



Themes of care giving and receiving in the interconnecting stories of a mother living with dementia and her adult son: A single-case life story study



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ABSTRACT

Life story work is generally regarded as a way for people living with dementia to maintain their connection with the past and facilitate meaningful communication in the present. This paper presents a single-case life story study that highlights themes of care giving and receiving in the interconnecting stories of a mother living with dementia and her adult son. The project methodology was informed by ideas and practices from both drama therapy and narrative therapy and, as such, combined a performative approach to life story work with a creative, collaborative approach to communication. The work is discussed in light of recent conversations about citizenship and dementia (Baldwin, 2008; Baldwin & Greason, 2016; Brannelly, 2016) that highlight the essential interdependence of people's lives and narratives as justification for more egalitarian relationships between people living with dementia and their partners in care.

Introduction

Life stories in dementia care

A growing number of researchers and practitioners in the field of dementia recognize the value of what Randall has called “narrative care” (Randall & L., 2009, p. 323; Villar & Serrat, 2017). Life story work is generally regarded as a way for people living with dementia to maintain their connection with the past and facilitate meaningful communication in the present (Brown Wilson, 2013; Downs & Collins, 2015; Gridley, Brooks, Birks, Baxter, & Parker, 2016). The incorporation of biographical knowledge into everyday care planning and practice has been shown to improve dementia care quality and facilitate a relationship-centred approach to care (Kellest, Moyle, McAllister, King, & Gallagher, 2010; McKeown, Clarke, Ingleton, Ryan & Repper, 2010; Wilson & Davies, 2009). In turn, life story skills that support narrative expression are increasingly recommended as an essential component of staff training (Brooker et al., 2016; Brown Wilson, Swarbrick, Pilling, & Keady, 2013; Cooney et al., 2013).

Life story work becomes especially important when the problem of dementia is seen to represent the truth of a person's identity. When we perceive people as no more than “a patient, a disease or a task”, social interactions, along with opportunities to tell a different story, are greatly restricted (Edvardsson, Fetherstonhaugh, & Nay, 2010, p. 2616; Ward, Vass, Aggarwal, Garfield, & Cybyk, 2008). Working with people

to narrate their life story is one way to counter the silencing effects of biomedical discourse and re-centre the person, but, equally, to re-story our understanding of dementia (Angus & Bowen, 2011; Angus & Bowen-Osborne, 2014). This has been borne out by a number of memoirs published by individuals living with dementia (Basting, 2003; Ryan, Bannister, & Anas, 2009) and Gilmour and Brannelly (2010) have since advocated for the inclusion of first-person accounts in nursing texts as a way to sensitize health professionals to the needs, desires and agency of people living with dementia.

More latterly narrative has been linked with a conversation about citizenship and dementia (Baldwin, 2008; Baldwin & Greason, 2016; Brannelly, 2016). For people who can no longer contribute in the active sense, these authors suggest, tracing the contributions they have made to the lives and stories of others can help to reveal and keep alive their on-going influence and contributions. In *Narrative(,) citizenship and dementia: the personal and political*, Baldwin (2008) introduces the concept of “narrative interdependency” to describe the way in which people's lives and narratives interact with and influence one another. Tracing a person's contributions over time, through the “stories that hold people together” (Baldwin & Greason, 2016, p. 291), thus becomes a way to uphold citizenship by reinstating people with dementia as contributing members of society. In *Citizenship and people living with dementia: A case for the ethics of care*, Brannelly (2016) introduces Tronto's *Ethics of Care* as a framework that can be used to guide inclusive citizenship practices. Caring, seen through an *Ethics of Care* lens,

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is part of human life, distinguished not by independence, but by interdependence and relationships of care giving and receiving that extend over a lifetime (Tronto, 1998). It is this relational quality of care, as outlined in Tronto's integrity of care phases, that holds potential to support citizenship as a practice, Brannelly argues, by providing both space and place for people with dementia to contribute. While Baldwin (2008) and Brannelly (2016) approach the subject from different angles, both authors highlight the essential interdependence of peoples' lives and narratives as a basis and justification for more egalitarian relationships between people living with dementia and their partners in care.

In this article I present a single-case life story study that highlights themes of care giving and receiving in the interconnecting stories of a mother living with dementia and her adult son. The case presented was part of a life story project that took place at a day program for older adults living with dementia. The project methodology was informed by ideas and practices from both dramatherapy and narrative therapy and, as such, combined a performative approach to life story work with a creative, collaborative approach to communication. In my presentation and discussion of this case, I shall be drawing on ideas, summarized above, about the interdependence of lives and narratives, and the relational nature of care. At the same time, I shall be exploring how these ideas intersect with certain ideas and practices inherent to the life story project methodology. In particular, I shall be discussing how *dramatic reality* from dramatherapy and *re-membering conversations* from narrative therapy combine in life story performances to foreground contributions made by people living with dementia to the lives of others.

The life story project

The life story project took place at a nonprofit adult day program for adults living with dementia situated in Ontario, Canada. The program is staffed by a team of activity/personal support workers and volunteers and, on a daily basis, accommodates a maximum of thirteen participants. The day program activities include arts and crafts, musical entertainment, gentle exercise and mental stimulation games. The life story project provided an opportunity for eight participants at the day program, four men and four women, to recall and record stories from their lives in a format that could be shared easily with others. In this way we hoped to increase opportunities for connection and communication between each storyteller and their community. The project was facilitated by a dramatherapist (the author) and the methodology combined ideas and practices from both narrative therapy and drama therapy. Narrative therapy is story-focused while dramatherapy offers a wide range of dramatic languages - bodily enactment, props, costume, sound and other multi-media effects - to help bring these stories to life. The storytelling process involved recording a story about a special time, place or person from each storyteller's past, followed by an interactive performance of their story in a group setting. In this way, the methodology emphasized the social and participatory aspects of both storytelling and theatre.

Referrals to the project were made by the program team leader, based on her judgement of whether individuals might enjoy participating. Each participant, along with members of their family, then met with the project facilitator to learn more about the project and life story process. Thereafter, the project facilitator met with each storyteller individually over a number of weekly sessions for the purpose of recording a life story document. Eventually, this document provided the basis for a life story performance script. Where possible, families were asked to supply photographs and memorabilia to assist their relative in their storytelling. They were also invited to attend the life story performances.

The life story project was exploratory rather than evaluative by design. A practitioner researcher framework of enquiry was chosen that combined reflective practice with participant feedback to develop insight into and fine-tune the methodology (Jones, 2010). In addition, a

photographer was engaged to capture "in the moment" embodied responses during each of the performances and, in this way, provide some indication of the subjective impact of the project on participants with dementia and their families. Our overall objective was to explore ways for people living with dementia to participate more fully in their social environment. As Dadds, 2008 explains:

"Practitioner research is not seeking generalizations in the way some large-scale forms of research attempt to do. Rather, it is seeking new understandings that will enable us to create the most intelligent and informed approach we can to improving our provision for those in our care" (p. 3).

Antonella's story²

Recording Antonella's story

Antonella was born and raised in Italy, and, at the time of her participation in the life story project, she had lost most of her English language communication skills. White (2007) uses the metaphor of "building a scaffold" to explain the narrative therapist's influence during a consultation. By carefully scaffolding conversations with therapeutic questions, narrative therapists make it possible for a person to access neglected, barely visible areas of their life and experience. For people living with dementia, verbal communication may become increasingly difficult however (Downs & Collins, 2015, p. 37) and for life story work to remain accessible Baldwin (2008) recommends the use of non-verbal and artistic means of narrative expression.

In this instance, we relied on images rather than questions to scaffold our conversations. To prepare for our first meeting, for example, I located a picture of the small Medieval town in Italy where Antonella was born. Antonella's husband supplied two further photographs. The first was a page from Antonella's passport, dated 1958, the year she left her family home and travelled by boat to Canada. The second showed two small boys, her sons, in their family back yard on the day of her youngest son's first communion. These visual prompts helped to allay word-finding and memory difficulties and enabled Antonella to tell her story in her own way. With Antonella's permission, I made a point of writing down her exact words and at the end of each meeting read these back to make sure I had captured her meaning correctly.

Performing Antonella's Story

Embodied storytelling

Life story performances are social occasions and the performances themselves are designed to be interactive. On the occasion of Antonella's performance, attendees included her husband and eldest son, day program staff and a number of Antonella's peers, who were themselves dealing with a range of cognitive and communication impairments. To facilitate engagement our storytelling included a variety of stimuli, from bodily enactment and physical expression, to props and costumes, music and other multi-media effects. During the opening scene of Antonella's performance, for example:

- we first projected the image of Antonella's home town on to a large screen;
- a basket of the produce - olives, tomatoes and potatoes - that Antonella's family would have grown and harvested was passed around;
- the women in attendance were invited to wear headscarves in the fashion of rural Italian matriarchs;
- and, to punctuate our storytelling, Antonella's husband played some traditional Italian folk music on his accordion.

² All names included in this account are pseudonyms.

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