ARTICLE FOR INTERNATIONAL JOURNAL OF LANGUAGE & COMMUNICATION DISORDERS

Research Report

Adolescents' experiences of communication following acquired brain injury

Abstract

Background: Paediatric Acquired Brain Injury (ABI) is one of the leading causes of neuro-disability in childhood. The long-term effects of ABI on cognition, behaviour and emotions are well documented. Previous research has found that communication is difficult for adolescents with acquired brain injury (ABI) compared to typically developing peers. Quantitative studies have identified deficits in specific domains of speech and language but there are no research studies which have sought to capture adolescents' lived experiences of communication or explored the multidimensional nature of this.

Aims: To explore adolescents' everyday experiences of communication following ABI. This research also offered adolescents an opportunity to give their views on an issue which has not previously been explored in relation to paediatric ABI.

Method & Procedures: A qualitative study was undertaken using Interpretative Phenomenological Analysis (IPA) for in-depth exploration of the lived experiences of communication following ABI. Participants were recruited from an NHS Trust in England. Six adolescents (aged 11 to 18 years) participated in semi-structured interviews. Data analysis followed the guides for IPA.

Outcomes & Results: The data revealed three main themes: the social world; communication competence and life in the classroom. Adolescents experienced communication changes and challenges, which affected functioning and

participation. Difficulties with communication affected identity, learning, relationships and confidence.

Conclusions & Implications: These findings provide insight into how communication is experienced in everyday life from the perspectives of adolescents with ABI. The study revealed that adolescents' individual experiences of communication were dependent on contextual factors. Sensitivity to communication changes was associated with the age when the ABI occurred. Difficulties with communication impacted on identity. Negative communication experiences at school affected sense of belonging; peer group support helped some adolescents to cope with the communication challenges they faced. Further research is needed to explore how participation in communication is affected by paediatric ABI and what could be done to support this. It is recommended that increased attention should be paid by professionals to the psychological impact of communication changes and difficulties experienced by this population.

What is already known on this subject?

Previous research has identified that despite good recovery of physical skills the quality of life for children with ABI is reduced compared to typically developing peers. Speech, language and communication skills are reported as problematic in this population but the full impact of these difficulties may not become apparent until adolescence. Whilst experiences of communication have been explored in other groups, no previous research studies have focused specifically on how communication is experienced following paediatric ABI.

What this study adds?

This study provided an in-depth exploration of the lived experience of communication for adolescents with ABI through a qualitative methodology. It provides insight into the challenges adolescents with ABI face when communicating with others and how these have the potential to impact on their sense of identity.

Clinical Implications of this study

This study deepens our knowledge of the impact of paediatric ABI on communication in everyday life. The study has revealed that the communication challenges faced by these individuals are long term in nature and unresolved. Speech and language therapists working with individuals post ABI in rehabilitation and community settings need to be equipped to provide psychological support to adolescents who have experienced changes to their communication skills. Professionals in education need to consider carefully how best to support adolescents with long-term communication difficulties post ABI in order to reduce the risk of isolation, bullying and stigmatisation. This should involve discussions with the adolescent and their family.

Introduction

The United Kingdom Acquired Brain Injury Forum (2013) Manifesto for Children and Young People with Acquired Brain Injury highlights the need to understand the long-term effects of ABI. This study aimed to add to knowledge about the impact of paediatric ABI by exploring adolescents' everyday experiences of communication. ABI is one of the main causes of disability in the UK for which the overall incidence rate is approximately 40,000 children per annum (NHS England 2013). Paediatric

ABI describes damage to the brain occurring after birth following a period of normal development. The term ABI encompasses both traumatic and non-traumatic injury. Traumatic brain injury (TBI) is defined as sudden damage to the brain from an incident such as a car accident or fall, whereas non-traumatic brain injuries occur due to illness, stroke or brain tumour (NHS England 2013). Recovery from paediatric ABI varies according to age, pre-injury abilities, level of unconsciousness and neurological damage. Although children may have good recovery of their physical skills, many experience problems with cognition, communication, behaviour and emotions 1 to 5 years after a brain injury (Anderson *et al.* 2012, Forsyth and Kirkham 2012).

ABI and adolescence

A brain injury in childhood is thought to have long term and cumulative effects on development and some deficits may not become evident until adolescence, when individuals face additional cognitive and social demands (Blosser and DePompei 2003). Adolescence is a period of rapid development after childhood and before adulthood between the ages of 10 to 19 years (World Health Organisation 2014). It can be a time of vulnerability, when the transition to adulthood is characterised by physical and emotional changes (Steinberg 2005). It had been assumed that children would make a better recovery if the brain injury occurred when they were young (Bennet *et al.* 2013). However, recent literature has introduced the concept of a "neurocognitive stall" which is defined by Chapman as "halting or slowing in later stages of cognitive, social and motor development beyond a year after brain injury" (2006: 11). This means that some children, in failing to meet development

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milestones, fall behind their typically developing peers (Savage 2012).

Speech and language skills following paediatric ABI

Communication function following paediatric ABI has largely focused on the use of quantitative measures in research studies to determine deficits in specific domains of language abilities, for example; naming, sentence repetition, sentence construction and word knowledge (Catroppa and Anderson 2004, Nippold *et al.* 2007). However most language assessments used in such studies were not designed or standardised for adolescents with ABI. For instance the Clinical Evaluation of Language Fundamentals – 3rd edition (Semel *et al.* 1995) was used as a measure of language functions in research studies (Hanten *et al.* 2009) without published data on its validity for this population. A standardised test; The Pediatric Test of Brain Injury (Hotz *et al.* 2010) has since been developed to assess neurocognitive and language functioning. The test is criterion-referenced rather than norm-referenced and could be considered for research studies proposing to measure change over time. As it can be difficult to gain a clear picture of the language deficits encountered by adolescents with ABI and how subtle impairments can affect everyday communication, studies of pragmatics which consider the use of language can add to our understanding. (Togher *et al.* 2014). However, these studies usually focus on specific dimensions of pragmatic ability. For example, Dennis *et al.* (2001) measured understanding of literal truth, ironic criticism and deceptive praise using pictured situations and found that children with TBI performed poorer than age match controls particularly with regard to deceptive praise. Due to the difficulty in replicating the pressures and dynamics of real life conversations in quantitative

research studies, Joffe and Nippold (2012) suggest the use of qualitative research to gain a better understanding of how this is experienced.

Childhood experiences of communication

Researchers have recently started to interview young people in order to explore how they have coped with adjustment after brain injury but only one study has published a small amount of data on communication. Di Battista *et al.* (2014) used a semi structured interview plus a Likert-type scale with adolescents who had experienced TBI. However, the four questions given as examples for the interview under the heading of 'Understanding and Communication' focused on concentration rather than communication. The emergent themes included fatigue, emotional distress, memory, social isolation and low mood but the authors did not present the qualitative data in relation to these. Researchers who have carried out in-depth studies on the lived experiences of communication in other groups include McCormack *et al. (*2012) who explored the childhood experiences of speech impairment with two young men and their mothers, using semi structured interviews. The data revealed that as the children grew older they became more aware of their communication difficulties. This was linked to the development of self-concept; as children age they become more aware of the differences between the skills of themselves and others and thus can identify the reason for communication breakdowns. Research by Markham *et al.* (2009) considered the quality of life experiences reported by children and young people with speech, language and communication needs using a qualitative methodology. Their thematic analysis found that school featured in most themes within the framework. Participants in focus group interviews spoke about the desire

to be as independent as possible but to receive the support they needed to help them understand instructions. Friendships were reported for some to be challenging and individuals cited experiences of bullying.

Rationale for current research

The main researcher developed an interest in this area as a result of her role as a Speech and Language Therapist in a paediatric ABI assessment service.   Many of the adolescents, referred by their General Practitioner or Child and Adolescent Mental Health Services (CAMHS), were several years post ABI and were stated to have difficulties at school and with peer group interaction. Some of the adolescents performed within the average range when formal speech and language therapy assessments were administered. However, these did not capture the often significant problems individuals reported with their everyday communication, affecting their participation in interactions with others.

The need to look beyond speech and language impairment was highlighted in a study by Yorkston et al. (2001), who explored the communication experiences of adults with multiple sclerosis. They found that even those who had been diagnosed with mild cognitive communication deficits encountered significant limitations to communicative participation. Similarly, adolescents with ABI may experience subtle impairments affecting their communication in everyday life (Blosser & DePompei 2003). Whilst quantitative research studies are valuable in providing a snapshot of a speech or language skill at a particular point in time, it is only through a qualitative methodology that an in-depth exploration of an individual's account can be made. No

previous research studies have specifically sought adolescent's views on how their communication has been affected following ABI, indicating a gap in the literature regarding this phenomenon.

Aims

This research study aimed to provide a small number of adolescents with the opportunity to discuss how communication is experienced for them in the context of ABI. This study aimed to provide insight into communication from the perspective of adolescents themselves rather than their parents, carers or educators. It sought to obtain an in-depth understanding of adolescents' everyday experiences of communication and by doing so contribute to knowledge about this. Additionally dissemination of the study results plans to increase awareness amongst health and education professionals of how adolescents' report their communication skills to be affected by ABI and raise discussion on how they could be supported in their day to day lives.

Ethics

The researcher undertook the study as part of a clinical research degree, funded by the National Institute of Health Research (NIHR). The study obtained ethical approval from the University of Brighton, Faculty Research Ethics and Governance Committee (FREGC) who acted as sponsors of the study. Full NHS Research Ethics Committee (REC) approval was obtained (REC Ref: 14/LO/1748) as well as Research & Developmental approval from the NHS Trust in which the research took place. The Data Protection Act (1988) was adhered to for data collection, handling and storage and all participant data anonymised

Methods

For this study, a methodology was selected that would provide the opportunity for adolescents to give voice to their experiences of communication thus allowing new insights. Since 1996, Interpretative Phenomenological Analysis (IPA) has been used to explore illness experience and neurological conditions (Smith 2011) and increasingly in studies with adolescents, for example Hilton *et al. (*2013). IPA is influenced by the work of a range of phenomenologists but particularly those such as Heidegger who were interested in the experience of what it is to be in the world; the lived experience (Smith *et al.* 2009). IPA is a person-centred and inductive approach influenced by three main areas of philosophy: phenomenology; which is the study of experience, hermeneutics; which is the theory of interpretation, and ideography; which relates to seeking in-depth understanding of the meaning of something for an individual (Smith *et al.* 2009). One of the key features of IPA is the role of the researcher who seeks to make sense of the participant who is making sense of the experience.

Use of this qualitative methodology enabled meaningful and in-depth exploration of the phenomenon of communication. It was considered an appropriate approach for adolescents whose sense of identity may have been shaped by ABI. It is acknowledged that the researcher's own experiences and previous understandings of the phenonomen will have influenced her interpretation of the participants' experiences. As recommended by Finlay (2011), the researcher kept a reflexive journal throughout the duration of the study. The journal provided a means to reflect upon how previous experiences, professional background, values and interests shaped the research design and findings. The principles outlined by Yardley (2000)

for ensuring rigour in qualitative research were adhered to; for example, the raw data from each interview was analysed on a case by case basis and there was a detailed and clear outline of each stage of the research process.

Patient Participant Involvement (PPI)

The Public Health, Awareness, Research (PEAR) project (NCB Research Centre 2010), which was set up to support young people's involvement in public health research, emphasised how important it was for them to be involved in the process of planning research. For this study, two adolescents with ABI were consulted about the design and their feedback used to develop the participant information sheets and question guide for the interview. They also commented on the invitation letter and practicalities of the interview, such as seating and refreshments. Another adolescent with ABI supported the development of an adolescent friendly version of the research findings. Each young person involved in PPI received a letter of thanks and gift voucher. These adolescents were not participants in the study.

Sampling and recruitment

Participants were recruited through an NHS organisation providing specialist services to young people with neuro-disability. Purposive sampling enabled the recruitment of six verbal adolescents between the ages of 11 and 18 years who were at least one year post a diagnosed ABI. Three of the participants were known previously to the main researcher in her role as a clinician undertaking speech and language therapy sessions on a paediatric rehabilitation unit. She had not worked directly with them for at least a year. The study excluded adolescents who had permanent bilateral hearing loss, pre-existing learning disability or speech and

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language diagnosis prior to ABI. Individuals receiving intervention from the researcher at the time of the study were excluded. Clinic leads sent out invitation letters and participant information sheets to parents of service users meeting the study criteria. Once an opt-in reply slip was received, the researcher made contact to discuss the study. In addition to written parental consent for those under 18 years, informed consent was sought from each participant on the day of the interview. As part of the consent process, each participant was given two cards and the use of these explained: a red card to use if they wanted to stop the interview for any reason and a yellow card if they wanted to take a break. Participants could request the presence of a parent during interviews but none chose to do so. A distress protocol outlined how this would have been recognised in participants and addressed if needed. The protocol detailed the steps which would be taken if a participant indicated they were experiencing a high level of stress or emotional distress or exhibited behaviours suggesting they could not cope with the interview. The steps outlined in the protocol included stopping the interview and audio recording, offering immediate support and discontinuing the interview if the participant was unable to resume. All participants were given the opportunity for debrief time following the interview.

Data collection

Participants were interviewed on the premises of an NHS Trust so that psychological support was available to them immediately following the interview should it have been needed.. A letter given to participants on completion of the interview provided details of a Psychological Therapist in case taking part in the study raised issues later for them. Semi structured interviews were conducted with the aim of obtaining

rich and detailed data from each participant. Questions were prepared to help guide

the interview. The questions explored what it was like for participants to

communicate with family, friends and at school. Participants were asked to give

examples of situations when they found communication difficult and what helped to

make communication easier. They were also asked whether the ABI had changed

their communication with other people. The use of semi structured interviews

provided the opportunity for issues important to each young person to be revealed,

as although there were some questions, the interview was primarily led by their

responses. Two of the youngest participants took short breaks, one using the yellow

card, the other making a verbal request but both returned voluntarily to complete the

interview.   None of the participants made use of the red 'stop' card. Demographic

information was collected at the start of the interview (Table 1). Interviews were

digitally audio recorded then immediately transferred to a password protected

computer at the NHS Trust and deleted from the recorder.

Table 1: Sample characteristics (n=6).

Name	Sex	Age	Age at ABI	Years since ABI	Cause of ABI	Type of School at time of interview
Aidan	M	13	2/4	11	Fall/Impact	Mainstream
Sabrine	F	14	4	10	Seizure	Home Education
Will	M	13	3	10	Brain tumour	Special school
Tom	M	18	13	5	Brain tumour	Mainstream
Alex	M	11	8	3	Gross hydrocephalus Brain haemorrhage	Mainstream
Maria	F	18	15	3	Fall	Mainstream

Data analysis

Transcriptions of the interviews were made directly by the researcher from the audio recording following each interview and this supported initial familiarisation with the data. Pseudonyms were given to the participants rather than chosen by them as this was a requirement specified by the local research consortium. Data analysis followed the guidelines offered by Smith et al. (2009). This was undertaken by the main researcher who met regularly with a study supervisor who had extensive experience of using IPA but who was not a speech and language therapist so could check for potential bias. Each transcript was read by the main researcher, with the first reading accompanied by the audio recording and the transcript reread. Initial exploratory noting related to descriptive, linguistic and conceptual comments for each transcript. Emergent concepts were then developed through exploring connections between the exploratory notes for each individual transcript. The concepts reflected the participant's original words yet involved interpretation by the main researcher with guidance provided by the supervisor particularly in the initial stages of this part of the data analysis. The main researcher had recorded her initial thoughts immediately after each interview in the reflexive journal and referred to this to support development of the concepts. For each interview a table was produced showing the original transcript, exploratory noting and concepts. Emergent themes were then developed through exploring connections between the exploratory notes for each individual transcript. These emergent themes were explored and mapped across the transcript to form clusters of related themes, which then led to the development of higher order themes and sub-themes for each participant. The

supervisor regularly reviewed the sub-themes emerging and provided feedback for the main researcher. A similar process then took place across all the transcripts, leading to a master table of over-arching super-ordinate themes and sub-themes that reflected the similarities and divergences in the adolescents' experiences. Both the main researcher and supervisor were involved in the finalisation of the master table and agreeing the super-ordinate themes for the group.

Results

This section presents the findings of the semi-structured interviews with the adolescents. Data analysis revealed three super-ordinate themes and seven sub-themes (Table 2). Whilst each individual had their own unique experience of communication, commonalities emerged to suggest shared experiences. Direct quotations have been used from the interviews to support the researcher's interpretation of the data.

Table 2: Super-ordinate themes, sub-themes and concepts generated from analysis of interview transcripts

Super-ordinate theme	Sub-theme	Concepts included
1. The social world	1.1 Facing disability	Before and after the ABI A hidden injury Permanency of changes Living with ABI since early childhood
	1.2 Outside of the group	Bullies Not being one of them Feeling inferior

2. Communication Competence	2.1 Stumbling over words	Explaining what is in my head The impact of fatigue Perceptions of others
	2.2 Recovery	Regaining control Speech and language therapy
3. Life in the classroom	3.1 Understanding our needs	Teachers knowledge of the ABI Changing the school environment Feeling abandoned Defining our problems
	3.2 Finding solutions	Teaching approach Taking responsibility Technology Being singled out

Super-ordinate Theme 1: The social world

In this theme, five of the participants described their reactions to ABI and how communication difficulties affected their identity and social interactions with others. The theme explores the concept of sudden communication changes in adolescence contrasted with the experiences of communication difficulties since ABI in early childhood.

1.1: Facing disability

This sub-theme revealed how participants' sense of identity was affected by ABI. It also explored the hidden nature of ABI. It highlighted how sensitivity to communication changes was linked to the age when the ABI occurred. Both Maria and Tom had aspirations for their future when they were faced with a sudden

deviation from their developmental path. They saw themselves as different individuals post ABI.

"Having the brain tumour it was a big sort of part of my life, like there was my life prior to the tumour and then my life now after the tumour which is I dunno it just seems worlds apart and it's really weird".

Maria had to cope with a different way of 'being' following a fall when she was 15 years old. As there was no visible physical damage, Maria struggled to convince others why this version of herself was different to the one that had gone before. She used the analogy of a broken arm to highlight how damage to a brain was hidden from view and so the effects were often misunderstood:

"It's more than having like a hurting head you know it's different to a broken arm, yes a broken arm it doesn't work as a broken arm but a brain does so much. I didn't realise before my head injury the impact of a head injury".

Facing the prospect of permanent disability filled Maria with dread. She worried that the problems she experienced with communication would be with her for ever:

"It was frightening as well the sort of not knowing whether this is going to get better, is this permanent, is this kind of normal."

As a result she spent about a year at home hiding away from others not wanting to do anything. It seemed that without the fluency of expression she once had, she

viewed herself as inferior and so removed her imperfect self from society. She explained how lack of confidence in her verbal competence affected her desire to interact with others:

"I don't know why I pushed people away but …you kind of think …oh not good enough I don't function as like as you know a talking person so I don't know like whether you're ashamed of that or something but yeah there was a time when I kind of didn't want people to see me in that state I wanted to be better for them".

Alex portrayed a pessimistic and gloomy picture of his experience of the world. He felt that very few people understood how effortful life had become since his ABI. He was left with a new normality in which everything he attempted to do was more difficult:

'*I still need help with stuff…they (people) just need to know how hard it is...all of this stuff".*

Aidan and Will had their brain injuries in early childhood and as a result their identity had not altered in the way other adolescents described. They spoke about "*my needs" or "my difficulties"* as though these had always been part of their being, rather than communication changes. Sabrine had an ABI in early childhood and rejected the notion that all her difficulties were attributable to ABI:

"It felt like too much sometimes, like there were excuses to why I did certain things or said certain things was to do with the brain and it's cause I understand I have these problems or I have certain things in my life that might be affected by it…but it doesn't

mean everything is to do with it"

1.2: Outside of the group

This sub-theme revealed experiences of bullying and difficulties in peer group relationships affecting five of the participants. Some participants sensed they were outside of a social group and this led to feelings of rejection. Three of the participants alluded to experiences of being bullied or picked on by people in their peer group at school. Alex was one of the participants who spoke about 'the bullies' and said how pleased he was when one of them left his school.

"Since my accident it's changed a bit… I've known some really mean people"
Alex had few friends and the one friendship he valued had broken down. Alex felt like an outsider, he sensed he was not one of *'them",* a term which he used in reference to the other children around him. The issue of being different was also raised by Aidan who made it clear that he did not want to be associated with other people who have brain injuries or disabilities. He felt this would stigmatise him and expressed the fear that a label would affect how he was perceived by others:

"I think people will think people with brain injuries are just a bit stupid. Most of the time they're not that smart….quite a lot of the people in our school with brain injuries have some sort of disability … no one wants to be friends with them...I don't want to be one of them".

Sabrine had spent a lot of her life trying to make sense of why she had never felt at

ease communicating with children of her own age. During the course of her interview it became apparent that she struggled to find a way of conversing with them which she reflected on:

"I mean I do like to talk...I have conversations with my friends about really funny things and stuff like that but I think it was too much at that stage I was just why can't we talk about how we're doing you know not just all this really silly girly talk"

The examples from these adolescents suggested that they felt rejected by their peers. In contrast, Tom had maintained the same close group of friends for over ten years and had a firm sense of belonging which helped him to cope with life post ABI some of his difficulties:

"They know I had a brain tumour and that so they're obviously a bit more caring sort of people that's obvious but I mean I don't see a major difference they're still my friends at the end of the day"

Super-ordinate Theme 2: Communication competence

The second theme highlights how word finding difficulties affected the communication of four participants and impacted on how they were able to portray themselves to others. They then discussed what helped in their recovery.

2.1: Stumbling over words

Four of the six participants experienced word finding difficulties which affected their expressive language skills. After recovering from a complete lack of speech following his brain tumour operation, Tom highlighted areas where difficulties remained:

"I stumble upon my words and mm erm like mm (long pause) like I sometimes get lost in what I'm saying and lose track yeah like (laughs) I go off on tangents a lot as well".

Tom's voice filled with emotion when reflecting on this and he appeared overwhelmed by the effort it took to express himself. He felt frustrated that his brain had let him down from proving his knowledge at school:

"Like in science especially to explain stuff a lot so try and find the right word...I would try and think of an alternative... but yeah it was hard.'

Similarly, Maria felt her word finding difficulty affected how she was perceived by others. When she was with familiar people Maria found it easier to talk because she had '*an established vocabulary in mind',* whereas with new people, who she wanted to impress, she felt her inability to manipulate language made her look foolish. Maria suspected that her word finding skills were affected by fatigue:

"I remember just kind of being like so tired that I couldn't respond in the way I wanted to if at all and thinking oh no I've kind of ruined it with that person or this teacher doesn't think that I'm kind of bright enough or something".

Alex also had difficulty with word finding; often during the interview he used short or incomplete sentences when responding to a question and speech seemed effortful for him. The interviewer reflected aloud that it appeared 'tricky for Alex to think of the words he wanted'. Alex then portrayed the anguish he felt in being unable to express himself:

"*If I could actually roll my eyes back into my brain I'd be able to show you I'd be actually able to tell you… if I could read you the stuff it was saying… yeah I really wish I could*".

It seemed that if others could read his mind, they would be able to see what he was thinking. His word finding difficulties meant his thoughts were locked inside his head and he had no way of releasing them.

2.2: Recovery

This sub-theme explored how the participants affected developed strategies to regain control of their word finding difficulties Maria and Tom who had an ABI in adolescence suggested that improvements with their skills happened over years rather than months:

"*I would say like over the past five years I've tackled that and feel like it's not much of a problem anymore I suppose*" (Tom).

Maria lost her feeling of inferiority when she noticed that most people have word finding problems, rather than viewing it as unique to her:

"What I didn't realise at the time is everybody sort of has I suppose word finding difficulties, everybody will forget a word".

Over time, both participants accepted they could use alternative words to the one they originally had in mind. This signified that they were adapting to a different way of expressing themselves and adapting to a new way of being after their ABI. Maria explained:

"I'm so lucky that I'm almost a normal person again now but it was really a case of time things slowly just starting falling back in place. I don't think there was anything that kind of suddenly fixed it".

Super-ordinate Theme 3: Life in the classroom

In this theme, all of the participants described what life was like for them in the classroom. The theme explores their views on teachers' understanding of their communication needs and what participants felt supported them or was less beneficial. The participants also spoke about their experiences in different types of educational settings.

3.1: Understanding our needs

This sub-theme reflects participants' views on how well they felt their communication

needs were understood and met by their teachers. All of the participants were included in this sub-theme.

When Tom returned to his school, most teachers knew what had happened to him and accommodated his new found difficulties well:

"Most of them knew I had a brain tumour so they were considerate about me and like I may need to ask again about something or whatever".

This was in direct contrast to the experiences of other participants who felt their teachers did not understand their communication difficulties. Aidan had two TBIs during early childhood and at the time of the interview was attending a mainstream secondary school. He believed that communication might be easier if all the teaching staff were aware of his brain injury:

"With some teachers not really know about it (the brain injury) but with the ones who do I find it easier to talk to".

Alex felt school had got worse for him since his ABI. His impression that his teachers did not listen to him led to feelings of anger which appeared to engulf his whole being:

"They're rubbish they just don't understand me like I said….yeah, no teachers understand me properly they're just rubbish just plain rubbish I dunno how I can explain rubbish any more they're just rubbish".

Alex expressed his desire to go to the type of secondary school where he felt teachers would be able to connect with him and truly understand his individual needs:

"I'd like to go to a school where they understand me and stuff…..just that really where they actually understand how hard things are for me".

Aidan also appeared to be floundering in a mainstream classroom. He talked about his teachers getting annoyed with him when he did not do his work or telling him off for doing it incorrectly. His resulting behaviour appeared to be a way of drawing attention to himself when he was ignored by the teacher:

"When I don't understand the work I sometimes ask the teacher but if the teacher doesn't like come over and help I just muck around".

He then explained how sometimes his friends might laugh at him or join in but largely they got on with their work and this left him with a feeling of detachment. Will's experience in mainstream primary school had been similar but when he moved to a secondary school for pupils with special educational needs he felt all the teachers understood his receptive language difficulties. There, he was one of a number of pupils with similar needs rather than an isolated individual. The way he spoke about school and the skills of the teaching staff was much more positive.

"I just put my hand up and wait for a teacher to come (they) say yes Will and I tell

what I don't understand…I just know that it's a lot easier in my school that I'm in

now… just the way the teachers do stuff I suppose".

Likewise, Sabrine found that in mainstream school the teachers did not have time to answer her individual questions in lessons. She felt that her chances of academic success had improved as a result of becoming home educated:

"*My teacher yesterday was saying it was so good that I asked these questions because then she knows if I understand it or not".*

3.2: Finding solutions

This sub-theme explores what participants felt about the strategies teaching staff used with them to support their communication. The data revealed what participants felt about being treated differently from their peers. All participants spoke about what they found helpful to support them in the classroom.   For example, Sabrine explained that if teachers used illustrations or put information into bullet points, this helped, whereas if she was asked to copy large amounts of text or read information she found that "*nothing went in*". Some participants appeared to resent being singled out from the rest of the class when they were given permission to use laptops. Whilst they recognised that laptops helped them to get information down, it marked them out as different from the rest of the class. For instance, Alex stated that it was usually just him and the *"dyslexic people"* who were allowed to use them. Will said he was regularly taken out of the classroom and whilst this may have been

done with the intention to provide him with individual support, he appeared to resent being separated from the rest of his class:

"They didn't understand what ….would help me so they just took me out of some lessons and well when I mean took me out I mean like took me out to do something else".

Tom recounted how he wanted to take control for his problems rather than rely on a helper in the classroom.

"I mean I feel like it's my processing or note taking problems… and obviously one I have to tackle by myself".

He explained why he was relieved not to have been treated differently from his peers on his return to school:

"No I mean I wasn't singled out 'cause I think they would probably think that was a negative if I was singled out. Like it would make me feel that I was sort of lesser of a person".

Discussion

This study aimed to seek a deeper understanding of adolescents' everyday experiences of communication following ABI and the use of semi-structured

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interviews gave them an opportunity to have their voices heard and valued. Throughout their interviews, participants reflected on their past, talked about their present and anticipated future events. Detailed examination of each participant's dialogue helped gain insight into how the world is experienced for them individually before common themes were identified.

Although this study did not specifically set out to explore changes in identity, the findings provided insight into participants' perceptions of themselves at different periods in their lives, both prior to and after ABI. Identity is a term used to describe how a person defines themselves and distinguishes themselves from others. Yet, despite a range of literature in relation to adults following stroke (Clarke 2005, Corsten *et al.* 2015), there is little published research about how paediatric ABI shapes adolescents' identity. This study revealed differences between individual participants in whether they experienced a sense of loss for who they were previously. This could be explained by the notion of "biographical disruption". It is a concept originally used by Bury (1982) in the study of chronic illness, to describe how an unexpected event or illness affecting the expected life course and aspirations of a person can lead to an altered sense of self. Those participants who had a brain injury when young did not see themselves as a changed person as they had fewer memories of their life prior to ABI. Their communication difficulties were already embedded within their identity and so were part of their biography. In contrast, participants who had a brain injury during adolescence had a clear sense of two different periods in their lives. They experienced a catastrophic loss of their communication skills and their comments reflected how the unexpected event of a brain injury had disturbed their 'taken for granted' world.

Participants' portrayal of themselves to the world was influenced by how they anticipated they would be treated by others. Some had concerns that they would be stigmatised and so rejected the use of the term "*brain injury*" when describing themselves. This concurs with a study by Connors & Stalker (2007) who found that children and young people avoid mentioning their disability or impairment in an attempt to pass themselves off as being no different from their peers. In the current study "normalisation" by rejection of the term brain injury did not ease the challenges encountered by participants. They revealed that at times they felt like outsiders, which affected their sense of belonging. This resembled the feelings of two young adult survivors of TBI featured in a study by Cahill *et al.* (2014: 98) who described themselves as a 'square peg trying to fit into a round hole'. Conversely, two participants in the current study told positive stories of supportive friendships with peers who accepted them for who they were. This bears similarities with the findings of previous literature which highlights that good peer relationships can help alleviate children's difficulties with speech, language and communication (Merrick & Roulstone 2011).

Lack of confidence in their expressive language skills left some participants feeling embarrassed or unworthy of attention. Akin to adults interviewed by Yorkston et al. (2001), some participants were aware that word finding difficulties hindered their contribution to conversations. They could not say the words that they had in their heads out loud and this affected how they saw themselves in relation to others and portrayed themselves to the world. As participants revealed how they felt about not being able to tell other people what they were thinking, their emotions became

evident in the way they described their word finding problems. The pressure encountered when they had a word finding difficulty was present throughout their whole body; they described panicking, stumbling and getting flustered. This was about more than the words that came out of their mouths; it exposed a disturbance in the relationship adolescents had with the world through their spoken language. This meant they were not able to express themselves as easily as they had been used to; speaking required effort and adaptation. The participants could not have the dialogue they wanted because their word finding difficulties "*got in the way"* of being able to tell others what they were thinking.

Some participants took responsibility for the difficulties they experienced with communication. For example, one participant decided to take his own notes in the classroom rather than rely on an adult helper. This feeling of the need to be in control has implications for identity as revealed in a study of adults with aphasia; it reflects individuals' ability to adapt to and compensate for deficits enabling them to cope in the future (Corsten *et al. 2*015). However, other participants experienced an ongoing struggle with communication preventing them from achieving a sense of belonging and well-being. Those who experienced ABI in early childhood were more likely to look to others to make adaptations for them. This is concurrent with literature suggesting that children who experience a brain injury when young do not have the previous life experiences or knowledge to develop compensatory strategies to support their functioning (The United Kingdom Acquired Brain Injury Forum 2013).

An insight into how children and young people with speech, language and communication needs cope at school was provided by Markham et al (2009). Their study highlighted the beneficial role of teaching assistants in specialist settings who

helped to explain instructions given by teachers.   In the current study, teaching assistants were mentioned in the data but their attention was often divided between different students. The participants who had experienced mainstream school settings tended to speak negatively about their experiences of communication with teachers at school; the findings revealing that they felt abandoned and misunderstood this appeared linked to being in a large class where participants did not receive individual support from a teaching assistant. The implications of participants not understanding what was asked of them in the classroom, ranged from getting angry, misbehaving or being left in a state of confusion. Participants felt that teachers who were aware of the ABI understood their communication needs better than those who did not have this knowledge. This problem was highlighted in a study by Hawley (2004), who found that of a group of 67 children who had returned to school following TBI, one third of the children's key teachers were unaware that they had suffered a TBI. In the current study, participants' feelings about teachers' behaviour toward them contributed to whether school provided positive or negative learning experiences. For one participant a move to a specialist setting with a class size of six, meant he received considerably more support than previously and the beneficial change this had on his view of school was mirrored in his comments. Participants gave examples of specific strategies used by teachers in the classroom, some of which were comparable to the recommendations made by Arroyos-Jurado & Savage (2008). These were breaking tasks down, individual teaching, use of assistive technology and provision of support for notetaking. However these strategies were not always welcomed by participants as it meant they were singled out from the rest of the class. This corroborates the findings of a study by Cahill et

al. (2014) that students who are offered extra academic support, may refuse it due to the perceived risk of stigmatisation.

Strengths and Limitations

The age of the participants, meant that ethical processes required the researcher to involve adult gatekeepers when sending information out by post. It is not possible to know whether there were adolescents who wanted to take part but lacked the support of their parents to do so. It is acknowledged that the requirement to be able to participate in an interview excluded those with significant expressive language difficulties. Older adolescents tended to speak in more depth about their experiences than younger participants and provided the rich data needed for analysis using IPA. It would have been valuable to trial different techniques alongside the interview schedule, such as use of Talking Mats (Murphy and Cameron 2008), which might have prompted richer data from younger participants.

The concept of data saturation is not always applied or thought to be necessary in the context of IPA (Saunders *et al.* 2018) IPA does not seek to generalise but aims to gather data that provides a rich insight into individual experiences. For this reason IPA studies use a small and purposively selected relatively homogeneous sample so that a detailed case by case examination can be undertaken.   The recommended sample size is between three to ten participants (Smith *et al.* 2009) to generate sufficient data from in-depth interviews to allow for exploration of the similarities and differences between participants. Whilst the experiences reported by this study are particular to each of these adolescents, the findings may resonate with others who have experienced ABI. There were differences in the age, background and, onset

and type of ABI of each participant but complete homogeneity is difficult to achieve from one NHS Trust. Future qualitative research studies should consider recruiting from a larger population to aim for closer homogeneity. This study demonstrates that it is possible to undertake research with children with ABI requesting them to reflect upon their communication experiences if handled sensitively. One participant commented after the interview that she felt if had been a positive experience to have her views listened to and that this was a refreshing change from having her speech and language skills assessed.

Implications of the Study

This study provided a unique insight into the communication experiences of adolescents following ABI and highlights how effortful life is for them. As previous research has highlighted (Ciccia and Threats 2015), when a brain injury occurs during a critical period of development we need to consider all of the personal and environmental factors which have the potential to influence long term outcomes for communication. By exploring how an individual functions in their changed world, professionals can gain a greater understanding of what issues are important to them in terms of communication. A relationship has been identified between mental health and communicative competence (Dockrell *et al.* 2014) and the current study identified a connection between the deficits adolescents felt they had compared to peers and self-worth. Mental health is of particular significance to this population as adolescents who experience ABI in late childhood may mourn for their lost communication skills resulting in the need for psychological support. They are likely to benefit from help in adapting to their new way of being and coping with the long

term consequences of a disturbance to their development. Changes experienced to speech and language skills need to be considered in the context of the whole person. In line with other studies such as Di Battista et al., (2014) the current study has shown that experiencing a paediatric ABI is likely to affect identity. Curriculum guidance for the for the pre-registration education of speech and language therapists in the UK (Royal College of Speech and Language Therapists, 2018) does not mention paediatric ABI and inclusion of this as a specific clinical area would raise awareness of the potential for acquired communication disorders to affect children as well as adults. Although there is content outlined in the psychological and social sciences discipline relating to impairment, disability and behaviour change, therapists who later specialise in working with adolescents post ABI would be advised to attend post graduate courses to develop their skills in counselling and use of personal narratives to help manage identity issues. Speech and language therapists should also seek the support of other practitioners skilled in this regard such as clinical psychologists working in adolescent mental health teams.

This study corroborated the narrative review of Ciccia and Threats (2015) that school is a significant factor affecting long-term outcomes many years after the brain injury occurred. Speech and language therapists who are involved in school transitions need to highlight to education professionals the risk of individuals with ABI becoming isolated from or even bullied by their peer group due to difficulties with communication skills. The findings of the current study suggest that poor confidence in expressive language abilities may contribute to an individual's feelings of loneliness and lack of belonging. For this reason, it is important for therapists alongside the family and school staff, to examine the circle of social support

available to that child and consider how their peers are likely to cope with the changed communication skills of their friend. The Communication Trust (2015) has published guidance on how children, young people and their parents can be involved in decision making to ensure the child's views are at the centre of this. One of the key themes arising from their research was that individuals with Speech, Language and Communication Needs (SLCN) do not want their peers to tease them and therefore it is important to address the attitudes and knowledge of those around the child or young person with ABI. However, the current study has shown that it needs to be balanced with the risk of stigmatisation. Any special measures which are suggested by a speech and language therapist need to be discussed with the individual first to see if they feel comfortable with them, in order to negate the possibility of lowered self-esteem.

Further research

Further studies are needed to deepen our understanding of how communication is experienced for children and young people following ABI. Some studies have considered changes in participation rates following ABI in out-of-school activities for instance (Anaby *et al.* 2012). However research is needed to explore more specific questions such as how communication experiences affect participation, and what environmental factors influence communication activity. The current study raised important findings about identity following paediatric ABI. This is an area which warrants exploration in its own right and examination of the support structures which are available to help adolescents adapt to their new identity. The results show that there were many more negative than positive points arising from participants'

experiences of communication at school. For some participants in this study a change in the educational setting to one which could meet their individual needs made a significant difference to their lives. Consideration therefore needs to be given on how barriers to education can be removed for children post ABI and communication experiences improved with both teachers and peers. Such research studies should involve the teaching profession to ensure their views on educating children with ABI are incorporated

Conclusion

Previous studies on paediatric ABI have focused on measuring speech and language skills but this study considered the multidimensional nature of communication and how it is experienced by an individual in their everyday life. The study found that individuals' coping mechanisms for their communication deficits coupled with the success of strategies used by other people around them affected adjustment to life with a brain injury. Although some of the adolescents in this study were several years post ABI, they continued to experience communication challenges on a daily basis, adding to previous literature supporting the call for paediatric ABI to be recognised as a long term condition (Savage 2012). The speech and language therapy profession needs to highlight how the sequelae of paediatric brain injury extend beyond the speech and language impairments themselves to affect an individual's identity. This is particularly important when working with our colleagues in education as they are the people who see these children on a day to day basis and so have considerable opportunities to influence communication experiences. They will however need guidance with this and it is

important that as a profession we do not neglect the possible long term speech, language and communication needs of children with ABI when commissioning services.

Acknowledgments

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Appendix: Question guide for the semi-structured interview

1. **Demographic information collection and opening discussion:**

   - **Age**
   - **Gender**
   - **Type of ABI**
   - **Age when ABI occurred**
   - **Type of school attended**
   - **Hobbies/interests**

2. **Can you tell me what's it like talking with your family?**

3. **How do you get on chatting with your friends?**

4. **What's your experience of school, how do you find talking and listening there?**

5. **Can you tell me about a situation when you found it difficult to talk with someone?**

6. **Can you describe anything other people do when they are talking to you, which you find helpful?**

7. *Is there anything else to tell me about how your brain injury has changed how you talk with other people?*