



ORIGINAL ARTICLE

'I am a normal man': a narrative analysis of the accounts of older people with Down's syndrome who lived in institutionalised settings

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Accessible summary

- This study is about the life stories of six older people with Down's syndrome who spent some part of their childhoods in institutionalised settings.
- They have interesting and moving stories to tell about their lives. They talked about their childhood and current lives, their likes and dislikes, their strengths and difficulties and their hopes and dreams. They also spoke about the important people in their lives.
- The participants did not talk about themselves as being 'old', 'disabled' or as having 'Down's syndrome'. They talked about themselves in other ways, such as being 'normal', being a 'man' or a 'beautiful lady'.
- The researcher learnt about herself whilst doing this study. She learned about the value of taking time to listen to people and she reflected on her own life story.

Summary

This paper is a narrative analysis of the accounts of six older people with Down's syndrome who spent part of their childhood in institutional environments. The study aimed to find out how the participants talked about themselves. Different types of narrative analysis were used, including those of Murray (*Qualitative psychology: a practical guide to research methods*, London, UK, Sage, 2003), Gergen & Gergen (*Hist Social Psychol*, Hillsdale, NJ, Erlbaum, 1984) and Labov & Waletzky (*Essays on the verbal and visual arts*, Seattle, University of Washington Press, 1967). All of the participants spoke about their childhood, current and future lives. Most participants were able to reflect upon their strengths, limitations and hopes. The analysis highlighted the commonalities across the accounts: loss, abuse, health, significant others, transition, resilience and identity. Significantly, none of the participants identified themselves as having 'Down's syndrome' or a 'learning disability,' nor did they identify with being 'older'. Instead, individuals identified themselves in relation to gender and social roles. The accounts varied in terms of their form, structure, coherence and reflexive capacity. Clinical implications are discussed.

Introduction

Historical context

Older people with Down's syndrome have lived through some significant historical changes over the past 50 years. These include the closure of institutionalised settings,¹ advances in healthcare technology and changes in societal attitudes towards people who have a learning disability.² People with Down's syndrome are now living longer. The average life expectancy of an individual who has Down's syndrome has increased threefold and is currently in the mid-fifties, (Trumble 2002).

Down's syndrome and Identity

There is a lack of research into the areas of identity and people with Down's syndrome. Cunningham *et al.* (2000) investigated the self-awareness of young adults. They used direct and indirect questions about Down's syndrome/disability and photos of people with Down's syndrome to investigate the self-awareness of 77 young adults. The authors reported that a person's verbal mental age was significantly associated with being able to make social comparisons and form social categories of Down's syndrome and disability.

There is a need to discuss older people who have Down's syndrome. In some ways this is a fairly exceptional group as many have lived through the experience of institutionalised care, which no longer occurs today. They are in the unique position to talk about how their lives have changed since leaving long stay hospitals. This will help us to understand how historical, social and cultural factors have influenced peoples' sense of themselves. Another reason for exploring how people with Down's syndrome talk about themselves is that historically people with disabilities have been represented by others (Atkinson & Walmsley 1999). Therefore, by listening to participants talk about themselves, it is hoped that they will feel empowered, which may facilitate a change in the power relationship between the researcher and the participants.

¹Institutionalised settings and long stay hospitals will be used interchangeably throughout this study.

²The term 'learning disability' will be used in this study, as this is the accepted terminology used by the health and legal systems.

Social identity theory

There are different theories of 'identity' and 'self'. Some researchers suggest the self is a relatively stable concept (Costa & McCrae 1992); others suggest it is more fluid and made up of multiple identities (Mead 1934; Stets & Burke 2005). In line with the idea that the self is made of multiple identities, one approach to studying identity and self-awareness is 'Social Identity Theory' (Tajfel & Turner 1979). This theory proposes that being a member of social groups is an important part of our self-concept. The theory involves social categorisation and social comparison processes. The outcome of the social comparisons contributes to a person's self-esteem: if a person belongs to a group, which s/he perceives to be superior to other groups, s/he will feel better about themselves.

In a literature review on how people with a 'learning disability' view their social identity, Beart *et al.* (2005) highlights that many people do not identify with the label. She discusses possible reasons for this lack of salience including: people being unaware of the identity as they are being protected by others (Todd & Shearn 1997); not identifying with the label as it does not fit with their lived experiences (Finlay & Lyons 1998); being in denial as it is too emotionally painful (Sinason 1992); not having the cognitive ability to understand what the identity means (Cunningham *et al.* 2000). The current study used Social Identity Theory as a theoretical framework to explore 'identity' of older people who have Down's syndrome.

A narrative approach

The research method used was a qualitative approach called narrative analysis. This is a phenomenological approach, whereby the researcher is interested in participants' perceptions and meanings of particular phenomena through the way they talk about their lived experiences. This was important to the authors, as they were interested in staying close to the participants' own words. There were several other reasons for choosing this approach. Firstly, narrative analysis is concerned with how a person's story is shaped by the historical and cultural context, which the authors believed would be of significance in this study, e.g. the effects of institutionalisation. Secondly, narrative approaches have been used to study the concept of identity, Lieblich *et al.* (1998). Furthermore, researchers have demonstrated how the approach is a non-threatening and ethical way of carrying out research with people with learning disabilities (e.g. Booth & Booth 1996).

Table 1 Demographic information of the participants

Name*	Age	Living situation	Ethnicity	Daily activities	Married
Elliot	50	Residential home supported 24 hours a day	White, British	Workshop for people with learning disabilities.	No
Lily	50	Residential home	White, British	Workshop for people with learning disabilities	No
John	55	Residential home	White, British	Day centre	No
David	55	Residential home	White, British	Day centre	No
Christopher	56	Residential home	White, British	Day centre	No
George	53	Residential home	White, British	Day centre	No

*Names have been changed.

The current study aimed to answer the following research questions:

- When invited, how do people with Down's syndrome who lived in long stay hospitals tell their life stories?
- Do people compare themselves to others (downward/upward social comparisons) and if so, how?
- Do people have positive or negative self-concepts? Are they aware of what they can and cannot do in relation to others without a diagnosis of Down's syndrome?

Method

Participants

Six participants were recruited via a local NHS Trust. Table 1 shows the main demographic details of the participants. Participants were selected who met the inclusion criteria below:

1. Diagnosis of Down's syndrome
2. Men or women
3. Older than 50 years of age. (For the purposes of this study, the authors decided upon 'older' being over the age of 50 years old. This was based on life expectancy data.)
4. Those participants with relatively good expressive and comprehensive language skills. This was assessed using their scores on the Picture Naming³ subtest of the Neuropsychological Battery for Dementia in Adults with Intellectual Disabilities (NAID), (see Crayton *et al.* 1998; Oliver *et al.* 1998, 2005). Participants were selected if they scored over 10 on Picture Naming.

³The Picture Naming subtest involves showing a participant 14 pictures (and two practice pictures), which have been taken from the British Picture Vocabulary Scale (BPVS), ranging from number 1 (hand) to 23 (arrow). The participant is asked to name each picture. Crayton *et al.* report that the Picture Naming subtest of the NAID has good reliability (Cronbach's alpha = 0.87; Spearman's Brown split half reliability = 0.90, K. Dodd, personal communication, 14 May 2007).

5. The authors looked at various health considerations: none of the participants had a diagnosis of dementia and none had any significant hearing or visual problems.
6. Spent some part of their childhood living in a long stay hospital.
7. English was their first language.⁴

Ethical issues

Ethical approval was obtained from the Local Research Ethics Committee and the University Advisory Committee on Ethics. The main ethical issues included: ensuring that the participants understood what was being asked of them and acquiring consent; explaining to participants that the interview may bring up difficult issues; reducing the potential for distress through developing a good rapport with participants and using a similar approach to Booth & Booth (1997) who adopted an informal style of interviewing to create a relaxed atmosphere; maintaining anonymity throughout the research process via changing any potentially identifying details about the participants.

Interview procedure

This study used a similar interview format to that of Booth & Booth (1997) who carried out three interviews with each participant in their own homes. A semi-structured approach was used as it was assumed that the participants might not have had the opportunity to tell their life stories before and hence may have had difficulties without some prompt questions.

The interview began by asking open-ended questions about a person's life such as, 'Please tell me about yourself'. Then questions about a person's current life were asked including, 'What do you like doing here?' It was decided to ask these more concrete questions relating to a person's

⁴This was because English is the main researcher's first language and it was believed that meaning and understanding may have been lost if an interpreter was used. In addition, resources were not in place to use an interpreter.

current life, due to the authors' wish to limit any potential distress. The interview then moved on to asking about significant past events such as, 'Where did you live before here?' Then, questions relating to self-concept and social identity were asked including, 'What are you good at?' Finally, questions about future aspirations were asked such as, 'What are your hopes in life?'

All interviews were audio-digitally recorded with the participants' consent. Booth & Booth's (1997) suggestion of using photographs and personal objects was used to facilitate the interview process. Participants brought along certificates of achievements, sports awards and photos. After the first interview, genograms and Makaton pictures were used as a way of considering participants' non-verbal abilities.

Data analysis

The data were analysed using a narrative approach, which drew upon ideas from different writers. Michael Murray's (2003) approach was initially used whereby a summary for each person's account was written and the main features were highlighted in the form of a three-part story (beginning, middle and end⁵). Additional analyses were carried out on the narrative accounts including considering the narrative structures (Labov & Waletzky 1967), identifying the narrative forms (Gergen & Gergen's 1984) and considering how the accounts were influenced by broader societal and cultural factors. After analysing each participant's account, a comparative analysis of all six accounts was carried out whereby the main themes were identified.

Quality control checks

Elliot *et al.*'s (1999) criteria for assessing the quality of qualitative research were used. This involved the main researcher owning her perspective through making her assumptions explicit in a research diary, situating the sample by providing basic descriptive data and grounding the main findings of the data in the form of direct quotations from the interview transcripts. Supervisors were asked to read the data and the main researcher attended a Narrative Analysis group whereby a colleague carried out an independent audit. These quality control checks confirmed the credibility of the data, ensured coherence and assessed whether the findings resonated with the reader.

Results

Six life stories were co-created by each participant and the main researcher using Murray's (2003) framework of

having a three-part story with a beginning, middle and end. The accounts varied in terms of their content, structure and form. The following section will present the main themes and describe the similarities and differences between peoples' accounts in terms of narrative form and structure.

Narrative themes

The main themes were as follows:

Loss

A sense of loss pervaded throughout all of the narrative accounts. Most participants spoke about the sadness of losing their parents. Speaking about his mother's cremation, Elliot said, 'It was very very sad... I was crying. I was crying. My mum. My brother. Everybody was crying. Crying all the time'. Similarly, David reflected on his sadness over the death of his parents, 'And my mum and dad died as well...Gone to heaven.... I was sad'. Most participants spoke about this sadness, apart from Lily who described how her mother was living in a 'different world'.

Abuse

Many participants spoke about how they had experienced physical abuse whilst living in the long stay hospitals. David frequently mentioned being assaulted whilst he lived in the hospital. He said, 'Someone hit me once... Big Mick... He whacked me in the face. (He demonstrates being punched in the face)... Bite my ear once. (Points to his ear)... I was really frightened... I don't want to go back there again'.

Transition

All of the participants spoke about moving homes and living in different places. For example, Lily and Elliot both spoke about living on many different wards in the hospital. The majority of participants preferred their current way of life as opposed to living in the institution. Lily explained about liking her current 'freedom' and having her own possessions. Elliot talked about liking the surroundings of the hospital; 'They had some lovely fields over there'. However, overall Elliot stated that he preferred his current home to the hospital. He said, 'It is nicer here'.

Health

Several of the participants emphasised their physical health during the interviews. They either mentioned it in relation to their own particular health problems or to how their bodies were injured. At the beginning of the first interview, when Elliot was asked to describe himself, he talked about how he

⁵The 'beginning' reflected childhood events, the 'middle' was current life and the 'end' corresponded to identity and future hopes.

'looks after himself'. He repeatedly spoke about his forthcoming operation on his toenail and about how he would be 'brave' for it. A significant feature of George's story was his 'heart trouble'. He said, 'For my heart trouble. You know what I got...My back you know, my back gets sore...'

Attachment figures

All of the participants spoke about significant people in their lives, such as their families, friends and support workers. For example, Elliot talked about how his father taught him to swim. He said, 'With my father, yeah. He had to hold me... He teach me to swim... Yeah, I can swim on my own now. (He smiles)'. This gave a sense of pride and achievement. The participants also spoke positively about attending various social groups, e.g. church, advocacy and drama.

Resilience

There was a sense of resilience throughout several stories. For example, a significant event in Lily's early life was moving into the long stay hospital when she was 6 years old. She explained that her mother had a 'breakdown' and that this was the reason that she had to move homes. She put on a brave face with regards to leaving her family home when she was a young girl, stating that she 'did not mind'.

Identity

Gender. The six participants talked about themselves in different ways. No one talked in terms of a having 'Down's syndrome' or a 'disability'. Four out of the six participants drew on gendered identities: 'I am a normal man' (Elliot); 'I am a beautiful lady' (Lily); 'I am a grown man' (George) and 'I used to be a kitchen boy' (Christopher). In particular, the accounts showed that many of the participants positioned themselves in line with a stereotype of what it is to be a man or a woman. For example, Elliot spoke about doing the gardening in the old hospital, his wish to work as a 'builder' and his enjoyment of going to the pub, drinking Guinness, playing darts and snooker.

Social roles. The participants also identified themselves in relation to social role identities. Lily identified with being her 'father's daughter', a worker, 'a bridesmaid', 'a Great Aunt' and a 'mate'. In contrast, Christopher's identity appeared to be wrapped up with his old job as a 'cleaner' in the hospital. He stated that he cleaned at the weekends and in the evenings and that his main strength was cleaning.

Age and physical characteristics. None of the participants described themselves as being 'old'. George said that he was a 'grown man'. Lily described herself as 'young' and 'little'.

Christopher was not sure what I meant when asked about what it felt like to be fifty-five. He stated, 'I don't know about that one'. John talked about himself in terms of his physical attributes. He said, 'I have two teeth'.

Social comparisons. Three participants understood when asked whether they were the same as or different from other people. For example, Elliot spoke about his siblings in terms of their age and in terms of their physical attributes. He spoke about how Trevor was 'younger' and 'very tall'. George compared himself with his fellow resident and said that he was not like him as his fellow resident had a hearing aid and he did not. John said that his advocate was not like him as he said his advocate was 'tall'.

Personal strengths and difficulties. The participants varied in how they spoke about their strengths and difficulties. For example, David talked about how he was good at sports, e.g. badminton. When asked about his difficulties, he stated that he wore glasses and that he did not read. George said that he found certain household jobs difficult because of his heart and that he had to be 'careful'. In contrast, Lily emphasised that she could do things on her own (e.g. cleaning) and did not refer to any personal limitations.

Narrative form and structure

Gergen & Gergen's (1984) approach was used to analyse the narrative forms in each of the six narrative accounts. For example, Lily's account could be interpreted as an *heroic* narrative as she talked about the obstacles she faced (such as having her clothes stolen at the institution) but also the ways in which these obstacles were overcome (for example her parents meeting with the hospital manager to help resolve the situation). In contrast, there was a sense of *tragedy* in Elliot's story, such as when he spoke about not being able to marry his girlfriend. The accounts of John, George, Christopher and David were interpreted as both *regressive* and *progressive* at times as they talked about the difficulties they experienced when they were younger as well as the more positive times in their lives, such as their holidays and interests.

The narrative accounts varied in their structure, coherence and reflexive capacity. As the interviews progressed, the topics appeared to be talked about in more depth. For example, the first interview with Elliot briefly covered many topics whereas the third interview went into the topics in more detail. The main researcher attributed this change to a development of the participants' narrative skill and to her interviewing skills, such as being able to stay with the participants when they spoke about uncomfortable life issues, rather than quickly moving on to the next topic. Labov & Waletzky (1967) framework was used to analyse

the narrative structures. In order to develop a sense of structure, the main researcher used many prompt questions. For example, the question, 'How did that make you feel?' was asked to gain the evaluation structure (reflexive capacity). The majority of participants were able to evaluate the significance of events to a certain extent. For example, Lily was able to say that she felt 'angry' when her housemates told on her for not doing the cleaning. Likewise, George spoke about feeling 'frightened' when he was beaten by his father. However, there were times when some participants did not offer many evaluative comments about their life experiences. For example, Elliot and John often said, 'it's alright', when asked to talk about the significance of something.

Questions such as, 'What happened?' were asked to gain more of the abstract, orientation, complicating action and resolution structures. However, despite using these questions, it was often difficult to analyse the narratives structures. Some accounts were more limited in terms of their content. For example, John spoke very little about his early life. He generally answered with one word or a very short response. A significant feature of David's interviews was the way he jumped from topic to topic. Hence, some accounts were more coherent than others.

Summary and conclusions

This study used a narrative approach to co-construct six accounts with older people who have Down's syndrome. With respect to the original research questions, all of the participants talked about their childhood, current and future lives. Each person's story was unique. However, there were several commonalities including, loss, abuse, transition, health, significant others, resilience and identity. Significantly, none of the participants identified themselves as having 'Down's syndrome,' and nor did they identify with being 'older'. Instead, individuals identified themselves in relation to gender and social roles. This study corresponds with other studies, e.g. Davies & Jenkins (1997); Finlay & Lyons (1998) which found a lack of salience with the disabled identity from the perspective of the person given that diagnosis, i.e. the participants see themselves as 'people' not 'disabled'. Half of the participants compared themselves to others, in relation to physical attributes. Most participants were able to reflect upon their personal strengths, limitations and consider future hopes.

The participants spoke about loss or abuse in their lives and the accounts varied in terms of their structure, coherence and reflective capacity. Fonagy (1994) argues that if a person has been abused it is beneficial for them to remember, reflect and make sense of that experience rather than putting it out of their mind. Some of the participants seemed more able to remember and reflect on their difficult

experiences than others. For example, Lily and Elliot were able to recall what happened to them in great detail whereas John gave a limited description. This could be due to a difference in the participants' coping styles, whereby they either repress or express their experiences. Another reason could be due to differences in peoples' narrative skill. Researchers emphasise that the way parents talk to their children can influence narrative skill development (Fivush 2001), as well as the emotional context of the family (Dallos 2004). Hence, the separation from their parents and move into the institutions may have been detrimental to the participants' narrative development. Another reason for this difference in peoples' narrative abilities could be related to people with learning disabilities having difficulties understanding timescales, learned acquiescence and language limitations (Booth & Booth 1996). It is therefore important to consider that the gaps in the stories could be attributed to the main researcher rather than the participants.

Critique of study

This study has been effective in exploring how older people with Down's syndrome see themselves. However, there are limitations. Firstly, Narrative Analysis privileges language and thus there was a reliance on the verbal abilities of the participants. This may have been demanding for some participants at times. The researcher attempted to minimise this by ensuring frequent breaks and carrying out shorter sessions. She also paid attention to 'even the small particulars and happenings' in the interviews, as recommended by Booth & Booth (1996).

Furthermore, although the authors sought to empower the participants, they were still very much guided by their research aims of studying the social identities of the participants. Even though these aims changed and became an exploration of the participants' lives, it could be argued that the authors did not fully involve the participants from the start of the research process. Hence, one improvement to the study could be to include the research participants from the very beginning. That is, to involve people with learning disabilities in the research topic selection, in the research design and in the production of any written reports. This would be more in line with Atkinson & Walmsley's (1999) approach to autobiographical research.

Clinical implications for practice and research

This study has shown how the process of creating a life story in a relational context can facilitate a person to talk about themselves and their lives. This has therapeutic implications in terms of allowing a person to feel empowered, use their own words and hence be in control of their lives, which fits with one of the basic principles of Valuing

People (Department of Health 2001). For example, when talking about the research process itself, Lily said, 'I like doing this' because 'I can do it on my own'.

In terms of labelling someone, this study has shown how it is important to use the participants' own words when considering how they see themselves. There is some positive literature available for children with Down's syndrome on this subject, e.g. Archer (2004) and for adults (e.g. Canadian Down's Syndrome Society 2006; Russell 2006). However, there are no books available for older people with Down's syndrome. Therefore, it would be helpful to create a book by older people with Down's syndrome for others like themselves. This would hopefully enable them to identify with the main character's life experiences of living in a long stay hospital, and moving out into the community and then engaging in positive everyday situations.

This study emphasises the importance of listening to people with learning disabilities. Lily said 'they listen to me' when she talked about her brothers and advocacy manager. Kraemer (1999) highlights how people who are able to overcome serious disadvantage usually have one or more supportive people in their lives or they may belong to a community. Hence, in this study the significant others and sense of community (e.g. hospital, church, immediate and extended family, advocacy, workshops) were likely to have contributed to the participants' sense of resilience. This study agrees with other researchers who suggest that having a wide range of social roles appears to buffer against the effects of negative social comparisons, Linville (1987) and increases a person's well being, Thoits (1983). This has implications for how services for people with learning disabilities are organised and how services need to consider a person's roles within a community.

Future research

This study shows the value of using narrative approaches with people with learning disabilities. It promotes the view that people with learning disabilities can narrate their life forming experiences. It is hoped that more researchers will use this method as a way of doing research with these individuals.

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