

Are parents identifying positive aspects to parenting their child with an intellectual disability or are they just coping? A qualitative exploration

Abstract

Although acknowledging the stress of raising their child with intellectual disabilities, parents also report that their child has brought about many positive changes for themselves and family. This study firstly reports what parents perceive to be a positive aspect of parenting their child as currently what constitutes a 'positive' is unclear. Seven key themes were identified; an increased sense of personal strength and confidence, changed priorities, greater appreciation of life, pleasure in the child's accomplishments, increased faith/spirituality, more meaningful relationships and the positive effect that the child has on the wider community. Secondly, interpretive examination of the themes reveals that the positive aspects identified consist mostly of meaning-focused coping strategies. These enable parents to adapt successfully with the stressful experiences of raising their child and therefore could be amenable to meaning-focused therapeutic interventions for parents with newly diagnosed children or for those unable to identify any positive aspects of parenting their child.

Keywords

Intellectual disabilities, caring, meaning-focused coping, positive aspects, positive reframing

Background

Most children with intellectual disabilities live at home with their parents, with the majority of parents providing lifelong support for their child (Emerson and Hatton, 2008). This support can include direct care (helping with activities of daily living i.e. washing or dressing), emotional care (providing support and encouragement), mediation care (negotiating with others on behalf of the individual i.e. services) and financial care (Horowitz, 1985). In addition the child will often experience long-term chronic conditions and/or complex health care needs that will also require on-going daily management, time and resources.

This need for lifelong support has led historically to research on parenting a child with intellectual disabilities to be framed within stimulus based orientation to stress models and the medical model, both of which construct intellectual disability as a series of functional deficits (Emerson & Hatton, 2014). Both focus on the child as a 'negative stressor' and report the negative impact or burden that the child's impairment(s) have on the parent or family, including higher levels of psychological distress, depressive symptoms and poorer general health than parents of typically developing children (Miodrag & Hodapp 2010, Woodman & Hauser-Cram 2013) with these poor outcomes increasing with the duration and intensity of the 'caring' role (Neece & Baker 2008, Department of Health 2010).

Anecdotal findings of parents reporting 'positive aspects' of parenting in studies exploring stress were initially seen as denial or as a maladaptive reality distortion (Affleck & Tennen 1996), however although often conceived as reflecting opposite dimensions, negative and positive appraisals of the impact of parenting a child with an intellectual disability have been found to be independent of each other and can also occur simultaneously (Stainton & Besser 1998, Hastings & Taunt 2002, Rapanaro et al. 2008).

Positive Aspects

The aspects that parents perceive to be positive are difficult to define as the disability field lacks theoretical models which address the idea of 'positivity' and in addition, the elements that contribute to the construct of a positive aspect are complex, not clearly defined and there is a lack of conceptual clarity leading it to be conceptualised differently between studies (Helgeson et al. 2006, Blacher & Baker 2007). Only a few studies have provided definitions of what a positive aspect is; "*any indication that the family or any of its individual members have benefited as a result of the child with disabilities*" (Helff & Glidden 1998:459) or the "*belief or conclusion that an adverse event or circumstance has revealed or evoked positive outcomes in one's life*" (Rapanaro et al. 2008:35).

In addition, the terms used by researchers to define these positive aspects are used interchangeably, the most common being positive impact(s) (Stainton & Besser 1998, Hastings et al. 2002, Blacher & Baker 2007a, Scallan et al. 2011, Lakhani et al. 2013, Blacher et al. 2013). Others variously describe positive perceptions (Hastings et al. 2002, Hastings & Taunt 2002, Baker et al. 2005, Greer et al. 2006, Vilaseca et al. 2013) as benefits or benefit finding (Rapanaro et al. 2008), Foster et al 2010, , positive contributions (Hastings et al., 2005), rewards (Grant et al., 1998), positive experiences (Kimura and Yamazaki, 2013), gratifications (Valentine et al. 1998), positive contributions (Turnbull et al. 1988, Behr et al. 1992,), stress related growth (King & Patterson, 2000), transformations (Scorgie et al., 2001) and positive aspects (Kenny & McGilloway 2007).

The positive aspects that parents identify can refer to actual changes that they have undergone or perceptions of change, however due to the lack of conceptual clarity this has resulted in a mix of quantitative instruments and measures being used which has generated results which are difficult to compare. Meta-analytic findings of benefit finding and growth (across a wide range of stressful events) suggest that benefit finding measured 'sometime' after the event reflects actual change or growth in the person, whereas measuring benefit finding soon after the event reflects

a cognitive strategy used to reduce stress, however they concede is difficult to pinpoint as it appears researchers are not all studying the same phenomenon (Helgeson et al. 2006).

Caregivers for older people with dementia who report positive aspects of caring have been found to have better self-reported health, less depressive symptoms and higher caregiving competence (Basu et al. 2015, Cheng et al. 2013). However, similar studies in carers supporting older people, (Cohen et al. 2002:188) express concerns for carers who are unable to identify any positive aspects of their caring role, one concluding; *“carers who cannot identify anything positive about caring may be at particular risk for depression and poor health outcomes in addition to institutionalizing the cared for earlier than others”* and Nolan et al (1996) report that a lack of carer ‘gratification’ could be an indicator of risk of abuse for older people.

Parents of children with intellectual disabilities spend the longest time as carers (it is estimated that 75% of parents have been caring for more than 20 years, compared to an average of 18.1% for all carers in England (Emerson et al., 2011) and this has been shown to impact on their wellbeing. Therefore it is important to understand what these parents perceive to be positive aspects and in addition whether the positives they describe could be amenable to therapeutic interventions which might increase positivity. This could be an important resource for parents of newly diagnosed children or for parents who are unable to identify any positive aspects.

In an attempt to draw conclusions about the nature of the ‘positive perceptions’, Hastings & Taunt (2002) compared five studies where parents were asked to describe ‘the positive impact that a child with a disability can have on the family’ and identified a framework of fourteen key positive themes. Despite differing sample sizes, methodologies and ways of conceptualising positive perceptions and experiences, they found consistent themes identified across all the studies as shown in table 1.

Table 1. Positive perceptions identified by parents: themes across five studies (Hastings & Taunt 2002:118)

- Pleasure/satisfaction in providing care for the child
- Child is a source of joy/happiness
- Sense of accomplishment in having done ones best for the child
- Sharing love with the child
- Child provides a challenge or opportunity to learn and develop
- Strengthened family and/or marriage
- Gives a new or increased sense of purpose in life
- Has led to the development of new skills, abilities or new career opportunities
- Become a better person (more compassionate, less selfish, more tolerant)
- Increased personal strength or confidence
- Expanded social and community networks
- Increased spirituality
- Changed ones perspective on life (clarified what is important in life, more aware of the future)
- Making the most of each day, living life at a slower pace

It has been posited however, that parents are not actually identifying positive aspects of parenting their child *per se*, but the positives they describe are adaptive coping mechanisms in which they engage in positive reframing, one of the most common components of meaning-focused coping (Hastings et al. 2002, Park & Folkman 1997). Some do not support this assumption and argue that these benefits are not artifacts of cognitive coping mechanisms (Taylor 1983, Stainton & Besser 1998, Greer et al. 2006) and that if a parent reports benefits, “we should take them at their word” (McConnell et al. 2014:1)

Meaning-focused coping

Coping is a response aimed at “diminishing the physical, emotional and psychological burden that is linked to stressful life events....” (Snyder & Dinoff 1999:5) and the transactional model of stress and coping (Lazarus and Folkman, 1987) highlights the cognitive and emotional aspects of the person experiencing the stress with the appraisal and coping process central to this perspective. This model includes ‘positive psychological states’ which are the result of meaning-focused coping strategies which involves searching for “*a more favorable understanding of the situation and its implications*” (Park 2013:40) and has been widely adopted for use in studies in families of children with intellectual disabilities (Grant et al. 1998).

Within meaning-focused coping, positive reappraisal (also referred to as positive reframing, positive cognitive restructuring and benefit finding) is the most commonly used strategy. Positive reappraisal is a way of viewing and experiencing the stressful events, ideas, concepts and emotions in order to find more positive alternatives; for example, deciding that there are 'more important things in life', 'something a lot worse could happen' or 'finding a silver lining' (Troy et al. 2010, Hill Rice 2012). In quantitative studies, positive reappraisal was found to be a significant independent predictor of positive perceptions in mothers of children with an intellectual disability after controlling for other factors such as social support and degree of care required (Hastings et al 2002).

'Meaning' is described as "making sense, order or coherence out of one's existence" (Reker et al. 1987:44). Meaning-focused coping is based on the assumption that individuals experience stress when they perceive discrepancies between their appraised meaning of a particular situation (degree of threat, harm, controllability, implications) and their global meaning (fundamental assumptions on life, values, goals, beliefs, desires) (Park & Folkman, 1997). For example, most parents assume that their child will be healthy and follow a normal development pattern and the diagnosis of intellectual disability is likely to violate their beliefs about the fairness of why this has happened to them. Most will be faced with how to resolve the incongruence between their global and appraised meaning. This will require them to re-evaluate their hoped-for future life goals, plans and priorities and this incongruence may be changed by searching for a more favourable understanding of the situation, reducing the mismatch between situational and global meaning (Park 2013).

Other strategies used in meaning-focused coping includes benefit reminding (making an intentional effort to recall previously found benefits), adaptive goal processes (revising goals and planning goal-directed problem focused coping which fosters meaning in terms of purpose and control), reordering of priorities (value based process where aspects of life move up or down the

priority ladder) and activating spiritual beliefs and experiences through which individuals find existential meaning (Park 2011).

Over the past 20 years there has been a small body of literature which has recognised the positive contributions, rather than the negative effect, a child with an intellectual disability makes to the family (Hastings & Taunt, 2002). However, exploring what parents describe or perceive to be positive and the factors surrounding their occurrence requires further investigation in order to understand this phenomenon more fully.

Aim of study

The aim of this study is to explore what parents perceive to be the 'positive aspects' of parenting their child with intellectual disabilities. Its objective is to clarify the nature of any positive aspects that parents describe. Secondary objectives are to ascertain if any positive aspects identified arise from parents reframing their experience which could be considered meaning-focused coping strategies or if there is a discourse of parenting a child with intellectual disabilities which is positive.

Methods:

This qualitative study was undertaken as the first phase of a sequential mixed methods study (Creswell and Clark, 2007) and is underpinned by the philosophy of pragmatism (Biesta, 2010). One of the fundamental components of pragmatism is that it is a process of 'knowing' the current situation and through action, re-shaping a new reality (Hartrick Doane and Varcoe, 2005). Ethical approval for this study was granted from the London South Bank University research ethics committee in September 2013 (UREC 1338).

Face to face semi-structured interviews were considered most appropriate as they would be more convenient for carers and allow them to respond to guided questions (Kvale, 2007; Mays and Pope, 2008) and were undertaken by the first author. The parents own characteristics and

attributes and the wider social/psychological environment were then explored through a series of questions included in the interview schedule (box 1). The interviews were audio-recorded and following each interview field notes were written which included the researcher's reflections.

Box 1: Interview Schedule

1. Tell me about yourself...
2. Can you tell me about your child?
3. Can you describe to me in which ways [child's name] had a positive impact on you or your family?
4. What makes these 'positives' meaningful for you?
5. Are there other words or a term you would use instead to describe the(se) 'positive aspects'?
6. In your experience, do/can these positive aspects change over the time/years you spend caring?

The audio files were transcribed verbatim, reviewed for accuracy and potential identifying features were anonymised. The data were then analysed using a thematic analysis (Braun and Clarke, 2006) to identify key themes at a semantic level which Boyatzis (1998) describes as not looking beyond what the participant has said. As the first author had already undertaken a systematic literature review on the positive aspects of parenting it was important while undertaking the data analysis, to avoid the unconscious 'seeing' of data that researchers expect to find (Crabtree and Miller, 1999) and also not to force the data into preconceived categories, affecting the confirmability of the findings. Multiple readings of the transcripts and field notes took place and annotations were added prior to coding. Coding was initially a phrase or a single word that captured the 'essence' of what a positive aspect might be and was undertaken firstly in individual transcripts and then across all 17 transcripts. Areas of consensus began to emerge and cluster as themes in relation to the research question and themes were then further clustered and assigned succinct phrases to describe the meaning that underpinned each theme. The adequacy and appropriateness of the themes were subject to interpretive rigor (Ezzy, 2002) as these were checked by two other researchers and any discrepancies or disagreements led to all the research team reading the transcript together and agreeing a coding and theme which increased the credibility and trustworthiness of the data interpretation. Following this analysis, the secondary objective of whether these themes could be considered meaning focused coping strategies was

explored at an interpretive level (Boyatzis, 1998) by scrutinising the 'broader meanings of the themes' (Patton, 2002).

Participants

Fourteen mothers and five fathers (includes two couples) were recruited through learning disability partnership boards and local MENCAP organisations from London boroughs between October 2013 and March 2014. Inclusion criteria for the parent participants were that the child they supported had a diagnosis of intellectual disability, parents had to communicate using English language, be aged over 18 years and that the child was over 5 years of age and lived in the same household. Between them the participants parented 10 males and 9 females who had a diverse range of intellectual and associated physical disabilities with two families containing more than one child with intellectual disabilities. Table 2 provides a summary of the characteristics of the participants and their child(children) at the time of the interview.

Table .2. Summary of the characteristics of the participants & their child(children)

| Parent | | | | | | Child/Adult with ID | | | |
|--------|--------|--------|---------------------|-------------------|--------------------|---------------------|--------|-------------------------------------|---|
| No | Age | Gender | Ethnicity | Marital Status | Occupation | Age | Gender | Diagnosis | Position in family |
| 1 | 62 | F | British | Married | Retired | 43 | F | GDD/ Physical disabilities | Only child |
| 2 | 53, 40 | M F | Caucasian | Married | Unemployed/ Carer | 15, 13 | M M | Both GDD, plus one also has ASD | 2 nd & 3 rd of 5 children |
| 3 | 64 | F | White South African | Divorced/Single | Retired | 12 | F | ASD | Only child (Grand-daughter) |
| 4 | 63, 64 | M F | Caucasian | Married | Retired | 34 | M | Spina Bifida, Hydro-cephalus | Youngest of 3 |
| 5 | 70 | F | Caucasian | Married | Retired | 7 | M | ASD | Only child (Grandson) |
| 6 | 45 | F | Columbian | Divorced/Single | Full time carer | 12 | F | ASD | Only child |
| 7 | 33 | F | Turkish | Married | Full time carer | 7 7 | M M | GDD, Blind, one also partially deaf | Only children (twins) |
| 8 | 40 | M | Asian | Married | Unemployed | 10 | F | GDD | Youngest of 3 |
| 9 | 59 | F | Caucasian | Married | Unemployed | 33 | F | Williams Syndrome | Youngest of 2 |
| 10 | 68 | M | Caucasian | Married | Retired | 32 | M | Down syndrome | Youngest of 3 |
| 11 | 49 | F | Jamaican | Single | Employed full time | 25 | M | GDD & ASD | Only child |
| 12 | 60 | F | Australian | Single | Full time student | 36 | F | Blind & ASD | Youngest of two |
| 13 | 51 | F | Caucasian | Married | Employed part time | 27 | M | Chromosomal abnormality | Youngest of 2 |
| 14 | 32 | F | Caucasian | Separated/ single | Full time carer | 15 | F | GDD/Physical Disabilities | Only child |
| 15 | 48 | F | Caucasian | Married | Employed part time | 23 | M | Down Syndrome | Youngest of 2 |
| 16 | 61 | F | Caucasian | Married | Retired | 31, | F | ASD | Middle child of 3 |
| 17 | 29 | F | Polish | Single | Full time carer | 7 | M | Acquired brain injury | Only Child |

GDD – Global developmental delay

ASD – Autism spectrum disorder

Findings:

All but one parent chose to be interviewed in their own home and each interview lasted approximately one hour. Despite the focus of the interviews being to identify the positives of parenting a child with intellectual disabilities, in every interview a much larger proportion of time was spent by the parent talking about the negative aspects of parenting their child which is consistent with other qualitative studies, (Rapanaro et al. 2008, Foster et al. 2010, Skotko et al. 2011). However, only the positive aspects will be reported here. Six of the overarching themes identified were broadly similar across the framework of positive themes identified by Hastings &

Taunt (2002) however, one theme was identified from this study which had not been identified by them, the positive effect the child has on others.

The seven key themes identified covered three broad areas. Intrapersonal factors, those which have a direct influence on the parent themselves (increased personal strength, changed priorities, a greater appreciation of life, increased spirituality/religiosity), interpersonal factors; factors which relate to aspects which exist between persons (more meaningful relationships with others, the positive effect the child has on others) and one factor where the child is the source of positivity, the child's accomplishments. These themes were identified in the transcripts of all parents irrespective of their gender or the age of the child.

Increased personal strength

This was the most common theme identified and without exception all the parents reported how they had changed and had become stronger, tougher and more confident as a result of their child. Some described gaining a new inner strength they did not have before and they compared this in terms of the 'old' me and the 'new' me. However, when they spoke about acquiring an increased personal strength, it became synonymous with 'fighting' in many cases as they equated it to how they needed to 'fight' for services and advocate on behalf of their children. They felt that now they could handle 'this situation' then they could handle about anything.

"I wouldn't be the same person if I didn't have him, um he's really made me be more proactive and confident. I was never like that before and he's made me, he's made me pull my socks up and get on with things." (parent 13)

Changed priorities

Every parent attributed how their perceptions of what was important in life had changed directly as a result of having their child, both in the way they approached life revising what was important to them in life. Personal changes included being less materialistic, less selfish and being more content. Four of the mothers had changed career paths of which two had become nurses and one a counsellor and another had given up well paid work to study, something she had always wanted to do.

"...I've realised what things are more important than other things, you know, there are things that I used to think were important and I look back and I think to myself they really had no value at all." (parent 5)

Greater appreciation of life

Despite unanimous agreement that their life had become harder and more stressful since having their children, parents spoke of a gaining a greater satisfaction and greater sense of life's values and having a new perspective and an increased appreciation of what they have in life. On the whole they had become more appreciative of the 'simple things in life' such as just

enjoying spending time with the child and others and approaching life one day at a time (some due to the uncertainty of their child's condition). Some described how easy it was in life to get caught up in keeping up with the expectations and views of others and society and that having their child had made them take stock and consider what they have in life and what is important.

"I think when you see the world through our sons and daughters eyes it makes it very clear that actually we've got so much to be happy for, be glad for, be grateful for in life." (parent 13)

Child's accomplishments

Without exception, every parent spoke about how much they loved their child. They described a positive aspect as the child's accomplishments, no matter how small, especially if the child 'triumphs over adversity', the pleasure gained from seeing their child accomplish something that they thought or had been told that they would never be able to do took on a special meaning. These accomplishments ranged from simple things such as just saying a new word, tying a shoelace and learning to walk to more serious incidents such as surviving serious illness.

"I'm saying to myself oh I'm so lucky, for example [childs name] is walking. It's such a big thing for me, I don't care what else is happening in the world, it makes my day to see him walk when they said he never would." (parent 7)

Increased spirituality/faith

Three parents described how they had initially 'lost' their faith (one permanently) and spoke about 'refinding' God as they believed the child had been brought into their lives for a reason. Others reported taking a more philosophical approach to their situation as although wondering why this had happened to them, they accepted that it was meant to be were going to get on with whatever life had in store for them.

"...because I just say maybe God thought – my belief, my strong beliefthere got to be a big reason for this – I don't know, I came here for her. I say that child needed a mother and that mother was me." (parent 6)

More meaningful relationships

Parents recounted how having more meaningful relationships with family members, others outside the family and with professionals had become really important to them. Two parents expressed how their child had strengthened their marriage, and others spoke about working well together, being closer and supporting each other through 'thick & thin'. Some described how through having their child they found out who their 'true friends were' and described friendships with other parents who had children with intellectual disabilities as 'deep' and 'special' due to the bond they shared with their 'special' children. Most acknowledged that they had become more patient, accepting and tolerant towards people in general and that they had experienced an increased sense of compassion and empathy towards others, especially those who were vulnerable or had disabilities as they felt that they knew what they were going through.

"I met a group of friends and we are friends to this day, most of them have children with learning disabilities, we understand what each other is going through....." (parent 1)

Positive effect of the child on others

Parents spoke about their child not only having a positive influence on their lives but also a positive effect on the lives of others who came into contact with them. They described how people meeting their children not only gained an understanding of intellectual disability, but also learned to see beyond the disability and got to know and love the real 'them'.

"The positive I guess the fact that he has improved our friend's attitude towards learning disabled because they have seen and they have got to know [childs name] and he is physically handicapped as well and it has changed their attitude to other people with disability." (parent 4)

The key themes, sub themes and further illustrative quotes are shown in Table 3.

Table 3. Key themes and sub themes identified relating to positive aspects

| Key themes | Subthemes | Illustrative quotes |
|-------------------------------|--|---|
| Increased personal strength | Fight for my child | <ul style="list-style-type: none"> “It’s made us both tougher. You need to be tougher and grow thicker skin when your child is disabled or else you just get trodden on and don’t get anywhere.” (parent 4) “... but it’s taught me if I want something for him, like from the erm council, I have to find the tools to get there and not to stop until I get it.” (parent 7) |
| | Inner strength | <ul style="list-style-type: none"> “... but I think this is good for me, I say this is building me up. This is giving me strength. This is making me a different person which many people say, ‘You have changed a lot. You have changed a lot.’ Right now I feel like I can do anything!” (parent 6) “That’s the word... I’m very headstrong now. I wasn’t before I had him and he’s made me stronger.” (parent 11) |
| Changed priorities | Life changing | <ul style="list-style-type: none"> “I did a masters degree you know, and then I thought oh f*** you I’ll do it, I’ll do a PhD as well, and I’ll do some work and I’ll do something else. I’ll do it all! Just finished my PhD and I’ve dedicated it to her... because without her I wouldn’t be doing it.” (parent 12) “... I do feel that it’s an honour that I’ve had [childs name] because I would not be the person I am now. I would not be as tolerant, I would not be as creative, I would not be as big a person as I would have been otherwise. I could not have envisaged the world as I do now if I hadn’t had him.” (parent 17) |
| | Material things don’t matter | <ul style="list-style-type: none"> “... I understand now life is important, life is so short and if you have health you don’t need to complain anymore. For example money is not important, but health and happiness is important.” (parent 3) “Money and all the trappings don’t mean much anymore our priorities have definitely changed...” (parent 9) “We treasure each day with her, just spending time with her. Before we had her all we used to worry about was work, work, work... how naive we were that that’s what we thought mattered most in our lives” (parent 16) |
| Greater appreciation of life | Live one day at a time | <ul style="list-style-type: none"> “Funny thing to say isn’t it? When I had him I thought I couldn’t live with him and now I couldn’t live one day without him and with his illness we just enjoy one day at a time...” (parent 10) “We live one day at a time, enjoying the best of life we possibly can...” (parent 7) |
| | Simple things mean more | <ul style="list-style-type: none"> “...we get a lot of pleasure just spending time with [childs name]. We don’t even have to be doing anything fancy you know, something like just taking her for a walk in the park, that’s what we enjoy, the simple things. Does that sound weird?” (parent 1) I think one of the positives is basic simple things in life are more apparent that I could enjoy are important more than other things perhaps I have not expressed it properly but perhaps it puts your priorities right.” (parent 14) |
| More meaningful relationships | Closer relationships with others | <ul style="list-style-type: none"> “... if I had not had (child’s name) I don’t think I would still be married ... because we’ve had [childs name] we’ve had to concentrate more on us. I think possibly we could have broken up. I think she has bonded us together. I think so, so that’s good. (parent 1) “...it’s pushed me out of my reservations but also it’s made me so, so much more tolerant of people.” (parent 11) |
| | Empathy with others in a similar situation | <ul style="list-style-type: none"> “...if you see someone in the street that is disabled and like I said before to you would feel now you want to go and talk to them, you relate to them you see them more as a person than before when you would see them just as the person with a disability.” (parents 4) “... although I’ve always had a certain amount of empathy...you actually grow...it grows huge because you then start thinking of how they’re feeling, and then when you start thinking of how other people are feeling when you say certain things to them, so then you then start thinking before you speak, because you’re thinking of how it will affect that person.” (parents 5) |
| Increased spirituality/ faith | Faith | <ul style="list-style-type: none"> “I’m a Christian and it’s very much a Christian teaching helping others, understanding others, not being so selfish being more humble too and I think in some ways that it’s almost good for me...” (parent 3) “I think sometimes God has some influence in your life and he brings people like those for you to become or accentuate your positive aspects towards people with learning disabilities.” (parent 8) |
| | Spirituality | <ul style="list-style-type: none"> “I’m definitely less judgemental, more empathic, more looking at the people inside, more spiritual, more looking at why these things happen in life...” (parent 2) “It’s just how you make it at the end of the day, it’s how you are and [child’s name] was given to us for a reason and we get on with it”(parent 5) |

| | | |
|---|--|--|
| Childs accomplishments | Triumph over adversity | <ul style="list-style-type: none"> • “If I hear someone turn round and say she can’t do it and then she does it, then I feel like rubbing that person’s face in it [laughter].” (parent 1) • “When I think of the phenomenal effort that [child’s name] puts into doing things and finally he does it you just think, I love him he’s so brilliant.” (parent 11) • ...when you see her really struggling to overcome something and she does, it's like massive (parent 12) |
| | Love for the child | <ul style="list-style-type: none"> • “Oh he’s such fun, he’s great. It’s a joy to have him around. I mean he’s a little monster and we’ve been through hell together this little monster and I, but I do love him.” (parent 5) • He’s absolutely adorable and I love him to bits... (parent 11) |
| Positive effect the child has on others | Acceptance from others | <ul style="list-style-type: none"> • “...when people come in contact with him they appreciate him and have got to love him like we do.” (parent 4) • “Everyone that comes into touch with her loves her.” (parent 12) |
| | Raising awareness of intellectual disabilities | <ul style="list-style-type: none"> • “... from our point of view she has definitely enriched our lives and enriches other people’s that other people have never come across disability in any shape of form.” (parent 1) • “I actually think that other people are better off for coming into contact with our children you know.” (parent 2) • “I think it brings something to people’s lives, I think it makes them better people when they come into contact with people like [child’s name] (parent 10) • I notice now as well the positives for other people from him just meeting them...” (parent 11) |

The broader meaning of each key theme was then scrutinised at an interpretive level (Boyatzis, 1998) and the transcripts also revisited to ascertain if any of the positive aspects identified arise from parents reframing their experience which could be considered meaning-focused coping strategies.

Discussion

Joy, hope, and pride were the most common terms used to describe their children and are examples of discrete positive emotions which counteract the physiological effects of negative emotions, facilitate adaptive coping (Folkman & Moskowitz, 2004) and fuel psychological resiliency (Fredrickson, 2001). The parents could be filled with 'hope' that their child would one day be able to achieve certain goals and hope in families of children with intellectual disabilities has been described as "*a complex intangible in the healing and coping process*" (Kauser et al. 2003:35). Love is a compilation of all of these emotions (Fredrickson, 2011) and every parent in this study spoke about feelings of love for their child and how proud they were when their child achieved something unexpected.

The parents also spoke about being thankful, grateful and optimistic. Gratitude is a feeling of thankfulness and is considered a positive emotion and a coping response (Fredrickson, 2004) with individuals who have higher dispositional gratitude viewing life experiences as more meaningful and are more likely to use positive reframing strategies to interpret negative experiences (Lambert et al., 2009), for example, parents being thankful for what they have in life and appreciating of the preciousness of life (Thoits, 1995). Gratitude is also related to dispositional optimism which has also been positively associated with positive reinterpretation and reports of positive life changes (Carver et al. 1989) and is the personality characteristic with one of the highest correlations with well-being (Wood et al., 2007).

Early publications describe how parents were acutely affected by the degree to which their child with intellectual disabilities was accepted or rejected by the community (Holroyd 1974, Bristol, 1984) and more recently (Esdaile, 2009) reported similar findings with mothers of children with intellectual disabilities seeking to have their children accepted and valued by others in society. Many families, (especially those with older children) remember having to fight to keep their child

at home with them and for them not to be routinely institutionalised and kept away from society. Reporting that their child had made a positive impact on others could be recognition to parents that their child has finally been 'accepted', leading them to feel a greater sense of social connectedness and belonging (Esdaile, 2009) and potentially contributing to the development of an extended social support system for their child should it be needed (Valentine et al. 1998).

Social support is defined as the "resources perceived as being available from others in social networks" (Lopez-Martinez et al. 2008:373) and it is suggested that this may promote growth related to interpersonal relationships and provide positive experiences which bolster positive affect (Cadell et al., 2003, Tedeschi and Calhoun, 2004). Parents also spoke about gaining and maintaining informal supportive family and friends networks and also engaging in more formal relationships with statutory professionals. One unique aspect of parenting a child with intellectual disabilities is the relationship the parent must enter with formal support services in order to arrange support services for the child throughout their lifetime. Formal support was found to be as effective as informal support by parents of children with intellectual disabilities, and the perceived helpfulness of formal support for parents has emerged as a significant predictor for positive perceptions in parents (Hastings et al., 2002). The importance of social and family support, improved relationships, and friendship with other parents in a similar position have been identified as positive aspects in a number of studies (Kimura & Yamazaki 2013, Rapanaro et al. 2008, Foster et al. 2010, Scallan et al. 2011). Parents in this study also spoke about more meaningful relationships with others by becoming more compassionate, more empathic, less judgmental and having increased tolerance and understanding towards others (especially those less fortunate than themselves) since having their child (Kenny & McGilloway 2007, Skotko et al. 2011). Compassion is an empathetic positive emotion and a major source of resilience (Lazarus, 1993).

This study reflects others that have reported parents having a changed outlook on life (Scallan et al., 2011), identifying things which were considered important before but were not important now such as becoming less materialistic and selfish (Kenny & McGilloway 2007), learning patience and how to advocate (Skotko et al 2011). As found in other studies, parents described themselves

as becoming better people with changes in their personal beliefs and values (Kearney and Griffin, 2001) and having a greater sense of personal fulfilment (Rapanaro et al., 2008). Three parents described how they now 'live for the day', and consistent with other findings they enjoyed the 'simple things in life' (Kenny & McGilloway 2007) like just seeing the child happy (Grant et al., 1998). This is consistent with meaning-focussed coping, where aspects of life move up or down in priority, allowing individuals to focus on what matters most and letting go of things that are no longer considered important, deciding 'there are more important things in life' and taking actions to alter some aspect of the 'self' such as changing career paths. Positive reappraisal enabled the parents to reorder their priorities, reconsider their global beliefs, revise their goals and sense of meaning in life which provided them with a renewed sense of purpose and a 'new or changed perspective on life' (Park, 2010, Wrosch, 2010).

Religion and spirituality play a crucial role in the meaning-making process as they are a core aspect of global meaning with individuals reappraising their situation as an opportunity for spiritual growth and feeling closer or reconnecting to God (Park & Folkman 1997, Park 2013). Faith, religious beliefs or spirituality have all been identified as coping mechanisms related to psychological adjustment to stress (Pargament et al., 1998) and this can also provide psychological and emotional support from others, such as members of the church (Skinner et al., 2001). Although some parents in this study spoke about spiritual growth, increased religiosity and spirituality, this was one of the least reported positive aspects.

Increased personal strength and the personal growth have been identified in a number of qualitative studies (Stainton & Besser 1998, Kearney & Griffin 2001, Greer et al. 2006, Rapanaro et al. 2008, Skotko et al. 2011, Kimura & Yamazaki 2013). This theme has also been identified as significant in a number of quantitative studies containing a measure relating specifically to 'personal/emotional growth and maturity' (Hastings et al. 2002, Hastings et al. 2005, Greer et al. 2006, Foster et al. 2010, Lakhani et al. 2013, Vilaseca et al. 2014). In a quantitative study comparing mothers and fathers, mothers reported higher personal growth (Vilaseca et al., 2013) and a longitudinal study found that mothers of children with intellectual disabilities were more

likely to perceive their parental role as a 'challenge' which then became the dominant issue in their lives (Pelchat et al., 2003).

The parents in this study spoke about focusing on the specific problems or situations and tried to generate alternative solutions, weighing up the costs and benefits of various actions, taking control, seeking information from professionals and mastering new knowledge and skills from this process, which could be construed as an active coping effort which includes positive reframing strategies (Carver et al., 1989) . Revising goals and planning fosters feelings of control and mastery and generates positive affect (happiness, joy, contentment) (Folkman & Moskowitz, 2000). Having a purpose in life, striving towards new goals and gaining control are problem-focused coping strategies which rely on the parents' ability to build on their personal experience and the expertise they have built up and was also the most commonly reported theme in a qualitative study of families with children with intellectual disabilities across the child's lifespan (Grant and Whittell, 2000).

The parents' new found strength could also be explained as increased self-efficacy. An obstacle, such as not being able to access services for their child, could motivate parents with high self-efficacy to put in greater efforts to pursue and attain these services and exercise control over their lives, a prerequisite for problem-focused coping. Self-efficacy beliefs have been found to enhance some dimensions of benefit finding such as personal growth, increased sensitivity to others, and acceptance of life imperfections (Tedeschi & Calhoun 2004, Luszczynska et al. 2005, Foster et al. 2010). Hastings et al. (2002) found that in mothers of children with intellectual disabilities, positive reframing was found to be a predictor of their personal growth and maturity.

When asked, not one of the parents was able to offer an alternative other word or term which summed up the 'positive aspects' they were describing and only one parent mentioned the word 'coping' throughout the interviews. However, the findings suggest that all the positive themes identified by the parents contained differing degrees of meaning-focused coping strategies which included positive reappraisal to deal with solving or changing the perceived cause of stress, revised identity, increased growth, changed views of the world, and a mixture of problem-focused

and support-seeking adaptive coping strategies to obtain emotional support. These strategies are not distinct coping styles, but are parts of the 'total coping effort' which people can draw on to produce the best adaptational outcomes for themselves (Park and Folkman, 1997). They were consistent with Folkman (1997) who described four coping strategies associated with searching for and finding positive meaning, *"positive reappraisal, goal-directed problem-focused coping, spiritual beliefs and practices, and the infusion of ordinary events with positive meaning all involve the activation of beliefs, values, or goals that help define the positive significance of events."* (p1215).

The parents in this study found positive meaning in the stressful events of having a child with intellectual disabilities. They used conscious cognitive effort to produce positive emotions which helps buffer against stress and generates experiences of positive emotion and positive affect as a way of buffering themselves from the distress (Folkman & Moskowitz 2000). Positive emotions may also accelerate the individual's ability to adapt to subsequent stressors (Ong et al 2006) which are seen as crucial in helping the individual adapt, cope or sustain efforts with stressful experiences, such as those associated with caregiving over long periods of time (Folkman & Moskowitz 2000, Hastings et al 2002).

Positive emotions such as happiness, pride, relief, love, hope, compassion, and gratitude were identified in these interviews but this is not unexpected. Lazarus (1993) argues that psychological stress theory and the theory of emotion are parallel as the two share overlapping ideas and that in addition to individuals identifying negative emotions as a reaction to stress (anger, anxiety, fright, guilt, sadness) there are also a small number of positive emotions brought about by a different appraisal of the personal significance of the stressor as appraised by the person who encounters it. Experiencing positive emotions promotes people to take creative actions, ideas and social bonds which builds their personal resources and psychological growth such as the parent who completed a PhD or the parents who set up support groups, all things they would never have considered prior to having their child.

The findings suggest that in this study the transactional stress and coping model (Lazarus and Folkman, 1987) would be a suitable theoretical framework to underpin the parents 'positivity'. It has an emphasis on meaning-focused coping, which includes positive reappraisal strategies, whereby parents search for a meaning for their situation by drawing on their beliefs, values, and goals to search for a more favourable and positive understanding of their situation.

However, this study raises a key question of whether the positive aspects identified by the parents are an exclusive phenomenon of parenting a child with an intellectual disability or if they are general adaptive coping strategies used by most people in stressful situations. Almost identical common themes to those identified by the parents in this study have been found across a wide range of studies exploring stress-related growth and coping in individuals who have experienced trauma, bereavement and chronic illness. Similarly, these studies report positive changes in social relationships, perceiving improved personal strength and self-assurance, and increased spiritual appreciation and changed priorities in life (Calhoun and Tedeschi, 2006; Joseph and Linley, 2006). This 'growth' is also assumed to arise as a meaning-making process and is referred to interchangeably as posttraumatic growth, perceived benefits, adversarial growth and benefit finding (Park, 2013). Blacher & Baker (2007) also argue that these positive aspects are not a unique phenomenon of parenting a child with intellectual disabilities, as findings from a comparison study showed similar themes also reported in families with typically developing children. Therefore, it might be hypothesised that only one theme identified by the parents in this study could be considered a 'unique' positive aspect of parenting a child with intellectual disabilities, 'the positive effect that their child has on others'.

Implications for practitioners

Practitioners should be aware that parents of children with intellectual disabilities spend the longest time of all carer groups caring. Carers in general are known to have poorer health than the general population but these poor health outcomes increase with the duration and intensity of the caring role (Neece & Baker 2008, Department of Health 2010) making these parents susceptible to poorer health outcomes.

Therefore, professional or therapeutic interventions should be considered to support parents to develop effective meaning-focused coping strategies as they have been shown to increase positive emotions. Positive emotions such as those expressed, have been found to enhance both emotional and physical wellbeing, serve as resources for people coping with adversity and help people cope with chronic stress (Folkman & Moskowitz, 2004). They have also been prospectively associated with greater health-enhancing behaviours, such as better diet, regular exercise, and improved sleep and this is a factor which improves health (Cohen and Pressman, 2006).

This could include psychological therapies as positive reappraisal underpins many forms of cognitive behavioural therapy (CBT). CBT it does not focus explicitly on the positive aspects of the situation, it concerns replacing negative thoughts with more rational ones (Moskowitz, 2011) and has been found to improve the well-being of parents of children with intellectual disabilities (Hastings and Beck, 2004; Wong et al., 2011). Interventions with individuals using meaning-making coping strategies have been found to produce higher levels of self-esteem, optimism and self-efficacy than a control group after controlling for baseline scores (Chan et al., 2007) and although its effectiveness for parents of children with intellectual disabilities has yet to be fully evaluated, mindfulness training programmes have shown to help people regulate emotions and growth in positive reappraisal coping in the general population (Garland et al., 2009). In addition, a parent skills training intervention aimed at teaching parents ways of successfully managing their children's problem behaviours has been shown to enhance a parents sense of mastery/self-efficacy (Hastings & Beck, 2004).

Strengths and limitations

This study contributes to the limited literature on understanding what parents perceive to be the positive aspects of parenting a child with intellectual disabilities. To our knowledge this is the first qualitative paper that explores what parents of children with ID report to be a positive aspect of parenting and whether this could be considered a meaning focused coping strategy. The themes and language used by the parent participants have been used to inform the development of a questionnaire instrument to be included in a survey for phase two of this mixed methods study. This will explore in more detail the relationship between positive aspects and the parents' self-

reported health and wellbeing. As the study was small in scale and based on a purposive sample, caution should be taken regarding the transferability of the findings to other parents of children with intellectual disabilities. Purposive sampling did however ensure that a broad age range of parents of both genders and from a variety of ethnic and social backgrounds who were at different stages of the caring lifespan. The range of factors that may influence stress-coping such as the parent's values, commitments, goals, personality and environmental factors (Lazarus & Folkman, 1987) and personality traits such as dispositional optimism, resilience or having high self-efficacy could not be explored in the study interviews. It is possible however, that a parent has always had these characteristics and therefore the reported positive impact that the child has had on the family simply reflects positive emotion-eliciting coping strategies such as positive reappraisal that are already possessed (Ong et al., 2006). However, it is unlikely that such individual characteristics would be held by all the families in this study. Parents who may not be able to identify any positive aspects will not have volunteered to participate, and although every parent spoke spontaneously at length about the negative aspects of parenting during the interviews, the negatives were not taken into consideration in the analysis.

Whilst undertaking the thematic analysis, it was not always possible to identify mutually exclusive sub-themes and hence when assigning statements to thematic categories some discrepancies may have occurred. Therefore, future studies should look into refining the methods followed to identify the themes.

Conclusion:

The lives of the parents in this study were changed forever by their child's diagnosis of intellectual disability. However, despite every parent acknowledging the daily stresses and strains that parenting their child brings, they also found meaning in their situation drawing on their beliefs, values, and goals to search for a more favourable and positive understanding of their situation consistent with the Transactional model of stress and coping.

The aspects they perceived to be positive were multifaceted and related to interpersonal, intrapersonal and child related factors. All could be attributed in differing degrees to the use of meaning-focused coping strategies; however intertwined were also support seeking strategies,

self-efficacy and the use of positive emotions. This demonstrates that parents use more than just a single coping strategy to find positive meaning in their situation and they are the outcome of complex cognitive appraisal processes rather than parents simply identifying positive aspects. Therefore, some parents may benefit from receiving additional professional or therapeutic interventions to support them to develop adaptive coping and problem-solving skills which would help build positive emotions and resilience. This could lead to an increase in positive wellbeing, reduce depressive symptoms and increased caregiving competence.

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