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Living with dementia

Curating self-identity

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Abstract This article describes an ongoing interdisciplinary research study[1] with community-dwelling people living with dementia. The article focuses on one person living with dementia, her family and support group. Seven people were interviewed and their stories woven into one narrative. Our interest is in her self-identity, which we explore through a participatory story-telling approach. In gathering stories with all people who are significant in her life we have observed that what is driving the stories is an ethical imperative that is shared across her social network. We have described this as an imperative to 'curate' her self-identity. 'Curation' combines telling 'about', 'for' and potentially 'with' the person living with dementia in interactions which reproduce and reconfirm her self-identity. We propose that the notion of curation offers a way in which people, research participants, significant others and health care professionals, can think differently about living with dementia. In particular, we argue that curation enables the person to be acknowledged in interaction as an individual with a coherent, evolving identity which spans past, present and future.

Keywords dementia; identity; narrative; interaction; social network; participatory research

Introduction

Current diagnosis, treatment and care of people living with dementia often neglects their changing identities and particular biographical, historical and relational contexts. Whilst some aspects of identity like age, gender or ethnicity tend to be fixed 'in advance', others reflecting personal qualities are more fluid and potentially subject to negotiation during interaction. Hence, identity is a dynamic process that evolves from ongoing interactions between the individual and more or less negotiable aspects of her social environment. The practical interest in the current study arises because those

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living with dementia are increasingly unable to maintain a coherent account of their own identities, which become progressively dependent on how others perceive and interact with them (Small, Geldart, Gutman, & Scott, 1998, p. 293). Identity as an interactional and communicative accomplishment reflects research on the narrative or discursive properties of communication with people with dementia which has identified several 'external' influences on the preservation of self or personhood in dementia (Golander & Raz, 1996; Kitwood & Bredin, 1992; Mills & Coleman, 1994; Nussbaum, 1991; Ramanathan-Abbott, 1994; Sabat & Harre, 1992). This research looks beyond the internal (i.e. neuropathological and neuropsychological) declines and addresses the equally important role of external, or social psychological, factors in maintaining personhood and well-being in dementia (Kitwood, 1990). Here, self-identity is considered to be constituted by and through social interaction (Coupland, Nussbaum, & Grossman, 1993; Hadden & Lester, 1978; Mead, 1934; Shotter, 1993).

In this article we draw on a case study of Laura, a person living with dementia, and her social network. The aim of the study is to develop a narrative to accompany, support and communicate Laura's identity to those who may become involved in her care. The boundaries of the case study are: (1) Laura, a community-dwelling person with a medical diagnosis of Alzheimer's disease (second stage); (2) her social/institutional environment; and (3) her social network. This study was approved by the University of South Australia Ethics Committee.

When recruiting participants for the study we were approached by Ellen, Laura's daughter. Ellen asked her mother, several members of her family, friends, and the General Practitioner, who consented both verbally and in writing, and then we commenced with story-telling. Each network participant reflected on the person's past, present and future interactions and identities. Observations of the settings in which the person interacts with others in their social network constitute the second data source. Both authors attended the interviews, and reflections about each interview were shared, documented immediately, and comprise the third data set.

Story-telling took place over six months in 2005. Stories were transcribed verbatim, and analysed using a story line protocol established for Participatory Action Research text (Koch & Kralik, 2006). Seven people were interviewed and their stories woven into one narrative. Methodological consideration are discussed in Koch and Crichton (in press).

Creating a narrative

As the emphasis was on the continuing identity of the person living with dementia, we have not focused on the person's past at the expense of their present. We have sought to provide a coherent picture which can inform future care, referenced both to the understandings of Laura and her support network and to future audiences who may be involved in care. This required us as researchers to attend to and reflexively monitor the emergent story in the light of emergent understandings. At the same time, we are implicated in and no less responsible than other network members for actively producing and reproducing the present identity 'with', 'for' and 'about', the person with dementia. It is current and active. It is ethical, it involves care, it involves networks and it involves an inextricable link between, interaction, self-perception and perceptions of others.

This, then, is a narrative with, for and about Laura. It has been woven together from interviews with Laura, Ron (her husband and full-time carer), Ellen (her daughter), James (her son), Myrtle (a friend and occasional respite home 'sitter'), Marjorie (her hairdresser) and her General Practitioner. The first and second authors are the interviewers. A narrative, comprising seven interviews, provided 're'authorship of her life. We suggest that it gives shape to her personhood, which she is not able to articulate herself. Family and friends may find that the story contributes to the preservation of her identity as her memory fades. The story-telling process combines telling 'about', 'for' and 'with' in reproducing and reconfirming self identity. In the following sections we share excerpts from the narrative as the full version would be too lengthy (6500 words).

With Laura

In listening to Laura recounting her life it became apparent that personal relationships are important. She said 'Well we've always got on very well'. Whilst she has only a few words to describe her feelings, as a listener one sensed that these relationships are core joys. Laura appeared especially grateful for Ron's routine, both as physical carer and as keeper of her emotional well-being: 'Yes, he's wonderful, he's really wonderful, and he does everything you know.' She praised Ron at every opportunity. 'Ron looks after me, he's wonderful'; 'Oh yes, he thinks of everything. He cooks so well too, he'd never have done any cooking before.' Previously an active person, she resents 'sitting around'. 'It is annoying! Well, I used to play bowls, I'm not well enough to play anything or do anything much now, I just sort of sit around.' With further prompts from Ron, Laura expressed her delight as a midwife: 'I used to just love delivering the babies and I did general nursing as well even though I did so many years of midwifery . . . 'I loved it and seeing them and then waiting for them to cry. Really I used to love handing them to the mother all dressed up and then to the father, that I used to think of as wonderful.' In talking about her time at a District Hospital, she said, 'Well it was lovely really; I loved every minute of it.' When given the last word, Laura said; 'I'd like to stay here, I wouldn't want to go from here.' What matters is that Laura can stay at home with Ron.

Ron speaks for Laura

Filling the gaps in Laura's story comes naturally to Ron. We begin to understand how their lives are intertwined. When asked about 'love and all that', she did write a letter to her mother and said 'she'd met a bloke over there' (she was doing midwifery in Sydney) and her mother wrote back and said 'Oh don't worry about him it's too far away.' Despite this they were married in October 1947 in the town where Laura was raised and 'we then lived with my parents for two years while I built this place [his house] myself'. They have been together for 58 years. Ron reminds her of the time, about two years after they were married, when she worked in an Emergency Department. 'I used to go over and pick you up on my bike and donkey [carry] you home.' Using humour to prompt Laura's memory was effective. She smiled at the mention of the bike trips and she nodded in delight when he told about 40 years of lunching with the five 'girls' with whom she had completed her nurse training. And for Ron the last words were 'Well I've made up me mind that I'd like to stay here as long as I possibly can and look after Laura.'

About Laura

Ron fills in with his interpretation of the events resulting in Laura's dementia: 'Started off with pains in her chest and we were sent to a Dr W. . . . on the machine with the pad on, and he could see that heart, you could see the heart pumping and the front part of the heart was dead so they say. At that stage no way would he operate on it but he went on holidays and she took crook [ill] and we put her into a private hospital and Dr L, he operated on her but she had all the trouble in the world. She had aneurism the size of Great Britain in her groin. So they operated on her on the Sunday to fix that and then she had a triple by-pass on the Monday. We do feel that the two operations so close might have been enough to set something going. They had to put a pacemaker in here somewhere for a couple of months while she was in hospital. They rang me one night that they'd given her a CAT scan, took her down to give her a CAT scan and she'd left us and they had to jump-start her. But she hasn't done anything since, I've done everything since.' Marjorie revealed that caring for Laura is 'an enormous responsibility, absolutely huge'. According to her, respite is being considered but 'Ron finds that a bit difficult to let go of her. He says that she'd get more anxious . . . . He's wonderful, he changes the wet beds, sees to the soiled clothing and things, he's very good, but he's very meticulous with his routine.' He has to do her thinking. She can't remember to think, to go to the toilet or sometimes he's found her quite distressed. He gets up to her in the night I think if he hears her restless.'

For Laura

From the son, what is important to share is that 'I'd like people reading this story to know that she was always a very caring person'. He recalls her as a strong, independent woman given the boundaries and norms acceptable for her generation. 'She had a really nice, very calm way of getting us as kids to do what we were supposed to do' . . . . 'Nevertheless, she was willing to open herself up to odd ideas, shall I put it that way, or things out of the ordinary'. According to her daughter being a nurse really coloured her life 'in everything'. Although stories of playing bowls are another common background story, her children are not too convinced that Laura liked it as much as others claimed. 'When my Dad started playing bowls, she really took that on too and said she hated that as well. This is interesting isn't it?' Appreciating the funny side of things is not lost on Laura. 'She can still laugh at herself and she still has a really strong wit about what is happening. A couple of weeks ago we [mother and daughter] were talking about my godparents chatting away and she looked at me and said 'So who's your mother?' and I said 'You're my mother.' And she seemed to recognize that she had just said something really silly. And that's fine because she still kind of knows and she doesn't get upset, whereas some people I have known with dementia get quite angry. She can still say 'that's really dilly'. But then she went on watching television for a while and then she looked at me, she said 'Now am I anyone else's mother?' We both just cracked up. I still see that wit, sense of humour. I suspect it won't ever go. It is an ability to always see someone who can laugh at herself. I don't think that will ever go no matter how unwell she is'.

Her close family circle is one area of her life identified by her GP as crucial for her; they play a substantial role in her care. For example, Ron has worked out ways to prepare food even when he is playing his one game of bowls a week. 'I can come home now and say to Laura 'What would you like, roast chicken, roast pork?' Ron emphasizes the importance of these routines, including the ways in which Laura can be settled at night to avoid wandering around the house. More importantly, Ron stressed that knowing the routine has prevented falls. Prior to this routine 'the ambulance called twice to pick her up off the floor'.

Being well groomed has been part of the routine and Laura's hairdresser visits every fortnight. 'She always used to have her hair done. Marjorie believes that maintaining a hair routine is 'a very important part of rehabilitation' and she noted that having one's hair done 'improves their confidence and once you've improved their confidence they then start doing their old routines'.

Being with Laura

Building a relationship with someone after dementia has taken hold is possible. 'I didn't know her before [dementia]'. Myrtle was a formal carer and although she no longer works, she continues her involvement as a friend. 'Every week, every Thursday for a couple of hours . . . I just sit with her and talk'. Myrtle enjoys sitting with Laura and still does this every few weeks. 'I just feel that she needs some company, different company every now and again. I just feel like I like to see her.'

Similarly, Ellen stresses that 'what matters is that they are treating her in a way that is respectful of her intelligence, her would-be intelligence'. This means not only recognizing that Laura deserves to be treated as a human being, but that people around her are sensitive to the way others respond to her. As explained by Ellen, 'When I think of my mother I think about this person that was always there for me and always had the practical, sensible answer and was always there to listen to and that person's not there anymore and that's just so incredibly sad. And because I remember that person so clearly when I see people come into her home and are a little condescending and talking in the short sentences. It is really disheartening.'

In the effort to sustain conversation, Myrtle uses long-term memory prompts to enable Laura to talk about things she liked many years ago. An old photo, a favourite television programme and Myrtle's understanding about some of Laura's past helps the conversation along. Cooking shows on television trigger Laura's recall being in the kitchen. 'We used to watch Huey . . . . She'd say "Oh I used to love cooking"'. These conversations appeared to be therapeutic, 'she can remember being out on the farm where she was brought up . . . and things that she liked, especially her nursing, she loved that, so she likes to talk about that. We'd just get on to things that she likes to talk about.' What is known about the person with dementia facilitates 'making' conversation: 'You have to know how to bring up the conversation', Marjorie said. Laura forgets what we've talked about but that doesn't matter. 'We chat about with something that she's done, like the time she spent in the beach holiday shack on the coast. I think they used to like going fishing, they'd wait for the boys to come back in again, they'd cook their fish that they'd caught for the day. She loved that.' Knowing what will ignite a conversation is important. 'I have to bring it up in conversation and then she will perhaps elaborate.'

Several months ago, Laura was admitted to the acute care sector for a medical emergency. Despite plans to the contrary, the medical team decided that Laura could no longer be maintained at home. Laura has since moved from her home into a Residential Care Facility. Her husband, Ron, visits every day. We gained further approval from the university ethics committee to maintain contact with Laura and with staff in this facility. Laura's narrative has been shared with the staff. We are currently working with Laura, her family and staff to evaluate the effect of the narrative on interaction and care. The study is ongoing.

Discussion: Curating identity

We have facilitated story-telling with Laura's social network and, in collaboration, have developed a narrative. We suggest that how the family and others are able to make sense of Laura's dementia and continue to shape her identity is through what we have termed 'curation', a process central to the fate of self-identity when someone lives with dementia.

Our interest in curation emerged through our experience that, when stories are told by those surrounding the person with dementia, the teller works hard to render the best possible storied account. This is a heavy responsibility and suggests the presence of 'care', and an ethical imperative. What is driving the stories is not a lifestyle choice, a biomedical history and functional/cognitive appearances, but a network with concern – to 'curate' the self-identity of the person living with dementia. Understanding the significance and implications of curation for care provides the interest for our ongoing inquiry. Curating is a social role arising from an active concern for the other. It combines action, realized primarily in language with an understanding of an ethical need and is collectively reproduced through interactions in social networks.

Self-identity is therefore fragile as it may be preserved by members of a social network. Curation is a construct linked to a support network, that comes into existence and is sustained on and by and through the interactions of the people on the network. It is this notion of collective care which we understand to be central to curation. In this process, curation involves telling stories not merely 'about' the person but simultaneously 'for' them, and potentially 'with' them when the person herself is co-present. In the latter situation, our study suggests that the selections and interpretations of the teller are cued by and referenced to their understanding of the responses of the person living with dementia – a process which combines telling 'about', 'for' and 'with' in a reproduction and reconfirmation of the self-identity of the person living with dementia. As a resource within the social network, we think of curation as intimately connected with narrative.

Drawing on narrative in five ways

We conceive curation as drawing on narrative in five ways: as language; in interaction; in institutions; in understanding; and in research. It is the first four aspects of narrative, we suggest, which enable the teller to speak simultaneously for, about and potentially with the person living with dementia, and thereby to carry forward her identity. The fifth aspect reflects on curation both as a focus and a mode of research.

As language

In relation to language, curation draws on sociolinguistic features of narrative. As a linguistic/textual resource, narrative enables tellers to recreate and reinterpret their own and other people's experience of the past. Four features of narrative are particularly salient here. First, narratives typically involve a sequence of narrative clauses; that is, 'clauses containing a verb in the simple past or, sometimes, the historic present tense whose order matches the real time order of the events described in those clauses' (Thornborrow & Coates, 2005). The capacity to tell a narrative about and on another's behalf therefore draws on the teller's ability to assign and sequence language according to the teller's memory of events. This makes memory doubly salient in curation because the need for curation is prompted by the loss of memory of the erstwhile teller which places an onus on the actual teller to remember for the other.

Beyond aligning the linguistic sequence to the event sequence, there is a need to render the narrative coherent, not merely a chronological list of rendered events but a story whose elements are described and interconnected in a way which makes sense to the receiver(s). What elements are included and how they are interconnected draws further on the sociolinguistic expertise of the teller. In order to introduce and present a story into an ongoing interaction, the teller must establish the relevance of the story to the conversation in play (Sacks, 1995). To accomplish this requires the teller to predict what the receiver(s) will count as salient, to monitor their reactions as he or she tells the story, and to adjust the unfolding story in anticipation of the receiver's perceptions of relevance. Again this aspect of narrative is doubly salient in curation because the teller must negotiate the relevance of the story with receiver(s) who potentially include the person whom the story is actually about. Even when the person living with dementia is absent, the need to establish the relevance of the narrative to their present and past perceptions is still pressing, and must be considered if the teller is to speak on their behalf. The following extract from our data illustrates these points. When asked to tell her mother's story, the daughter makes clear that there are multiple possible stories, and that these draw both on her memories and on her mother's.

> Tina: It's up to you where you want to start in telling the story.
>
> Ellen: There are probably quite a few stories in this. When I spoke to you last time I was talking about my experience with my mother then and my experience with my mother now. I think what's become very evident is the change in roles, especially for my father in this process and to a greater extent the changing relationship with my brother.

The selection of content, then, is not just a matter of recalling a chronological sequence but of shaping a story that respects the teller's understanding of the person living with dementia, other members of the support network, acknowledges the teller's own role in interpreting the story and is salient to the interaction at hand, and to the mutual knowledge of the interactants.

In curating identity, the teller draws on the capacity of narrative to provide two vantage points from which the teller can present an identity: through the events of the narrative and as the teller. This is possible because we are able to present ourselves both as a character within the narrative and as the narrator. In doing so we can simultaneously present ourselves at two different times: in the time of the narrative, and in the time of the telling (Georgakopoulou & Goutsos, 2000). These two vantage points enable the teller to present the identity of the person living with dementia, on her behalf, within the time scheme of the story, while retaining the teller's own identity in the time and place in which the story is told. In this way curation may occur as co-present with or 'at a distance' from the person living with dementia.

In interaction

It is a feature of narratives that the teller can move between these two vantage points in different roles. These shifts exemplify Goffman's (1981) notion of 'footing' and highlight how curation draws on interactional aspects of narrative. A shift in footing 'implies a change in the alignment we take up to ourselves and the others present as expressed in the way we manage the production or reception of an utterance' (p. 128). Drawing on Goffman's work on footing, Shiffrin (1990) shows how tellers move between four roles in these two time schemes:

- animator (the person who physically produces the narrative);
- figure (a person portrayed in the events of the narrative);
- author (the person who creates the content of the narrative);
- principal (the person responsible for what is said).

In curation, the teller configures these different roles in order to present the story of the person living with dementia on her behalf. When not co-present, the teller retains the role of animator and the person living with dementia is presented as a figure. The roles of author and principal may be less clearly distinguished in the story which is told on behalf of another. Here the teller may work to ensure that the receiver(s) understand that the teller is standing in for the person with dementia, that while the teller is the animator, the story reflects as closely as the teller can achieve what the person with dementia would want. In this scenario the teller takes on the roles of author and principal simultaneously for him or herself and by proxy on behalf of the person living with dementia – telling of him or herself in telling of the other. It is this feature of the narrative which enables the teller to take on a double weight of responsibility, both for the veracity of their own narrative and also for the veracity of the narrative as a reflection of what the person living with dementia would want. We see this double responsibility as characteristic of curation.

When co-present, the teller may share the role of animator with the person living with dementia, as in the conversation with Laura and her husband. In our data, the husband took opportunities to shift his footing by sharing with Laura the role of animator, a shift in which she moved from being a figure in his story to the teller of her own, and took the roles of author and principal for herself. This pattern is illustrated in the following example in which he asks her to confirm parts of the story he has told. In inviting her to confirm, he is offering her the authorship and the role of principal in her own story, and – for as long as she is able to maintain her footing – to relinquish his role in both:

Ron: I represented South Australia in . . . interstate bowls carnivals. When the carnival's held here, which is every six years, Laura has been Chairwoman . . . and she handled that very well, taking the ladies on bus trips and all that kind of business.

Laura: I've had quite a good life you know.

Ron: When we were fit and able we went to Caloundra [in Queensland] seven years running.

Laura: Seven years, did we?

Ron: Yeah, two months at a time, two and a half months.

Laura: Time flies.

Ron: That was always very nice, the weather was so nice and we could go up the . . . .

Laura: It was lovely.

These shifts of footing underscore the fact that curation is a performance within an interactional context. Within this context the meaning of the narrative is co-constructed by the teller and receiver(s). Where the person with dementia is present, as in the example above, the teller may actively seek to engage her in the process of co-construction. In either case, the teller is 'front stage' (Goffman, 1959), meaning that his own identity is on the line, dependent on his capacity to render the story in a way which meets his double responsibility. In the case of curation, it is not only the teller's identity that is front stage. In telling the story on behalf of the person living with dementia, he places her identity front of stage along with his.

From this interactional perspective, curation is more complex still. The telling of the narrative implies particular interactional roles for the teller and receiver(s) (Ochs & Taylor, 1992). They will have different rights and obligations depending on how they each perceive their own and each other's expectations of the purpose of the interaction; whether this be to evoke, confirm or justify memories, to elicit sympathy, to share a humorous experience, to seek support, to elicit advice or any other of the myriad interpersonal functions that a narrative might perform. In telling on behalf of the person living with dementia, the teller is again doubly obliged: he or she must negotiate the purpose of the interaction both for himself or herself and for the person living with dementia. Moreover, in telling the narrative for the person living with dementia the teller 'performs' both his and her identity by drawing on and enacting language associated with particular social categories (Butler, 1990). This is a further way in which curation draws on narrative as an interactional resource and places a double responsibility on the teller. The teller has to decide how to describe the life of the person living with dementia, what to include in the palate of language, in terms that she herself would identify with, and at the same time to consider how the receiver(s) will interpret these descriptions.

In institutions

In relation to institutional uses of narrative, we have already signalled how curation carries forward the identity of the person living with dementia through their life within the support network. The support network is itself an institution. Institutions include families, schools, universities, hospitals, courts and care facilities. Each institution has:

> . . . its own set of speech events, its own differentiated settings and scenes, its cast of participants, and its own norms for their combination – for which members of the cast may participate in which speech events, playing which parts, in which settings, in the pursuit of which topics or goals, for which institutionally recognised purposes. (Fairclough, 1985, p. 749)

Narratives, and the language in which they are enacted, are important in institutions. They are the 'raw material' for much institutional work in institutions whose interest is in managing or otherwise affecting the lives of members and non-members. Narratives enable institutions, for example, to construct the identities of members and non-members; hold people accountable for their actions; and decide when and how to intervene in people's lives (Hall, Sarangi, & Slembrouck, 1997). To do this, institutions include types of interaction, such as interviews and appraisals, that are designed to elicit narratives. In the process of being elicited, these narratives are typically transformed to render them tractable for institutional purposes.

In the case of curation, it is the transition from the support group to the care facilities that initiates this process of transformation. In Laura's case, when she entered a care facility a standardized procedure was enacted in an interview with her husband conducted by a member of the care staff. The staff member is trained to elicit and summarize the aspects of a person's life which may be salient to care. The interview is guided by the need to complete a report. The report is then made available to care staff. The report comprises closed, standardized questions in areas such as interests, 'emotional highlights' and 'What makes you feel happy or sad?', followed by a section designed to summarize the key points that have arisen in the interview. The resulting report captures those aspects of the person's life which are anticipated by the institution as salient to care. Fortunately for Laura, her husband is enormously dedicated and has a profound knowledge of her life and care needs, which he was able to articulate to the interviewer who was herself skilled in completing the report. According to the director of the care facility, it is unusual for a person living with dementia to have such a capable person to tell their story. Other's stories may be lost in the transition into a care facility, or truncated by the lack of a competent teller or the need to render the story in a way which is tractable within the institution, or fail to be read by pressured care staff. Moreover, we would argue that such a report does not constitute the life story of the person as articulated by and maintained across her support network. Our experience in the study suggests that this story is not reducible to a standardized format, and is inherently fragile and richly nuanced – wrought with the different interpretations of those on the network.

In understanding

The issue of interpretation brings us the final point in our theorizing of curation. While curation draws on sociolinguistic, interactional and institutional aspects of narrative, it is the lived experience of the person who curates and the person living with dementia which we place at the centre of our theorization of curation. To this we also bring a narrative focus, drawing on the work of Paul Ricoeur (1984, 1985, 1988, 1992). Ricoeur has been influential over the last 20 years in raising awareness of the role of narrative in human experience, in particular through his development of the notion of 'narrative identity'. According to Ricoeur, narrative is not just a valuable way of representing our experiences to ourselves and others; it constitutes how we interpret our experience of ourselves and others in time. Ricoeur emphasizes narrative as contributing in three interconnected ways to the constitution of experience.

Firstly, he argues that our perception of events as temporally situated depends on our bringing a narrative structuring to experience. Summarizing this position, he states that 'time becomes human to the extent that it is articulated through a narrative mode, and narrative attains its full meaning when it becomes a condition of temporal existence' (Ricoeur, 1985, p. 52), In other words, our understanding of time and our capacity for narrative are mutually dependent and reinforcing: narrative makes our experience of time meaningful. Secondly, he argues that as a condition of our experience of ourselves and others in time, narrative also provides the interpretive frame through which we interpret each other's identities. We understand who we/others are to the extent that we are able to 'story' our own and other's lives. In making this point he emphasizes that the starting point for understanding another person is to question 'who' he or she is, and to answer the question 'Who?' . . . is to tell the story of a life. The story told tells about the action of the "who". The identity of this "who" therefore itself must be a narrative identity . . . .' (Ricoeur, 1988, p. 246). Thirdly, Ricoeur links the role of narrative in constituting experience and personal identity to an ethical aspect. He argues that our ethical judgements about each other and the ethical responsibilities we perceive ourselves to have are based on how we 'story' our own and other's lives:

> The subject [person] then appears both as a reader and writer of its own life . . . the story of a life continues to be reconfigured by all the truthful or fictive stories a subject tells about himself or herself. This reconfiguration makes this life a cloth woven of stories told. (Ricoeur, 1988, p. 246)

Combining these three aspects, narrative for Ricoeur is a condition for the ethical treatment of ourselves and others, it makes meaningful our experience in time, and it is the basis on which we ascribe continuity of identity to ourselves and others. We suggest that these aspects of narrative underpin the process of curation, in which the teller draws on narrative to perpetuate the lived experience of the person living with dementia, and in doing so carry forward her identity as a person and thus maintains her personhood as a focus of ethical attention.

In research

Finally, in relation to our research, curation has been both a focus of our participatory work with Laura and her social network, and it has shaped our interactions with participants. Our research design has ensured that we ourselves have joined Laura's social network and in this way we have become part of the same processes of curation which are the focus of our research. This is a mode of participatory research in which we have, ipso facto, recounted and elicited stories of Laura along with members of her social network. We have spoken for, about and with her and in doing so have played a part in curating her identity. This was clear when we drew together the stories from the social network members into Laura's life story. While this was done in collaboration with the social network, we were nevertheless agents in the process.

Our roles in the study have raised methodological questions which we see as inherent in participatory research of this kind. These questions relate to co-construction (Who constructs the narrative?); to reflexivity (How do the researchers' identities affect the research?); to ethicality (How can the identities of the participants be safeguarded?); to ownership/authorship (Who 'owns' the life story?); and to analysis (What is relation between the researchers' interpretation of the stories and those of the tellers?). We have not sought to resolve these questions 'in advance'. This would be to misunderstand their significance. They arise from the intimate relationship within the study between curation as focus of research and as mode of engagement with participants. But most importantly, we have understood these questions in relation to the purposes of the study. We are not producing a chronological life story: not a list of events sequenced in order of occurrence, selected according to a particular interpretation of their significance for the person, and presented as complete. We are producing a collaborative narrative which combines multiple accounts of the person's life from the person themselves and people who know her, woven together in collaboration with the tellers on the understanding that the narrative is open ended, for others to read and potentially to extend through their interactions and new understandings of the person.

Consequently we have sought to be alert to these questions as they arise through the study, to talk through the questions with participants as they arise, to be accountable to their responses, and in doing so to acknowledge the inevitability of our roles as both researchers and members of the social network. Moreover the salience of these questions does not finish after the study is completed. The life story will continue to be read and read differently – the process of co-construction will continue.

Final comments

Based on the findings of this case study, we suggest that ‘curation’ is a necessary condition for the maintenance of the self identity of people living with dementia. Curation is therefore significant for care because: (1) an understanding of the continuing self-identity of any person is necessary for communication with them *as* a person: that is, as an individual with their own, coherently connected, past, present and future life; (2) such communication contributes to the well-being of the person living with dementia and in turn of their support network; and (3) is essential for the acknowledgement and promotion of self-identity within person-centred care.

As our study continues to unfold, we anticipate that improved communication with the person with dementia will be the outcome to have most impact in care, as health professionals are themselves able to build on network knowledge in their interactions, both with the person living with dementia and with members of the network.

Further questions we are exploring focus on the nature of curation as active, ethical, caring and situated across networks. What happens when networks wane or have disappeared? The circle of people around the person with dementia is often disinterested, fearful or includes members who have wittingly or unwittingly resisted acknowledgement of dementia. Our interest here is in the potential for an understanding of the curation of identity to provide insight into not only the conditions under which people thrive but also where their identity is at risk.

Meanwhile, we recognize that the identity of the person with dementia is only understandable within the network that supports them. This raises a further obligation on researchers to attend to the future identity of the person, and how the narrative foreshadows and effects future interactions in care. Unless there is some kind of carry-over of that identity, that network knowledge, into future care then it is not only going to be lost but it is going to be displaced, along with the ongoing project of identity co-construction through story telling which we have termed curation.

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