

Participatory arts programs in residential dementia care: Playing with language differences

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Abstract

This article examines connections between language, identity, and cultural difference in the context of participatory arts in residential dementia care. Specifically, it looks at how language differences become instruments for the language play that characterizes the participatory arts programs, TimeSlips and the Alzheimer's Poetry Project. These are two approaches that are predominantly spoken-word driven. Although people living with dementia experience cognitive decline that affects language, they are linguistic agents capable of participating in ongoing negotiation processes of connection, belonging, and in- and exclusion through language use. The analysis of two ethnographic vignettes, based on extensive fieldwork in the closed wards of two Dutch nursing homes, illustrates how TimeSlips and the Alzheimer's Poetry Project support them in this agency. The theoretical framework of the analysis consists of literature on the linguistic agency of people living with dementia, the notions of the *homo ludens* (or man the player) and ludic language, as well as linguistic strategies of belonging in relation to place.

Keywords

participatory arts, personhood, dementia care, play, language play, Alzheimer's poetry project, TimeSlips, homo ludens, language differences

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Participatory arts programs can position people living with dementia in creative roles in healthcare environments that are otherwise restrictive. These failure-free programs offer the opportunity for participants to express themselves and to engage in meaningful relations and to build a sense of connection and belonging. However, there is very little research on the participatory arts with regard to the social processes of personhood and in- and exclusion among people living with dementia in residential care. This article focuses on connections between language, identity, and cultural difference in dementia care. It looks specifically at examples of ways that language differences among residents and the facilitator become instruments for the language play that characterizes two spoken word-driven participatory arts programs—TimeSlips (TS) and the Alzheimer’s Poetry Project (APP).

Theoretical background

People living with dementia as linguistic agents

Difficulties in both language production and language understanding are features of dementia in general, although specific language difficulties may differ by dementia type (e.g. Alzheimer’s disease versus Lewy body dementia) (Blair, Marczyński, Davis-Foroque, & Kertesz, 2007; Guendouzi & Müller, 2005; Reilly, Rodriguez, Lamy, & Neils-Strunjas, 2010). Common changes in language production include word-finding difficulties, idiosyncratic word uses, semantic (i.e. replacement of one word for another in which the meaning of the latter is related to that of the intended word) and phonemic (i.e. the substitution of a word with a non-existing word that preserves some of the segments or syllables of the intended word) paraphasias, the use of semantically empty words (e.g. unrecoverable referents), reduced phrase length, diminished grammatical complexity in sentence production, and the flattening of pitch. Problems related to language understanding comprise, for instance, metaphor comprehension, the ability to understand grammatically complex utterances, and perceptions of linguistic and emotional prosody. Although these difficulties jeopardize communication processes, they do not imply that the linguistic agency of people living with dementia should be underestimated or ignored. Even people with advanced dementia are often able to communicate aspects of their experiences and perceptions (Clare, Rowlands, Bruce, Surr, & Downs, 2008).

By studying language in the context of social interaction (as opposed to in test settings), several scholars have argued that people living with dementia are “willing and able conversationalists” (Mok & Müller, 2014, p. 850). Stephen Sabat (2001) was one of the first academics to suggest that people living with dementia still have the intention to communicate verbally even if they are no longer able to successfully complete speech acts. As such, it is necessary to understand the peculiarities of their discourse for verbal exchanges to be productive. In a similar vein, Tom Kitwood (1997) famously argued that, since we are all relational beings, the way we engage with people living with dementia either upholds or undermines their personhood. Many of the examples of malignant social psychology that Kitwood identifies, such as mockery and infantilization, are performed through language.

Mok and Müller (2014) single out casual conversation “as a promising activity to encourage positive interpersonal processes” for people living with dementia (p. 834). This explains why participatory arts programs that are based on spoken-word traditions (instead of music, visual arts, or dance) can be an effective way of stimulating the exchange with and among people living with dementia despite it seeming counterintuitive at first. Just like any

other art program, spoken-word approaches draw on the communicative strengths of people living with dementia, such as the motivation to participate and connect and the ability to create and maintain rapport and alignment (Guendouzi & Müller, 2005; Roberts & Bowers, 2015; Saunders, de Medeiros, Doyle, & Mosby, 2012).

Language play and the human condition

In their article, “‘Play’ and people living with dementia,” Swinnen and de Medeiros (2018) introduce the concept of the *homo ludens*, coined by Dutch historian Huizinga (1949), into research that has been characterized as the “personhood movement in dementia studies” (Leibing, 2006, p. 242). The notion of *homo ludens* or ‘man the player’ is rooted in the belief that play is an essential human activity that a person never outgrows and that gives meaning to life. With the concept of “man the player,” Swinnen and de Medeiros aim to further develop research that has drawn attention to models of subjectivity that depart from the hypercognitive notion of the Cartesian subject. Just like the notion of the embodied subject (Kontos & Naglie, 2009) and the relational subject (see above), the concept of the playing subject is able to emphasize the similarities rather than differences between people living with and without dementia and, therefore, support the development of more inclusive societies. Furthermore, the concept of “man the player” broadens the discussion on the effectiveness of art programs in dementia care. If play has no other purpose than play itself, as Huizinga argues, and forms one of the fundamental characteristics of the human condition, measurements of art programs’ health benefits along biomedical standards (de Medeiros & Basting, 2013; Zeilig, Killick, & Fox, 2014) appear in a new light.

In his book on language play, Crystal (1997) integrates Huizinga’s theory with the field of linguistics. In Crystal’s (1997) view, linguistics tends to overlook the ludic function of language because of its single focus on language as “transmission of knowledge, however this is defined—as concepts, facts, opinions, emotions, or any other kind of ‘information’” (p. 1). In contrast, ludic language aids humor and enjoyment. Neither children nor adults mind when a conversation is temporarily disrupted because of language play for the sake of play. In addition, following Huizinga, Crystal (1997) argues that language play, just like play in general, is part of what makes us human and what gives meaning to life (p. 6). Crystal (1997) also makes the interesting observation that our ludic abilities in a foreign language are more limited than in our mother tongue, which becomes especially clear when dialect humor is considered (p. 18).

Cook (2000) points out that different genres of adult language play occur in both private and public settings (pp. 60–61). He follows Wolfson’s (1990) “bulge theory” which asserts that two extremes of social distance (i.e. relationships built on intimacy and equality versus those with blatant power differences) call for very similar language behaviors. In both opposing relational contexts, language play is used socially as an instrument to force people apart (competition) and/or to bring them together (collaboration). A secured ward for people living with dementia is a realm in-between the public and the private. Within this context, residents—just like any other people—negotiate roles and relations with one another as well as with care staff. A facilitator of a participatory arts program who visits the ward’s residents automatically becomes part of this negotiation process as the facilitator’s use of language may determine whether he/she is viewed an outsider or part of the group. This begs the question of what the role of language is in negotiation processes of social belonging.

Linguistic strategies of belonging

The transition to residential care settings has an impact on the social networks that people have built throughout the years. Yet, a new living environment also offers the opportunity to develop new ties. For people living with dementia in secured wards, it is more challenging to create new social relations as cognitive decline hampers communication. Nonetheless, the Friendship Study described by Saunders et al. (2012) shows that residents with dementia in long-term care do foster relationships through conversational (linguistic) interaction which include language features such as accommodation and recognition of other speakers' contributions. Yet, the agency of people living with dementia (e.g. strategies to cope with disabilities) and the new friendships they have developed among themselves are often underestimated by caregivers.

Thissen (2013) argues that the relation between language practices, feelings of belonging, and place mainly have been studied by linguists on the level of the nation-state, especially differences between linguistic practices of migrants and non-migrants in urban settings. Instead, she focuses on linguistic variation as social meaning-making processes in the Dutch periphery, the southern province of the Netherlands called Limburg (the setting in which our fieldwork took place). The linguistic "otherness" of the inhabitants of Limburg (Limburgers who speak with a soft instead of hard /g/) is deeply entwined with a sense of a distinct and peripheral identity of Limburgerness. This identity is constructed around notions of conviviality and a Bourgondian lifestyle. Thissen unravels the dynamics and multilayeredness of positioning through linguistic practices in everyday conversations. Since experiences of belonging inside or outside a community are constantly performed through language (Cornips & de Rooij, 2018), it is possible that this also applies to residents living with dementia in a closed ward. Thus far, little research has focused on linguistic practices of belonging in nursing home settings (Makkinga-Clijisen, 2017).

Methodology

Poetry and storytelling cabinet

This article draws on data resulting from the project "Poetry and Storytelling Cabinet," conducted in Maastricht (NL) in the period October 2015–May 2016. Twenty spoken-word workshops based on the methods behind TS and the APP were conducted for people with dementia living in two local residential care centers. TS (Basting, 2001) is a collaborative storytelling technique that starts from a visual cue. Answers to open-ended questions are echoed by the facilitator, recorded on a flip chart, and systematically retold. APP (Glazner, 2014; Swinnen, 2016) is a participatory poetry program based on group recitations of poems through call and response as well as poetry improvisations developed from answers to open-ended questions. Language play is characteristic of both approaches since the goal was not to convey knowledge but to invite imagination. TS (30 minutes) and APP (30 minutes) were presented back to back in alternating order each week for 10 weeks for a total of one hour each week. Residents were free to come and go at will. Eight people on average attended workshops at both locations.

Setting and participants

Participants were older residents identified by staff as having moderate to advanced dementia from secured wards in two residential care facilities, De Beyart (4 men, 10 women) and

Scharwyerveld (2 men, 9 women), both in Maastricht. We followed the regulations of each institution to get ethical approval for the study. We obtained written consent from the legally authorized representatives (LAR's) for residents of De Beyart. LAR's from residents of Scharwyerveld were informed about the study through a letter providing them with the possibility to opt out. Although staff occasionally observed sessions, they did not have a formal role in the study. Privacy regulations at both places prevented us from gathering more extensive demographic or health data. Therefore, we were not able to capture information such as age, specific dementia diagnosis, or specific level of severity of the disease.

Data collection and analysis

An ethnographic approach (Nippert-Eng, 2015), including participant observation and auto-ethnographic reflection on the part of the facilitator (first author), was chosen to study the meaning-making potential of TS and APP for people living with dementia. Data collection consisted of field notes on and audio recordings of the workshops as well as flipcharts and transcriptions of stories and poems. Through memoing and close reading, we singled out instances of language play based on language differences between the participants and the facilitator and among the people with dementia themselves. Two illustrative vignettes are presented below. They are written in the first person to indicate the perspective of the facilitator.

Findings

Playful language crossing: Flemish Dutch-Limburgian



Vignette 1 (De Beyart, Workshop 9, 9 December 2015). “Who could these be?” I ask. “Unmarried boys,” Mrs. R. replies. She adds in dialect that they are good looking. I try to repeat her words but fail to reproduce her sounds convincingly. Mrs. R. and the other

participants, including the care professional who is present, chuckle. Again, I try to imitate Mrs. R.'s input but the words do not sound any better. We all laugh together. On the flipchart, I try to write Mrs. R.'s contribution down phonetically. This annoys Mrs. H. who, like me, does not master the dialect. She always enjoys reading the words from the flipchart together with me, which now becomes slightly problematic. With each round of telling back parts of the story, I try reproducing the words of Mrs. R. according to the sound of her dialect. I always look at her when doing so. Despite my efforts, I keep failing in my attempt. With each failure, the group and I laugh together over my incapacity to pronounce Mrs. R.'s words "properly."

Later in the workshop, during the joint poetry performance, I announce that I would like to introduce my favorite lullaby, "Slaap als een reus" [Sleep like a giant] (1927). It is written by Paul van Ostaijen who, just like me, comes from Flanders. Some of the words that he uses might, therefore, be unfamiliar to them. When I recite the poem the first time, I pause when the first unusual word, "reuzeke" [little giant] occurs. The participants look puzzled at me. I then break the word down into its semantic kernel and diminutive signifier so as to get its meaning across and invite the participants to repeat after me. They do so hesitantly. We reiterate this process a few times. When the participants have grown in confidence, I combine the word with other words from the poem that are constructed in a similar way, such as "rozeke" [little rose] and "dozeke" [little box]. The participants respond to my call of the words. I also add words of my own that fit the series of diminutives and, presumably, have a comic effect, such as "zoeteke" [sweetie] and "zotteke" [little fool]. I repeat the call of the words several times and accelerate the speed till the participants burst in laughter and signal that they no longer can follow.

Discussion. Since the workshop facilitator grew up in Belgium in a family in which the standard Dutch characteristic of Flanders (the Dutch-speaking part of Belgium) was practiced, her language use—especially in terms of phonetics and sometimes-even semantics—differs from the discourse of people living with dementia who participate in the workshops. Most participants come from Maastricht or its direct surroundings and some of them consistently formulate their input in a Dutch-Limburgian dialect. Moreover, the professional care workers from De Beyart who participate in the workshops also consequently address residents in dialect. The vignette demonstrates the ways in which the language differences between the facilitator and the participants are not necessarily a communicative challenge. Rather, these differences put all those involved on an equal footing which provides the opportunity for collaborative play.

During the TS-structured parts of the workshop, the facilitator pays particular attention to copying the verbal input of the residents meticulously, as the method stipulates. This includes imitating the particular sound of the words and writing them down accordingly. As the vignette illustrates, Mrs. R. provides the facilitator with verbal input and the latter's attempt to reproduce this input, results in comic laughter. The facilitator, rather unfamiliar with this particular language use, invites Mrs. R. and the other group members to teach her how to "do" the language pronunciation right and, in doing so, she recognizes the linguistic identity of Mrs. R. and the group. The facilitator shows the residents that she appreciates their input and that she isn't afraid of getting it wrong. On the contrary, mistakes become a source of play. In this process, the professional caregivers occasionally function as interpreters, bridging the language differences between the facilitator and the residents.

During the collective poetry recitations following the call and response technique (as part of APP), it is apparent from the very beginning that words characteristic of the

Dutch practiced in Flanders are difficult to repeat for most residents. In earlier sessions, this prompted the facilitator to exchange these words for words that the participants were more familiar with so as to get the stream of words flowing. Yet, after a couple of weeks, when the participants had gotten used to her presence as well as the procedure behind the art workshops, the facilitator started experimenting with the introduction of some Flemish words as part of language play. For example, she calls the residents “little rose,” “little giant,” “sweetie,” or “little fool” and invites the residents to repeat after. This provides the residents with the opportunity to now affirm the facilitator’s linguistic identity. Even though the facilitator presents herself as an expert in these instances and addresses the incapacities of the participants, this did not result in frustration.

Participatory arts programs are often understood to provide failure-free environments in which people living with dementia are enabled to express themselves without being corrected or reprimanded. From the vignette, it follows that a failure-free environment does not necessarily imply refraining from risks, such as introducing language variation that the participants are not used to hear or produce in their everyday setting. Language use signals belonging to a particular social group. In the course of the workshop, the residents and facilitator are constantly negotiating their identity through phonetic, morphological (cf. diminutives), and semantic features. Mrs. R. takes over the facilitator’s expert role, and, thereby, negotiates who is in charge. Furthermore, by insisting on her Limburgian dialect, she builds a sense of solidarity among the residents who share her knowledge, while distancing herself from the resident (Mrs. H.) who does not. Through her tenacious attempt at reproducing the particular sound of Mrs. R.’s verbal input, the facilitator shows her willingness to try another language variant (i.e. language crossing), even though she risks losing face (Goffman, 1955) when doing so. This implies that she does not shy away from showing her vulnerability, much like those attending the workshop who also show their vulnerability. Maintaining face in poetry performances on the part of the residents is accomplished when they manage to repeat the line introduced by the facilitator. By first enabling the gentle rebellion of Mrs. R., the facilitator prepares and creates the opportunity to invite the residents to engage in playful language crossing (the call and response of “Flemish” variants of Dutch words) in their turn, without alienating them from the process of collaborative play. A sense of reciprocity occurs and the willingness of both parties to step into unfamiliar territory and to change roles turns the workshop into a success.

Negotiating social belonging in language play

Vignette 2a (Scharwyerveld, Workshop 4, 26 October 2015). I introduce the poem “Zeeklacht” [Sea complaint, with “Sea water is always salty” as its first line] (1960) by Cees Buddingh, a Dutch poet known for his laconic and humorous observations of everyday life. Several rounds of call and response of the poem are meant to serve as inspiration for the collaborative improvisation of a new verse based on different sensations of taste. First, I ask the participants what, in their experiences, tastes sweet, then, what they associate with a salty taste, and finally, what things taste sour or sweet-and-sour. When one of the caregivers encourages Mrs. M., who is from Indonesian descent, to think about her experiences from years of preparing Indonesian food, this results in Mrs. M. introducing Indonesian/Malaysian words¹ for the group poem. At the beginning, Mrs. M. seems to hold back a little and only timidly mentions that the Indonesian word for sour is *kecut* and for salty *oeia* (the latter I could not find in the dictionary). Yet, when I give the newly generated poem

back to the group through call and response, she becomes increasingly enthusiastic and talkative. We find out that *manis* is the Indonesian word for sweet. *Nona manis* refers to a sweet girl. Mrs. M. starts singing a popular song to demonstrate its meaning. She continues with explaining the difference between *nona* and *nonja* or an unmarried (or a virgin in Mrs. M.'s words) versus a married woman. Other residents listen attentively and Mrs. L even asks Mrs. M. to elaborate on the differences between *nona* and *nonja*. Eventually, the new poem includes several Indonesian words for the whole group to practice through call and response. It seems not to be an issue at all that the poem has become bilingual. On the contrary, the residents enjoy repeating the lines after me:

Sugar is sweet/Syrup is sweet/Biscuit is sweet/Spiced biscuit is sweet/Porridge I find sweet/Rice pudding is sweet/Sweets are sweet/Sweet is manis/Nona manis/Nona and nonja/Unmarried and married/Salty is salty/Sea water is salty/Oeia is salty/Friendship is sour/Sour is sharp/Kecut is sour/Sweet-and-sour is 110/Sweet-and-sour is ketjap manis/Amen.

Vignette 2b (Scharwyerveld, Workshop 10, 8 December 2015). Today, I give the famous Dutch poem “Herinnering aan Holland” [Memory of Holland] (1936) by Hendrik Marsman a try for call and response. I have adapted it to make its solemn language and long sentences more accessible. The participants find the poem “difficult yet beautiful.” I tell them that we will elaborate on the poem and ask them consecutively what comes to their mind when “thinking of Holland” (which is the original poem’s first line), the Netherlands, Limburg, and Maastricht. Mrs. M. points out that Maastricht makes her think of its “strange Limburgian language” and the people. She then claims that the people living in Maastricht differ from the people living in Holland in that they are “kind” rather than “rigid.” Also, she explains that she decided to stay when she first came to Maastricht after a considerable period in Holland. Mrs. N. who turns out to come from the province of Zeeland disagrees with Mrs. M. She says: “I am here [Maastricht] somewhere else” and “I wish I would be back there [Zeeland].” Upon hearing this, I incorporate Zeeland into my open question as well as Indonesia. “What comes to your mind when you think of Zeeland or Indonesia?” Mrs. N. thinks back off the traditional costume characteristic of the region where she grew up. Mrs. M. confesses that she prefers Indonesia over Holland because of the weather. She adds: “It’s too hot for them” to which I reply with “You mean us.” Mrs. E. now brings into memory that she comes from the Indonesian isle of Ternate known for its volcano (Volcano Gamala). I integrate all of this input, without trying to reconcile different experiences, into a new version of “Herinnering aan Holland” and we recite it through call and response to everyone’s satisfaction.

Discussion. Workshop 4 offered Mrs. M. the opportunity to introduce and teach Indonesian words to the group. Mrs. M. is part of the approximately 2% of the Dutch population from Indonesian and mixed (Indo) descent.² With the help of the facilitator, Mrs. M. teaches her co-residents a few Indonesian words. The group members display openness to her input and may even be acquainted with a word like *ketjap* from their experiences with the popular Indonesian cuisine. Yet, learning cannot be the primary function of Mrs. M.’s contribution, as the other participants are no longer able to memorize these words. In fact, they can only reproduce them through call and response. As such, the contribution with a few words of her (presumed) first language, shows first and foremost that the language play upholds Mrs. M.’s personhood. In this sense, the function of the Indonesian words that become part of the new poem is comparable to the line

“sweet-and-sour is 110,” the number being the only remainder of the repertoire of Mr. F. who used to be a math teacher. Both participants are empowered to contribute with the language that characterizes them as individuals.

The poetry improvisation of workshop 10 results in a conversation about belonging. This may be triggered by the fact that the term “Holland” in the title of the original poem is often used to refer to the whole of the country of the Netherlands (instead of the province) to the dismay of many people from other parts of the country, including Limburg. Mrs. M., of Indonesian descent, now clearly identifies with her location in Limburg and distances herself from people living in Holland. She taps into familiar yet-clichéd presumptions about the connections between language, place, and identity by describing the Limburgers as friendly as opposed to the rude Hollanders (cf. Thissen, 2013). Mrs. N. does not agree with Mrs. M. and brings her Zeelandian ancestry into memory. Zeeland is located closer to Holland than Limburg. When it comes to choosing between locations, Mrs. M. prioritized Indonesia. She refers to Indonesian people as “us” versus “them,” the people from the Netherlands, which the facilitator emphasizes by aligning herself (as Belgian ironically) with the Dutch (“us”). Mrs. E. who also is of Indonesian descent clearly takes Mrs. M.’s statement as an invitation to start talking about her connection to Indonesia. It is the play with language inspired by the poem “Herinnering aan Holland” that facilitates these different types of positioning.

Unmistakably, positioning practices are fluid and flexible. What all participants have in common is their hybrid identity—being both Indonesian and Limburgian, Dutch and Flemish, Limburgian and Dutch, etc. The language play that unfolds through the course of the workshops becomes an interpersonal process through which participants form and maintain different group identities. This demonstrates that dementia as a disability is certainly not the identity marker that defines all residents, as biomedical approaches sometimes seem to suggest. Despite language difficulties, the short and fragmentary speech acts of the participants illustrate their competencies as capable linguistic agents (cf. Mok & Müller, 2014) who can voice very nuanced understandings of what it means to relate to multiple groups. The group setting and collaborative poetry-based process provide the space and mechanisms for residents to express and negotiate senses of belonging.

Study limitation

There are several limitations that must be acknowledged. First, we were not able to obtain demographic or health information for the residents. Participation may have been influenced by the residents’ age or other demographic features. In addition, dementia type is an important consideration. For example, a person with Alzheimer’s-type dementia may participate in a very different way than someone with Lewy body or frontotemporal dementia. We also have not discussed challenges that residents may have encountered. Certainly not everyone participated at the level of those described in the vignettes. The examples were meant to show the possibilities of language play rather than provide a critical description of arts-based interventions.

Conclusion

In this article, we have argued that play in the context of spoken-word-based arts approaches to dementia care can function as equalizer by drawing attention to the

humanness that all people involved share. We have focused on language differences as one of the categories of difference that define identities. Identities are never stable and require ongoing processes of negotiation. Our data suggest that people living with dementia—despite language decline—are linguistic agents capable of participating in these processes on their own terms. The language play that is characteristic of TS and APP supports this agency in exceptional ways.

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Notes

1. Mrs. M. uses both terms interchangeably.
2. Statistics Netherlands lists 107,541 first generation migrants and 262,120 second generation migrants in 2015 who moved to the Netherlands after the recognition of Indonesia’s independence in 1949. This population is relatively well integrated.

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Kate de Medeiros, PhD, is an associate professor of Gerontology in the Department of Sociology and Gerontology at Miami University, Oxford, Ohio. Her dementia-related research includes the meaning of place and friendships in long-term care, self and personhood, and the role of the participatory arts. She co-developed (with C. Lyketsos) the Neuropsychiatric Inventory Clinician Rated assessment, a revised tool to measure behavioral changes in people with dementia. Her research has been funded by the National Institutes of Health and the Alzheimer's Association.