Navigating Through the Narrative Montages: Including Voices of Older Adults With Dementia Through Collaborative Narrative Inquiry

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Abstract
Having the opportunity to express oneself is an important right to every human being. However, narratives of older adults with moderate to severe dementia are constantly ignored for their incoherence and inaccuracy. In most studies, their narratives were solely collected to measure their cognitive function, rendering their lived stories untold, unheard and undocumented. To include voices of older adults with moderate to severe dementia in research and liberate them from the patient identity, this article proposes collaborative narrative inquiry as a method to explore the meaning-making mechanisms and selfhood construction processes embedded in their incoherent narratives. Integrating narrative inquiry and collaborative analysis, collaborative narrative inquiry aims to collect, construct and deconstruct narratives of participants through an iterative and reflective way, in collaboration with caregivers. This method requires a paradigm shift from generating one essential truth of people’s lived experience to co-creating plural lived truths situated in different temporal, social and cultural backgrounds. Facilitating the proliferation of identities beyond the patient identity among older adults with moderate to severe dementia, collaborative narrative inquiry generates counter narratives against a single disease narrative. It de-marginalizes this group by inviting their voices back into the society, and destigmatises them by creating a new way to engage with them.

Keywords
collaborative narrative inquiry, inclusive approaches, de-marginalization of people with dementia

Introduction
Older adults with moderate to severe dementia encounter multiple difficulties constructing narratives of their own, due to both physical and environmental hindrance. As the disease progresses, incoherence, repetition and twisted memories increasingly emerge in their narratives, making them less comprehensible to others (Potkins et al., 2003). Caregivers’ common responses to such language impairment is to debate about the truthfulness of the narratives, ignore the seemingly meaningless narratives, or assess their narratives according to standardized measurements (Small et al., 2000). These responses may exclude older adults with dementia from meaningful communication with others, and therefore impair their narrative identity—the self-constructed through the synthesis of one’s experiences (McAdams & Janis, 2004; Zimmermann, 2017). Gradually, older adults with dementia lose the opportunity to create identities other than ‘patient’, or to tell stories that are not ‘behavioural and psychological symptoms in dementia’ (BPSD) (Baldwin & Group, 2008; Herrmann et al., 2018; Low & Purwaningrum, 2020).

Kitwood (1997, p. 19) summarized this phenomenon as ‘malignant social psychology’ and considered it a form of stigmatization and marginalization of older adults with dementia. With such attitude prevalent, the public may practice
discrimination towards older adults with dementia before they actually interact with them (James Rupert Fletcher, 2019), or overly expressed concern and sympathy, also known as ‘benevolent othering’, which may increase felt stigma among this group (James R Fletcher, 2021). How to conduct research that resist reproducing malignant social psychology towards this population, however, is comparatively less discussed. Studying lived experience of service users is particularly important for theory building and practice design in health service research.

Scholars have applied diverse methods to explore the experience of older adults with dementia, including diary interview (Bartlett, 2012), grounded theory approach (Clare et al., 2008), participatory approach (Dewing, 2007), ethnographic observation (Kontos, 2004), phenomenological hermeneutics (Mjorud et al., 2017), art-based approach (Fornazzari, 2005; Kontos & Naglie, 2006; Silveri et al., 2015) and narrative approach (Russell & Timmons, 2009). However, older adults with moderate severe dementia are largely excluded from life experience research. A scoping review of approaches involving people with dementia in dementia are largely excluded from life experience research. A

Three decades ago, Spivak posed an inspiring question, ‘Can the subaltern speak?’ problematizing past postcolonial work in which the elite represented the subaltern, and thus reinforced the silencing and marginalization of these groups in a less visible way (Darder & Griffiths, 2018). Scholars have since cautioned against exploring life experiences of the deprived using essentialising, dominant discourses from a centralized perspective. Indeed, it is important to include discourses and voices of the subaltern group, so as to open up a space for counter narratives. These implications are applicable to dementia research, as scholars in this field are also working with one of the most deprived and marginalized groups in society. Although numerous studies have been conducted to understand dementia, lived experience of older adults with moderate to severe dementia is still mostly told through a single narrative about the disease, rather than the person (Davis, 2004).

One of the fundamental missions of qualitative research is to counteract traditional assumptions about knowledge production and to transgress the golden rule of objectivity so as to explore the discomfort and disruptions within human experience (Denzin, 2017; Gray & Kontos, 2018). By unfolding meanings people attach to experiences, qualitative researchers produce knowledge about the hidden stories behind people’s behaviours and beliefs (Sparkes, 2012). Dementia research guided by the biomedical framework, admittedly important, inevitably views older adults with dementia with an ‘anatomo-clinical gaze’, separating the person from his/her body (Foucault, 1973, p. 126) and limiting their narrative space. Narrative methods, attaching greater significance to the personal experience than the medical condition, may provide a more holistic view of this population (Holloway, 2005, p. XV). In addition, the therapeutic effects of treatments and interventions are not independent from people’s experiences, and thus, the study of experience facilitates the understanding and development of health services (Stanhope & Henwood, 2014).

In recent years, qualitative health researchers have increasingly adopted inclusive approaches to democratize the knowledge production process and bring about substantial social changes (Edwards & Brannelly, 2017). In line with these beliefs, this article introduces collaborative narrative inquiry, a narrative method designed under the participatory paradigm and its utilization in dementia research.

Narrative Space and Social Justice

Narrative researchers are encouraged to always start from themselves, so as to reflect upon and make transparent their individual motivations, interests and inevitable biases (Clandinin, 2016). This section reflects on my original encounter with dementia, so as to reveal the positionality, intentionality, and emotional preparedness of the researcher in designing and conducting this study (Chen et al., 2021; Fenge et al., 2019).

My interest in doing narrative research among older adults with dementia started with my acquaintance with Atlas (pseudonym), a gentleman who had lived with dementia for more than 10 years. He refused to engage in any group activity at the day-care centre, and no matter what the staff said to him, he replied with routine answers: either a direct rejection or a blessing. Feeling embarrassed, his family and caregivers told us that he had stopped making sense for long and asked us to ignore what he said.

But I could not ignore his words, and the fact that we were asked to ignore him in front of himself. Atlas apparently had something to say, something excluded from the normal communicative script by careless actions of silencing. What he said was common conversation stoppers in Chinese: sending people away by an abrupt no or a blessing. Did he feel insecure when talking to others? I consulted a care worker that had worked with him for many years and he told me Atlas developed aphasia a few years ago, and as people failed to understand him, he shut himself down dramatically. Suddenly, I heard the fear behind those sentences, the fear of being belittled and challenged.

I hoped I could engage with him in his own world, so I sat beside him, thinking about a conversation starter. Suddenly he knocked off two pieces of dominoes and looked anxious. I naturally said his words: ‘I get it, none of your business’. He replied ‘Thank you!’ in English.

Everyone was surprised, as Atlas had not spoken English for a long time, and this time not only were his words accurate, but he was also making a genuine interaction. After that, people around Atlas responded to him with a supportive and understanding attitude, no matter what he said, and his speech began to gradually diversify. One year later, my colleague met him again, and Atlas greeted him warmly with a joke.

Apparently, what we did there was nothing more than listening to his narratives carefully and trying to understand them, while this
process was considered healing in Atlas’s life. This experience made me realize the importance of creating a safe space for people with dementia to construct more narratives. This objective cannot be achieved by researchers alone. It requires collaboration among those who work with and live with them. When older adults with moderate to severe dementia present only fragments of certain stories, caregivers familiar with them may lead us to better comprehension of them (Baldwin & Group, 2008).

People do not die when our hearts stop beating; they die when people stop seeing them as humans. When one’s narratives are constantly invalidated, so is their selfhood. Qualitative researchers shoulder the responsibility of unfolding the hidden experience and meanings of human beings, especially those who live with multiple shackles. This was the original reason for me to design collaborative narrative inquiry—a research method that includes and encourages narratives of older adults silenced by dementia, and interpret their narratives in an iterative, reflexive way, with contribution from those who work closely with them.

Methodology

This section provides a detailed description of a study investigating lived experience and narrative selfhood of older adults with moderate to severe dementia adopting collaborative narrative inquiry. This research method was designed to (1) explore voices of older adults who can no longer provide consistent and coherent narratives due to moderate to severe dementia; (2) analyse incoherent narratives through multiple, situated theoretical lenses and collective, iterative reflections; and (3) create counter narratives which de-stabilize their patient identity. Study design, data elicitation approaches, analytical methods, ethical issues as well as epistemological stance are discussed, respectively.

Context

This study took place in a public nursing home in Yuen Long, a remote district in Hong Kong. The nursing home was located within a public housing community. Only older adults with severe diseases or very low mobility and self-care ability are accepted in nursing homes, and they usually have to wait for three to 5 years before getting accepted by free public nursing homes, due to limited resources. Residents of the studied nursing home were previously Mainland immigrants dwelling in public housing community and reported comparatively low socio-economic status.

This study was part of a community-based participatory research project on developing and contextualizing the Play Intervention for Dementia, and the principles and implementation of the intervention were published elsewhere (Li, 2021).

Sampling

Purposive sampling was adopted to select the participants who are ‘information rich’ (Devers & Frankel, 2000). The basic inclusion criteria were as follows:

- Aged above 65;
- Diagnosed with one or more types of dementia by medical professionals;
- Level of dementia is moderate to severe (MMSE <20).

Sample selection was conducted with the assistance of care workers at the nursing home, and the focus of the selection was to identify older adults with rich narratives, including verbal and embodied narratives, and high motivation to participate in the study. Five older adults with dementia joined the study, and all of them were reported to have BPSD. Although all the participants were still able to speak, their speeches were often considered ‘irrelevant’ and ‘unreal’ by staff, and therefore were mostly stopped without further interpretation. The following Table 1 summarizes the demographic and documented information of the participants:

| Name  | Gender | Age | MMSE score | Stage of dementia | Description |
|-------|--------|-----|------------|-------------------|-------------|
| Mary  | Female | 83  | 16         | Moderate          | Delusion; irritation; very poor memory; immobile |
| Flora | Female | 91  | 10         | Severe            | Delusion, irritation; very poor memory; mobile    |
| Gendry| Male   | 93  | 19         | Moderate          | Sleepiness   |
| Sophie| Female | 94  | 9          | Severe            | Severe irritation; delusion                       |
| Melisa| Female | 89  | 18         | Moderate          | Depression   |

Notes.

*Name is pseudonym.

*MMSE refers to mini-mental state examination.

*Stage of dementia is based on MMSE score (Perneczky et al., 2006).
they create purposes. Connecting each other’s stories creates an open space where different experiences are reconceived, re-visualised and eventually reformed (Greene, 1995, p. 5).

A personal narrative is a distinct form of communication that creates meanings, expresses emotions, and constructs identities (Bamberg, 2012; Chase, 2018). Narrative, be it articulated, fragmented or embodied, is a central element in the construction of personhood and the self (Baldwin & Group, 2008; Schechtman, 2011). Through narratives, people give an account of their lived experiences (Widder, 2011). In addition, narrative resistance should aim to improve social justice by bringing to light marginalized people’s experiences, and generating practical application of narrative inquiry in real-life contexts (Chase, 2018).

Narrative analysis should be ‘a hermeneutics of faith, which aims to restore meaning to a text, and a hermeneutics of suspicion, which attempts to decode meanings that are disguised’ (Josselson, 2011, p. 226). To understand life experiences far from normal life, researchers need to be critical and reflexive in order to discern how inequalities and institutionalization may twist people’s stories. Furthermore, narrative resistance towards the mainstream script is particularly important for social changes (Weis & Fine, 2012).

**Collaborative Analysis**

Collaborative analysis has been used to understand the experiences of marginalized groups (Fraenkel et al., 2009; Kong, 2016) and stimulate real changes in a specific context. The meaning of collaborative analysis is threefold. First, it democratizes scientific practice and gives a voice to all stakeholders; second, it opens up a space where perspectives and insights can interact with each other; third, it creates a learning space for all stakeholders to re-examine their practices as well as the contexts of practices.

When researching older adults with dementia, collaborative analysis between the researcher and the caregivers is of particular significance, as caregivers are much more familiar with the meaning-making schemes of the older adults they work with. In-depth discussion is constantly needed to acquire true meanings of the narratives. This process can be executed in a spiral of reflective cycles: the researcher interviews older adults with dementia, conducts original analysis, reflects upon the analysis together with caregivers, conducts follow-up interviews when necessary, and constructs narratives reflecting lived truth and selfhood of the participants.

**Data Elicitation**

**Unstructured Interview**

Unstructured interview was chosen to investigate the participants’ life stories as it provided them with adequate space for free expressions (Svanström & Dahlberg, 2004). The interviews commenced with the researcher’s self-introduction and the invitation ‘Please tell me something about yourself’. The researcher would facilitate participants unfolding the stories they chose to tell, without any attempt to change the topic. In the belief that the participant is the expert of their experience (Fraenkel et al., 2009), the researcher totally followed the participant’s chain of sense-making, suspending pre-existent assumptions about the participant, the definition of lived experience and even the definition of ‘meaning’. If possible, the researcher would invite the participant to send one message to an audience of their choice, as a summary of their narrative. In this way, the researcher maximizes the narrative space for the participants and gains access to the chaotic and silenced subjective world of life with dementia. Each interview lasted from 30 to 150 minutes.

**Art-Based Interview.** Participants might feel anxious during a long interview, or chose to stop talking for other reasons. In these situations, artistic processes including singing, musical instrument playing and image sharing will be adopted to facilitate experience sharing. For example, when the participant felt difficult to express him/erself, or showed anger and fear during the interview, the researcher would provide them with small drums, a djembe or maracas and play with them. The rhythm and beats produced during improvisation helped the researcher understand the emotional state of the participant, and such improvisation sometimes elicited more narratives.

**Observation.** Due to both disease-related difficulties and cultural factors, it was challenging for some participants to finish a verbal interview (Bond & Corner, 2001). Also, Chinese older adults with dementia sometimes find it difficult to express their personal needs and challenges through words (Liu et al., 2008; Mok et al., 2007). Therefore, non-intrusive observation was also adopted as a way to collect data, with attention attached to the interactions and embodied expressions of participants. The observation was documented by fieldnotes.

**Data Analysis**

There are three main principles for data analysis in collaborative narrative inquiry.

**Rethinking ‘Truth’: Resisting the Positivistic Prejudice**. Instead of summarizing the narratives into an essential, representative story of the entire population, the analysis of this study seeks to create thick description of situated meanings and identities created in the participants’ world (Carnevale, 2020). To achieve this, the epistemological prejudices that determine what counts as ‘knowledge’ and ‘truth’ need to be reflected upon.

The question about the truth is a recurring theme in the development of narrative research (Chase, 2018). Denzin (1989) once argued ‘true stories are stories that are believed’, emphasizing the subjective element of narratives. Heidegger (2002, p.8) also argued that truth might have...
nothing to do with assertion of the facts, but was more about ‘unhiddleness’ (Tamboukou, 2012). Therefore, whether a person has a realm to tell the subjective truth he lives determines the level of freedom they enjoy (Peters, 2003). The subjective world of older adults with moderate to severe dementia can be greatly influenced by the disease, and their scattered narratives are the only pathways through which we might take a glimpse of their truth. The fundamental principle for conducting analysis of their narratives is to suspend our assumption of ‘truth’ and fully dwell on the situated meanings, emotions and identities expressed in their narratives.

**Beyond Narrative Coherence.** A caregiver once said that listening to narratives of older adults with dementia was like ‘navigating through a montage movie’, where one can never organize events chronologically. Rather, the narratives were like jigsaw puzzles that require the audience to assemble. Researchers’ general preference for narratives that ‘proceed in a linear, chronological way’ and remain consistent over time can exclude the voices and experiences of those who cannot produce such narratives (Hyvérinen et al., 2010, p. 2). This preference may result from the pursuit of consistent identities and efforts to avoid challenging and scattered cases in research (Hyvérinen et al., 2010, p. 10). Most studies on dementia choose people with mild dementia as their sample and exclude those who have moderate to severe dementia, deepening the level of marginalization. To truly enter the life world of the elderly with moderate to severe dementia (or at least try to), we need to resist temporal linearity as well as thematic coherence (Hyvérinen et al., 2010, p. 8), and instead focus on fluid, context-specific and relationally situated narratives (Georgakopoulou, 2006, 2007).

**Selfhood as an Alternative Interpretive Framework.** Selfhood is constructed through narratives (Schechtman, 2011). Unfolding selfhood behind the narratives potentially help older adults with dementia create identities other than their patient label.

Conventional narrative analysis includes chronologically sequencing the events, selecting theme-relevant events, establishing connections and writing up the story (Polkinghorne, 1995). As narratives in life with dementia trespass temporal and spatial boundaries, chronological sequencing and thematic synthesis may not be applicable. Structural analysis, which focuses on the telling and linguistic devices of narrative is also not suitable as the essentialist presumption of a stable structure behind narratives does not apply to lived experience of dementia, which consists of scattered memories and fluid persona. Therefore, interactional analysis, which attaches significance to the dialogic process between the audience and the narrator, and performative analysis, which explores the performed identities behind each story (Hydén, 2013; Riessman, 1993, 2003), were chosen for the current study. In this study, data analysis mainly includes collaborative interaction analysis that reflects upon the interactions between interviewer and participants, and collaborative performative analysis that explores the selfhood behind the discursive, situated and sometimes embodied narratives of participants (Riessman, 1993).

The researcher began the analysis by generating a general picture of participants’ narrative identities based on the transcripts and field notes. Then she shared the original analysis and confusions with caregivers of the participants through focus-group interviews to collaboratively triangulate the analysis. Most importantly, the collaborative analytical group discussed possible practical changes, including new ways of communicating with the participants and tailored activities for the participants, based on the analysis. This analytical cycle can repeat several times. Such group analysis may generate new ways for the researcher to conduct follow-up interviews and new practices for the caregivers to engage with the participants. Therefore, contrary to finding common characteristics of the participants, this analysis aims to reveal the complexity and uniqueness of participants’ narratives (Riessman, 2003; Russell & Timmons, 2009), providing new insights for both the researcher and the caregivers. To achieve thick description and in-depth interpretation, multiple theoretical lenses were adopted with flexibility during the analysis (Chase, 2007). The following Figure 1 demonstrates the specific procedure of this methodology:

**Ethics**

Older adults with dementia generally experience physical and mental vulnerability (Dresser, 2000), so researchers should try to minimize the harm and maximize the support when working with them (Murphy et al., 2015). Based on this objective, the researcher designed several rules for ethical concerns before the study:

- All interviews were conducted at the nursing home where participants can access medical support when necessary.
- A safe, supportive and confidential space should be provided for participants to express their emotions, and the researcher should validate their emotions even when they were associated with delusions (Britzman et al., 2009).
- Although written consent was obtained from family members, verbal consent was still sought from each participant before each interview (Dewing, 2007; Hubbard et al., 2003). Interviews were rescheduled whenever a participant felt reluctant to it.
- The interviewer may not debate with the participant about accuracy, temporal linearity, and coherence of their narratives (Hyvérinen et al., 2010), but focus on following up with the emotions and specific contexts related to their narratives.
- Different methods would be used to communicate with participants when they are incapable of verbal communication (Hubbard et al., 2003).
Some interviews were conducted with caregivers present, as familiar faces give participants a sense of security. The researcher and caregivers participating in this research all need to sign a written confidentiality agreement. Also, they need to follow the principles of appreciative inquiry, in which the main goal is to collaboratively identify and enhance positive forces among participants (Cockell et al., 2020).

**Findings**

After several weeks of data collection and collaborative analytical meetings, we constructed the scattered narratives of participants into personal stories, with focus on the lived meaning, the selfhood and the narrative context.

‘Buy nice shoes!’: the story of a resilient woman

Mary was an 83-year-old woman who greeted me with a warm smile when we first met. She communicated with me smoothly in a soft voice. She started her narrative by introducing her name and age and then expressed her gratitude towards the caregivers at the nursing home. She even described in detail the different soups offered at the canteen. The conversation continued in the current time and location, and then abruptly, she shifted to a time in the past, when she was sitting in front of her old house:

M (Mary): …The other day I was sitting on my chair at my house, and someone came to me, didn’t know who, could be my second daughter (laugh). I have too many daughters to remember. She put a baby in my arms, and I looked at it. Ha! A little red hat, a little red jacket and a pair of little red pants. There were diamonds on the hat, and some green leaves. Looking at the little red hat I knew it was a baby boy, as baby girls wore those white dresses with long sleeves…

I was not sure I understood her story, so I listened quietly. She repeated this narrative for six times, and each time there were only slight changes. Despite the confusion, I did not interrupt her. After the seventh time, she said:

I was so happy! What have I done to deserve a grandson? I had no son of my own, and now I have a grandson, I said to myself, “Mary, this is solid proof that you haven’t done anything wrong!”

Suddenly I could connect with her feelings—the traditional belief that giving birth to sons represents proper femininity, and the guilt such belief imposed on her, after all these years! Had she felt guilty for not having a son? Has the moment of seeing her grandson become the symbol of excitement after dementia took away other memories of her? These narratives shocked me and naturally I replied: “You definitely did nothing wrong.”

Hearing this, Mary showed more trust on her face and continued to tell me two other stories about herself. One was about how she donated one of her kidneys so as to earn the right to stay in the hospital for free as a lonely old woman, and the other was about how she never left her home for half a year after she left her husband, due to fear of the outside world. When asked if she felt vulnerable as a woman, Mary said:

My mum told me to not control my husband. She said in Hong Kong men are the centre. It’s just normal for them to play with women. But you can’t mess with them. Luckily, I can live here alone. So, I’m free.

Interviewer (I): Do you find it unfair?

Mary (M): Yes. It’s very unfair. But everyone’s poor. The lower class never dares to rebel. Especially women. Men may go on parades and protests when they are not happy, but we women dare not do those things. Why? Because we know women are bullied by men. When you rebel against this and that, aren’t you throwing
away your rice bowl? You won’t have food. You only make people hate women more. So I’ve decided not to protest.

R: I see. Men bully women. What should we do then?

M: Buy nice shoes. Don’t buy the ones that are slippery when it’s wet. It’s the most important thing! Clothes are fine as long as they are warm, but shoes must be good. Otherwise, if you fall down, there’ll be no one to pull you up. What if the car comes your way when you fall down? I’ve tried this, and ended up crawling to the curb. So I guess it’s better to wear thick pants, too. Jeans when it’s warm and flannel when it’s cold. This way you won’t hurt your legs when you fall down.

During the analysis, caregivers pointed out that the kidney donation might not be true, but everyone was deeply touched by the loneliness, resilience and humour embedded in Mary’s story. Although she currently lived in a safe and isolated environment, her identity performance still reflected the complicated interplay of various socio-cultural factors, such as intimate relationships, class and gender roles (Surr, 2006). Disease might not be the sole reason marginalization and stigmatization of older adults with dementia, as the inter-sectionality of gender, class, socio-economic status and education level may all influence people’s experience of ageing and dementia.

Bourdieu coined the concept of ‘positional suffering’ (Bourdieu & Accardo, 1999, pp. 4–5) to understand the life experience and identity construction of people living within multiple oppressions. He warned researchers of the dangers of locating participants within a single context and using a sole factor to explain their suffering, because in that case we may distort the situation from our perspectives while providing a simple answer to a rather complex question.

‘I’m fierce!’: the story of a family protector

Sophie was a 94-year-old woman diagnosed with severe dementia and accused of frequent verbal violence towards caregivers. When I interviewed her, she just finished a fierce fight with a caregiver and developed a sore throat. But after I greeted her, she said:

S (Sophie): I’m a very nice person. Won’t swear. Well, I swear sometimes, but only when people are bad. See now it’s hurting my throat.

I: (laughs) So you’d like to educate people when they are bad?

S: Yeah, actually I’m very bad-tempered. I scold people all the time (laughs). I scold people to silence very often. I’m fierce.

I: Why do you scold them?

S: I’ve been like this since I was a little girl. You don’t count the days to scold people, do you?

I: You often get angry?

S: Yes. I was sooo angry yesterday. That person, so unreasonable! Makes no sense.

I: What makes you so angry?

S: I… I… so upset!

Sophie encountered difficulty expressing herself. But he looked at me seriously, showing the intention to continue the conversation. After stumbling for a while, she said:

S: Well it’s not good to tell others about your suffering…my sister said she was miserable…

R: You were worried about your sister?

S: Yes, yes (starts to sing)

In the next 15 minutes, Sophie sang a very sad song in a coarse voice, with tears rolling from her eyes. It was vaguely about her family’s suffering and how she missed her sister who had passed away. Then I invited her to play some musical instruments with me. She chose a drum and gave some very powerful stroke to it. It sounded like the roaring of an angry little girl, standing against whatever that brought suffering to her family.

When reading Sophie’s narratives, one caregiver said: “I was so afraid of Sophie when I started working here. But maybe that’s the only way she feels safe.” Maybe. At least since then her swearing meant something more than behavioural problems.

‘Even Li Ka Shing called me tough’: the story of an independent woman

I was shocked by Flora’s passion and communicative fluency the moment I stepped into the room, as she was marked as having severe dementia with BPSD in her documentation. She said a series of beautiful Chinese blessings to me at the very beginning, and loudly gave a self-introduction:

I: (laughs) So you’d like to educate people when they are bad?

I: What makes you so angry?

S: Why do you scold them?

S: I’ve been like this since I was a little girl. You don’t count the days to scold people, do you?

I: You often get angry?

I: Maybe. At least since then her swearing meant something more than behavioural problems.

When asked if it was tough to be a single mother and did a man’s job, Flora said:

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I’m 85 years old, and I’m the youngest daughter in my family....I’m very easy going...My husband died when I was 35. My two brothers both despised me. I have a son, and I raised him on my own (weeping), I worked as a carrier...yes it’s hard, but what can you do. You only have food when you work hard. In Hong Kong, you won’t have food if you don’t work, and you will be despised if you’re poor...I was poor but I had a strong mind. I wouldn’t beg for others’ help.

When asked if it was tough to be a single mother and did a man’s job, Flora said:

No man is good, and if you die in their hand it’s miserable. So I depended on myself, and never asked for help from men. I raised my son on my own. And that’s all. If you marry a man, and give birth to many children, and you have to feed them, isn’t that
miserable? I’m not that silly. When do you meet a man that treats the wife well? Well, maybe there is. But why risk it? I’m quite free, eat until I’m full and then feel sleepy (laughs).

At first Flora cried when talking about raising her son alone, but she also expressed pride when she told the story for the second time:

My elder brother was doing fine, but I’ve never asked for a single penny from him. I was poor but I got my pride. I worked as a carrier and raised my son fine, and now he owns an apartment and I’m very happy here. I’m happy that when I face God, I can proudly say that his child Flora is a woman with a spine (laughs)!

Li Ka Shing once told me, you know; I’ve worked for him for long so he talked to us, he said ‘Ha! You bloody women are quite something!’ (laughs) He knew we were his good workers. (Laughs) We were a bunch of strong women. It’s important that women don’t claim failure. You want that money and you need to do the job well enough. Respect your job, and how can your boss refuse to respect you? Li Ka Shing even called us big sisters…nowadays I heard many young lads are gloomy and lazy and I want to meet with them and say ‘Hey kid, why aren’t you happy? Get drunk when you still have the wine and weep for the troubles only when you get one!’ (laughs)

Flora’s identities were clear and coherent in her narrative: a single mum, a hard worker and an independent woman with an optimistic mind. She often loudly sang a song about poor single mum, a hard worker and an independent woman with an optimistic mind. She often loudly sang a song about poor single mum, a hard worker and an independent woman with an optimistic mind.

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‘Why is everything a zero?’ – the story of loss

Gendry was a 93-year-old man who would always sit quietly in his wheelchair. When I invited him to introduce himself, his first response was “I know nothing.” When I asked again, he said “Call me Gendry, and I received little education… I have no strengths…” I learned from my brother… My dad had a little shop, I had two brothers and I was the youngest. I was free then, and my dad was fierce… we sold yellow beans, broad beans, chips… then the Japanese…and there’s no shop. My mom was forced to kneel on fragmented glass… Because you’ve got money. The poor were united and they hated you. The Japanese came and we lost all the shops. We couldn’t recover even if we wanted to. (sigh…silence) Let bygones be bygones, and don’t even think about it. Think too much and I’ll get sick. Can’t think back. And I don’t know about tomorrow.

Later when I asked if he wanted to share his stories with others, he responded:

I’ve got no communicative skills, and no memories. For example, others talk about something to you, but you can’t understand. Even if you understand, soon you’ll forget… losing memory is a very sad thing for me. Now I only ask for two meals a day and that’s all… I’ve spent my life like this for several years… I feel empty, the entire person. You walk out, and don’t know the roads, so you come back. I’m 90 years old, and I feel, yes, I’m still a person, I have a head, but no brain. I can’t think. Walking, eating, all need care. If I walk, I’ll fall, and if I fall, I’ll die. It’s like, you’re sitting here, people see a person, but I’m empty. Empty inside. You still wake up, but your brain has no thoughts. I can’t control my brain anymore. I always think, a person is still a person, but why is everything a zero?

There were two temporal contexts in Gendry’s stories, and both are vivid scenes of losing something, one shaped by external forces (World War II) and one caused by internal diseases. With powerful metaphors and stone-like gestures, Gendry described loss in a heart-breaking way. For him it was a zero, but for us it was the richest narrative of emptiness.

Similarly, Melisa, an 83-year-old woman originally from Shanghai, China, also told a story of World War II when introducing herself:

Life is miserable, young lady… we lost everything… I came to Hong Kong when I was 13. I was a Shanghainese, came to Hong Kong to escape the Japanese. Escape was not easy. We walked at night but we were afraid tigers came out to eat us… the Japanese raped people, even old women. It’s miserable, wars. A big pit, and we lost everything… I came to Hong Kong when I was 13. I was a Shanghainese, came to Hong Kong to escape the Japanese. Escape was not easy. We walked at night but we were afraid tigers came out to eat us… the Japanese raped people, even old women. It’s miserable, wars. A big pit, and we lost everything.

Melisa told a story of a victim and a lonely old woman who has witnessed too much loss. Unlike the others, the context of her narratives was always in the past, until the moment I held her hands and told her to get warmer. She said “Thank you” and that was the only moment she was in the present.

Certain elements in the participants strongly reflected the characteristics of the era in which they once lived. For example, the hard-working spirit that inspired a generation of people in Hong Kong and the collective traumatic memory of World War II were common elements in participants’ narratives. Cultural memories and social habits can be important resources for selfhood maintenance as the disease deteriorates (Kontos, 2012).
Discussion

Collaborative narrative inquiry is a methodology specially designed for older adults with dementia, especially those who have been marginalized and silenced by severe symptoms of this disease. It achieves social impact through three ways: promoting social inclusion of older adults with dementia by constructing counter narratives of this population; bridging theories and practices through collaboration with frontline caregivers; and transforming the practice context with alternative lenses for viewing this population.

Counter Narratives of Dementia

Adopting an iterative and reflexive way of data analysis, collaborative narrative inquiry generates rich, authentic narratives of participants that resisted the single label of patient (Laceulle, 2017). Participants un-became patients with biological deficiencies and re-became wives, mothers, survivors, defenders, educators, and so on. The supportive environment encouraged them to continuously present different identities, and through identity proliferation, they regained agency of the narrative self (Baldwin & Group, 2008).

Besides verbal narratives, embodied narratives also carry transformative power. Participants’ linguistic habits, bodily movements, gestures, facial expressions, gazes and artistic expressions were increasingly paid attention to during the research. During one interview, a participant suddenly sang a song of which the lyrics were not comprehensible. But the sorrow in the song was clearly felt by everyone present. One caregiver reflected in the analysis meeting: “I never heard her sing. Or maybe I didn’t pay attention as for me she’s always a scary, angry woman. But it was beautiful! Maybe we should try to sing with her in the future.” And she did, gradually to find that the improvised song of the old lady was about one of her sisters who had long passed away.

The nursing home voluntarily published several stories collected during the research in their community education materials, with identification information removed. They believe these stories could resist the dominance of medical discourse in dementia care, and encourage people to prioritize the person when interacting with them.

Research as Praxis: Bridging Theories and Practices

This methodology attempts to bring about social changes by bridging theories and practices and producing situated knowledge that potentially transform the practice context. Caregivers construct the living environment for the residential older adults with dementia, and failing to consider their active and agentive role may hinder the knowledge transference in real-life contexts (Duncan et al., 2010; Kitto et al., 2013). In addition, the relationship between caregivers and participants as well as their practice wisdom is beneficial for navigating through the narrative fragments of older adults with dementia (Brooker & Woolley, 2007). In this methodology, these problems were addressed by the inclusion of caregivers in the analytical meetings. Caregivers constantly brought in new perspectives and personal knowledge of participants, and transformed periodical analysis into their daily care practices. Clashes and inspiration constantly emerged when theoretical lenses met with practice experience. These immediate, situated dialogues the researcher and practitioners generated fresh momentum for changes. Therefore, collaborative narrative inquiry can be seen as a praxis that integrates practices and theories, and establishes a sustainable reflexive system within the research context.

Apparently, this methodology requires the researcher to have a comparatively long-term commitment to the researched context. The conventional linear pattern of entering the field as a stranger, sometimes even an authoritarian stranger, collecting data and conducting analysis afterwards is not suitable for researching the marginalized group. Data are not pre-existent for researchers to ‘collect’, as this group had long been silenced. Instead, data are co-constructed and created by both the researcher and the participants (Brinkmann, 2014, 2018). The data construction process not only describes previous experience of the subject, but more importantly, produces a situated subject (Foley, 2012).

In addition, delayed data analysis seldom has influence on real-life practices. To bring about social changes through narrative research, situated knowledge production and constant dialogues with the practitioners are necessary. In this way the researcher was able to test theories within practice and gain immediate feedback from practitioners, while the practitioners might gain new insights after theoretical discussions. The continuous dialogues may kindle micro changes that eventually transferred into social impact.

From Patients to Story Tellers: Listening as an Emancipatory Approach

When attention is attached to the narratives and how participants construct identities through them, the gaze surrounding participants became less judgemental, emancipating authentic expressions from participants (Sabat & Collins, 1999). Older adults were able to construct narrative identities even in later stages of dementia, as long as they are listened to with focus on selfhood.

Caregivers used to find these narratives meaningless, as participants constantly shifted temporal, spatial and social contexts in their narratives, and sometimes fabricated events. Some scholars have considered such incoherence a symbol of dissolving selfhood (Davis, 2004), while others view it as a sense-making mechanism (Örulv & Hydén, 2006). But as the narrative journey went on, the prioritization of a coherent self-constructed from factual events and conscious reflection was gradually replaced by a less rigid interpretive framework that appreciated the discursiveness of selfhood (Brown, 2017). Caregivers became more attuned to emotions and the transient
self-images in their interactions with participants. This practice reflects post-structural views of the self, which deconstructed an essential self and conceptualizes self as a fiction of fragmented episodes (Brown, 2017). Embracing this view of older adults with moderate to severe dementia, caregivers emancipated participants from the biomedical institutionalization, and emancipated themselves from simply providing the service. One caregiver said: “I never thought about the emotional world and the subjective world of them before. And now I’m really curious. What is happening in their mind? This curiosity motivates me to engage with them even when they are making troubles.”

Conclusion

This article introduces collaborative narrative inquiry as an innovative way to include voices of older adults with moderate to severe dementia in research, and to bring about practical changes in collaborative with caregivers. This methodology, adopting an emancipatory design, aims to demarginalise older adults with dementia by constructing counter narratives of them, and developing new interpretive frameworks of their narratives.

Narratives have proved to be influential amongst different audience, and the biggest contribution of this methodological innovation is to initiate authentic communication between older adults with dementia and the rest of the world, starting from people working with and living with them. Instead of generalizable conclusions, this methodology opened up questions that await further exploration, and instead of instructions, it created puzzles, curiosity and actions that may transfer into changes at a greater level. Narrative research may not produce neat and tidy conclusions, but rather, expands the narrative space for previously silenced experiences, and make the invisible stories seen by a wider audience.

Limitations

This study has several limitations. First, the ethical issues cannot be fully addressed in research including older adults with dementia, and it is possible for the interviews to cause psychological disturbances among participants; second, observation of participants cannot be fully non-intrusive, and this way of data collection inevitably has observation effect; and third, the collaborative analytical process is inevitably influenced by power dynamics, potentially hindering the democratization of knowledge production.

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