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Personal experiences disclosed by parents of children with Autism Spectrum Disorder: A YouTube analysis

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Abstract

The current study used YouTube as a data source in order to observe parents of children with ASD speaking about their experiences in a 'naturalistic' setting. Fifty videos made by parents of children with ASD were collected and qualitatively analysed using a content analytic procedure. This revealed a number of common themes expressed by the parents about their experiences across these video clips. The topics mentioned most were Issues of self; Issues with the child; Relationships; Autism and daily life; Solidarity between parents; Diagnosis; and Treatments and available services. Implications of the study emphasise a need for more social support, and more positive representations of parenting a child with ASD.

Keywords: parents' views; acceptance; grief; communication; YouTube; content analysis, ASD.

Capturing the ‘voices’ of parents of children with Autism Spectrum Disorder (ASD) regarding their experiences has become an important research focus (e.g., DePape & Lindsay, 2015; Reid, 2011). Parenting a child with ASD produces a range of experiences, some of which are reported as positive (Hock, Timm, & Ramisch, 2012; Markoulakis, Fletcher, & Bryden, 2012), and some as negative (DePape & Lindsay, 2015; Myers, Mackintosh, & Goin-Kochel, 2009). Such experiences have been shown to impact parents’ health and quality of life (Allik, Larsson, & Smedje, 2006; Reed, Sejunaite, & Osborne, 2016), which is important in itself. However, another reason to place emphasis on establishing the range of parental experiences is that, through their effects on parental functioning, they can impact the development and prognosis of the child (Osborne, McHugh, Saunders, & Reed, 2008; Robbins, Dunlap, & Plienis, 1991). Despite acknowledgement of these important aspects of parental experiences, relatively little research effort has been devoted to obtaining the views of parents about their range of experiences.

To date, the experiences of parents of children with ASD have been captured in a variety of ways. For example, some studies have set out to psychometrically-measure precise dimensions of these experiences, such as their psychological states, parenting stress, or positive growth following diagnosis of their child (Osborne, McHugh, Saunders, & Reed, 2008; Phelps, McCammon, Wuensch, & Golden, 2009; Zablotsky, Anderson, & Law, 2013). Other studies have directly asked parents through interviews about particular aspects of their lives (e.g., Benderix, Nordström, & Sivberg, 2006; Hock et al., 2012; Hodgetts et al., 2013; Myers et al., 2009; Osborne & Reed, 2008). Clearly, the research interview has been an extremely important tool in developing and understanding this area (see DePape & Lindsay, 2015, for a review). However, it remains only one way through which parental views and experiences can be collected, and one that has some associated problems (see Hepworth & McVittie, 2016; Roulston, 2016). In particular, the information obtained during an interview typically comes from a specifically-focused question, and the interviewer-interviewee interactions can often be shaded by the needs of the question-focused data collection process (Roulston, 20916), which often reinforces existing theoretical models of the problem (Hepworth & McVittie, 2016; see Osborne, Dixon, Edwards, Begum, Younis, Lucas, & Reed, 2016, for an example in another health-related area). No study, to date, has attempted to capture parents freely expressed views on what they feel are the most important aspects of their experience.

Social media sites have become increasingly used by individuals over the past decade, and such sources of data, including YouTube videos, are increasingly employed as a source of information in the social sciences (see Giglietto, Rossi, & Bennato, 2012, for a review). Some of the broad advantages for using this information are that such posts are highly accessible, give access to a range of individuals who might otherwise be difficult to reach, and offer the chance of replication across studies. It also represents an opportunity to research on 'real world' interactions, rather than experimentally studies ones. This analysis trend is now being seen in many areas of health-related psychology (e.g., Fernandez-Luque, Elahi, & Grajales, 2009; Garg, Venkatraman, Pandey, & Kumar, 2015; Jurgens, Anderson, & Moore, 2012; Paek, Kim, & Hove, 2010). These studies have used analysis of the content of YouTube videos to assess the type of information contained in informational videos (Paek et al., 2010), and the accuracy of the information contained in the videos (e.g., Garg et al., 2015; Jurgens et al, 2012). However, recently this source of data has also begun to be used to assess the type of personal information disclosed in people with some forms of chronic condition (Fernandez-Luque et al., 2009). It has been argued that such data may have advantages over the interview for this purpose, as individuals tend to highlight only positive attributes for self-enhancement in such cases (Schlenker & Pontari, 2000) until the interviewer is well known (Greene, Derlega, & Matthews, 2006). In contrast, it has been noted that individuals disclose personal information more readily through social media (Christofides, Muise, & Desmarais, 2009), which is also realistic and typically honest especially when it is felt that the content can be checked (Hew, 2011). However, placed against these advantages, it also has to be acknowledged that some individuals can use this content to present a distorted view of themselves to please an audience (Chen & Marcus, 2012).

However, analysis of social media sources has not been employed widely, if at all, in the context of ASD, and use of this approach may capture a more extensive representation of the parental experience, and assess the issues that parents spontaneously feel are important without being asked specific questions in the context of a research interview. Given this, the current expanded the research documenting parental experiences, by analysing topics that parents discuss without prompting and without a set series of specific questions. In order to do this, the YouTube posts of parents of children with ASD were qualitatively analysed to determine the types of issues and experiences mentioned by this group of individuals. It was hoped that this would not only allow a new source of information to shed light on this important topic, but also would allow previous work to receive some validation from another source where the informants were not forced to answer about experiences in a particular area of their lives.

Previous work has identified a range of negative experiences that parents of children with ASD report. For example, such parents experience higher levels of parenting stress than parents of typically developing children or parents of children with other developmental delays (Estes, Munson, Dawson, Koehler, Zhou, & Abbott, 2009; Osborne & Reed, 2009a; Pozo, Sarriá, & Brioso, 2014). Increased anxiety and depression are also noted in this population (Hamlyn-Wright, Draghi-Lorenz, & Ellis, 2007; Taylor & Warren, 2012; Zablotsky et al., 2013). These findings are important, as impaired parental functioning affects the whole family, in particular limiting the benefits of early intervention (Osborne et al., 2008; Robbins et al., 1991), increasing child problem behaviours (Lecavalier, Leone, & Wiltz, 2006; Osborne & Reed, 2009b), and reducing parents' communication and involvement with their child (Konstantareas & Papageorgiu, 2006; Osborne & Reed, 2010).

A key issue raised by many parents of children with ASD concerns their dissatisfaction with services and the diagnostic process (Bishop, Richler, Cain, & Lord, 2007; Chamak, Bonniau, Oudaya, & Ehrenberg, 2011; Osborne & Reed, 2008). Levels of support for parents can be limited, and many parents require professional help to deal with their reaction to the diagnosis (Wachtel & Carter, 2008). As a result of difficulties with childcare/respite services, 40% of parents have reported problems with employment (Montes & Halterman, 2008), exacerbating pre-existing financial strains (Bae, Jackson, Lo, Su, Lykens, & Singh, 2011). Another well-documented concern for parents are social attitudes towards their children (DePape & Lindsay, 2015; Portway & Johnson, 2005), often leading to strangers assuming that the child's behaviour is a result of bad parenting (Farrugia, 2009). The lack of support leads to parents often being the main advocate for their child, taking on multiple roles, fighting for and organising treatments and interventions, resulting in them being overwhelmed with duties and anxiety (Hoogsteen & Woodgate, 2012; Wachtel & Carter, 2008).

Although a wide range of negative experiences are reported by parents of children with ASD, the positive experiences of these parents should not be overlooked (e.g., Altiere & von Kluge, 2009; Hock, Timm, & Ramisch, 2012; Markoulakis, Fletcher, & Bryden, 2012; Myers et al., 2009). For example, recent research has focused on growth, development, and enrichment of the parent-child relationship as a result of the child's ASD (Myers et al., 2009; Phelps, McCammon, Wuensch, & Golden, 2009). Additionally, there are also cases where relationships between parents have become stronger as a result of having a child diagnosed with ASD (Hock et al., 2012; Markoulakis et al., 2012). These positive aspects of parenting a child with ASD have often been pointed to as being important in supporting the functioning of the parents, their child's development, and also to re-assure other parents of children with ASD that their situation can be associated with positives (see DePape & Lindsay, 2015; Kayfitz, Gragg, & Orr, 2010; Tugade & Fredrickson, 2004). Capturing such positive aspects of parenting a child with ASD presents a more rounded view of the experiences of these parents, and may help in being able to plan services for parents, by being able to capitalise on any such sources of positive experience that may be there already.

Method

Ethical Approval

Ethical approval for this work was given by the Psychology Department Ethics Committee at Swansea University.

Search strategy and videos analysed

Videos were found on YouTube by using the search term: "parents autism", and filtering the search for videos between 30s and 15 min in length that had been posted during the last 6 years. This search initially yielded 5,110 videos. A number of further exclusion criteria were adopted: videos made as part of an ASD awareness campaigns; videos showing only a child; videos showing two parents together; videos made by ASD professionals; videos directly about one particular therapy; and videos in a language other than English, were all excluded. Each video was viewed and checked for relevance to the current topic by two researchers, who independently watched the videos to ensure that they discussed experiences of parenting a child and fulfilled the above criteria. Only if both viewers agreed about a video's inclusion, was it used for further analysis.

This process resulted in 50 videos being collected. There were 4 distinct types of video: *Talking heads*: the traditional home video where the parent is simply speaking to the camera on their own, or with their child or partner. (28 videos); *Interview*: another person is present, asking the parent questions about their experiences (14 videos); *Slide-show*: a PowerPoint style presentation using photos and text (5 videos); and *Commentary*: the parent speaks over various images (3 videos). The total length of video material analysed was 4 hours 6 min 48 s, with a mean video length of 4.56 min (SD ± 3.22; range 37s – 14.48 min). There were 11 male and 39 female parents included. There were 3 parents from Australia; 1 from New Zealand; 37 from the USA; 4 from the UK; and the nationality of 5 was unknown. There were no videos from non-developed or ‘non-westernised’ countries, possibly as a joint product of the English language requirement and YouTube access. The total video views of these videos at the time of analysis was 875,782, with a mean view per video of 17,515.64 (+ 69806.40; range = 7 to 439,708).

Procedure and content analysis

The comments made in the videos selected for inclusion in the study were transcribed. The video was watched several times in order to ensure the accuracy of the transcription. Content analysis was conducted on the transcriptions in line with the recommendations made by Vaughn, Schumm, & Sinagub (1996; Osborne & Reed, 2008), and as has been employed for analysis of You Tube videos previously (Paek et al., 2010). This content analytic procedure was conducted by two experienced raters of qualitative data and content analysis. These phases are outlined in Table 1.

Table 1 about here

The transcripts were initially read by two independent researchers, who gained an impression of the categories that emerged from these transcripts, using external notes and memoing procedures. The researchers then independently re-read the transcripts and broke down the statements into the smallest units of information that would bear interpretation. These units had to be able to stand on their own and important a meaningful and informative statement. Those statements made in the videos that contained more than one such unit of information, such as very long sentences that made a number of points, were divided into several smaller separate units.

At this point, the researchers compared the units that they had derived to ensure that they had parsed the data in the same way. Any discrepancies were settled by discussion. The units were then read alongside the initially developed categories, to ensure that these categories would cover all of the units, and, where necessary, the themes could be added to or altered.

The researchers then independently placed the units into the categories that best described their content. Once this had been done, the degree of agreement between the classification of the units into the categories by the two coders (number of agreements divided by number of agreements plus disagreements multiplied by 100) was calculated at 92.4%. Discrepancies were fully discussed, and a final set of allocations of units to categories was arrived at.

Following this the original categories were read by the two researchers together, to see if any categories appeared to deal with broadly similar and related issues to one another. If they did, these categories were placed together into a super-ordinate theme.

Results

Tables 2 and 3 about here

The overriding super-ordinate themes, and their corresponding categories (and the number of items relating to the theme, and this number as percentage of total items), are presented in Table 2. There were seven super-ordinate themes that emerged from the analysis of YouTube content: Issues of self; Issues with the child; Relationships; Autism and daily life; Solidarity between parents; Diagnosis; and Treatments and available services. These themes are discussed in greater below, as are there relationship with the initially derived categories. The number of occurrences of each category is presented in Table 3, together with the percentage of the videos in which this theme occurred.

Issues of Self

Much of the footage involved the parents discussing their thoughts and feelings about having a child with ASD, such as their initial reactions and coping strategies. These themes clustered together into: celebration and acceptance of the diagnosis, grief, depressive symptoms, and guilt. *Celebration and acceptance* was the most common theme in the videos, where parents took a positive stance on their child’s diagnosis (48% of all themes; *“X’s autism has been a blessing… if it wasn’t for the experience we wouldn’t have the perspective that we have about simple blessings”).* Many of the parents used words such as “unique” to describe their child, as well as “a blessing”, and commented on how it had made them a better parent than they could have imagined. However, *Grief* was also a common theme (26%) in many of the videos; once the diagnosis of autism had been given, hopes, dreams, and expectations that parents had for their child were altered (“*There’s a sense of* *grief, a sense of loss. It's almost as if you've lost everything you thought your son was going to be."*). *Depressive symptoms* were present in a reasonably high number of the videos (*16%*; *"That was a scary moment for me… I realised I had sat in the car for about 15 minutes and had actually contemplated putting X in the car and driving off the X bridge.").* *Guilt* occurred in some videos (6%), and included a combination of comments relating to protective parental behaviours plus speculation about the cause of autism ("*Could it have been the chemicals I was inhaling?*; *Was he not getting the right vitamins?"*).

Issues of the child with ASD

Parents used the videos in order to air their experiences of ASD itself, often discussing the symptoms of their child. *Discussion of symptoms* many parents began their video with a description of when they first noticed something was wrong (22%; *"around 18 months, she still wasn't talking, or even trying to talk"*). *Invisible illness* (10%) this theme involved discussion of ASD in relation to why it is so difficult to raise a child with ASD (*"autism.. I feel is a hidden disability, there are so many disabilities that have a physical expression… the child looks so normal"*). *Claims of a cure* in addition to claims regarding recovery, these statements often expressed negative connotations towards ASD, and about accepting ASD as anything other than a disorder (4%;*"there's really no better feeling than to bring your child back from the terrible place that he or she is heading"*).

Relationships

Many parents reported marital difficulties and a reduction in social interactions. *Marital/relationship issues* (16%; *"I didn't give that marriage what I could have 'cause I had nothing left to give";" Good luck finding somebody who's gonna really be able to deal with this stuff day in day out"*) were repeatedly mentioned in the videos, although hardly any discussed divorce. Difficulty in initiating a relationship was also mentioned. *Loneliness* (14%) parents discussed how it soon became difficult to have any friends who did not have any experience of ASD, and how it becomes very lonely ("*you feel just totally abandoned …even family were really quiet… friends started drifting off"*; *"They just didn't get it; they just didn't want to get it"*). *Relationship with typically developing children* (18%) parents discussed the difficulties of balancing their attention between a high-needs child and a typically developing child, which often caused tension between siblings (*"X has made a lot of sacrifices as a child because she had a sister with a disability"*).

Autism and daily life

This category consists of parents discussing the everyday routine tasks affected by ASD. *Everyday difficulties* (38%; *"driving in the car with X can be dangerous and nearly impossible at times. There are situations where I've had to pull the car over on the highway four times in 45 minutes because he was beating himself so badly"*) refers to any discussion of mundane activities that every family has to undergo, which become extremely challenging due to the unpredictable nature of ASD. *Financial struggles* (8%) parents spoke about difficulties with money ("*It hits you economically because... you have to buy all kinds of things that you don't have to buy for a regular child… but it also hits you because it really prevented me from working at all so we lost the big income and had all this expenditure at the same time"*). *Social Attitudes* parents often mentioned that other people didn't fully appreciate that the child has autism, assuming that the child is just naughty (14%; *"It's heart-breaking… when X was on the swings and crying, the other moms were sort of looking and wondering why this 8 and a half year old girl was screaming and carrying on because she didn't want to get on the swing"*).

Solidarity between parents

One of the larger themes to emerge was solidarity between parents of children with ASD. Some form of contact with someone in the same position appears to act as a huge support to parents of children with ASD, whether it is just through advice or through an active community. *Asking for advice* (4%; *"that would be some great input from you guys just to see how you deal with those things when people are looking at you differently and you're trying to keep your cool"*) parents used YouTube to ask other people for advice, sometimes rather than speaking to a doctor or a professional. *Giving advice* (24%; *"I would just tell the parents that are newly diagnosed or still struggling to find the right therapies for your child to trust your own intuition… you know your child better than anyone else"*) many parents used their videos to give advice, such as the first signs of ASD to look out for, and even medical advice ("*If you've got autistic kids and you haven't heard of omega 3, then you go ahead and try it, it's harmless so you're not risking anything, readily available, not expensive…"*). *Importance of contact with other ASD parents* (24%; *"it takes so much pressure off and there's always someone who's willing to contribute or lend support in some way"*) a lot of the parents mentioned how much support speaking to other parents with ASD children can offer. Some parents attended an autism parent community, and others connected online.

Diagnosis

This theme refers to successes or disappointments related to the diagnostic process. *Positive experience* (6%) mainly referred to the relief when it was to discover that there is a cause for their child's behaviour ("*…as distressing as it was it was also a moment of relief for us because all of a sudden we started to understand our child"*). One parent also mentioned the planned changes in the DSM-IV diagnostic categories as being a positive change ("*it's* *kind of a good thing for us because if we stayed with the diagnosis of PDD-NOS our services in the future… maybe would have been more difficult to receive for X*”). *Negative experience* (12%) were more prevalent than positive experiences, and included things such as misdiagnosis, lack of knowledge by professionals and the length of diagnosis (*“I don’t know if other health issues take so long to diagnose but I know with autism and Asperger’s… it’s long”*; *“I brought X to the doctor because he had stopped looking at me, talking, responding to his name… the doctor told me ‘he has a cold, come back in two weeks’. It has been 6 and a half years now – this has been one hell of a cold.”*).

Treatment and available services

Many parents wanted to discuss the treatment plans for their child, and also their opinions on the available services such as special needs schools. *Treatment* (18%; *“[the speech therapist] has a little PECS board system... and she lets him choose what he wants to play with… she has certain choices to use at certain times just to work on different language”*) refers to parents speaking about the treatment or therapy that their child is receiving. *Failures in available services* (16%) parents talk about their negative experiences with the available services, mainly with the school system (“*none of these schools are ready for it, they have county schools, they have county programmes for children with severe disabilities that require wheelchairs everything but these kids* [children with ASD] *are just left in the blue and they’re supposed to somehow fit into a school system that they’re not ready for”).* *Successes in available services* (20%) was mainly in reference to specific organisations rather than schools (*“I wish Therapy X would have been our first step… the information and the knowledge that you get from the people, and the patience and the time and the understanding and the compassion even… it’s not something you get all the time”*). *Awareness/available information* (20%; *“the first that we heard that our child had autism we* *had no idea what it meant"*; *"around 1 in 100 children have autism, yet people know little about what it is and how it affects lives"*) this theme included the information provided by professionals, and general awareness of ASD.

Table 4 about here

In order to discern whether there were any differences between the themes emerging from the videos from mothers and fathers, and whether different themes were elicited from interviews compared to other forms of video, the percentages of super-ordinate themes for each of these sub-groups were calculated. These are shown in Table 4. Comparison of these themes between mothers and fathers demonstrated that where there were differences, mothers were more likely to express issues with the self, relationships, and solidarity between the parents. Whereas, fathers tended to express opinions on the child, services, and diagnosis procedures, more than mothers. There were few differences between the themes that emerged from interviews and other form of video, with the latter

Discussion

By using YouTube as a resource, the current study aimed to extend the research base regarding parental experiences by measuring and qualitatively analysing the topics that parents of children with ASD want to discuss without prompting. The top five mentioned categories that were revealed through watching the videos were: acceptance and celebration of child, everyday difficulties, grief, giving advice, and solidarity between other parents of children with ASD.

Table 5 about here

Some of these topics have been noted previously in studies that have used interview procedures (DePape & Lindsay, 2015; Hamlyn-Wright et al., 2007). In a review of the qualitative literature, DePape and Lindsay (2015) noted that six main themes emerged from their overview of the literature on parental experiences: pre-diagnosis, diagnosis, family life adjustment, navigating the system, parental empowerment, and moving forward (see also Reed & Osborne, 2014). Many of these themes share overlapping content with those noted in the current study (see also Table 5 for an overview of the themes that have emerged from previous work in this area). For example, acceptance and celebration from the current study shows similarities with the parental empowerment theme noted in the review by DePape and Lindsay (2015). To the extent that these themes emerge from studies using different data sources suggests that confidence can be placed in these topics as capturing the lived experience of parents of children with ASD.

Although the overall themes from this You Tube study did show some similarity with previous work (DePape & Lindsay, 2015; Reed & Osborne, 2014), and such positive views have been noted (see Altiere & von Kluge, 2009; Hoch et al., 2012; Kayfitz et al., 2010; Myers et al., 2009; Phelps et al., 2009), the level of these positive statements in the current study was high. It could be that such positive experiences are underrepresented in research that is focused on topics such as parental stress and depression (see Osborne & Reed, 2009a), child behaviour problems (Hodgetts et al., 2013), or about understanding the diagnostic process (Chamak et al., 2011; Osborne & Reed, 2008). As the current data set was not constrained by a particular question, it may be that the YouTube videos allow such positive representations to be observed more easily.

Having made this point, many parents recalled everyday experiences that have been made considerably more difficult by having a child with ASD. Most of these experiences were somehow related to challenging behaviours that the child has emitted in a public place, and this reflects previous work relating parenting stress to child characteristics (Lecavalier et al., 2006; Osborne & Reed, 2009b). This finding also highlights some advantages in using YouTube, as it allows the parent to directly communicate to others in a similar situation and suggest coping strategies in how to deal with tantrums in public. In fact parents did use the videos to ask for such advice.

There was a degree of psychological distress described in the videos, which also corresponds with previous findings (see Myers et al., 2009). O'Brien (2007) describes the often expressed feeling of bereavement as 'ambiguous loss', due to the difficulty in predicting the child's outcome and the lack of participation the child has in the family. Past research has stressed the need for more emotional support following the diagnosis (Wachtel & Carter, 2008), and it would appear that the current study reveals that this is still an issue which needs to be addressed. It would be perhaps be valuable to offer parents some sessions with a professional after the diagnosis, in the hope that this would encourage them to begin to work through feelings of grief and guilt and would assist them in taking a more constructive view point of their situation.

Giving advice through YouTube videos was the fourth highest mentioned theme found in this study. The advice was predominantly emotional, for example *"trust your own intuition".* However, some of the advice was much more medical: in one video, the parent only spoke about the first signs which parents should look out for, in another, a mother shows how she gets her child with ASD to take their medication. It is important that these videos are checked for their medical accuracy. If parents are not satisfied with knowledge of professionals (Osborne & Reed, 2008), they may turn to the internet for further advice, following advice that could potentially be dangerous. Nevertheless, support groups and online forums, where parents are able to share advice based on their experiences seem to serve a positive function for parents of children with ASD.

The importance of social support, specifically the support of parents in the same situations, was mentioned frequently. Many parents mentioned the difficulty of being friends with parents who have neuro-typical children, due to the lack of understanding and patience. This links in with the theme of loneliness, and some parents felt they had no one to talk to and had put videos online purely to reach out to other ASD parents. This point is of particular importance, because previous research shows that the more social support a parent has, the more positive outcomes they experience (Ekas, Lickenbrock, & Whitman, 2010). It also improves their general psychological adjustment and coping (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001). Therefore, it may be of benefit that professionals provide and inform each parent of the available online social networks made specifically for parents of children with ASD.

Another theme which stood out during the analysis was the lack of awareness which parents felt there was about ASD. Osborne and Reed (2008) revealed that the diagnosis came as an extra shock to some parents because little is generally known about the disorder. This links in to the theme of social attitudes towards children with the disorder. Although this is something that may be difficult to change immediately, studies have shown that providing people with just a small amount of information about the disorder may result in a more favourable perception (Iobst et al., 2009).

Two of the videos in the sample used in this study spoke about a cure for ASD. Although this is not a high number, these videos had the 3rd and 9th highest number of views out of all 50 videos. There is currently no known cure for the disorder; therefore, the productivity of parents watching videos claiming that there is must be questioned. Searching "curing autism" on YouTube reveals 2500 results, most with much higher views than more videos about living with ASD. Parents should be made aware of internet content such as these videos, as it may initiate false hope and prevent them from accepting and coping with the diagnosis.

There are limitations to the current study, such as biases in the participant sample as, of necessity, the sample was self-selected. In relation to the last point, individuals with access to technology, and individuals who *choose* to self-disclose their child/family's situation, may present a different set of issues to the more general population. In addition, the data gathered from this type of analysis represent only a snapshot in time for a given family (and, thus, limit the ability to learn about changes in parent experiences over time, which can be gained from longitudinal work or interview questions that ask families to reflect on the past). It is possible that the parents who post videos online are parents who feel more positive and empowered regarding their child's diagnosis, which could explain the greater mentions of positives of the diagnosis than is found in extant qualitative examinations of this topic. There was also an overrepresentation of mothers. This imbalance could be responsible for the number of positive experiences shared, with some research suggesting that women tend to focus more on positives than men, especially on social media (Kivran-Swaine, Brody, Diakopoulos, & Naaman, 2012; Simpson & Stroh, 2004).

Future research along these lines may also be able to develop these analyses in more focused ways. For example, issues such as gender difference in the themes expressed would be of interest. In the current study, mothers tended to express more themes relating to their own feelings and relationships (which might be termed internally-focused issues), whereas fathers tended to concentrate their expressions of the child, and services (externally-oriented themes). This would seem to follow what might be expected on the basis of previous research. However, given that this was not the main focus of the current work, perhaps not too much reliance should be placed on such differences. The current work produced different numbers of such videos, which might have impacted the outcome (although it might be noted that the initial analysis conducted on this topic revealed little difference between the genders). Additionally, it might be of interest to note whether different forms of video are more associated with different themes – particularly, if videos of interview produced different results to those that were more ‘spontaneous’, as suggested as possible in the Introduction. Unfortunately, there was little difference noted in the themes emerging from these different forms of video, but there may be reasons to be cautious about over interpreting such data. For example, it is difficult to ascertain whether the interview was conducted by a person known to the interviewee, in the current videos, which would confound the analysis. Morover, making a Youtube video of any sort might elicit positivity, because parents might understandably want to project an image of themselves that they know will be viewed by many others, rather than a single interviewer, as positive, strong people. This factor may have impacted the themes, and also masked any interview versus other video differences. Future work might be able to develop this issue further.

The current study was able to contribute to the existing literature giving a more comprehensive representation of parental experience, and revealing issues that parents of ASD believe to be important. Although it is clear that parenting a child with ASD may be extremely challenging, the positive and uplifting messages present in so many of the videos may provide others with hope and encouragement.

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Table 1: Phases in the content analysis (after Vaughn *et al*., 1996).

1. Identification of key themes or 'big ideas' within the data, following reading and re-reading of each transcript.
2. Identification and highlighting of units of information (phrases and/or sentences) relevant to the research purposes.
3. Selection of category headings to sort and group these units of information.
4. Units of information are coded according to category headings, to enable most of the units to be placed within a category.
5. Negotiation between the researchers to agree the category headings that most economically accommodate the relevant units of information.
6. Categories generated in the first phase of data analysis are reviewed and revised.

Table 2: Super-ordinate themes emerging from the analysis (number of items, percentage of total items).

Super-ordinate Themes	*Subordinate Themes*
Issues of Self (48, 25%)	- Grief - Guilt - Depression / depressive symptoms - Acceptance of autism (positivity)
Issues of the child with ASD (18, 9.4%)	- Discussion of symptoms - Autism as an 'Invisible illness' - Claims of a cure
Relationships (23, 12.5%)	- Marriage/ romantic issues - Loneliness - Relationship with normally developing siblings
Autism and daily life (30, 15.6%)	- Everyday difficulties - Financial struggles - Social attitudes
Solidarity between parents (26, 13.5%)	- Asking for advice - Giving advice - Importance of contact with other autism parents
Diagnosis (9, 4.7%)	- positive experience - negative experience
Treatment and available services (37, 19.3%)	- Treatment - Failures in available services - Success in available services - Awareness/ available information

Table 3: Number of mentions of each category, and this number as a percentage of all units in descending order.

Title of Theme	*Theme description*	*Frequency*	*Percentage of all themes*	*Percentage of videos with this theme*
Celebration/acceptance	*Refers to a parent giving a positive slant to the diagnosis, showing acceptance*	24	12.5%	48%
Everyday difficulties	*Everyday activities made difficult by having a child with ASD*	19	9.9%	38%
Grief	*Parents describing the experience as similar to bereavement*	13	6.8%	26%
Giving advice	*The parent addresses the viewer, giving tips on how to cope or treatment suggestions*	12	6.3%	24%
Autism parents	*The parent stresses the importance of communication with other parents of children with ASD*	12	6.3%	24%
Child’s symptoms	*Discussion of the child’s symptoms*	11	5.7%	22%
Services positive	*Positives directly related to school systems, or doctors*	10	5.2%	20%
Available info	*How much is known about autism? E.g. is*	10	5.2%	20%

	the parent provided with enough information?			
Treatment	*Discussion of specific treatment plans.*	9	4.7%	18%
Other children	*Tensions or difficulties with other offspring e.g. balance of attention*	9	4.7%	18%
Depressive symp.	*Direct mention of depression, or descriptions of extreme unhappiness or hopelessness*	8	4.2%	16%
Marriage	*Romantic relationship issues, the difficulties that are experienced due to parenting a child with autism*	8	4.2%	16%
Services negative	*Negatives directly related to school systems, or doctors*	8	4.2%	16%
Loneliness	*Parental discussion of feelings of isolation*	7	3.6%	14%
Social attitudes	*The negative attitudes that other people have towards the child.*	7	3.6%	14%
Diagnosis negative	*Negatives directly related to the diagnostic process*	6	3.1%	12%
Invisible illness	*The contrast between a healthy looking child and unusual behaviours*	5	2.6%	10%

Finance	*Financial difficulties due to expensive therapies and specialised toys*	4	2.1%	8%
Guilt	*The parent speculates about whether the diagnosis was their fault*	3	1.6%	6%
Diagnosis positive	*Positives directly related to the diagnostic process*	3	1.6%	6%
Asking for advice	*Asking for help with a certain aspect of parenting*	2	1%	4%
Cure	*Claiming that their child has been cured*	2	1%	4%

Table 4: Percentages of super-ordinate themes emerging from the analysis for mothers versus fathers, and for interview videos versus other forms of video. Numbers are percentages of responses across all categories for the sub-group.

Super-ordinate Themes	**Parent**		**Video**	
	Mothers	**Fathers**	**Interviews**	**Others**
Issues of Self	26	22	26	24
Issues of the child with ASD	9	12	11	10
Relationships	14	8	11	13
Autism and daily life	14	15	16	15
Solidarity between parents	18	10	12	13
Diagnosis	4	8	5	5
Treatment and available services	15	25	19	20

Table 5: Summary of themes emerging from qualitative investigations of patents' views.

	N	**Method**	**General Impact on Family**	**Specific Impact on Functioni**
Brobst et al. (2009)	25	Interview	➢ Child issues	➢ Stress ➢ Lower relationship satisfac
De Grace (2004)			➢ Whole family revolves around ASD	➢ Feeling robbed
Hall & Graff (2010)		Focus Groups		
Hoogsteen & Woodgate (2012)	28	Semi-structured Interview	➢ ASD Central to family life ➢ Making it visible	
Meirsschaat et al. (2010)	17	Open interview	➢ Whole life impacted ➢ Inaccessible care systems	
Myers et al. (2009)	493	Question-naire	➢ Whole family impact	➢ Stress ➢ Child-behaviours ➢ Well-being ➢ Social isolation
Nealy et al. (2012)	8	Interviews	➢ Negative impact	
Neely-Barnes et al. (2011)			➢ Blame	

Phelps et al. (2009)	80	Question-naire	➢ Family Economics	➢ Psychological ➢ Social ➢ Child’s future
Resch et al. (2010)	40	Focus groups	➢ Financial	
Schaaf et al. (2011)	5	Semi-structured interview	➢ Impact on family	
Woodgate et al. (2008)	16	Interviews	➢ Isolation	