



Narrative competence in caring encounters with persons with profound intellectual and multiple disabilities

Anita Gjermestad

VID Specialized University, Sandnes, Norway

Email: anita.gjermestad@vid.no

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Abstract

Background: Persons with profound intellectual and multiple disabilities form a vulnerable group within the Norwegian health and social care system, whose needs can be poorly understood due to their cognitive and communicative challenges.

Aim: This article aims to contribute to a richer understanding of persons with profound disabilities as narrative agents, and to highlight how the narrative competence of healthcare staff can be instrumental to a person-centred approach.

Method: The methodology used was a practice development project in residential housing for persons with profound intellectual and multiple disabilities. Dialogue seminars and reflection seminars with staff were conducted, and a group interview was carried out.

Results: Episodes of emotional, embodied and silent narratives were identified. These episodes illustrated the staff's narrative competence in bodily enacted caring encounters.

Conclusion: This small-scale practice development project can contribute to changes and new ways forward towards person-centred care for adults with profound intellectual and multiple disabilities living in residential housing.

Implications for practice:

- Staff narrative competence is crucial to facilitating person-centred care for persons with profound intellectual and multiple disabilities
- This narrative competence can be developed through providing arenas for discussion and reflection among staff
- Sharing various interpretations of the non-verbal and bodily expressions of persons with profound intellectual and multiple disabilities can contribute to a richer understanding of these individuals, and promote and strengthen their fundamental human rights

Keywords: Profound intellectual and multiple disabilities, narrative, embodiment, narrative competence, caring

Introduction

Persons with profound intellectual and multiple disabilities are among the most vulnerable and dependent groups within the Norwegian health and social care system. They experience prejudice, discrimination and low expectations (Mansell, 2010; Kittay, 2011), and it is common to look on them as passive recipients of care rather than as citizens or agents (Vorhaus, 2016). They are highly dependent on others, with a need for lifelong care and support from family members and professionals, as their cognitive and communicative challenges make it difficult for them to speak up for themselves and mean their voices can remain unheard and neglected in caring practice. It is crucial for such persons to be surrounded by people who know their histories and are willing to understand them (Dennis, 2002; Mansell, 2010), since listening to them and construing their meaning carries a major risk of misunderstanding and misinterpretation.

A recent Norwegian Official Report, NOU 2016:17, (Norwegian Ministry of Children and Equality, 2016) concerning the living conditions of persons with intellectual disabilities highlights major violations of fundamental human rights within the country's health and social care system. The report illustrates the risk of persons with profound intellectual disability being 'invisible' and of their being a 'silent user group'. Compared with other Western countries, in Norway few adults with such disabilities live with their families; most live in residential housing or have their own flat, and receive support from staff employed by local municipalities (Norwegian Ministry of Children and Equality, 2016). These employees are largely poorly educated in terms of the needs of those they support and often lack sufficient sensitivity and competence when listening to residents. There is also a high turnover rate that can diminish care standards. People with profound intellectual and multiple disabilities are at risk of being neglected, marginalised, socially excluded and devalued (Mansell, 2010; Vorhaus, 2016). To counter this, there is a need to acknowledge and embrace their potential as well as their abilities, capabilities, and narrative competence (Vorhaus, 2016).

Persons with profound intellectual and multiple disabilities form a highly heterogeneous group, and it is challenging to avoid categorisation and pathological language when trying to describe them as individuals. Each is a unique citizen, with the same rights as everyone else to achieve their potential and live a good life. Their health and functioning is hampered by reduced cognitive and body functions, but also by social, institutional and cultural barriers that restrict engagement and participation. The World Health Organization (1992) estimates that a person with profound and multiple learning disabilities is someone with an IQ of less than 20. Reduced cognitive function affects ability to use conventional language; these individuals may communicate through non-verbal expressions and body language, and idiosyncratic communication is dominant (Grove et al., 1999; Lacy et al., 2015). This means that each person deploys distinctive and unique communication methods, which need to be interpreted in the light of the actual situation and context, as well as historical knowledge of the person's expressions and utterances. In addition to communicative challenges, these individuals might have vision, hearing and movement impairment, while other health problems that require extensive help and care are also common. Together, these factors mean people with profound intellectual disabilities face limitations in both understanding and in being understood in everyday care practices.

Person-centred care in this context demands sensitive, passionate and effective staff who listen to and try to understand and interpret the meaning of individuals' non-verbal expressions (Pawlyn and Carnaby, 2009; Horgen et al., 2010). In Norway, knowledge about person-centred approaches is deficient and insufficient, especially those addressing the needs of adults with profound intellectual and multiple disabilities receiving long-term care in residential settings (Norwegian Government, 2016). There is a need to highlight person-centred approaches that enable caregivers to identify residents' experiences, capabilities and needs (Pawlyn and Carnaby, 2009). Narrative approaches are promising in terms of involving the views of people with profound intellectual and multiple disabilities (Fennefoss and Jansen, 2004; Nielsen, 2006; Grove, 2007; Goodwin, 2013). To acknowledge their views and experiences, it is essential that staff possess narrative competence, which means the ability to

verbalise or narrate their needs (Charon, 2001; Fennefoss and Jansen, 2004). Research also shows that the quality of caring encounters is highly dependent on levels of staff education, and the facilitation of staff in their daily care should focus on communicative competence and strategies (Chadwich and Jolliffe, 2008; Goldbart and Caton, 2010).

According to Pawlyn (2009), person-centred care of persons with profound intellectual and multiple disabilities involves providing and organising services rooted in the needs of the people receiving care – meaning emphasising and acknowledging each individual’s unique abilities and needs, and getting close to their perspective. Narrative is a central aspect of communication, learning and development, and it is through narratives that we understand each other (Bruner, 1989). A narrative approach in staff training is a powerful strategy that can contribute to staff achieving new insights and understanding of the lived experience of people with profound intellectual and multiple disabilities (Fennefoss and Jansen, 2004; Grove, 2007).

Against this background, a practice development project (Garbett and McCormack, 2002) was initiated with staff in a residential housing complex (Gjermestad and Luteberget, 2016) to increase quality of care and facilitate new and richer understandings of residents with profound intellectual and multiple disabilities as agents, as well as of their capabilities and needs in everyday caring encounters with staff.

Aim

This article aims to contribute to the understanding of persons with profound intellectual and multiple disabilities as narrative agents and to highlight how staff narrative competence offers a potentially promising person-centred approach.

Narrativity and embodied activity

We live in a storytelling world, and we are all narrative beings surrounded by stories of ourselves and others (Bruner, 1987; Ochs and Capps, 2001). According to Bruner (1987), narratives allow humans in different cultures to relate to others. Through narratives, people understand each other’s experiences and make them meaningful. Narratives develop from birth and throughout everyday interactions between people, and they are crucial for building and sustaining relationships with others. All people start their narrative development before they are verbal. Narrative can be described as meaning that is communicated and meaning that is interpreted (Andrews et al., 2013).

Narrative also plays a central role in how people understand those with profound intellectual disability, and help construct the meaning of what is communicated by them. Narratives cannot be developed alone; they need to be listened to, which means they are co-constructed with others (Bruner, 1987). This co-construction process highlights the importance of support and a scaffolding process for the listener towards the author or narrator. Listeners help the story move forward, confirming and acknowledging the story or the expressions and utterances being told. The ability to ‘listen’ to verbal and non-verbal expressions, like fragments of stories, and interpret them into a meaningful whole is important in the co-construction process (Bruner, 1987).

The most common understanding of narratives and storytelling is that they are told or communicated verbally, and storytelling is challenging for those whose ability in this respect is limited by communicative and cognitive impairments (Hydén and Brockmeier, 2008). To shed light on how the stories of persons with profound intellectual and multiple disabilities are told in interaction with others, there is a need to extend the ‘traditional’ view of how narratives can be told or performed (Antelius, 2009). Stories and narratives are not restricted to being told verbally – they can also be enacted.

To understand storytelling as performing means imagining the space between teller and listener being filled in a psychic, spatial and bodily fashion. In telling, the entire bodily presence and identity of the narrator are staged, inviting the listener (co-narrator) to join the performance in a similar enacting mode. Conceiving of narratives in this way seems to be a particularly promising approach to

understanding forms of communication and reflection in individuals suffering from severe illness and disabilities (Hydén and Brockmeier, 2008, p 10).

So the stories of persons with profound intellectual and multiple disabilities can be performed as an embodied activity involving body and mind (Hydén and Brockmeier, 2008; Hydén and Antelius, 2010). Storytelling for these persons involves considering their bodies as 'actual bodies' rather than just physical bodies (Hydén and Antelius, 2010, p 599); actual bodies can be described as present, related, intended and communicative bodies. Viewing the actual body as an integrated part of and a resource for persons with profound intellectual and multiple disabilities, opens up the acknowledgement of non-verbal and communicative recourses, such as gestures, sounds, eye movements and other bodily utterances as part of the storytelling (Hydén and Antelius, 2010). This puts the body at the centre of caring encounters as a medium for clinical communication between co-narrators – the carer and the person being cared for (Engelsrud, 2013).

This embodied activity is anchored in the storyteller's body and that of the listener. This anchoring is crucial for stories to be told, understood, and interpreted. According to Hydén and Antelius (2010, pp 599-600), bodily storytelling includes three central aspects:

- It takes place within social relations, which are crucial to the creation of narrative meaning
- The body is used as a communicative instrument for both speaking and listening
- There is sympathetic emotional engagement, which means full body and mind involvement in the storymaking process

This can also be understood as an intuitive and intersubjective understanding (Trevarthen, 1979) between the person with profound intellectual and multiple disabilities and the caregiver (Gjermestad, 2009), where the other's body is sensed via one's own (Abram, 1997).

During caring encounters with persons with profound intellectual and multiple disabilities, there is a need to generate stories from and with actual bodies. We tell stories 'about, in, out of, and through our bodies' (Smith, 2007 *in* Hydén, 2013, p 126). There has been a tendency to leave the body out of storytelling because it is not seen as being related to cognitive and information processing. In caring encounters with persons with profound intellectual and multiple disabilities, there is a risk of overlooking the storytelling body because of illness, impairment and cognitive dysfunction. Such cognitivist discourses are dominated by conceptions of communication competence and narrative as only verbal (Antelius, 2009). The body is left out of such conceptions. Cognitive knowledge seems to overlook and exclude embodied knowledge (Kontos, 2005, p 553). Because we live in a 'hypercognitive culture' (Post, 2000), we tend to view people who communicate differently from us as alien. Verbal language in Western culture has a privileged position compared with other forms of expression. For people whose main communication is unconventional or without words this can be devaluing and challenging.

Persons with profound intellectual and multiple disabilities are co-narrators who communicate their likes, dislikes, desires and potentials but are dependent on family members and professionals who try to interpret their non-verbal and bodily utterances. Person-centred care approaches that involve and treat family members as experts and focus on the quality of staff relationships are therefore needed (Mansell, 2010; Vorhaus, 2016). Parents, siblings, other family members and friends who know the person well tend to be a rich source of knowledge.

Listening to and interpreting meaning from the non-verbal and bodily utterances of such persons involves functioning as their vicarious voice (Hydén, 2008). The vicarious voice function is a recourse, but it also adds certain dilemmas and the potential for misunderstanding. According to Hydén (2008), there is always the risk that the caregiver's voice may carry too much weight in the meaning-making process, making it a bit like telling stories in the third-person perspective without getting proper access to the

first-person perspective. It is impossible to avoid some level of uncertainty when seeking recognition, approval or acknowledgement from the person with profound intellectual and multiple disabilities.

Method

The study was conducted as a practice development project (Garbett and McCormack, 2002) led by staff in a residential housing, in partnership with academics with experience of the methodological approach. The project was inspired by empathising and sensitising methods in care (Hundeide, 1996) and a social/relational model of disability (Reindal, 2008). Its main focus was to facilitate new knowledge and understanding of the residents as agents in order to improve the quality of staff care for the residents, several of whom had profound intellectual and multiple disabilities. In addition, the practice development project was based on the foundational value and philosophy of participatory appreciative action and reflection design (Ghaye et al., 2008). Emphasis was placed on dialogical, reflective and cooperative approaches to create new understanding of care quality by acknowledging resources, strengths, capabilities and opportunities in the staff and residents. Three days of dialogue meetings with workshops and four half-day reflection seminars were carried out over a period of two semesters. The dialogue meetings were conducted with a dual focus on introduction to theoretical concepts, followed by dialogues, reflections and sharing experience between staff and academics, who facilitated the dialogues. The half-day reflection seminars took place between the dialogue seminars, with an emphasis on pursuing the reflection from the dialogue meeting in relation to participants' practical experience. Data were generated from field notes, minutes from the dialogue and reflection meetings, informal/formal conversations and group interviews with staff.

From the data, material traces of valuable stories were identified for further analysis by the author, who read the data several times and put together the fragmented reflections and stories as a whole. The author identified episodes of non-verbal, emotional, embodied interactions between staff and the various residents and conducted a narrative analysis. These episodes, described as 'silent narrative practices' (Squire et al., 2014, p 11), were analysed, reconstructed, and rewritten by the author. These shed light on staff's narrative competence in their reflections about their caring encounters with the residents. In this article, two examples of emotional, embodied and 'silent' practices are extracted, presented and discussed. Both examples represent and illuminate a pattern observed throughout the material, relating to how staff developed their new understandings and narrative competence with all the other residents in residential housing.

Ethical approval

The Norwegian Centre for Research Data approved the project. Ethical issues were established and discussed with staff throughout the project. Staff reflections, dialogues and experiences regarding everyday caring encounters were told anonymously, with respect, dignity and ethical sensitivity towards the residents with profound intellectual and multiple disabilities. Staff received oral information about the project. Because the residents were not able to give consent when they were informed, it was sought from their families or guardians. All names were anonymised in logs, minutes and interviews. When reporting/publishing the project, information about context, gender and activities was also changed to secure anonymity.

The limitations of this study were its small size and its single setting. Despite these factors, the knowledge generated could potentially be transferred to similar settings. The involvement of family members in the practice development project could potentially have been sought at an earlier stage, which could have added further depth of knowledge to the findings.

Results

In this section, I draw on examples of silent narratives identified and based on staff reflections and dialogues about their everyday caring encounters with persons with profound intellectual and multiple disabilities.

Eric is a middle-aged man with profound intellectual and multiple disabilities. When sitting in his wheelchair, he makes loud noises and rocks back and forth. In addition to challenges in communicating and expressing himself verbally, he also has a history of pain due to several health problems. The staff initially described Eric's communication in terms of loud shouting and noise. Staff told stories of difficulties related to Eric's care due to the noises and the fact that he seemed to be in pain. Stories of disability and pathology seemed to dominate the interpretations of Eric's bodily narrative/stories. However, Eric was invisible as a person or agent in these stories.

As the dialogue sessions continued, the stories changed. The staff started reflecting on how to interpret and understand Eric's loud noises. As the sessions proceeded, the staff drew new meanings based on Eric's bodily and non-verbal expressions. They started to understand Eric and his loud noises and rocking body in new ways, and discover that these were his unique way of communicating and expressing himself, or even his way of telling stories in everyday care. The staff started to explore their varied understandings of Eric's non-verbal expressions, and identified nuances. These stories included noises of pain, noises of joy, and even noises of music and melodies from well-known songs. One staff member stated:

'This is Eric's way of communicating, and it is our responsibility to create meaning in the everyday care interactions with him. I have been blind to what Eric really can do and more focused on what is wrong with him.'

During the reflection sessions, the care staff altered their awareness of Eric's unique way of communicating and expressing himself, and grew to view Eric as a person with resources and capabilities in melody and musicality.

Filip is in his thirties and has profound intellectual and multiple disabilities. Due to severe motor and sensory impairments, contractions, spasms and scoliosis, Filip cannot sit on the sofa on his own. He needs to sit close to someone who can hold and support his body to keep him from falling. When the staff described Filip, they used phrases like 'he is locked in himself', saying he was silent, and non-communicative. Most found it challenging to communicate with Filip, except for a few who had known him for a long time. One of the staff members who knew him well described a moment when she was sitting with him on the sofa. They were enjoying each other's company, relaxing and listening to music together. He enjoys listening to music and listening to the voice of the caregiver singing. While sitting close to Filip, the caregiver said that she felt that his body was becoming more relaxed as the music went on. She said:

'In my body I can feel that he likes sitting like this. I can feel his breathing is getting calmer, and I know he is relaxed and is feeling well. His body is telling me that he is having a nice time with me and that he likes to sit like this. I feel that it is very important to prioritise moments like this and to take advantage of these "nice moments" together with him in the everyday situations. It feels as if I get to know Filip better in close moments like this with him together on the sofa.'

Discussion

These examples of silent narrative practices from Eric and Filip will be discussed according to the theories of narrativity and embodied activity. The article will then discuss possible implications for practice in terms of how narrative competence is crucial to person-centred care for persons with profound intellectual and multiple disabilities. Both the examples illuminate how these individuals are unique agents, bodily actors and persons with narrative competence (Hydén and Antelius, 2010; Simmons and Watson, 2014). The examples show how staff co-construct meaning (Bruner, 1987), and this increases their understanding of the nonverbal and bodily utterances (Hydén and Brockmeier, 2008) in everyday care encounters. Throughout the dialogues, staff developed new ways of speaking to and understanding Eric, Filip and the other residents. For Eric, the caregivers developed a new

understanding related to his noisy and bodily communication (Hydén and Brockmeier, 2008). These new understandings allow for greater sensitivity to Eric as an agent and a person (Vorhaus, 2016). He could sing and hum songs that he liked. His sounds, gestures, bodily expressions and rocking in his wheelchair were interpreted in new ways during the project.

The case of Filip especially illustrates how the staff used the body as a communication instrument in interactions, understandings and interpretation (Hydén and Brockmeier, 2008; Antelius, 2009). The staff member used her body as a communicative resource in relation to her intuitive and intersubjective understanding (Trevarthen, 1979; Gjermestad, 2009) of Filip while they sat together on the sofa. Her body felt that Filip was getting calmer and more relaxed and that he seemed to like sitting together singing on the sofa. Both examples show how staff were able to use the dialogue sessions to develop and uncover new meaning (Bruner, 1987) and understanding of non-verbal and bodily communication. The examples also illustrate how staff function as vicarious voices (Hydén, 2008) for Eric and Filip. Even though Eric and Filip are unable to communicate their experiences verbally, they use their bodies as agents of non-verbal communication (Abram, 1997; Hydén and Antelius, 2010).

These findings also illustrate how staff members focus on impairments and residents' lack of communication skills in their daily caring encounters (Simmons and Watson, 2014; Vorhaus, 2016). This supports discourse within this field to examine the impaired ability of individuals with profound intellectual and multiple disabilities to articulate their own stories – a lack of 'tellership' (Simmons and Watson, 2014). These authors affirm that persons with profound intellectual and multiple disabilities tend to be described in terms of lacking agency and free will. Other authors question such persons' ability to communicate intentionally and meaningfully with others (Coupe O'Kane and Goldbart, 1998). In line with this, staff understanding tends to be linear, focused on pathology and disempowering (Fischer and Goodley, 2007). Staff members tend to de-emphasise the potential, resources and capabilities of persons with profound disabilities in caring encounters, but the examples from this project show how this approach can change to become more person-centred as a result of dialogue meetings. Staff began to look beyond the diagnosis and disability and viewed Eric and Filip as unique persons and storytellers. This outcome highlights the importance of the staff sharing stories and reflecting on different understandings of the utterances of persons like Eric and Filip.

The two examples point to the need for a certain kind of narrative literacy or narrative competence (Charon, 2001) when listening to and co-constructing stories with persons with profound intellectual and multiple disabilities in person-centred care practices. User participation and person-centred care are central political goals, embedded in the ideology and values of our health and social systems (McCormack and McCance, 2010; Norwegian Ministry of Health and Care Services, 2012-13; Norwegian Ministry of Children and Equality, 2016). Staff must acknowledge and listen to the users' own experiences to provide the best possible care; to appraise and acknowledge the perspectives of persons with profound intellectual and multiple disabilities in caring encounters, the staff's narrative competence is crucial (Charon, 2001). This narrative competence is built on the ability to recognise, sensitise, be moved by, interpret and respond to individuals' stories or narratives (Charon, 2001; Hovland, 2011), as seen in the examples.

This narrative competence requires familiarity with nuances in stories told and enacted by persons with profound intellectual and multiple disabilities. This is not a standardised skill, but a competence that needs to be developed through practice and training focused on narrative sensitivity (Baldwin, 2005). To achieve it, staff members need to spend time with, listen to and get to know the person well. The relevant knowledge can only be gained through sensitive and attuned interactions within the context of everyday routines such as eating, getting dressed, visiting the bathroom, going to the day centre or going shopping. Within these everyday routines, mutual understanding and meaning-making can develop (Goodwin, 2013).

Another important aspect of narrative competence is that staff need to listen to and learn from those who know the person well – family members, significant others, friends or other caregivers with longer-term knowledge of the person. They are valuable holders of knowledge about the person, their ways of communicating and how to interpret of their non-verbal and bodily utterances (Baldwin, 2005; Vorhaus, 2016). Interacting with persons with profound intellectual and multiple disabilities and their caregivers, family, and friends naturally involves different meanings and interpretations of non-verbal and bodily utterances (Grove et al., 1999; Ware, 2004). Findings in this project show that different staff members derive different understandings and interpretations of one person's communication so discussion and reflection with colleagues is necessary to build and nurture narrative competence (Goodwin, 2013). Providing the settings where reflection among staff can take place is essential for facilitating and training this narrative competence.

In caring encounters the narrative competence of staff also entails a moral commitment (Dennis, 2002), that is, the act of listening. The implication is that the caregiver has a moral duty to listen to what the narrator has to say (Tetzchner and Jensen, 1999; Dennis, 2002, p 240). For staff as listeners and co-narrators for persons with profound intellectual and multiple disabilities, this obligation must embrace 'the values of curiosity and possibility' (Blotzer and Ruth, 1995, p 3) and focus on finding likeable qualities in the person (Blotzer and Ruth, 1995 in Dennis, 2002, p 240). The findings from the projects and examples of Eric's 'musicality' and Filip 'having nice time and feeling relaxed' might indicate how, during the project, staff developed a moral sensitivity towards the residents, which is part of their narrative competence.

These overall experiences from the project indicate that narrative competence can contribute to new understandings of persons with profound intellectual and multiple disabilities as narrative agents and people. They are subjects with unique capabilities who use their bodies as tools for communication. Staff reflections and dialogues about their different understandings of a person's utterances can be a promising way to secure person-centredness in these care practices. Dialogues and reflections among staff within reflection groups can reduce professional bias, inferences coloured by personal values and attitudes, and misunderstandings – all of which are a danger when functioning as someone's vicarious voice (Hydén, 2008).

Conclusion and implications for practice

Small-scale practice development projects like this one can contribute to fruitful changes and new paths to person-centred care for adults with profound intellectual and multiple disabilities living in residential housing. This project's theoretical inspiration and methodological approach can serve as an example of how simple strategies can help staff in residential housing develop new understanding of such persons as agents. It also shows how narrative competence is crucial to providing person-centred care, promoting sensitivity and communicative competence in caring encounters with persons with profound intellectual and multiple disabilities.

Focusing on staff narrative competence through reflection is a promising way to enhance person-centredness and personalisation in care encounters with people with profound intellectual and multiple disabilities. Facilitating staff narrative competence takes time and effort and must be developed through dialogue and hands-on experience. This development can also help to counter devaluing attitudes and assumptions in institutionalised care – attitudes that risk reinforcing the view of these residents as non-agents and simply care recipients, rather than participants.

The fact that staff members derive different understandings and interpretations of a person's non-verbal utterances in caring encounters can be addressed by dialogue and reflection with other caregivers and also with family members, and providing the settings for such reflection is important in terms of facilitating the development of narrative competence and encouraging person-centred care. This project can serve as a model for enhancing and encouraging person-centred support for adults

with profound intellectual and multiple disabilities living in residential housing. However, although staff narrative competence is a resource for person-centred approaches, it is important to be aware of the risk of giving too much weight to a caregiver's voice in the story of the person with profound intellectual and multiple disabilities.

Addressing devaluing attitudes by focusing on the capabilities and agency of persons with profound intellectual and multiple disabilities also promotes and strengthens these persons' fundamental human rights. Promoting human rights in caring encounters can help to balance the prevailing emphasis on care efficiency and budget restrictions.

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Anita Gjermestad (PhD, M SpecialEd, B SocialEd), Disability Nurse and Social Educator, Associate Professor, Faculty of Health, VID Specialized University, Sandnes, Norway.