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ORIGINAL ARTICLE



Using photographs to explore self-understanding in adolescent boys with an autism spectrum condition

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ABSTRACT

Background: Research evidence suggests that self-understanding is likely to be limited in individuals with autism.

Method: Photo-elicitation interview was used to explore self-understanding in five adolescent boys diagnosed with an autism spectrum condition.

Results: An interpretative phenomenological analysis yielded three superordinate themes: self in action, self extended in time and self in relation to others. These themes captured how participants understood themselves in terms of their actions and abilities, in the context of their past and future and in relation to others.

Implications: The findings suggested that self-understanding is informed by relationships with parents, self-other comparisons and by reflecting on past and future selves, as well as on activities engaged in. Photo-elicitation was effective in engaging participants with the research process.

KEYWORDS

Autism; self-understanding; interpretative phenomenological analysis; photo-elicitation

Research has consistently demonstrated that autism spectrum conditions¹ (ASCs) are associated with difficulty understanding and predicting the thoughts, feelings and behaviours of other people (for a review see Baron-Cohen, 2008). Insight into the thoughts and beliefs of others is considered crucial to developing an understanding of ourselves (e.g., Bosacki, 2000; Hobson, 2002). Evidence that understanding of self and others follow the same developmental trajectory suggests that these abilities are intrinsically connected (Carruthers, 2009; Wellman, Cross, & Watson, 2001). This parallel development of self and other understanding has led several authors to hypothesise that self-understanding is likely to be limited in individuals with autism (Damon & Hart, 1988; Farley, López, & Saunders, 2010; Frith & Happe, 1999; Hobson, 2002; Loveland, 1994).

Several researchers have used the “self-understanding interview” to investigate self-understanding in individuals with autism (Damon & Hart, 1982, 1988). Interview items explore aspects of the “self-as-object” (physical, active, social and psychological) and the “self-as-subject” (agency, continuity and distinctness). Participants’ statements are scored according to which facet of self-understanding they apply to and are rated against four developmental levels that capture the complexity of understanding.

Lee and Hobson (1998) found no significant difference between an adolescent ASC group and a control

group matched for verbal mental age in their understanding of the “physical”, “active” and “psychological” self. However, the ASC group did produce significantly fewer “social” self-statements (no participant with autism referred to a friend or social group) as well as fewer statements considered to be at a developmental level representative of social qualities. The authors suggest that individuals with autism may not “anchor their self-attributes in social activities and relations” (Lee & Hobson, 1998, p. 1140).

Farley et al. (2010) administered the “self-as-subject” questions to adolescents with autism and typically developing control participants individually matched according to chronological and verbal mental age. The ASC group produced more responses at the highest level of complexity for continuity whereby “self-continuity is established with reference to the relation between one’s earlier and present characteristics of the self” (Damon & Hart, 1988, p. 73). However, they had a relative difficulty answering questions about agency (e.g., “how could you become different?”). Consequently, the authors suggest that only some aspects of self-understanding may be “impaired” in people with autism (Farley et al., 2010). Participants with autism also gave fewer responses overall, suggesting possible difficulty remaining engaged with the interview process.

The same interview was used to assess self-understanding in children with autism (aged 9–13) relative

to two typically developing control groups: one matched for age and one for language ability (Farmer, Robertson, Kenny, & Siitarinen, 2007). The ASC group made significantly more references to their “psychological” self (e.g., emotions, preferences and cognitions) than either control group. Farmer et al. (2007) hypothesised that this emphasis could represent “preoccupations” relating to anxiety and stress. The proportion of references the ASC group made to their “social” self was significantly less than the two control groups which could suggest an under-developed interpersonal self-understanding not attributable to language problems. The meaning of these group differences was further explored using content and thematic analysis. The authors concluded that participants with autism considered friendships to be important but were less able to discuss their development and maintenance. While many participants with autism mentioned social characteristics such as being kind, nice and funny, few elaborated on the significance of these qualities.

While these studies demonstrate the importance of examining multiple aspects of self-understanding, they are limited by measures developed with and for a typically developing population. Arguably they show differences in self-understanding between ASC and typical adolescents rather than the characteristics of self-understanding as experienced by individuals with autism. This approach is inaccurate and risks promoting the view that ASCs are “disorders” characterised by “deficits” rather than differences (Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013; Molloy & Vasil, 2002). Consequently, when participants with autism made fewer statements than control groups it was considered to reflect an “impairment” (Farley et al., 2010). When an ASC group made more statements than control groups this was thought to represent a “preoccupation” (Farmer et al., 2007). Researchers also had difficulty engaging participants with autism with the standardised interview process.

The current study aimed to overcome some of these difficulties by using an innovative approach (photo-elicitation interview, PEI) whereby participants take photographs and talk about them in an interview (Mandleco, 2013; Samuels, 2004). In research with typically developing adolescents, it has been reported to be engaging, to facilitate talk about complex ideas and keep discussions focused (Collier, 2001; Drew, Duncan, & Sawyer, 2010; Lachal et al., 2012). As participants create the photographs and guide the interview, this method helps to create collaboration between participant and researcher (Clark, 1999; Drew et al., 2010; Guillemin & Drew, 2010). The use of photographs may also reduce the pressure of verbal interaction and help establish rapport

(Darlington & Scott, 2002). These considerations are of particular importance when carrying out research with individuals with autism who have specific difficulties with social interaction. Furthermore, evidence from descriptive sampling research and autobiographical accounts suggests that individuals with autism have a predominantly visual style of thinking (Grandin, 1992; Hurlburt, Happé, & Frith, 1994). Therefore, the use of photographs may be more engaging than verbal interviews and particularly well suited to carrying out research with an ASC population.

While established in a range of academic fields (e.g., Kaplan, Lewis, & Mumba, 2007; Rasmussen, 2004), PEI has been used only once with an adolescent ASC population. Hill’s 2014 study explored the lived experience of mainstream secondary school pupils with a diagnosis of ASC. While the focus of this study has no bearing on the current research, participants found the approach to data collection positive and engaging.

The specific aim of the present study was to use photo-elicitation interviews to explore the nature of self-understanding in adolescent boys diagnosed with an ASC. An adolescent population was chosen because adolescence is thought to be a crucial time for the development of self-understanding (Erikson, 1970; Marcia, 1980; Markus & Nurius, 1986). In order to obtain a homogenous sample and in recognition of the fact that diagnosis of ASC is more prevalent within the male population, adolescent boys were interviewed for this study (Brugha et al., 2009).

Method

Design

An interpretative phenomenological analysis (IPA) approach (Smith, Flowers, & Larkin, 2009) was used for the development of the interview guide and analysis of data. IPA was considered appropriate to use in conjunction with photo-elicitation as both approaches emphasise participant–researcher collaboration and the importance of allowing participants to explore their own understanding.

Participants

One special educational needs school for boys assisted recruitment of five adolescent boys who: were aged between 13 and 15, had a formal diagnosis of Autism or Asperger syndrome, were aware of their diagnosis, spoke English as their first language and had parents with a reasonable command of written English. Participants were included if considered by staff to be

cognitively and linguistically able to complete the photography task and interviews.

The Autism Quotient-Adolescent Version (AQ-AV; Baron-Cohen, Hoekstra, Knickmeyer, & Wheelwright, 2006), a parent-report questionnaire designed to assess autism-related traits, was used to independently support formal diagnoses. In accordance with changes to diagnostic criteria, no distinction was made between Autism or Asperger syndrome (American Psychiatric Association, 2013).

Ethical considerations

This study was given a favourable ethical opinion by the University of Surrey Faculty of Arts and Human Sciences Ethics Committee (830-PSY-12). Ethical standards defined by the British Psychological Society (2009) were adhered to. Participants were informed that if they wanted to take photographs of other people, they needed to ask for permission and for the individual/s to sign a consent form. In accordance with school policy, and taking into account the Data Protection Act (United Kingdom Parliament, 1998) and Human Rights Act (United Kingdom Parliament, 1998), participants were permitted to take photographs within the school setting. As creators of the images, participants are the legal owners of the photographs, so permission to feature photographs in this report was sought from parents and participants.

Procedure

Parents of eligible participants were sent an information sheet, consent form and the AQ-AV questionnaire (Baron-Cohen et al., 2006). Participants met with the same researcher in a quiet room on the school premises on three occasions.

First meeting

After explaining the study and gaining written consent, participants were given a disposable camera (27 exposures). They were asked to create a series of photographs that represent who they are and return their camera to a named member of staff within three weeks.

Second meeting

Participants were first to view their photographs and given the opportunity to remove any that they did not wish to discuss. As recommended by Croghan, Griffin, Hunter, and Phoenix (2008), participants laid their photographs out, talking for the length of time they wished and in a sequence of their choosing. An interview guide, informed by methodological literature and

consultation with an experienced PEI researcher, provided prompts (H. Frith, personal communication, November 28, 2012). Participants were asked to tell the interviewer about each photograph ("could you tell me about this photo?") and the collection as a whole ("what do you think/hope this collection of photographs shows me about you?"). The interviewer also asked "is there any one photo that best captures who you are?", "is there anything you would have liked to photograph but weren't able to?" and "how easy/difficult was it to decide what to take photos of?" The individual context of each interview dictated how open-ended, semi-structured questions were used, adjusted and elaborated upon, or whether they were omitted entirely (Taylor & Ussher, 2001). This process enabled participants to take the lead and identify issues of particular importance and relevance to them. Photographs were numbered and referred to during the interview so that the researcher knew which ones were being discussed when listening to recordings.

Third meeting

Follow-up interviews were scheduled to take place three weeks later. This allowed time for participants to digest questions from the previous interview and for the interviewer to formulate follow-up questions (Kinavey, 2006). One participant could not attend a meeting within this time frame creating an 11-week gap.

Analysis of transcripts

Photographs were used as a tool to facilitate the interview process and therefore were not themselves analysed (Lachal et al., 2012). All interviews were transcribed by the lead researcher.

Transcripts were read and re-read by the researcher. Close line by line descriptive analysis was conducted to assist engagement with the transcripts (Smith et al., 2009). Initial exploratory comments were analysed to identify emergent themes that captured and reflected an aspect of self-understanding (Smith et al., 2009). Themes captured not only participants' words but also the researcher's interpretations and account of the interview process (Smith et al., 2009). Cross case analysis identified superordinate themes across the participant group. A single researcher analysed the data drawing on supervision from two experienced qualitative researchers to ensure consistency of the analysis (Noble & Smith, 2015). Findings were also discussed with an academic clinician who has published an exploratory study of self-understanding in adults with Asperger syndrome (P. G. Jackson, personal communication, March 4, 2014).

Reflexivity

The researcher's experience, understanding and cultural knowledge were explored reflexively throughout the analysis through regular supervision and the keeping of a reflective diary (Finlay, 2014). This included reflection on the fact that before designing the current study, the lead researcher had carried out a literature review regarding sense of self in young people diagnosed with an ASC. Knowledge of findings from previous studies as well as models of self-understanding inevitably influenced the questions that participants were asked. It is also possible that pre-existing knowledge of the topic area meant that some aspects of participants' accounts were explored in greater detail than others. Aware of this possibility, the interviewer endeavoured to follow the participants' lead by inviting them to select which photographs to prioritise.

Results

Three superordinate themes were identified: *self in action*, *self in relation to others* and *self extended in time*. *Self in action* captures participants' understanding of themselves as derived from their actions and abilities. *Self in relation to others* explains the ways in which participants understood themselves in the context of their relationships. *Self extended in time* explores how participants understood themselves in the context of their past and future. These superordinate themes and their related sub-themes are presented in detail below. Participants' names and possible identifying details have been changed to preserve anonymity.

Self in action

I am what I do

This sub-theme encapsulated how participants' made sense of themselves in relation to an everyday activity, or an activity that they particularly enjoyed or disliked. Sam used his photograph collection to depict activities he was most interested in: "The first thing is that I like planes, I actually do, yeah I like building and disassembling them". In the course of discussing photographs depicting his hobbies, Sam reflected upon the personal qualities that they represented, for example: "The air cadets basically says that I'm disciplined, which I am, because you've got to be disciplined".

Reviewing his collection of photographs as a whole enabled Jack to reflect on the personal characteristics demonstrated by those depicting "the things that I enjoy", which included walking his dog, attending air shows and holidays in the Lake District. "I'm sort of



Figure 1. Photograph taken by Jack while walking his dog.

quite active and adventurous, I don't like being inside, I'm always outside" (Figure 1).

I am what I do with other people

This sub-theme, captured participants' understanding of particular activities as an important means of establishing and maintaining relationships. Rory, for example, described a shared interest in playing with Lego as having provided the catalyst for the development of a close friendship with a school friend who, six years later, he had grown to think of as "a bit of a brother to me".

When we first met I had brought in some lego with me so I brought like an old batman set containing Batman, The Joker, batwing and Joker's helicopter and that. And Robert was the new guy then and Robert came up to me then and introduced himself and told me that he was the new guy and then he asked if he could play and I allowed him ... that was great fun. (Rory)

Henry commented that while the early morning starts and lack of free time in the evenings associated with his music playing had prompted him to consider "giving it up", he had not done so because he viewed it as an important means of both avoiding boredom and developing and maintaining valued relationships with his teachers. "Like if I quit now I think I'd be so bored it would be unbelievable. And I would probably miss it as well cos you get on really good terms with the teachers".

While having an interest in and being good at an activity was thought to help build relationships, being "rubbish" at running and placed in a "low sports group" was perceived by Henry to have had a negative impact on his relationships with other teachers: "I don't think the sports teachers particularly like me because I don't put much effort in stuff and when I do everyone laughs at me ... so what's the point?".

The photograph that George identified as the best representation of who he is captured him engaged in one of his favourite and most frequent past times

“around my mates, just chatting”. In addition to shared activities, George appeared to view the act of doing things for one another as helping to mediate friendships.

Basically, my friends they’ve done loads of stuff like they’ve been really nice and stuff and they’ve like earned my respect. Like they do stuff like, say they go get something for me, then I will respect them for that. Because they’re doing something that you’ve just asked them to do.

For each participant, references to doing things with or for other people seemed to provide a tangible means by which to assess and portray important relationships.

Self in relation to others

Although participants differed in their representation of how relationships contributed to their self-understanding, each spontaneously spoke about themselves in the context of their social world.

I am like my parents

Participants’ relationships with their parents appeared to contribute to their self-understanding. Relationships with parents were often characterised by shared interests, joint activities or practical support and therefore relate to the sub-theme *I am what I do with other people* considered above. However, the sub-theme *I am like my parents* is distinct, as relationships with parents transcended active qualities, with some participants perceiving themselves as either sharing characteristics with, or having “inherited” traits and interests from, their parents.

I get it from my dad and I think cos he’s quite silly and he’s quite funny. (Jack).

I literally inherited the car loving from my dad and inherited the fashion loving from my mum cos my mum was really, really fashionable. (Rory)

In addition to having “inherited” interests, Rory understood himself as an extension of both parents. He described a close relationship with his father characterised by shared beliefs “me and my dad always think that” and sometimes emotions “my dad was a bit upset for me as well”. He also commented on characteristics he shared with his mother who had died five years earlier. He spoke of preferences of his mother’s that he did not share but still wanted to represent in his photographs, indicating that he perceived his mother as a part of who he is.

Rory: I think I should have taken a picture of David Bowie because David Bowie was my mum’s favourite singer.

Researcher: Do you like David Bowie?

Rory: He’s ok

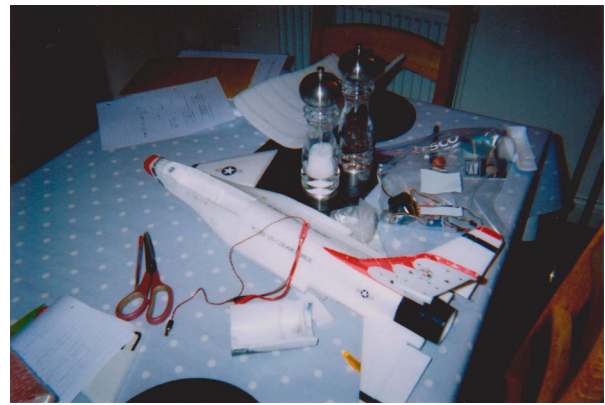


Figure 2. Sam’s photograph of a model aeroplane.

Sam and Henry chose not to take photographs of their parents. Sam primarily represented himself through his hobbies and in particular, his interest in model aeroplanes. The repeated references that he made to his father were primarily in the context of joint activities and the help he provides Sam with his special interest. In this way, his father’s significance to his self-understanding can be seen to be derived indirectly from his participation in Sam’s interests (Figure 2):

Researcher: Does your dad share these hobbies?
Sam: Yeah, he helps me to build and disassemble planes such as these.

Like Sam, Henry did not take photographs of his family or other people but made it clear that their lack of photographic representation did not indicate they were not important to him.

Henry: I would have put my parents and stuff in but I don’t really like taking pictures of people
Researcher: Why’s that?
Henry: I don’t know, I just find it really kind of that you’re invading someone else’s personal space even with their permission I don’t really like it.

Rather than seeing himself as an extension of his parents, for Henry, the significance of family relationships was derived from frequency of contact and practical assistance.

I mean they [mum and sister] pull me around and stuff like that, taking me to places and stuff but, no I don’t think they have a lot [of shared interests]. Like every day I’m normally here and my mum works full time and my parents are divorced so I never really see my dad So I suppose they’re probably the biggest, out of all my family, they might be the biggest help. (Henry)

I am different

Participants' shared an understanding of themselves as different from other people through making social comparisons. Some seemed to have internalised the self-other comparisons other people had made, whereas some made their own comparisons: "Everyone kind of likes sport and Chelsea and I hate football personally" (Henry). While he thought that "everyone" his age likes sport, Henry spent most of his free time playing music. Categorising his peers as a generic group that everyone else belongs to seems to emphasise his separateness from them.

I don't think any of them [other people my age] would have put that much music stuff in them [photographs] but I know they would have put like a ton of sports and stuff like that in them [photographs]. (Henry)

Jack identified common knowledge, interests and values with his parents, but spoke of people outside his family in terms of characteristics that differentiated himself from them. For Jack, being different from others contributed to a positive sense of himself as being special or unique.

One thing about me is that I know loads of facts and really obscure facts that no one does and I know loads about films and I know loads of old films that my parents know but no one else knows. (Jack)

Jack's understanding of himself as being different to his peers appeared to be at least partly based on and maintained by the feedback he received from adults in his community.

He [adult from my village] said "you are the only teenager I know who would get up early and actually want to do this" because most teenagers are lazy. There are some teenagers who live next door to me and they like don't do anything in the village, but then he was just like, he said "it's amazing how you want to get up early and want to endure the wet weather and want to work and get on with things". (Jack)

Jack may have incorporated other people's responses to his actions into his self-understanding. Through his own and other peoples' comparisons Jack had learned that he was more active, had different interests, a superior knowledge base and a greater sense of social responsibility than his peers. Such assessments enabled him to characterise himself in concrete terms such as: "factfile", "old-fashioned", "active and adventurous", "reliable" and "helpful".

Jack did not acknowledge comments made by the interviewer that indicated shared interests. Perhaps any identification of common ground between interviewer and interviewee might challenge his understanding of himself as unique.

George appeared to define himself by his inclusion in a wide social group, producing 11 photographs of friends and explaining that he had "always had loads of friends". Although George characterised himself as someone with "special needs", this classification only seemed relevant in an environment where others do not have special needs. This suggests that George's experience of being different may be dependent on others' attitudes and behaviour towards him: "to me it's just normal. I'm used to it. At this school no one can really take the mick out of you because everyone has some sort of special needs". George's account conveys a sense that his self-understanding is both variable and influenced by his social context.

Self extended in time

In different ways, each participant conveyed an understanding of themselves as having the same self over time, derived from who they have been, how they have changed and who they hope to become. These themes are related to *self in action* as active attributes were often cited as indicators of consistency, change or progress. They are also linked with *self in relation to others* as past experiences and changes to self often took place in the context of relationships.

I am who I have always been

For some participants, reflecting on the past contributed to self-understanding. Rory recalled a series of specific events including a birthday celebration, a difficult situation that led to the development of a close friendship, a "funny story" relating to a family friend and a "scary" car crash.

I remember this day and it was really, really funny. We were driving to school and it was really icy, this road that was a bit of a shortcut, and we [Dad and I] call it cat road because we see lots of cats and it was actually quite scary because it was really icy and dad accidentally crashed into the back of this van. (Rory)

Rory's recollection of salient memories did not just provide context to his self-understanding in the present but represented a desire to preserve the past: "It's nice to have memories because they are, because then you can try and re-live the past but in your imagination". The death of his mother provides an important context in which to interpret Rory's attempts to hold on to his past. "I have a special memory box about my mum and whenever I think of a good memory of something, I put it in this box".

Rory's relationship with his mother played a crucial role in his understanding of who he is, her loss



Figure 3. George's photograph of his "teddy".

challenging this and recollections potentially helping re-establish a coherent sense of self in the context of loss. Rory's description of putting memories into a box conveyed a sense that he understood his memories to be located in objects such as Lego: "I also have a bit of a Lego set in a memory box that I made and it's a piece of Anakin Skywalker's Starfighter. Me and my mum built that together. So that's a memory".

In his description of cuddly toys "having" memories, Henry also appeared to externalise his memories: "I've had them quite a long time and they, they have a lot of memories".

George also presented a photograph of his "teddy", the significance of which was attributable to having always owned him rather than the memories it embodied. "My teddy. I just got him when I was born and ever since" (Figure 3).

George made frequent references to the activities that he had "always done" or friends that he was "always around" as well as being someone who is "always falling over" and "always in trouble". He seemed to define himself most readily by what he conceived as being permanent and unchanging characteristics. Objects appeared to provide a tangible link with the past and with significant relationships, and contributed to a sense of a continuous self.

I have changed

Participants also described changes in self characteristics, Jack, for example reflecting on how his taste in music had developed.

I didn't have a real interest in music when I was younger I just went with what was sort of the tracks of the day. Then basically my dad gave me these Beatles CDs. And then my sister's boyfriend gave me a Kinks CD for my birthday two years ago and then The Who one at Christmas and that really got this retro music thing started off really. (Jack)



Figure 4. Jack's photograph of his CDs.

Introduced to a genre by others, this change in taste seems inextricably linked to his relationships. His change in preference from contemporary to "retro music" can be seen as one way in which Jack identified himself more with his parents' generation than with his peers and is perhaps representative of a shift in terms of social reference (Figure 4).

Henry also reflected on how he had developed a better understanding of what he enjoys doing by spending more time playing music. The majority of Henry's photographs were related to his musical interests and he referred to himself as a musician.

At the start of the year I wasn't really sure if I liked the trumpet and even this year I might have a moment when I think, 'how much easier would it be at school if I did not play an instrument', but then I think that I wouldn't have anything, I wouldn't have anything to be. (Henry)

The notion that music offers him something "to be" emphasises the importance attributed to his new identity and conveys an understanding that he had no sense of himself as a unique individual before becoming a musician. As well as providing a sense of self by being a member of ensembles, bands and orchestras, it is

possible that this new identity also secures group membership.

While Jack and Henry reflected on the change and development of interests, Sam gave an account of what he called a “personality change”. He described a new friendship as bringing an unexpected change in his understanding of, liking for and behaviour in response to jokes.

He is sort of the person who has made me more, cos before I didn't get jokes and I didn't like jokes at all but because of him I started to like jokes, I like jokes now, I laugh at them because I think they're funny. And when I actually told a joke to my parents they were like “Sam has never made jokes before!” and I said “well I do now!”. (Sam)

The developmental stories that participants told about themselves demonstrate how properties of the self in the present were related to, but not the same as, those attributed to their younger selves. Making causal links between the past and the present may be important in maintaining a sense of being the same person in the context of change. Changes to self were influenced and recognised by others, suggesting an intrinsic link with relationships.

I am in progress

Holding in mind a future possible self appeared to help participants make important decisions and provided motivation. Having established his identity as a musician, Henry hoped to attend a prestigious music school and pursue a career as a music teacher. Holding this future in mind reinforced his commitment to current musical endeavours.

If I don't do it [music practice] I'm going to be stuck and then there's no point in me carrying on is there? Not if you've got nothing to show what you've done and if [I do] by year 11 or maybe year 10 I would be able to teach people how to play the trumpet. (Henry)

Henry emphasises the importance of having direction and continuing to take action that helps him progress towards his goal.

Sam also considered the future implications of his actions and the importance of not making the “wrong” decision about his GCSE subjects. Sam can be seen to understand his future self as changeable and influenced by his action in the present: “This decision is quite difficult because what decision I make will affect me in the future. So it's the biggest decision I've had to make”.

Researcher: How important do you think it is to plan for the future?
Sam: Very important because if you do something wrong it affects your entire life.

Overall, the accounts that participants gave of their self-understanding pertaining to the two superordinate themes *self in relation to others* and *self extended in time* demonstrate the complexity of how they understood themselves in the broader context of both relationships and time.

Discussion

Through taking photographs and talking about them at interview, each participant was able to reflect upon what is important to them in understanding their embedded relational self. Self-understanding was derived from actions, interactions with others and understood in the context of their past and future.

The significance of other to the embedded self was seen in differentiation from others as well as self-other comparisons and feedback from other people. This contrasts with Lee and Hobson's (1998) finding that participants with autism scarcely mentioned family and friends in response to questions from the Damon and Hart (1988) self-understanding interview. It is argued that this difference may be accounted for by methodological difference.

Personal photography is thought to be an inherently social practice serving functions of: capturing group memories, social communication and facilitating the development and maintenance of relationships (Haldrup & Larsen, 2003; Van House, 2011). Therefore, asking participants to take photographs may have implicitly invited greater representation of other people than in traditional verbal interviews. Not all participants took photographs of people, but all discussed photographs in a way that embedded them in a social world. This suggests that some findings may be artefacts of methodology rather than representing the abilities and understanding of people with autism (Hobson, 1993; Loveland, 1993; Neisser, 1993).

Research using measures developed for comparing the abilities of individuals with autism against neurotypical comparison groups may result in underestimation of the importance of relationships for self-understanding in individuals with autism. Where a study focuses on the nature of relationships rather than identifying differences in the number and complexity of social self-states, participants with ASCs may be able to demonstrate that they also incorporate others' characteristics into their understanding of self (Aron, Aron, & Norman, 2001; Farley et al., 2010; Lee & Hobson, 1998).

The present study does suggest a difference between participants with ASCs and neurotypical participants, in the emphasis they place on shared activities and interests in characterising their relationships. While

typically developing children, when asked about the meaning of friendships, tend to refer to common activities (McDougall & Hymel, 2007), their early adolescent relationships are increasingly characterised by loyalty, self-disclosure and emotional support (e.g., Berndt, 1986; Furman, 1982). Participants in the current study perceived shared interests as a fundamental aspect of relationships. Activities were considered to be important in mediating and maintaining social relationships, as well as demonstrating particular personal qualities. Given the participants' age (13–15) this suggests a difference in the meaning of friendships relative to typical development. Further research is necessary in order to explore this possibility.

All participants recalled memories embedded in social relationships. This is in keeping with the idea that in addition to providing a sense of self-continuity, one of the main functions of autobiographical memory is to facilitate social interaction and reinforce social bonds (Lampinen, Odegard, & Leding, 2004, p. 245; Neisser, 1988; Nelson, 1992). This function is exemplified in Rory's interview. Having lost his mother, he relates stories from his past perhaps to re-establish self-continuity and reinforce his understanding of himself in relation to others. This finding resonates with research in a typically developing population that demonstrated nostalgia ("a sentimental longing or wistful affection for the past". *The Pearsall & Hanks*, 1998, p. 1266) plays an important role in re-establishing self-continuity and strengthening social bonds in the context of disruptive life events (Sedikides, Wildschut, Arndt, & Routledge, 2008).

For some participants, special objects were the guardians of specific memories that connected them with their past. This is not uncommon within the typically developing population in which photographs, souvenirs, toys, trophies and everyday objects act as repositories for memories (Belk, 1990). They are thought to help maintain a sense of the past which is necessary in order to establish a sense of self as continuous (Belk, 2000; Tabin, 1992). This finding is particularly interesting in light of a recently proposed model of "collecting and hoarding behaviours among individuals diagnosed with autism" (Skirrow, Jackson, Perry, & Hare, 2015). Skirrow et al. hypothesise that individuals with autism may lack a sense of internal self-continuity and that the collecting and hoarding behaviours as well as rigid routines that often characterise ASCs may help maintain a sense of continuity through external means, a scaffolding of identity. If this is the case, then photographs could be used clinically to create an external representation of self-continuity (Gergen, 1994; Shotter, 1993). Indeed, Skirrow et al. in a series of case studies provide an account of how the photograph collection of an adult with autism

"appeared to provide a means of maintaining links with the past, and without it, AB was seemingly unable to experience a continuous sense of self" (Skirrow et al., 2015, p. 3).

Lack of self-continuity has been linked with anxiety, dissociation and suicide in typically developing populations (Chandler, Lalonde, Sokol, & Hallett, 2003; Lampinen et al., 2004). In helping to construct a coherent life story, considered important for establishing a sense of self-continuity, photographs may have clinical benefit within and outside of ASC populations.

Those participants who described change over time all cited a cause for that change. According to the developmental model of self-understanding, understanding the self's characteristics as having evolved from earlier ones is characteristic of late adolescence (Damon & Hart, 1988). Therefore, this finding could demonstrate an intact or even developmentally advanced understanding of self-continuity. However, it should be noted that the changes participants described were in objectively recognisable characteristics, rather than the personal feelings and beliefs which are thought to characterise this stage of development (Damon & Hart, 1988). Again, it is possible that this represents a tendency to use objective or external information to establish self-continuity. This finding suggests that self-continuity may be developed and maintained through different or additional means to those identified for typically developing populations.

For some participants, holding in mind a possible future self seemed to inspire action and reinforce commitment in the present. This finding resonates with the concept of "possible selves" proposed by Markus and Nurius (1986) where identity relevant beliefs and behaviour are influenced by future possibilities, derived from past experience and sociocultural context. This aspect of self-understanding is deemed necessary in order to make plans and commit to occupations (Parfit, 1971).

Reflection on the research design

Participants demonstrated their willingness to engage in the photography task as well as an ability to reflect on the nature of their self-understanding. This contrasts with previous research in which participants with autism have been reported to have difficulty talking about themselves (e.g., Jackson, Skirrow, & Hare, 2012; Lee & Hobson, 1998). This disparity is perhaps accounted for by the difference between purely verbal interviews and the PEI approach. Most participants reported that they looked forward to seeing their photographs; in this way the PEI approach helped to engage participants in the project. Several participants commented that they would have found it more difficult to talk about themselves

without photographs. Photographs were described as “helping out with extra knowledge”, “giving people an insight into me as a person” and “taking a lot of the talking off me because you can see what I mean”. The fact that three participants spontaneously introduced additional material lends support to the premise that PEI empowers interviewees to teach the researcher about their world (Gauntlett & Holzwarth, 2006). Further research could accommodate this in the design.

Remembering to keep the camera nearby, returning it and deciding what photographs to take was challenging, but these issues are also reported in research using this approach with typical populations (e.g., Clark-Ibáñez, 2004; Drew et al., 2010).

Due to time constraints it was not possible to evidence participants’ cognitive and linguistic abilities. This may limit homogeneity of the sample.

Three participants stated that their parents had provided advice concerning what to take photographs of. It is possible that their involvement in the process contributed to the high prevalence of references to parental relationships, but may also reflect the central role their parents play in identity. Interviews provided participants an opportunity to talk about themselves in their own words without restriction to talking about the content of photographs (Drew et al., 2010).

Future research

Self-understanding is considered to be a core developmental task for human beings (Lewis, 1990). This task is never complete as self-understanding is thought to continue to develop across the lifespan (Damon & Hart, 1988). Future research could usefully explore the developmental trajectory of self-understanding in individuals with autism using longitudinal methods. Finding an appropriate measure to use with different age groups is one of the difficulties associated with longitudinal studies (Waterman, 1999). Having received support for its use with children, adolescents and adults, and having now been used with individuals with autism, it is possible that PEI could be a useful interview tool for the longitudinal study of self-understanding (Rasmussen, 2004). More broadly, by creating a context in which participants direct the interview, PEI could be used as an engaging method with which to identify and explore a variety of issues that are of particular importance to individuals with autism.

Conclusion

Findings of the current study suggest that participants understood themselves in the context of relationships

and that relationships with parents were particularly significant. For these participants self-understanding incorporates a sense of self-continuity that is derived from memories and may be facilitated by external means.

Note

1. The term “autism spectrum condition” is used rather than “autism spectrum disorder” as it is less stigmatising (Baron-Cohen et al., 2009).

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References

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM 5*. Washington, DC: Author.
- Aron, A., Aron, E. N., & Norman, C. (2001). Self-expansion model of motivation and cognition in close relationships and beyond. In G. Fletcher & M. S. Clark (Eds.), *Blackwell handbook of social psychology: Interpersonal processes* (Vol. 2, pp. 478–501). Oxford: Blackwell.
- Baron-Cohen, S. (2008). Theories of the autistic mind. *The Psychologist*, 21, 112–116.
- Baron-Cohen, S., Hoekstra, R. A., Knickmeyer, R., & Wheelwright, S. (2006). The autism spectrum quotient (AQ) – adolescent version. *Journal of Autism and Developmental Disorders*, 36, 343–350. doi:10.1007/s10803-006-0073-6
- Baron-Cohen, S., Scott, F. J., Allison, C., Williams, J., Bolton, P., Matthews, F. E., & Brayne, C. (2009). Prevalence of autism-spectrum conditions: UK school-based population study. *The British Journal of Psychiatry*, 194, 500–509. doi:10.1192/bjp.bp.108.059345
- Belk, R. W. (1990). The role of possessions in constructing and maintaining a sense of past. *Advances in Consumer Research*, 17, 669–676.
- Belk, R. W. (2000). Are we what we own? In A. L. Benson (Ed.), *I shop therefore I am: Compulsive buying and the search for self* (pp. 27–53). Maryland: Jason Aronson.
- Berndt, T. J. (1986). Children’s comments about their friendships. In M. Perlmutter (Ed.), *The Minnesota symposia on child psychology, cognitive perspectives on children’s social and behavioral development* (pp. 189–212). Hillsdale, NJ: Erlbaum.
- Bosacki, S. L. (2000). Theory of mind and self-concept in pre-adolescents: Links with gender and language. *Journal of Educational Psychology*, 92, 709–717.

- British Psychological Society. (2009). *Code of ethics and conduct*. Leicester: Author.
- Brugha, T., McManus, S., Meltzer, H., Smith, J., Scott, F.J., Purdon, S., ... Bankart, J. (2009). *Autism spectrum disorders in adults living in households throughout England: Report from the adult psychiatric morbidity survey 2007*. Leeds: The NHS Information Centre for Health and Social Care.
- Carruthers, P. (2009). How we know our own minds: The relationship between mindreading and metacognition. *Behavioral and Brain Sciences*, 32, 121–138.
- Chandler, M. J., Lalonde, C. E., Sokol, B. W., & Hallett, D. (2003). Personal persistence, identity development, and suicide: A study of native and non-native North American adolescents. *Monographs of the Society for Research in Child Development*, 68(2), 1–138.
- Clark, C. D. (1999). The autodriver interview: A photographic viewfinder into children's experience. *Visual Sociology*, 14, 39–50.
- Clark-Ibáñez, M. (2004). Framing the social world with photo-elicitation Interviews. *American Behavioral Scientist*, 47, 1507–1527.
- Collier, M. (2001). Approaches to analysis in visual anthropology. In T. van Leeuwen & C. Jewitt (Eds.), *Handbook of visual analysis* (pp. 35–60). London: Sage. doi:10.4135/9780857020062.n3
- Croghan, R., Griffin, C., Hunter, J., & Phoenix, A. (2008). Young people's constructions of self: Notes on the use and analysis of the photo-elicitation methods. *International Journal of Social Research Methodology*, 11, 345–356.
- Damon, W., & Hart, D. (1982). The development of self-understanding from infancy through adolescence. *Child Development*, 53, 841–864. doi:10.2307/1129122
- Damon, W., & Hart, D. (1988). *Self-understanding in childhood and adolescence*. New York, NY: Cambridge University Press.
- Darlington, Y., & Scott, D. (2002) *Qualitative research in practice: Stories from the field*. London: Open University Press.
- Drew, S. E., Duncan, R. E., & Sawyer, S. M. (2010). Visual storytelling: A beneficial but challenging method for health research with young people. *Qualitative Health Research*, 20, 1677–1688. doi:10.1177/1049732310377455
- Erikson, E. H. (1970). Reflections on the dissent of contemporary youth. *International Journal of Psychoanalysis*, 51, 11–22.
- Farley, A., López, B., & Saunders, G. (2010). Self-conceptualisation in autism: Knowing oneself versus knowing self-through-other. *Autism*, 14, 519–530. doi:10.1177/1049732310377455
- Farmer, M. R., Robertson, B., Kenny, C., & Siitarinen, J. (2007). Language and the development of self-understanding in children with communication difficulties. *Educational and Child Psychology*, 24, 116–129.
- Finlay, L. (2014). Engaging phenomenological analysis. *Qualitative Research in Psychology*, 11, 121–141. doi:10.1080/14780887.2013.807899
- Frith, U., & Happe, F. (1999). Theory of mind and self-consciousness: What is it like to be autistic? *Mind and Language*, 14, 82–89. doi:10.1111/1468-0017.00100
- Furman, W. (1982). Children's friendships. In T. Field, G. Finley, A. Huston, H. Quay, & L. Troll (Eds.), *Review of human development* (pp. 327–342). New York, NY: Wiley.
- Gauntlett, D., & Holzwarth, P. (2006). Creative and visual methods for exploring identities. *Visual Studies*, 21, 82–91. doi:10.1080/14725860600613261
- Gergen, K. J. (1994). Mind, text, and society: Self-memory in social context. In U. Neisser & R. Fivush (Eds.), *The remembering self: Construction and accuracy in the self-narrative* (pp. 78–104). Cambridge: Cambridge University Press. doi:10.1017/CBO9780511752858.007
- Grandin, T. (1992). An inside view of autism. In *High-functioning individuals with autism* (pp. 105–126). New York: Springer. doi:10.1007/978-1-4899-2456-8_6
- Guillemin, M., & Drew, S. (2010). Questions of process in participant-generated visual methodologies. *Visual Studies*, 25, 175–188. doi:10.1080/1472586X.2010.502676
- Haldrup, M. L., & Larsen, J. (2003). The family gaze. *Tourist Studies*, 3, 23–46. doi:10.1177/1468797603040529
- Hill, L. (2014). 'Some of it I haven't told anyone else': Using photo elicitation to explore the experiences of secondary school education from the perspective of young people with a diagnosis of autism spectrum disorder. *Educational and Child Psychology*, 31, 79–89.
- Hobson, R. P. (1993). *Autism and the development of mind*. Hove: Lawrence Erlbaum.
- Hobson, R. P. (2002). *The cradle of thought*. Basingstoke: Macmillan Education.
- Hurlburt, R. T., Happe, F., & Frith, U. (1994). Sampling the form of inner experience in three adults with Asperger syndrome. *Psychological Medicine*, 24, 385–396. doi:10.1017/S0033291700027367
- Jackson, P., Skirrow, P., & Hare, D. J. (2012). Asperger through the looking glass: An exploratory study of self-understanding in people with Asperger's syndrome. *Journal of Autism and Developmental Disorders*, 42, 697–706. doi:10.1007/s10803-011-1296-8
- Kaplan, I., Lewis, I., & Mumba, P. (2007). Picturing global educational inclusion? Looking and thinking across students' photographs from the UK, Zambia and Indonesia. *Journal of Research in Special Educational Needs*, 7, 23–35.
- Kapp, S. K., Gillespie-Lynch, K., Sherman, L. E., & Hutman, T. (2013). Deficit, difference, or both? Autism and neurodiversity. *Developmental Psychology*, 49, 59–71. doi:10.1037/a0028353
- Kinavey, C. (2006). Explanatory models of self-understanding in adolescents born with spina bifida. *Qualitative Health Research*, 16, 1091–1107. doi:10.1177/1049732306292092
- Lachal, J., Speranza, M., Taïeb, O., Falissard, B., Lefèvre, H., Moro, M. R., & Revah-Levy, A. (2012). Qualitative research using photo-elicitation to explore the role of food in family relationships among obese adolescents. *Appetite*, 58, 1099–1105. doi:10.1016/j.appet.2012.02.045
- Lampinen, J. M., Odegard, T. N., & Leding, J. K. (2004). Diachronic disunity. In R. D. Beike, J. M. Lampinen, & D. A. Behrend (Eds.), *The self and memory* (pp. 227–253). New York, NY: Psychology Press.
- Lee, A., & Hobson, R. P. (1998). On developing self-concepts: A controlled study of children and adolescents with autism. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 39, 1131–1144.
- Lewis, M. (1990). Social knowledge and social development. *Merrill-Palmer Quarterly*, 36, 93–116.

- Loveland, K. A. (1993). Autism, affordances, and the self. In U. Neisser (Ed.), *The perceived self* (pp. 237–253). New York, NY: Cambridge University Press. doi:10.1017/CBO9780511664007.014
- Mandleco, B. (2013). Research with children as participants: Photo elicitation. *Journal for Specialists in Pediatric Nursing*, 18, 78–82. doi:10.1111/jspn.12012
- Marcia, J. E. (1980). Identity in adolescence. In J. Andelson (Ed.), *Handbook of adolescent psychology* (pp. 159–187). New York, NY: Wiley.
- Markus, H., & Nurius, P. (1986). Possible selves. *American Psychologist*, 41, 954–969. doi:10.1037/0003-066X.41.9.954
- McDougall, P., & Hymel, S. (2007). Same-gender versus cross-gender friendship conceptions: Similar or different? *Merrill-Palmer Quarterly*, 53, 347–380.
- Molloy, H., & Vasil, L. (2002). The social construction of Asperger syndrome: The pathologising of difference? *Disability and Society*, 17, 659–669.
- Neisser, U. (1988). Five kinds of self-knowledge. *Philosophical Psychology*, 1, 35–59. doi:10.1080/0968759022000010434
- Neisser, U. (1993). The self perceived. In U. Neisser (Ed.), *The perceived self: Ecological and interpersonal sources of self-knowledge* (pp. 3–21). Cambridge: Cambridge University Press.
- Nelson, K. (1992). Emergence of autobiographical memory at age 4. *Human Development*, 35, 172–177. doi:10.1159/000277149
- Noble, H., & Smith, J. (2015). Issues of validity and reliability in qualitative research. *Evidence Based Nursing*, 18(2), 34–35. doi:10.1136/eb-2015-102054
- Parfit, D. (1971). Personal identity. *The Philosophical Review*, 80, 3–27. doi:10.2307/2184309
- Pearsall, J., & Hanks, P. (Eds.). (1998). *The new Oxford dictionary of English*. Oxford: Clarendon Press.
- Rasmussen, K. (2004). Places for children – Children's places. *Childhood*, 11, 155–173.
- Samuels, J. (2004). Breaking the ethnographer's frames reflections on the use of photo elicitation in understanding Sri Lankan monastic culture. *American Behavioral Scientist*, 47, 1528–1550.
- Sedikides, C., Wildschut, T., Arndt, J., & Routledge, C. (2008). Nostalgia past, present, and future. *Current Directions in Psychological Science*, 17, 304–307.
- Shotter, J. (1993). *Conversational realities: Constructing life through language* (Vol. 11). London: Sage.
- Skirrow, P., Jackson, P., Perry, E., & Hare, D. J. (2015). I collect therefore I am – autonoetic consciousness and hoarding in Asperger syndrome. *Clinical Psychology & Psychotherapy*, 22, 278–284.
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. London: Sage.
- Tabin, J. K. (1992). Transitional objects as objectifiers of the self in toddlers and adolescents. *Bulletin of the Menninger Clinic*, 56, 209–220.
- Taylor, G. W., & Ussher, J. M. (2001). Making sense of S&M: A discourse analytic account. *Sexualities*, 4(3), 293–314. doi:10.1177/136346001004003002
- Van House, N. A. (2011). Personal photography, digital technologies and the uses of the visual. *Visual Studies*, 26, 125–134. doi:10.1080/1472586X.2011.571888
- Waterman, A. S. (1999). Identity, the identity statuses, and identity status development: A contemporary statement. *Developmental Review*, 19, 591–621. doi:10.1006/drev.1999.0493
- Wellman, H. M., Cross, D., & Watson, J. (2001). Meta-analysis of theory-of-mind development: The truth about false belief. *Child Development*, 72(3), 655–684.