dependent), disgust (at losing decorum and autonomy) and guilt (for becoming a burden to others).

By contrast, the political/relational model suggests that "the problem of disability no longer resides in the minds or bodies of individuals but in built environments and social patterns that exclude or stigmatize particular kinds of bodies, minds, and ways of being" (Kafer 2013: 6). According to this model, dementia is "experienced in and through relationships" (8) and subjectivity emerges from interactions with other people (Gilleard et al. 2005). Hence, when people are confronted with memory loss that starts interfering with their daily activities, their surroundings need to help them uphold who they were and support the person they will become. The political/relational model goes beyond the stimulation of the participation of people who live with dementia through different types of activities and the improvement of accessibility. It aims to honour their voices and empower them to advocate for themselves. The model also serves to acknowledge and fight against the many injustices and micro-aggressions that people living with dementia are confronted with because they depart from the norm of able-mindedness. In this sense, Kafer's political/relational model – which is not specific to dementia – resonates with what Tom Shakespeare, Hannah Zeilig and Peter Mittler argue: "what is required is a stronger response, an equalities-based approach, that recognizes that people with dementia are a minority group in society, who are poorly served in many environments, and who consequently face exclusion, even oppression" (2019: 1080). In the words of Dragana Lukić and Anne Therese Lotherington, we must start "appreciating life together in difference" (2019: 119).

In this chapter, I first present the case of Hugo Claus, a renowned Flemish poet who opted for euthanasia a few years into his Alzheimer's diagnosis. I show how the medical/individual conceptualisation of dementia made it hard for the poet to imagine a meaningful future with the disease. I then contrast this case with two participatory cultural arts activities for people who live with dementia that are based on the spoken word, namely the approaches of the Alzheimer's Poetry Project and Shared Reading. I have selected these uses of literature because they are still underexamined in comparison to other activities in dementia care settings that include singing, dancing and arts and crafts. I argue that both approaches are inspired by the political/relational model of dementia. In an ideal scenario, the activities of APP and SR do not only facilitate participation but engender inclusion by destabilising the hierarchical binary between neurotypical and neurodiverse people.

The case of Hugo Claus

A mediatised death

Hugo Claus (1929-2008) was an acclaimed Flemish writer, painter and theatre and film maker. In his rich oeuvre, he advocated liberties such as sexual freedom, abortion, secularisation and euthanasia. As such, it is not surprising that Claus, with support of the organisation "Recht op waardig sterven" (The right to die with dignity), opted for a self-chosen death two years into his diagnosis of Alzheimer's disease and after seven years of living with memory loss.[2] Claus passed away on 19 March 2008, a few days before his 79th birthday. His death became mediatised in an unprecedented way. The cultural elite of Flanders and the Netherlands attended Claus's funeral at the Bourla Theatre in Antwerp on

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[2] I refer to the timeline in Claus's "Biography" on the website of the Hugo Claus Centre at the University of Antwerp (https://clauscentrum.be/biografie2000.html).

29 March 2008. Flemish and Dutch television broadcasted the ceremony in which actors read from Claus's poetry and selected acquaintances painted a picture of him. The general tone was one of admiration for Claus as a literary phenomenon and for the death he had chosen. The remarkable public interest in Claus' passing not only stemmed from the fact that he was Flanders' most renowned writer, often tipped for the Nobel Prize in Literature, but also because the Belgian law that enables people with dementia to opt for euthanasia when they are competent to decide autonomously had only recently been adopted. Proponents of euthanasia have introduced the term "Claus-effect" to suggest that the mediatised death of the writer increased public awareness of euthanasia, also in relation to dementia (Rogiers and Claeys 2017).

The speech (2008) Erwin Mortier gave at Claus's funeral has left a lasting impression on the Flemish collective memory. Mortier (a friend and a colleague of Claus) presented him as the last representative of the generation of artists born before and shaped by WWII that advanced the cultural, social and philosophical emancipation of Flanders. Mortier called on his fellow writers to honour the master by writing in the service of "radical freedom and equality, and to expose all powers that want to gag or enslave them" (2008: 20). He then sneered at agents of these "powers" who questioned Claus's choice of euthanasia. Many interpreted this as an attack on cardinal Godfried Danneels who, in his 2008 Easter homily, disapproved of the disproportionate media attention that euthanasia was receiving compared to the disregard for people in need of care who decided to face their vulnerabilities until the very end (De Dijn 2008).

Mortier and Danneels represent two opposing ideological sides in the Flemish euthanasia discussion. Mortier believes it to be factually true that dementia equals unbearable suffering and presents euthanasia as the ultimate act of agency and triumph of autonomy and a commonsensical solution to this suffering. Following a debatable progress narrative, he positions people who question euthanasia as religious torment-worshipping bigots who are stuck in the past, incapable of showing empathy (De Dijn 2008: 158). Despite initiatives such as the campaign "Vergeet dementie onthou mens" (Forget dementia, remember the person/Mensch), developed by the Expertisecentrum Dementie Vlaanderen, Mortier's view has come to dominate public discourse in Flanders. There is little room in this discourse for the many ways in which the lives of people with dementia are entangled with their surroundings and the impact of this entanglement on how the disease is experienced, how the person behind it is valued and how care is organised (De Lepeleire et al. 2008: 179). It is in this social context that Claus was confronted with Alzheimer's disease and chose to die.

Anticipating later life with cognitive decline

Our knowledge of the final years of Claus's life, when he lived with Alzheimer's disease up to the day he died, is hardly based on biographical information. This is partially because the author was never keen to reveal much about himself, about the man behind the work. Claus did not believe in the notion of a fixed and coherent self; he compared himself to a chameleon (Schaevers 2004: 187). This explains the subtitle of the abecedarium *Hugo Claus: Een groepsportret* (Hugo Claus: A Group Portrait, Schaevers 2004), a compilation of his most pertinent quotes from the period 1951–2004. The quotes present Claus as a postmodern subject with different faces. They also show, however, great consistency in Claus's views on the meaning of writing, his fear of decline, the comfort of a self-chosen death and the relative significance of an artistic legacy. These views are informative for our understanding of how the poet anticipated cognitive decline in later life and its impact on his creativity.

Writing had no therapeutic effect for Claus but it did give meaning to his existence (Schaevers 2004: 88). He turned Descartes' "cogito ergo sum" into "I write, therefore I am" (414). This does not imply, however, that he experienced writing as an easy task: "Writing is a torment but also a delight" (335). Poetry was at the core of Claus's literary practice and, in his later years, he felt it should become his sole priority (293–94). He was adamant that writers do not retire and, in a 2000 interview, foresaw that he would work to his very end (288). In his view, ageing is a natural part of life (280). He did not fear death; he feared the possible decline preceding it. As early as 1978, he stressed in an interview the importance of having control over his life's end. Claus recounts approvingly how Hemingway committed suicide when he experienced early symptoms of forgetfulness after he had watched his father "become senile" (430). In a 1986 interview, Claus remembers how his own father begged his general practitioner to help him die because he was suffering immensely (11). Just like him, Claus would have wanted to have a suicide pill at hand. In another interview, he characterises a self-chosen death as “very festive and comforting” (431). Long before his own diagnosis of Alzheimer’s disease, Claus is firm in his statement that “If I start to ‘get demented’, they have to kill me soon” (11). In 1999, he admitted that he was experiencing word-finding problems when talking about the novel *Elegy for Iris* (John Bayley’s memoir about his marriage to the writer and philosopher Iris Murdoch) that portrays “one of the most glorious intelligences of England” as less competent than a three-year-old child (11). About the motivations underlying his particular fear of cognitive decline, we learn that Claus did not want to become a burden on others (430) and that he wished to preserve his dignity (95).

These quotes from interviews with Claus show how he envisaged writing poetry in his final years unless he would be affected with dementia. Following the rationale of the medical/individual model of the disease, Claus is unable to imagine that a life with dementia could be meaningful and that he would be able to adapt and enjoy his literary practice as a result. Fear of an undignified and dependent life is the emotion behind the quotes above. It is not caused by lived experience but based on his observation of people such as Hemingway, Murdoch and his own father. His reaction is to locate the responsibility for the problem of dementia in the individual and he views euthanasia, portrayed as a dignified and joyful death, as the only answer to his fear. What is presented as a logical “solution”, however, is characteristic of a neoliberal masculinist and rational order that presents death as preferable to becoming the fearful Other (Shildrick 2015). As Lukić and Lotherington write: “Suicide [in relation to dementia] is a fatal act of agency, while at the same time an effect of the us-them binary that powerfully stigmatizes ‘them’” (2019: 118). This resonates with what Margaret Gullette (2011) has called “the duty to die” for all older people who are unable to live up to the ableist ideal of successful ageing.

There are some elements in the collection of quotes, though, that offer a glimpse of a counter narrative. Claus hints at a notion of a relational self when acknowledging that “Others resonate. [They function as a] soundboard. You only live through others” (Schaevers 2004: 22). In addition, he recognises the importance of being in the present rather than in the past or in the future (260, 269). He also acknowledges that no one knows whether Murdoch was mentally happy or unhappy when living with Alzheimer’s (11). *Hugo Claus: Een* *groepsportret* includes quotes up to 2004. The question is what happened to Claus and his literary practice between 2004 and the day he died?

Final words?

In 2011, *De wolken: Uit de geheime laden van Hugo Claus* (The Clouds: From the Secret Drawers of Hugo Claus, Schaevers) was published posthumously. It is a collection of work from Claus's archive, containing photographs, manuscripts, letters, notes and more in anticipation of scholarly editions to follow in the years after Claus's death. In the last chapter, also entitled "The Clouds", editor Mark Schaevers explains that Claus's archive includes a large package of "scribbled paper" with the "vague contours" of what the writer envisioned would become his final work. According to Schaevers, the papers contain ideas for characters, scenes, and plot development but he also suggests that they mainly illustrate Claus's writing struggle. There is, indeed, a difference between these notebooks and the earlier handwritten texts by Claus included in the book. His handwriting is less firm. The pages remain largely empty and the text that is there is fragmentary and testifies to word-finding problems. The pages also include drawings that hook together. This seems to confirm the account of Claus's final years by his last wife Veerle de Wit: "he suffered unbearably when he found he could no longer write. He had been trying it for a long time. But the sentences no longer went smoothly from left to right; they ran right off the page" (Rogiers and Claeys 2017).

Some reviewers found it incomprehensible and painful that Schaevers decided to include evidence of Claus's decline in the posthumous publication (Gerreway 2011). I would argue, however, that the final chapter of *The Clouds* shows us first-hand that Claus kept writing despite what was happening to him, which both confirms and denies what he predicted all along (as shown above). What does the so-called pack of "scribbled paper" tell us about his late-life experiences? Schaevers gives readers a clue by including notes, selected from workbooks, diaries or loose pages from the period 1960–2008 and printed in red, at the bottom of the final chapter's pages. I suspect that they were chosen because of their poetic potential – they seem to be showing some continuity in who Claus was as a personality and an artist. The first note is: "The silences when he is invited to visit friends. / Vanriet: 'And what do you think about that, Maestro?'/ He is less invited. / (Which is not true, too much awe, staring at, various symptoms. Very personal.) (Schaevers 2011: 322). Assuming that this note is, indeed, from Claus's final years, it relates to his feelings about the ways in which he is positioned by friends and colleagues. They still address him playfully and collegially with "maestro" while asking him for his opinion. However, simultaneously, the note suggests that Claus felt scrutinised for behaviour that departs from what is expected and could be attributed to his Alzheimer's diagnosis. It is difficult for Claus to navigate between the star persona of the maestro that puts him on a pedestal and the stare that separates him from neurotypical people when he blunders. The second note reads like a rhetorical question: "The doctor said you have the heart of a horse / the rectum / the lungs of the late Stan Ockers [famous Belgian cyclist] / the tail / but what don't I have" (342)? Some readers may easily fill in the blanks with "a healthy functioning brain" or "a good working memory" – hereby locating the problem in the body, symmetrically following the structure of the other lines. By withholding an answer, though, Claus leaves open the suggestion that he may lack something of an entirely different order (The companionship of people who accept him for the person he has become? The ability to imagine a meaningful life with dementia?).

If it is true that Claus co-staged his funeral himself as many news items asserted, it is worth having a closer look at his (re)appearance on stage in the form of a pre-recorded video. In this video, Claus reads his "Sonnet XV" (1986) above the coffin with his mortal remains (Claus 2008: 140). According to Dirk van Hulle (2005), "Sonnet XV" is an adaptation of William Shakespeare's "Sonnet 107". This poem starts off with the sentiment of love's uncertainty and ends with the realization that the lyrical I and his true love, the Fair Youth, will outsmart death by means of the poem that testifies to their love (My love looks fresh, and Death to me subscribes / Since, spite of him, I'll live in this poor rhyme). Claus does not only change the form, rhyme and meter of Shakespeare's sonnet but also turns its meaning upside down. Van Hulle argues that, while Shakespeare's poem describes the development from insecurity to certainty, Claus sings the praises of uncertainty itself and renounces the confidence that he associates with youth (Now the world is mortal as I / and that's it. / Only uncertainty gives me a kick, / I don't believe a thing). As such, "Sonnet XV" disavows a profound belief in the power of poetry to leave an eternal mark on earth. Yet, it is significant that Claus recites this poem from beyond the grave and that his words were supplemented by actors who read his other work at the funeral. Thus, Claus's words could still be heard even after his passing. The overall effect of this particular stageing is as ambiguous as the ultimate answer of the chosen death itself.

The Alzheimer's Poetry Project and Shared Reading

I now turn from the sobering case of Claus to two ways in which poetry making and reading have been successfully implemented in activities for people who live with dementia. This move is characteristic of what has been called "post-critique" in literary and cultural studies (Felski 2015), which implies a renewed interest in literary practices by lay persons in everyday settings since the rise of reader response criticism and the sociology of literature in the 1960s. The practices under focus are The Alzheimer's Poetry Project and Shared Reading.

The Alzheimer's Poetry Project (APP) is an oral poetry method developed by the slam poet Gary Glazner. It has been implemented in several dementia care settings in New York (http://www.alzpoetry.com). Glazner's workshops include both poetry recitations and improvisations. In the poetry recitations, Glazner (2005) as Poetry Facilitator[3] starts from a corpus of existing poems and invites participants who live with dementia to join him through call-and-response. Body movements such as motoric gestures (e.g. hand clapping, feet tapping) and illustrative gestures (i.e. showing the meaning of phrase) may accompany the recitations. Poetry improvisations start from open questions on topics such as love, autumn, or ice cream to which the participants respond. Glazner collects these responses and turns them into poems suited to poetry recitations. In 2014, I went to Brooklyn, New York, to observe and learn about Glazner's work in The Brooklyn Memory Center for five months through a participatory ethnographic approach (Swinnen 2016). Back in the Netherlands, I organised 20 workshops ("Poetry and Storytelling Cabinet" project) that introduced the oral poetry method[4] to the closed dementia wards of De Beyart and Scharwyerveld (Swinnen & de Medeiros 2018) in Maastricht. I took on the role of Poetry Facilitator and kept a research

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[3] Glazner does not use the term Poetry Facilitator. I introduce it here to draw a parallel with the Reader Leader of SR.

[4] I combined the approach developed by Glazner with the storytelling method TimeSlips (Swinnen and de Medeiros 2018), which falls beyond the scope of this chapter.

diary. Student assistant Helen Verploegen helped organise the sessions, recorded them and made field notes.

Shared Reading (SR) is an approach established by a British organisation called The Reader (https://www.thereader.org.uk). It entails reading sessions in which literary texts – excerpts from novels and short stories as well as poems – are read aloud by a Reader Leader who invites participants to engage in an open discussion. In the Netherlands and Belgium, SR has been adopted by De Culturele Apotheek (The Cultural Pharmacy, https://www.cultureleapotheek.nl) and Bond zonder Naam (Union Without Name, https://www.bzn.be/nl/home) respectively. These organisations aim to contribute to the wellbeing of participants and to improve social connectivity through literature as a shared experience. From June until October 2021, I studied the practice of SH in the Dutch-speaking context during the COVID-19 pandemic when people, after a longer period of lockdown, gradually started to return to life as it used to be ("Shared Reading in Times of Lockdown" project). Student assistant Maike Brinkman and I were able to observe 12 SR sessions in the Netherlands and Flanders. SR was not specifically developed to cater to people who live with dementia but it has been successfully integrated in health and social care (Billington et al. 2013; Gray et al. 2016). In the Netherlands, De Culturele Apotheek has introduced SH in Odensehouses, i.e., walk-in-centres that were originally established in Denmark that focus on the empowerment and wellbeing of people who live with dementia and their caregivers. For this chapter, I focus on two sessions that were observed, recorded and transcribed verbatim by Maike Brinkman in Odensehouse Amsterdam and Odensehouse Haarlem. The Reader Leaders in these sessions were two volunteers of De Culturele Apotheek.

Close reading and listening (cf. Bernstein 1998) approaches served to analyse the data with particular attention to the interactions among the participants, the input of the Poetry Facilitator/Reader Leader, responses to individual literary texts, procedures of the participatory literary activity, expressions of personhood and evidence of inclusion. When possible, cross-coding (with the student assistant or the co-author) helped to increase the validity of the interpretation. For all projects, informed consent was secured and the data have been anonymised for this chapter.

What a poetic form entails and what distinguishes it from prose has been up for debate for decades in literary scholarship (Wolf 2005). In what follows, rather than focusing on distinct features of poetry both semantically and syntactically, I will address how they function in the APP and SR as specific literary practices (thus pragmatically). What is it that makes both APP and SR meaningful approaches when collaborating with people who live with dementia? Following the political/relational model of dementia, with meaningful, I refer to opportunities for them to interact and connect with other people, to express themselves creatively without restriction or reprimand and to appear as individuals with their own unique characters and preferences.

The comfort of repetition

In one of my earlier pieces on the APP, I argue that to value poetry as a meaningful "intervention" in dementia care, we must approach it as literary performance rather than as a printed text that remains unchanged over time (Swinnen 2016: 5). When literature is performed, repetition becomes "the ultimate vehicle for meaning and artistry" (5). The approach behind the APP capitalises on this characteristic of oral poetry to include people who live with dementia in the activity. Call-and-response builds on the possibility of participants to repeat poetic lines after the Poetry Facilitator. The lines are short enough for people to remember and to recite them – sometimes by only moving their lips. The integration of the accompanying gestures also has an element of repetition in it as they repeat the rhythm or the content of the poem in other systems of signification. In addition, the chosen poems themselves may include an element of repetition. One example is "Polonaise" (1927), a poem by Paul van Ostaijen from which I used the first eight lines for call-and-response sessions in the Dutch context:

> I saw Cecilia coming
> on a summer night
> two ears to hear
> two eyes to see
> two hands to grab
> and ten fingers far

I saw Cecilia coming
On a summer night

The composition of this excerpt relies on the repetition of words and the symmetry of phrases: “two” in combination with body parts connected to the senses. The poem also builds on circularity. Even though new lines follow on the second “one summer night” in the original, I chose to start over again as if the poem contained a loop. Furthermore, recording the participants’ contributions in the rounds of poetry improvisation and literally giving the words back to them is illustrative of how important repetition is to make the activity work. For an outsider, the different layers of repetition may seem excessive but, for the target group of people who live with dementia, it turns so-called shortcomings associated with their disease into something fun and empowering. There is no need to generate words autonomously or understand them cognitively. Instead, words can resonate for what they are, i.e. a relational tool in a conversational turn taking or even mere sound.

Although SR as an oral literature practice differs greatly from the APP and the Reader Leader is less of a performer than the Poetry Facilitator, the analysis of the sessions in the Odensehouses confirm the importance of repetition. SR starts with the Reader Leader reading a text aloud. If this does not immediately generate responses from the participants, she reads the text once more. When the group discussion has reached a point of saturation, the Reader Leader invites a participant to read the text once more. As such, the same short text can be repeated up to three times in a time span of approximately 20 minutes. The fact that the participants get a copy of each text so they can follow it on paper also empowers them to repeat some words and lines verbatim, even though this is not explicitly anticipated by the design of the cultural activity as is the case in the APP call-and-response sequences. In addition, participants also literally repeat what other participants, or the Reader Leader, say and, in her turn, the Reader Leader validates the input of contributors by replicating it:

SP4 You can’t walk much on a ship.
SP5 On a ship…
SP4 So it takes place, if I understand correctly, this is someone who is on a ship.
SP5 Yeah, a ship? Yes.

SP4 But the ship, yeah, that can never be very big.

SP5 It’s not a rowboat, hey? A ship you can walk on, yes.

RL But what kind of ship could this be?

(Odensehuis Amsterdam, July 2, 2021)

This exchange was inspired by a passage from Toni Morrison’s *Beloved* (1987) that starts with the phrase “there is a loneliness that you can cradle”. Speaker 5 says after Speaker 4 that the text concerns a ship and pairs the noun with the verb “walking” as initiated by Speaker 4. The Poetry Facilitator invites both speakers to continue the conversation on the type of ship, thereby welcoming them to reiterate that it could be a rowboat. Again, what for neurotypical people could come across as an unusual, perhaps inefficient way of interacting through the spoken word, is here a tool to participate, connect and receive affirmation.

From mono-perspectival poetic fragment to collective experience

For literature to be successfully included in APP and SR activities, it must be short. In the call-and-response sessions of the APP, poems that are already brief in themselves are further condensed. “The Tyger” (1794) by William Blake, for instance, becomes little more than its famous lines “Tyger Tyger, burning bright / In the forests of the night”. SR makes use of poems and excerpts from novels and short stories. Without introducing the literary context of these excerpts, they become more poetic in the sense that their degree of narrativity declines (Billington et al. 2013: 166). Werner Wolf writes that the lyric offers a “mono-perspectival point of view of consciousness” that is used “not as a means of shedding light on elements of external reality but on revealing itself, its thoughts and in particular its emotions” (2005: 36). Shorter texts are automatically lower in narrativity than longer texts because they include fewer characters, events and temporal and spatial changes.[5] Instead, they offer a glimpse of a scene, an experience, an emotion, which is oppositional to chronologic and causality. A passage from Vonne van der Meer’s novel *De vrouw met de*

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[5] It is, for this reason, that Synnes et al. (2021) suggest using Orr’s term “lyric stories” to value the poetic contributions of people who live with dementia.

sleutel (The Woman with the Key, 2011), for example, discloses only that a lonely woman starts writing an ad in which she offers to tuck people in and read aloud to them at bedtime.

Neither in APP nor in SR sessions is there an exclusive invitation for participants to fill in the gaps of the literary texts and turn the scarce information that they are given into an interpretative whole. Call-and-response does not require the participants to comment on the meaning of the poems. And, although SR is based on open questions that invite participants to respond to a text cognitively, the method is open to emotional and experiential responses as well. Indeed, the questions are not only focused on what the literature is about but also on what it means to the participants who are encouraged to make connections between the text and their personal lives. Often, the Reader Leader asks whether some aspects of the reading are familiar to the participants or whether they recognise themselves in the text (which differs from reminiscing):

> RL Do you ever stand waiting at an exit?
> SP1 Yes.
> RL And do you also experience doubt whether it is this exit?
> SP1 Yes, I have that a lot.
> RL And do you recognise that a bit here in the text?
> SP1 Well, I was then waiting for a region [taxi] that dropped me off there and I was waiting in a different place. So, I was also at that exit, exactly what you say. Yes, I remember that very well.
> RL Yes, do other people recognise this?
> SP2 Yes, because, when you get to the station, you have two entrances, in the front and back side. You can get out through both.
> RL Oh yeah.
> SP2 Yes, I sometimes wonder sometimes where she will come from.
> (Odensehouse Haarlem, 15 June 2021)

This type of prompting – here in relation to the poem “Vier manieren om op iemand te wachten” (Four Ways to Wait for Someone, 2001) by Joke van Leeuwen – is somewhat comparable to the open questions[6] that the Poetry Facilitator asks in the poetry improvisation sessions, although in the APP approach there is less emphasis on recognition and a new poem created on the spot is the foreseen result.

Every response to a literary text is coloured by the background and experiences of the reader/participant. As Maurice Hamington and Ce Rosenow write, “A reading … its performance, if you will, is a relationship with a singularity: an interplay between the words/form and the audience (which can be as few as one) who brings to the event a history and disposition that shape the experience” (2019: 75). Characteristic of the APP and SR is that there is ample room for voicing and sharing these experiences in the group. The poem “Vier manieren om op iemand te wachten”, which offers a mono-perspectival point of view on waiting, resulted in a conversation of approximately 18 minutes about possible misunderstandings over where and when to meet that started with the example above. The participants talked both about their fear of getting this wrong and the self-doubt resulting from it. They validated each other’s input, built on each other’s stories and encouraged each other to contribute to the conversation. In this way, a single voiced poem turned into a polyphonic exchange of experiences, a multi-voiced social event.

The beauty of this SR session lay in the fact that, even though the setting was an Odensehouse, the participants did not suggest a causal relationship between their forgetfulness on the one hand and anxiety over making mistakes in planning and organisation on the other hand. Fears and moments of panic were presented as things that anyone could overcome. Therefore, there was no need for shame. Instead of zooming in on an individual illness experience and its detriments, the notion of commonality prevailed. Key is that both text and responses do not have to be upbeat and happy to be meaningful; the APP and SR activities make it possible to share all kinds of vulnerabilities.

Poetry as a portal to the imagination

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[6] The RL starts with yes/no questions in this example but then introduces open questions, as the SR approach envisions.

Poetry theorists argue that poetic language differs from prosaic and everyday language in the way it signifies (Wolf 2005). As such, ordinary meaning-making processes do not suffice to fully understand it. Because of the delay in and complication of signification, we associate reading poetry with intricate deciphering processes. Surprisingly, this hermeneutic stance may create space for neurotypical people to accept the unanticipated everyday language of people who live with dementia (Synnes et al. 2021). Creative activities such as the APP and SR offer failure free zones in which participants are safe to contribute according to their capabilities and without standing corrected. This implies that it is no longer relevant whether the input of a participant is indicative of an immediate creative outburst or of word-finding and comprehension problems that are characteristic of some types of dementia.

Verbal input that departs from the expected can become a portal to an imaginative excursion that others may join. An example of this dynamic from the SR sessions can be found in the responses to the poem “Nu en straks” (Now and Later) by Tsaed Bruinja that was published on 15 December 2020 at the beginning of a second lockdown in the Netherlands. The poem imagines what life could be like after the COVID-19 pandemic without explicitly mentioning the words lockdown, pandemic or corona. Remarkably, the poem gave rise to an exchange between participants about a man who decides to leave his wife and family for another love interest from a different gender (Odensehouse Amsterdam, 2 July 2021). This narrative was triggered by the poetic start of the text “in the new soon/near future” that, in the view of four participants, referred to “a new boyfriend”, “a new relation” and a “new partner”. They continued to connect the successive lines of the poem to their alternative narrative for almost 10 minutes.

While the dialogue evolved, the Reader Leader was slightly taken aback. On the one hand, she kept on positively acknowledging the input of the participants. On the other hand, she tried to direct the participants’ attention to specific parts of the poem to make their interpretation more in line with her own. When this did not work out, she threw the pandemic into the conversation: “What I like is how you can read it in different ways. As a personal love history or indeed as a, as a society, how we get out of the corona crisis. I think you mean that or not? That that’s the change”? The participants validated her input but circled back to their own interpretation unruffled:

SP5 It can be anything.

RL It could be anything. Yes, yes.

SP3 It was, of course, a big mess.

RL Yes, yes.

SP6 Well, I’m also making up my experience [interpretation] here on the spot, so, I don’t know what the real background is either.

RL That’s what we’re here for.

SP6 So, it’s very good that you throw in corona, I think.

SP3 Yes, also for just the kids.

SP6 Yes, also.

RL What’s it like for the kids?

SP6 Yes, in a new hetero relationship, this can of course also prevent a new partner from again distancing himself from that past, from that family, and from those old friendships, I think.

The participants mirrored the Reader Leader’s role by acknowledging her input and complementing her (“it’s very good that”) but did not approach her intervention as decisively significant. Thus, it was the reading of the neurotypical Reader Leader that did not match the collective interpretative process rather than the other way around.

What happens in this instance goes beyond what is usually understood by participation and inclusion of people who live with dementia. Rather than participants having to conform to an interpretative standard set by neurotypical people, the literary text now serves as a vehicle for playful exchange that does not remain limited to the semantic and syntactic parameters of the poetic words. While, in the example of the previous section, the conversation still focused on recognition and experience, here the poem becomes a portal to the imagination. This imaginative space is an alternative for the reality where participants are constantly confronted with the fact that their medical condition sets them apart from people who do not have it, which is much in line with Anne Basting’s (2009) well-known credo “forget memory, try imagination”. The SR approach turned the poem “Nu en straks” into a means for the temporary upheaval of power differences among neurotypical and neurodiverse people. When the participatory arts are recommended for their transformative potential, this is exactly what people hope to achieve. It also explains why I argue that AAP and SR are exemplary not just of the relational model of dementia but also of the political. Although the Reader Leader in this example was not entirely comfortable with the direction taken in the group discussion, she did have the sensitivity not to position herself as the expert with the power of the ultimate interpretation.

Conclusion

In this chapter, I have examined the relation between poetry and dementia by contrasting two conceptualisations of the illness and by showing how they play out in two case studies, the case of the Flemish poet Hugo Claus and of two literary practices in dementia care, the Alzheimer's Poetry Project and Shared Reading. The first case illustrates how poetry and dementia become irreconcilable when the latter is solely understood as a dreadful disease that implies the loss of personhood and of creative talent. At the beginning of this chapter, I referred to the poet Leo Herberghs who acknowledged change, relativised the significance of able-mindedness for his literary practice, and surrounded himself with people who helped him sustain what he called his "existence in words." Claus, on the other hand, had a writer's persona to live up to and was hyper visible in a societal and artistic context that prioritises the medical/individual model of dementia. This left little room for him to appreciate poetry as an existential tool, even in times of cognitive vulnerability, instead of as an aesthetic accomplishment and a profession. The tragic outcome of this logic is the perception of euthanasia, a so-called dignified death, as ultimate remedy to the threat of an anticipated undignified life. By contrast, APP and SR activities are "potential site[s] for collective reimagining" (Kafer 2013: 9) through the engagement with and the lived experiences of people with dementia who join these activities. The aesthetic and pragmatic affordances of poetic language as a live event offer participants opportunities to contribute and connect and, in doing so, encourage the formation of new bonds and the strengthening of self-worth. The political/relation conceptualisation of dementia that underpins these activities, furthermore, helps us think the future differently – Kafer calls this "a politics of crip futurity" (3). It stimulates us to reflect on what a good life with dementia could mean and how it implies a destabilising of the boundaries between neurotypical and neurodiverse people.

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