

Research Report

Communication and self-esteem in adults with Down syndrome

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Abstract

Background: It is estimated that around 50–90% of people with learning disabilities experience difficulties in communicating. Previous research has linked communication difficulties and self-esteem in other populations, yet this relationship has not previously been investigated for people with Down syndrome.

Aims: To explore the relationship between communication and self-esteem in adults with Down syndrome. This research also aimed to offer an empowering and inclusive opportunity for adults with learning disabilities to be involved in research.

Methods & Procedures: Recruitment took place via a charity established for people with Down syndrome. Twelve adults with Down syndrome and an adult they nominated were approached. A qualitative methodology was selected to explore communication and self-esteem. A thematic analysis focused on the qualitative data collected via semi-structured interviews.

Outcomes & Results: Major themes within the data revealed that a relationship between communication and self-esteem may exist for adults with Down syndrome.

Conclusions & Implication: This study demonstrated that people with Down syndrome may experience low self-esteem that may be linked to communication. The clinical implications of this are considered and areas for future research are identified.

Keywords: communication, self-esteem, Down syndrome, adults.

What this paper adds

What is already known on this subject?

Communication difficulties and self-esteem have been linked in other populations that experience difficulties in communicating; however, the relationship between communication and self-esteem has not been investigated for people with Down syndrome. The prevalence of communication difficulties in people with Down syndrome is high, therefore contributing to the rationale for further investigation into the link with self-esteem.

What this study adds?

This study provides an exploration into communication and self-esteem in adults with Down syndrome through qualitative methodologies. Themes within the data identified a relationship between communication and self-esteem. People with Down syndrome may experience low self-esteem as a result of difficulty communicating. In addition, low self-esteem may impact on an individual's communication. Clinical implications of the findings have been identified.

Introduction

The aim of this study was to explore the relationship between self-esteem and communication for adults with Down syndrome. Traditionally the views of people with learning disabilities have been ignored and it is now acknowledged that without increased involvement there will be a significant gap in research in the field (Ware 2004). Many changes have been made to the way in which people with learning disabilities are valued within today's society, which may in part be due to the introduction of the Department of Health (DoH) White Papers, *Valuing People* (DoH 2001) and *Valuing People Now* (DoH 2009). The UK government's vision is that all people with a learning disability have the right to lead a life like any other.

The terminologies that have been used to refer to 'people with learning disabilities' have changed over the years, and capture a wide population of people. Broadly consistent with the International Classification of Disease (ICD-10) (World Health Organization (WHO) 1994), a person with a learning disability has an IQ of 70 or below and has impairments in coping with daily living, including difficulties with communication, social skills or self-care. Many different terminologies are used to define 'learning disabilities', such as intellectual disabilities and learning difficulties. A person who is de-scribed to have a 'learning disability', for the purpose of this research, is an individual who fits within the ICD-10 criteria of intellectual disability, as opposed to a person who has a specific learning disability, such as dyslexia, or another specific learning associated difficulty. These individuals, whilst having a difficulty in a particular area of learning, would otherwise have an average or above IQ, and generally be functioning at an average level. The term 'learning disability' is used throughout this report in relation to the current research.

There are many different causes of a learning dis-ability. Down syndrome is a genetic syndrome most commonly caused by a third copy of chromosome 21 (trisomy 21) although a small number of cases are due to mosaicism and translocation of material from chromosome 21 (Udwin and Kuczynski 2010).

People with learning disabilities, including those with Down syndrome, often present with difficulties in communicating. Broadly, delays may be experienced in speech, language use and pragmatic functioning. Some individuals may never develop speech and alternative forms of communication may be relied on (Sigafoos et al. 2010). Whilst there are similarities between the language profile of adults and children with Down syndrome, there are some additional difficulties that may heighten during adulthood; stuttering¹ is commonly noted in adults with Down syndrome (van Borsel and Tetnowski 2007).

People with learning disabilities have often been excluded from participating in research for various reasons, including difficulties with their communication. Research is now beginning to involve people with disabilities, as either participants or researchers and methodologies such as 'participatory research' and 'emancipatory research' are commonly being employed. A benefit of this is to provide a voice to a group of people who have historically been marginalized. Recent years have witnessed changes to research to increase inclusivity and accessibility for people with learning disabilities.

It has been well acknowledged that many people with learning disabilities experience difficulties with communicating. Less well understood is the presence of mental health disorders in people with learning disabilities. Mental health disorders such as depression are common amongst people with learning disabilities, and evidence still suggests that particular risk groups for developing depression may include people with Down syndrome (Prasher 1999). It has been argued that through a combination of early diagnosis and available support, people with Down syndrome may be 'protected' against psychopathology (Dykens and Kasari 1997); however, this may be a naive view and could lead to a neglect of possible psychological disorders in some people with Down syndrome. Many concepts are linked with mental health, one of which is self-esteem.

Self-esteem

Both researchers and clinicians within psychology view positive self-concept as a desirable characteristic (Marsh and Craven 2006). There is general agreement that there is a link between self-esteem and various social and emotional difficulties (Owens and Stryker 2001). Self-esteem is associated with a variety of clinical conditions, including depression (Roberts 2006). A review of the literature conducted as part of a doctoral thesis

(Jackson 2012) identified three main areas that impact on self-esteem in people with learning disabilities: self-awareness, social comparison and stigma. These are briefly discussed below.

Self-awareness

There is evidence to suggest that the level of an individual's IQ may be related to their self-esteem. Appleton et al. (1994) found that as children's IQ increased, they reported lower self-esteem. In this instance it seemed that the degree of intellectual disability may have served to reduce the distress associated with having a learning disability. Those individuals who were most aware of their disability (and had a higher IQ) reported lower self-esteem. This finding was also supported by Cunningham and Glenn (2004) who found that children with a higher verbal and non-verbal mental age were able to make links to the concept of Down syndrome and attach negative experiences to this category. Appleton et al. found that self-esteem was related to awareness of their disability however Cunningham and Glenn found the opposite; they reported no relationship between self-esteem and awareness of disability. This may be explained by differences in the groups of participants; Cunningham and Glenn's participants had lower cognitive ability than the participants in Appleton et al. (1994). Thomson and McKenzie (2005) reported that when asked if having a learning disability was a good thing, 35% of those with a learning disability felt it was. However, when compared with individuals without learning disabilities, adults with learning disabilities scored significantly lower for self-esteem. These studies demonstrate that people with learning disabilities may report lower self-esteem when compared with individuals without learning disabilities. The level of learning disability had a differing impact on individuals' reported self-esteem.

Social comparison

Social comparison describes the process by which people compare themselves with others (Festinger 1954). Festinger's (1954) social comparison theory proposed that people should compare 'upwards' to others, thus comparing oneself with someone who is perceived as 'better' in some dimension (Sztivos-Bach 1993). However, Festinger's theory has since received criticism and evidence has been found for the opposite, downward comparison. Much research with populations of people with disabilities would indicate that downward comparison is more commonly used than upward comparison.

Li et al. (2006) found that higher self-concepts were found in individuals with intellectual disabilities, as compared with the group without disabilities. However, almost 75% of participants attended specialist education, thus creating in-group comparison with individuals with more severe disabilities. Finlay and Lyons (2000) also found that their participants presented with high self-esteem which may be explained by downward comparison. Whilst most research evidences downward comparison amongst people with learning disabilities, Paterson et al. (2012) found that people with learning disabilities did not differ in their comparisons with people in the community or other service users with disabilities. However, findings indicated that the more negative the social comparison, the lower the reported self-esteem. Findings therefore suggest that when downward comparison is used by people with learning disabilities, they report higher self-esteem. This may be due to the social group that they use as a reference, which is affected by where the individual works or socializes, i.e. whom they have available to compare themselves with.

Social comparison has also been linked with depression. A group of depressed individuals with learning disabilities were found to have higher levels of negative social comparison between themselves and others, than a group of non-depressed individuals (MacMahon and Jahoda 2008). In addition, higher self-esteem was found in individuals without depression. Self-esteem and social comparison have also been found to be associated with depression; individuals who are more depressed are more likely to make more negative social comparisons (MacMahon and Jahoda 2008). Social comparison and self-esteem may be characteristics that could help identify individuals who are at risk of developing depression.

Stigma

Recent work recognizes the potential impact of stigma on individuals' or groups' psychological well-being (e.g. Paterson et al. 2012). As a group, people with learning disabilities have historically been subject to

stigmatization (Baum 2006). There is evidence that students who had the greatest awareness of stigma also had the lowest self-esteem (Paterson et al. 2012). In addition, Abraham et al. (2002) found that students with the highest self-esteem showed least awareness of stigma. This suggests that perceiving stigma may lead someone to rate themselves as having lower self-esteem. However, it may be that having lower self-esteem may also render an individual more vulnerable to perceiving stigma.

Many factors appear to impact on the self-esteem of an individual with learning difficulties. However, within these three broad subject areas that have been explored in the literature, namely self-awareness, social comparison and stigma, communication is not explored as a factor. Communication and its impact on self-esteem has been explored in other populations. Due to limited availability of research on communication and self-esteem in people with learning disabilities, knowledge must be gained from other populations who also experience difficulties in communication.

Communication and self-esteem

Crichton-Smith (2002) found that participants who had a stammer limited their communicative experiences due to stammering and avoided situations requiring fluent speech, such as speaking in meetings. Stammering resulted in some participants experiencing low self-esteem. Some participants also experienced negative reactions from others due to their stammering; these negative stereotypes could in turn impact upon individuals' psychological well-being.

Research conducted with people who are deaf can be drawn on to explore communication and self-esteem and may provide a useful comparison group. There is evidence that communication difficulties in a deaf population increased the risk of developing depressive symptoms (Sheppard and Badger 2010). A lack of communication also led to a deflated sense of self-worth. Group identification appears to affect one's self-esteem within a deaf population. The evidence appears to suggest that individuals who identify with the deaf or bicultural (deaf and hearing) groups had higher self-esteem. There may be many explanations for this occurrence, however Bat-Chava (2000) links this with personal resources; those who identify with the more stigmatized groups, in this case deaf or bicultural, need to employ stronger mechanisms to protect themselves from the negative attitudes they receive belonging to this group.

Another population which may provide a useful comparison group is that of individuals with specific language impairment (SLI). SLI is a developmental disorder affecting language development, which persists into adulthood (Wadman et al. 2008).

Wadman et al. (2008) reported that young adults with an SLI may be at risk of lower global self-esteem when compared with their peers. Individuals with an SLI also avoided communicatively demanding situations or times when they were required to speak to someone new, such as a cashier (Törnqvist et al. 2009).

There are obvious limitations to applying what is learnt through studying other populations with communication difficulties, to the situation of people with learning disabilities. A primary consideration is that people with learning disabilities will have additional cognitive and intellectual disabilities which will affect the generalizability of the findings. However, there is evidence to suggest that communication difficulties, specifically in people with communication disorders, people who are deaf, and those with an SLI, can negatively impact on self-esteem.

The research reviewed highlights the impact of communication difficulties on individuals in their daily life. It could be argued that avoidance of situations may also have additional effects such as reduced confidence and increased mental health concerns. This highlights some of the potential effects of communication difficulties on mental health. In people who are deaf, a lack of communication was linked with low self-worth demonstrating direct links between communication difficulties and self-esteem.

Rationale for current research

Communication difficulties have been researched in other populations who experience difficulties with communicating as described above. However, communication and self-esteem have not been explored with people with a learning disability. It is estimated that between 50% and 90% of people with learning disabilities will have a communication difficulty (Jones 2002), which highlights the importance of exploring the relationship between communication and self-esteem in this population. Furthermore, people with communication difficulties are often excluded from research based on their communicative ability (e.g. Li et al. 2006); therefore their views and experiences are not well represented.

Aim and objectives

The aim was to explore the relationship between communication difficulties and self-esteem for adults with Down syndrome. This research aimed to fulfil the following objectives: to identify links between communication and self-esteem based on interviews with the subject group; to identify clinical implications of the findings; to offer an opportunity to include a historically marginalized group within the research; and to identify areas for future research.

Methods

Design

A review of the literature discussed in the previous chapter identified that there is a dearth of research focusing specifically on the impact of communication difficulties on self-esteem in adults with Down syndrome. The current research aimed to address this gap. People with learning disabilities have often been excluded from research due to their communication difficulties therefore the current study aimed to provide opportunities of participation for a group of individuals whose views are not well represented within research. A qualitative design was most appropriate for this study in order to explore the topic of communication and self-esteem and to gain individuals' interpretation of these topics.

Accessibility and readability of the research materials and procedure were enhanced by gaining the views of people with learning disabilities before commencing the research. Initial research ideas were presented at a service user group for people with learning disabilities where individuals were encouraged to comment on the research. To aid this process and to involve individuals irrespective of their ability to communicate, the information sheet and consent form were presented with a choice of pictures. Individuals indicated the picture they thought best represented the text. The final pictures used in the main research were chosen based on these responses.

The research study was presented at a service user group in London run by a charity for people with Down syndrome, using the information sheet. The initial discussion aimed broadly to inform individuals about the objectives and process of the research. Further recruitment was conducted from the charity's support group in Essex, and a satellite group of the London group which was originally involved. Participants were asked to complete a consent form at an initial meeting which was read through to them to ensure their understanding. After the consent form was completed, an interview was arranged with each participant. Individuals were interviewed at the service user group location, either before or during the monthly meeting, or at their homes or places of work.

Each individual participated in a semi-structured interview with the researcher. The interviews varied in length depending on the needs and circumstances of the individual; some chose to be interviewed over two or more occasions, whilst others wanted to complete the interview in one meeting. Participants were supported to decide whether they wanted someone else present at the interview; some requested the presence of a parent, whilst others preferred to be interviewed alone. Regular checks were made to ensure that the individuals still consented to participate.

The interview script was developed to explore the impact of communication on self-esteem. The first few questions explored how the individual communicated, and with whom. Within these questions there was

an exploration of how they felt about using different types of communication, and of any circumstances when communication might be easier or more difficult. The later questions focused on the individual and how they would describe themselves, and features that they might like or dislike.

Interviews were video recorded with the consent of participants. This aided transcription and allowed for further analysis of the content. A semi-structured interview was also conducted with the nominated person chosen by the participant. The interview was based closely on the interview script developed for participants with Down syndrome. This enabled topics to be explored within both interviews and allowed comparison between the two.

Sample

Purposive sampling was used to recruit participants through a charity established for people with Down syndrome. Twelve participants with Down syndrome were recruited. The inclusion criteria were that individuals must be aged over 18 years and have a diagnosis of Down syndrome. In relation to the study's objective of including a historically marginalized group, no individual was to be excluded on the basis of their communication ability. Each adult with Down syndrome was asked to nominate a person to be interviewed who knew them well, such as a parent or carer. In the event, all nominated persons were mothers of the participants.

Demographic data were obtained from the Questionnaire and are presented in table 1. Some individuals had different living arrangements during the week and the weekend so reported more than one living arrangement which results in the total scores exceeding the number of participants.

Table 1. Demographic data for participants (N = 12)			
	Age		
	18–25 years	26–34 years	Total
Frequency	6	6	12
<i>Gender</i>			
Male	3	2	5
Female	3	4	7
<i>Living arrangements</i>			
On your own	1	2	3
With friends	1	1	2
Group home	1	0	1
With family	5	3	8
<i>Jobs/activities</i>			
Job	2	5	7
College	2	2	4
Clubs/activities	5	6	11

Ethical considerations

The procedure was explained to participants and consent was gained. Consent was considered not as a one-off event but rather as a process running through all stages of the research. The consent form was revisited at every meeting and participants were asked if they still wanted to be involved.

The notion of implied consent was considered in addition to the consent form to ensure full consent of the individual. Any indication that the individual did not want to continue would have been responded to, and safeguards were put into place to ensure this. Throughout the meetings individuals were asked if they were happy to continue and it was made clear that the interview could be terminated at any stage. Consent was

obtained from both the adult with Down syndrome and the person they nominated to be interviewed. These two individuals consented separately for their own participation in the study. The study was approved by an NHS Research Ethics Committee and by the University of Essex Research Ethics Committee.

Data analysis

The qualitative data were analysed using thematic analysis. Thematic analysis can be defined as ‘a method for identifying, analysing and reporting patterns (themes) within data’ (Braun and Clarke 2006: 79). The analysis consisted of a number of phases, based on those outlined by Braun and Clarke (2006).

Familiarization with the data began by transcribing the interviews verbatim. Transcripts were read and reread to allow for a process of becoming immersed in the data. During this phase, any initial thoughts and ideas were noted by the researcher.

Initial codes were generated with the use of a qualitative data analysis computer software package MAXQDA (2007). As suggested by Braun and Clarke the data were coded for as many themes and patterns as possible, and were coded inclusively, ensuring that data surrounding the code was also captured.

Table 2. Seven themes represented within the data

Theme
Disability and difference
Exposure
Independence
Identity
Communication difficulties
Communication modifications
Resources/strengths

Once all the data were coded, a list of initial codes was developed for each of the two datasets. This provided an initial framework within which to understand and analyse the data. Quotes were allocated to support each code at this stage. The lists of codes were checked for reliability in two ways. The test–retest reliability was explored by applying codes to the same piece of text allowing a number of days between each application. Inter-rater reliability was assessed through discussion of the codes with independent coders. This was carried out with the two additional authors with 75% of the scripts.

The next step involved sorting codes into broader themes. At this stage, there was a focus on how different codes might be collated to form a larger theme (Braun and Clarke 2006). Once the themes were established, the entire dataset was reread to ensure further validity of the data, but also to recode any additional data in relation to the themes. A final thematic map of the data was produced, and the themes were named and defined. These themes were used to create a picture to represent the dataset (Braun and Clarke 2006).

Results

This section presents the findings of the semi-structured interviews both with the adults with Down syndrome and the nominated adults. Seven major themes emerged through the data, which are presented in table 2. These were themes that spanned both the interviews with the adults with Down syndrome and those with the nominated adults.

Quotations taken directly from the interviews are used to provide examples to illustrate the themes; (DS) and (NA) are used to indicate the origin of the quote, whether from an adult with Down syndrome (DS) or a nominated adult (NA).

Disability and difference

Having a disability

Disability and difference was present in the majority of interviews. Few participants directly described themselves as having a disability, though some did, 'Erm Because I'm disabled and Down syndrome' (DS). 'Down syndrome' was only used as a direct self-description by one participant; however, it did arise through discussion at other points during the interviews. Participants used a variety of terms including disabled, Down/Down's syndrome, disability and special needs. Nominated adults reported that some individuals identified themselves as having a disability, whilst at times others did not, 'she doesn't see herself as having a form of disability' (NA). Some were unsure, 'cause for a long time we weren't sure whether she, whether she knew she had Down's' (NA).

Participants were aware of the permanency of disability, 'but, you know, you can't change that, I know that yeah' (DS). This was also described by nominated adults, who felt they had to support the individual to accept this, 'you have Down's, there's nothing you can do about it' (NA).

Having a disability was experienced by several participants as something that negatively impacted upon them, 'she doesn't like people sort of staring at her and she doesn't like being special needs at all' (NA). Individuals described experiences of wanting to be without disabilities, 'I'd rather be like any normal girl' (DS). When participants described themselves as having a disability, these were often negative descriptions, but not always, 'he'll always go over and speak to them or tell me that they've got Down's syndrome' (NA).

Bullying/stigma

Participants described experiences of bullying which impacted on their self-esteem and confidence, 'and it's like, people watching, and I get a bit nervous' (DS). Individuals described an awareness of bullying and were able to comment on it, 'someone takes the mick out of you, and I don't like that' (DS). Participants also described an awareness of stigma, 'when I'm out with someone with special needs, I feel like someone is going to say things, like spastic, stupid' (DS). This appeared to affect friendships, as participants wanted to physically distance themselves from others with disabilities by not attending or engaging with groups established specifically for people with learning disabilities.

Limitations

Experiences of limitations due to the presence of a disability were discussed in the interviews, 'I'd probably rather if I wasn't special needs being normal, I think I would want to do X' (DS). Participants often described attributing difficulties to the presence of a disability, 'she went through a phase of very much of, a few years back of, I've got Down's and that's what's stopping me' (NA).

Vulnerability

This captured descriptions of times of individuals' vulnerability due to their communication, 'a bit too trusting with strangers, he gives too much information out to strangers if they asked him' (NA). Difficulties with this were described as a source of concern for families, 'I hope he knows now to be more cautious when he's out, when he was younger I used to be a little bit worried' (NA).

Exposure

Exposure to difficult situations

Several participants described the impact of exposure to situations which require communication, and the subsequent impact of this on self-esteem 'I'm yes I'm not sure she has had a huge amount of nasty experiences where she would have had to communicate out of trouble' (NA). There was an acknowledgement that limited exposure to difficult situations may reduce the negative impact on their self-esteem. Limited exposure was

subsequently spoken about as a form of ‘protection’ against potentially difficult situations which required communication to manage.

Support from others

Support from others was linked with communication and discussed in the majority of interviews, ‘yeah but he’s always with me, so I do it’ (NA). Direct references were made to receiving support when communication was required, ‘Mum normally explains . . . I wouldn’t talk’ (DS). During the interviews participants often looked to those in the interview with them for support, ‘do you, Mum say something Mum’ (DS). Support from others appeared to link with a reduction in exposure to situations where communication would be difficult.

Familiarity

When communicating with unfamiliar persons or exposed to unfamiliar situations, the individuals’ communicative ability decreased, ‘oh er when I see someone new I get worse like, in a way, I get worse for me’ (DS). Unfamiliar situations also impacted their feelings, ‘erm depends when you first go get a bit nervous and the more you go, don’t get nervous any more’ (DS). Though not directly linked, when in new or unfamiliar situations or with unfamiliar people, participants described difficulty in communication, which subsequently led to withdrawal, ‘she won’t say anything then, because she thinks they, they’re not wanting to talk to her’ (NA).

Integration

Individuals exposed to integration in the community highlighted the positive aspects of this, such as being part of a community, ‘very often when you’re out and about lots of people say “oh hello X”’ (NA) and the effect on communication, ‘he’s listening all the time, he’s bombarded by normal patterns of speech’ (NA). However, ‘the flip side of that is being in the mainstream, being integrated he’s having to deal with the problems that we all deal with’ (NA).

Independence

Independent living

Several participants spoke of their enjoyment of independent living, ‘I go I I I catch a bus on on my own now’ (DS). Nominated adults often commented on the positive impact of this on the individuals’ self-esteem, ‘he’s doing a lot, and I think, and travelling on a bus on his own, on a London bus, he just thinks, he’s just so proud of it’ (NA). Many references were made to the positive self-esteem experienced by elements of independent living, ‘I’m not aware of any, of any tremendous frustrations that she may have. . . . I think it’s because of, yeah, because of the independence’ (NA). Many participants described a desire to live independently, ‘but I would like to move away home’ (DS).

Independence from family

Individuals expressed a wish for an element of independence from family, ‘my parents get involved, and I I don’t want that’ (DS), however this seemed to co-exist with a dependence on family to communicate, ‘yet we’ve gone to other doctors at other occasions and she goes ‘you tell them’, you tell them and she just won’t talk about it’ (NA).

This subtheme portrayed tensions with independence for both families and the individual with Down syndrome. Parental concern was described in situations in which there was an element of dependence on the family, ‘only because, I said to him we might not be able to look after you forever . . . you never know what happens to anyone you know whatever you do’ (NA). In addition, there was a recognition of the difficulties associated with creating this independence, ‘And I keep trying to take that step back, to try and let him do things on his own, but it’s difficult when you’ve done it for so long’ (NA).

Identity

Physical appearance

Many participants made reference to things they did or liked when describing themselves and appeared to find it difficult to describe themselves. A negative opinion of one's physical appearance impacted on self-esteem, 'she's very aware, she'll sometimes say I like him he's really nice but he wouldn't want to fancy me because I'm ugly' (NA).

Although it was mentioned, there were no direct references made about appearance being linked with the physical characteristics normally associated with Down syndrome, though this was something which was mentioned, 'I don't know whether that's because she's seeing the Down's face' (NA).

Comparisons with others

Many nominated adults described times when the adult with Down syndrome copied others, 'you should be your own person, but sometimes you, you're not you copy people' (NA). Participants often made reference to characters from films that they desired to be like.

Comparisons were also made to others without disabilities, 'he does compare himself, he wants to drive a car, he's quite, he understands, I tried to explain it but he's disappointed' (NA). There was an awareness of comparison with others without disabilities, 'certainly she knows that she will never be like those people' (NA). Comparisons to others without disabilities were often described as causing a negative impact which was linked with awareness of limitations.

Some participants described their identity as linked with a role, such as when with other people with disabilities, as being someone that helps them, 'she saw her role there as looking after the people in the wheelchairs' (NA) rather than identifying with the other people with disabilities that were present. The group with which one identified was sometimes linked with communication, due to seeking out those with whom it was perceived one could communicate, 'She likes to communicate, therefore she will gravitate in any group situation to the people who chat to her' (NA).

Group identification

Individuals described identifying with different groups. Identification with people with disabilities was often referred to negatively, 'they were all special needs and she didn't want to be typecast with them' (NA). Individuals were described as communicating more with adults or staff than other peers, 'she was always better at communicating with, not her peers but people who were teachers and people who were older' (NA). Individuals also sought to separate their identity from people with disabilities, 'but she would see that as erm, making her different from most of the other young special needs people that she meets' (NA).

Loneliness

This captured direct references made to feeling lonely due to difficulties with communication, 'loneliness, which comes from not being able to sustain a communication with a friend' (NA). Participants spoke of wanting more friends, 'I like to go out and do things, wish I had more friends' (DS). This linked with self-esteem and low mood, 'she does find it quite hard to sort of . . . um have friendships with her peers, you know, to keep conversations going' (NA). A common experience was that of wanting a girlfriend or boyfriend.

Communication difficulties

Awareness of communication difficulties

Many examples of difficulties in communicating were described within the interviews, 'I think he's, he understands how far he's come in being able to communicate, but it is quite sad, erm because you can see that he's understanding' (NA). There was an acknowledgement that often communication fell behind an individual's

understanding, thus holding them back. The degree of awareness of communication difficulties ranged from those who may not be aware of this, 'maybe she is, but I don't know to what extent' (NA), to those who were aware of the difference and able to describe this, 'I know what I'm like, I do miss out words like, like saying what clothes I wear, I do miss out words' (DS).

Stuttering

Many of the participants described themselves, or were described by someone else, as having a stutter. A number spoke about the impact of stuttering, often that this was something they disliked, 'he says he wish he didn't have a stutter' (NA). Having a stutter was sometimes linked with difficult situations, or low mood, at which times the prevalence of stuttering increased.

Participants were able to describe what it was like to have a stutter, 'it is hard like for me, hard to think a word like how to say it' (DS). The effect of stuttering was described as a reduction in the individuals confidence, 'I think he, he loses his confidence, his confidence starts to go' (NA).

Confidence

When individuals had low confidence and self-esteem, this rendered them more vulnerable to awareness of stigma or differences, 'when he's got no confidence he will notice people staring at him, he'll notice people, um, er sort of, he notices it more, when, when he's got low self-esteem' (NA). A reduction in confidence was linked with feelings of low mood, and a lower self-esteem and appeared to have a negative impact on communication, 'I think he lost confidence, absolutely, I think his speech suffered' (NA).

Not being heard

Individuals described experiences when they had spoken, but had not been 'heard' by others. Participants often internalized this as to something they were doing wrong, 'erm, I had a bit of a dry throat I think' (DS).

When participants found it difficult to explain things, they reported that 'Sometimes I shout' (DS) to get themselves heard. Participants described an awareness of ways to get their voice heard, 'so I think I need to be more louder I'm quiet' (DS). This may demonstrate their belief that they need to raise their voice to be heard. However, it may also indicate a feeling of 'not being heard' that goes beyond simply raising their voice and appeared a common experience for these participants.

Communication partner

Difficulties experienced were described as due to difficulties with the 'communication partner', i.e. the other person in the communicative exchange, 'there is a correlation there's no doubt, between erm his ability to communicate, his ability of, his ability to communicate, the competence of the people understanding him' (NA). Dependence on others adapting their communication to include the individual with Down syndrome was described, 'Answer him appropriately or word their questions appropriately so he understands, um and that, you know, they'll understand him, but there are people who won't do that' (NA).

Mood

Participants expressed evidence of links between mood and communication, 'and being happy within himself, speech is relaxed, he's more relaxed about speaking openly and sharing a bit more' (NA). The opposite was also experienced whereby individuals' communication was negatively impacted on by their mood or feelings, 'because if he is relaxed, he will speak fluently, and he will think about what he's saying, but then, caught in a corner, the speech goes, and becomes quite dysfluent' (NA).

The experiences of participants portrayed times when difficulty in communication led individuals to become frustrated and angry, 'He couldn't communi . . . , you know frustration, he'd hit his head against the wall and things like that' (NA). This was expressed by the majority of participants to differing degrees, 'she does have, not so much a temper, but she does, she does get frustrated and get annoyed about if things aren't,a, and people don't respond' (NA). The opposite was experienced by others, 'the only time he really does get in a pickle is when he's angry, or anxious or things like that or upset' (NA). Some participants experienced difficulty in expressing their feelings, 'she doesn't always know how to tell you how she's upset, why she's upset' (NA).

Communication modifications

Withdrawal

When communication became difficult, individuals described withdrawing, 'he can understand to a point, but then it all runs away with him and you, he would withdraw' (NA). However, individuals also withdrew if they perceived themselves as unable to cope, 'that's his reaction to things he thinks he's not going to cope with, because of communication, his reaction is "I don't want to do it"' (NA) and, 'I think she'd sort of sidle off, she wouldn't be rude, but she would remove herself from the situation, she'd find a way to get out of it' (NA). Withdrawal was also linked with difficulties in understanding; when individuals felt out of their depth they would withdraw, 'think she felt, she was sort of out of her depth and not able to communicate the way that normal people can, so that's how it manifests itself by going off and well she went and watched a DVD' (NA).

Strategies to manage situations

Several participants spoke of relying on talking about a topic in which they were knowledgeable, 'I'd think she would try to turn the conversation back to something she was familiar with' (NA). When participants were engaged in difficult conversations, this may be a way in which they can remain engaged and in control of a communicative situation.

Participants described tools to increase their communicative ability, 'He, even if it's us, if there's something that he's trying to tell us that we can't understand what he's saying, he'll go and get something . . . to show you what he means' (NA). Participants described ways in which others communication could be modified to make it more accessible, 'ermmm I don't know actually, just want them to take it slowly, talk slowly to me' (DS). Several participants also spoke of repeating information which was helpful, 'I have to repeating it, that helps me and it does helps them' (DS).

Modes of communication

Multiple modes of communication were described by participants. The majority used technology to communicate, such as texting or using the telephone. This was described as something individuals were competent in, 'he's very good at it' (NA). Participants described using the computer to communicate, such as using e-mails or Facebook.² Whilst this facilitated communication, difficulties were also described, 'we found on Facebook, where it's very easy to misunder . . . , mis-interpret, what people are saying' (NA).

Sign language had been used by most participants when they were young but no one was currently using this as a mode of communication. Visual communication was commented on by some, 'So everything that he learns is very visual' (NA), and families described using visual images to aid communication at times, 'it's a new, something new we want to explain to her, or show her, or tell her about, then we might find pictures and things' (NA).

Strengths and resources

Positive descriptions

Many individuals reported positive aspects of themselves and their lives, 'I feel alright with everything' (DS) and, 'I'm really happy and pleased, I feel like that all the time' (DS). Many participants reported a positive sense of self-esteem, 'I like myself really' (DS). Nominated adults also described individuals' positivity, 'I think she feels quite happy within herself' (NA).

The majority of participants spoke about their family, and expressed an enjoyment in being with them and spending time with them. This theme also captures descriptions of participants' families, in particular their mothers. Many participants described their mothers positively within the interview, 'I love my Mum' (DS), 'my special Mum' (DS) and, 'she's a pretty lady' (DS). This was quite prevalent across the interviews. Individuals also spoke about other family members, but to a lesser extent.

Ambitions

Participants were able to explain future plans, and their ambitions, which included getting married and having children, buying a car and getting a job, 'yeah have job yeah' (DS). All participants described activities they enjoyed, and were able to explain hobbies.

In communication

Instances of positive communication were described, 'no she's always been very good at communicating' (NA). Many individuals spoke of having the confidence to communicate, 'she's quite confident, she rings up the Doctor's, she'll make an appointment' (NA). Many descriptions of the sociable nature of individuals were described, 'she really does love meeting people' (NA).

Discussion

Although this research is exploratory, links have been suggested between communication difficulties and self-esteem. It appears that having difficulties with communication may negatively affect an individual's self-esteem. In addition, low self-esteem may affect the communicative ability of an individual. Low self-esteem appears to be further exacerbated by comprehension levels exceeding communicative ability and also specific communication difficulties such as stuttering. Many other factors were also identified within the research which may complicate the relationship between communication and self-esteem.

Mood was found to link with communication; difficulties in communication led to frustration and anger, whilst frustration and low mood also impaired communication. The experience of identifying oneself as an individual with a disability was linked with low self-esteem. Individuals' identity was also affected by comparison with others. Improved self-esteem appeared to relate to incidents when individuals compared themselves with others with disabilities. Stigma was linked with low mood, and it appeared that low confidence due to difficulties in communication may heighten perception of stigma.

Difficulties with communication also led individuals to withdraw or avoid situations, resulting in loneliness for some. An additional factor which impacted on communication and self-esteem was independence. This increased self-esteem for many individuals, whilst also creating greater need for support. Increased independence inevitably exposed individuals to communicatively more difficult situations and experiences. This highlights the need to consider communication when promoting independence to prepare individuals for when they are exposed to potentially difficult situations.

Society's perceptions affected individuals' self-esteem. Individuals with learning disabilities may be perceived as less able based on their communicative ability. Alternatively, fluent speech may mask additional communicative difficulties. This highlights the importance of addressing both aspects of the communicative encounter. Communication requires both a sender and recipient and therefore in addition to supporting adults with Down syndrome with their communication, it is essential that changes are also made within society.

It is important to recognize however that not all participants reported low self-esteem, or reported consistent communication difficulties. Whilst this may be affected by the individual's awareness and their ability to

communicate this within the research, it would be interesting to explore whether there were any protective factors involved in the relationship between communication difficulties and self-esteem.

Methodological considerations

This study aimed to ensure that people who presented with difficulties in communicating were not excluded from the research, thus participants were provided the opportunity for the study to be conducted in their preferred mode of communication. However, a replication of this research could aim for greater levels of involvement of people with learning difficulties in the research process. Pretesting of the interview script could have increased the validity of the interview, however this was not possible within the remit of this research. Space does not permit a full critique of the interview script however there were questions which appeared less useful than others. The question ‘What do you like about yourself?’ generated greater discussion than ‘How would you describe yourself?’ Alongside this, ‘Is there anyone that finds it hard to understand what you are saying’ appeared more useful than ‘If someone doesn’t understand what you say, what do you do?’

The participants were all aged between 18 and 34 years, and represented a slightly higher proportion of females to males (seven versus five). Independence was a subject that arose in many of the interviews; with that in mind it should be acknowledged that the participants in the current study were all fairly young adults, which may contribute to the dominance of a narrative about independence. This research has been conducted in the UK and will be affected by this context. Cultural factors have not been considered and ethnicity was not directly recorded. Participants were also not required to provide information on the subtype of Down syndrome, however this diagnosis may impact on the results. Differences have been indicated between subtypes of Down syndrome, including psychiatric co-morbidity and level of learning disability (Prasher 1999).

The qualitative method chosen aimed to offer an opportunity for participants to be empowered to speak about their experiences. Participants were also encouraged to choose the person that they wanted to be interviewed, thus giving choice and power to the individual.

Implications of the study

The research has implications for clinical practice. There appears to be a need for increased intervention around social communication for adults with Down syndrome. This would serve to decrease loneliness and to help sustain friendships. In addition, many participants in the current study indicated a want to establish a relationship with a significant other. Interventions to increase social communication may help individuals to achieve their goals.

This research highlighted the support that participants sought from others such as family. This may be of interest clinically as it may impact on the way that services promote inclusion of additional family members. Indeed when individuals were more familiar and confident with a task, this improved their ability to communicate and their self-esteem. This should be held in mind as novel tasks or environments may make it more difficult for individuals to communicate, thus practice of tasks may be of benefit. This could be implemented, for example, by encouraging initial meetings between staff and patients with learning disabilities to help increase familiarity. This would however need to be managed in consideration with an individual’s right to privacy and independence.

There is evidence that adults with Down syndrome do experience low self-esteem. Mental health disorders are often not well understood in people with learning disabilities and therefore this highlights the need for support to increase awareness of self-esteem in individuals and in families and services. There is a need for greater availability of information and support for individuals, their families and services. Preventative work may go some way to avert the development of mental health problems

The findings suggest that low mood and self-esteem may impair communication. It is important to be aware of this as it may affect whether an individual feels able to request help if feeling low or to utilize their skills to get better.

This research has shown that there is a link between communication and self-esteem. Whilst the importance of speech and language intervention in children with Down syndrome is well known; there may be a need to continue supporting individuals with their communication into adulthood. This may be delivered through social and life skills interventions for adults.

Conclusions

This research has provided an exploration of the relationship between communication and self-esteem in adults with Down syndrome. The findings indicate that communication and self-esteem may well be linked for this population of adults. Difficulties in communication led to a decrease in self-esteem, and low self-esteem also exacerbated difficulties in communication. A number of factors appeared to be involved in the relationship between communication and self-esteem, including identity, social comparison and mood, thus highlighting the importance of research in this area to improve understanding. These findings are important clinically for adults with Down syndrome. Preventative work with individuals with Down syndrome may promote positive self-esteem and equip individuals with the necessary skills to maintain good psychological health. This would ensure individuals were able to reach their goals in life, but also to develop and sustain friendships and integrate in the community. However, it is important to consider that individuals reported happiness and positivity in their lives, in spite of perceived difficulties in communicating. This may suggest the presence of additional protective factors, other than levels of awareness or social comparison that have been explored in past research. This research aimed to involve and empower people with learning disabilities throughout the research process, and endeavoured to create an opportunity for sharing of their experiences.

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Notes

1. Stuttering is also commonly known as stammering.
2. Facebook is a social network website (<http://www.facebook.com>).

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