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‘They Got It’: How professionals can support the emotional wellbeing of parents of a child with a learning disability, or who are autistic

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Abstract: Studies suggest that parents of children with a learning disability or who are autistic (i.e., parent carers) are at greater risk of poorer mental health. Several models and interventions have been utilised to support parent carer wellbeing; few have asked parents themselves what they find helpful. Furthermore, there is limited information for practitioners supporting this group. An interpretive phenomenological study explored emotional wellbeing with 17 parent carers. Themes were developed using Template analysis. Participants reported myriad factors that helped their wellbeing that were developed into three broad themes: i) Relationship with others ii) Protecting their sense of self, and iii) Managing the ongoing emotional rollercoaster. Participants also identified ways in which professionals could better support their wellbeing including: providing a safe reflective space, flexibility of support and awareness of the parents’ context (e.g., disability awareness; the systems around the child). Flexibility included offering online appointments and enabling parents to ‘dip in and out’ of counselling at key points in the child’s life. Furthermore, the breadth of wellbeing strategies identified by participants suggests that an integrative approach may be best placed for ongoing support of parent carer wellbeing.

Keywords: Parent carers, caring, emotional wellbeing, learning disability, parenting

This paper focuses on emotional wellbeing in parents of children with a learning disability or who are autistic, or both (i.e., parent carers). Interviews with parent carers explored how, despite the recognised challenges, they supported their own emotional wellbeing. Participants described various wellbeing strategies and processes as well as ways in which professionals can help. The author is also a parent carer and a counselling psychologist, and the process involved interpretive and reflexive elements which are considered throughout.

Research commonly suggests that parent carers are at greater risk of poor mental health (Rydzewska et al., 2021; Totsika et al. 2011). This is often due to the context in which they find themselves, such as practical challenges (e.g. limited support, socio-economic adversity) (Stanford et al., 2020) rather than the child’s diagnosis per se.

A psychosocial approach is particularly important for this cohort (Woolfson, 2004) as parent carers are affected by several different systems, including microsystems (parts of the environment that they engage with frequently) and macrosystems (national, political and economic systems) (Bronfenbrenner, 1977). While the professionals around such families (e.g., health, education and social care professionals) can be supportive, they can also be experienced as invasive to family life and disempowering. As Kelso et al. (2005) state: 'as advocated by much of the child disability literature it is crucial that professionals work in partnership with parents to reduce the feeling of "them and us"' (p. 9). Furthermore, often the focus of those around them (and the parent themselves) is on the child and therefore the parents' own wellbeing can become neglected.

Parent carers can also experience 'affiliate stigma' (prejudice or discrimination through their association with their disabled child) (Mitter et al., 2019). A survey by the Disabled Children's Partnership (2021) reported that 97% of parent carers felt that society did not understand their child and a further 43% of individuals in wider society have never met anyone with a disability. It has been suggested that society largely operates under a system of disability apartheid (Shakespeare, 2018).

It is estimated that the economic contribution of the unpaid labour of family carers in the United Kingdom is approximately £162 billion annually, greater than the cost of the entire National Health Service (Petrillo & Bennett, 2021). Unfortunately, many families find it difficult to access support such as paid carers or respite services (McConkey et al., 2010). The continuous care responsibilities can therefore contribute to high levels of stress and burnout (Rydzewska et al., 2021).

Importantly, though, despite the 'dominant cultural model of disability [being] inexorably negative… the majority of parents [also] report positive impacts' (McConnell et al. 2015, p. 39). When asked, many parent carers identify positive aspects of parenting their child (e.g., the love for their child, appreciating what is really important in life) (Hastings, 2016; Jess et al., 2017). It therefore makes sense to ask parent carers themselves what supports their emotional wellbeing and ways in which professionals can help.

Given the increased risk of poorer mental health amongst parent carers it is unsurprising that a number of different interventions have been applied to this group by professionals and researchers. These include different theoretical approaches and conceptualisations such as coping and stress models (Lazarus & Folkman, 1984; Myers et al. 2009), third wave cognitive behavioural therapies (e.g. mindfulness, acceptance and commitment and therapy (ACT)) (Gore & Hastings, 2016; Jones et al., 2017; Reid et al., 2016) and positive psychology (Pit-ten Cate, 2003; Seligman, 2011). As suggested in Griffin & Gore (2023), different models or approaches target different aspects, for example, coping and stress models look to reduce stress and thereby increase positive affect (i.e., hedonic approach). Other approaches may look at enhancing meaning-making (i.e., eudaimonic approach) (Ryff, 1989).

Other studies refer to the importance of parent carers managing the tension of holding onto hope while preparing for the worst. Suggesting that the emotional experiences of parent carers are not always straightforward, Larson (1998) refers to embracing the paradox of mixed emotions, both 'negative' and 'positive', that are part of being a parent carer. Kashdan and Rottenberg (2010) also highlight the value of both positive and negative emotions and that at times, negative emotions are more useful in achieving goals. In Woodman and Hauser-Cram's study (2013) mothers of children with disabilities frequently reported denial as helpful, which was noted as inconsistent with prior research on coping.

In addition, some parent carers experience trauma that meets the criteria for post-traumatic stress disorder (Emerson, 2019) or complex trauma (Blackman et al., 2022). A related concept is that of post traumatic growth (PTG) (Calhoun & Tedeschi, 2010), which is linked to meaning making, and refers to the positive change some individuals report after experiencing adversity. It is suggested that making meaning helps resolve ambiguity (Lazarus & Folkman, 1984, p. 295) and provides a sense of personal control. When negative things happen, finding a sense of significance (e.g., the belief that their life matters), and coherence (i.e., the experience fitted with their life story) (Martela & Steger, 2016) provides a way to understand an event (for example, reminding oneself that the world is unpredictable or that you are doing your best). This approach has been found to be beneficial to parent carers (Cadell et al., 2014). Another study used parent carers' self-identified descriptions to design an outcome measure, called the Positive Gain Scale (e.g., I have grown as a person) (Pit-ten Cate, 2003).

The intervention models (e.g., mindfulness, ACT) summarised above have been applied to parent carers but have tended to be applied in a generic way, rather than specific to the needs of parent carers. Given the complex context for parent carers, as outlined earlier, the practical elements of any interventions need to be accessible. For example, committing to regular sessions may be difficult for those with caring responsibilities who are managing many different demands. A couple of studies did make adjustments, such as delivering *online* mindfulness-based interventions alongside peer support (Flynn et al., 2020) and providing a shorter CD recording of mindfulness practices to use at home (Jones et al., 2017). However, many studies did not use adaptations which appears to be a significant omission.

Whilst there is research into this cohort, what is often missing is the parent carer voice. This void can also be found in service development and delivery more broadly (Stanford et al., 2020). Interventions that involve a professional *doing to*, rather than *working with*, parent carers may mirror the disempowerment that is inherent in some of the professional relationships around a family with a disabled child. Working with parent carers to co-design and co-deliver wellbeing interventions is welcomed by parent carers (Sutherland et al., 2025), however, this tends to be the exception rather than the rule (Apanasionok et al., 2025).

There is also limited literature providing guidance for practitioners working with this client group and texts that are available are not recent (Hilton, 1993). Furthermore, many approaches focus on change at an individual level whereas community, societal and structural changes may be more relevant and have a greater positive impact.

Given the complex and varied interventions, theories and conceptualisations surrounding parent carer wellbeing there is a strong argument for exploring, with parent carers themselves, how they make sense of, and support, their own emotional wellbeing. Sharing these findings will add to a greater understanding of the experience thereby making a positive contribution to future research and therapeutic practice.

There is growing acknowledgement that peoples' lived experience should form a key part of research, including increased use of patient and public involvement (NIHR, 2021). As a parent carer as well as a Counselling Psychologist the author was in a prime position to harness the benefits of insider research (Berger, 2015).

Aims of the current study

Some of the findings from this study have already been reported (Griffin & Gore, 2023). This paper develops the concepts further with particular consideration of how professionals can support parent carers.

This paper's aims therefore are to:

1. Explore parent carers' descriptions of what supports their emotional wellbeing.
2. Consider how professionals can best support them, with a particular focus on the counselling/psychotherapy profession

Method

An interpretive phenomenological (IP) approach (Benner, 1994; Heidegger 1962) was adopted, which allows an exploration of the meaning and significance of parents' lived experiences. It is couched in the belief that while we can examine a phenomenon our perspective is always interpretive. This study is also underpinned by the philosophy of pragmatism (Rorty, 2018). By exploring participants' lived experiences and recognising nuance, complexity and context, the study's focus is on what is useful for parent carers. Rather than 'truths', findings are valued for being 'both accessible and useful for practitioners and policymakers' (Willig, 2017, p. 286).

Concepts used in IP which are relevant to this study include dasein, pre-understandings and hermeneutics (Tuohy et al., 2013). Heidegger used the term 'dasein' (Being-in-the-world) to describe how we are always already embedded in a world of meaning (van Manen & Adams, 2010). The author was transparent, from the beginning of the study, about their position as a parent carer.

IP acknowledges the importance of social, political and cultural contexts, which is of particular significance to parent carers. IP has been utilised in other similar studies exploring the experiences of carers (Benner, 1994; Tuohy et al., 2013).

In addition, IP acknowledges that we have prior assumptions (pre-understandings) and there is an iterative process between the hermeneutic (interpretive) and phenomenological (the descriptions by participants) supported by researcher reflexivity. Rather than attempt to 'bracket' (Finlay, 2011) prior knowledge and experience, IP requires the researcher to be transparent and open to change to allow additional insights and relational development of ideas. Therefore, 'data is seen to emerge out of the researcher-co-researcher relationship' (Finlay & Evans, 2009, p. 29) and moves between understanding the whole and its parts.

This study utilised Template Analysis (TeA) (King, 2004) which is a flexible form of thematic analysis that involves developing a coding template. TeA provides the flexibility to develop *a priori* (theoretical) and *a posteriori* (interview-driven) themes.

While the potential epistemological challenge of using IP and *a priori* codes in Template analysis has been noted, it is suggested that researcher reflexivity and treating *a priori* themes cautiously can help reconcile tensions (King & Brooks, 2017). Furthermore, Template analysis provides an 'evident trail of analysis and interpretation' (Crabtree & Miller, 1999, p. 171) through the various templates as well as making explicit the researcher's initial assumptions in the *a priori* template.

TeA has been used in other studies from an interpretive phenomenological stance (Brooks et al., 2015). In Turley's (2016) research *a priori* themes were drawn from 'salient findings from the first stage of the work' rather than current literature (Brooks et al., 2015, p. 13); this was in part due to a lack of research on the topic.

In the current study there was considerable research, however, it was piecemeal and sometimes disjointed which at times the author found overwhelming. Initial templates (prior to interviews) described pre-understanding in a transparent format which could be shared with the peer network and aid reflexivity and consideration of biases and assumptions. During the literature review and building on the author's experience of working with parent carers for many years, an initial template was developed to highlight areas that appeared relevant to parent carer emotional wellbeing. This process also helped to provide a framework for making sense of the varied literature.

An example of a section of the *a priori* template is provided in Table 1. This highlights some of the complexity and overlap of the literature.

Coping strategies:

i) Coping as a process. Seen as a 'bridging concept' (McCubbin & Patterson, 1983) between cognition and behaviour. Coping as a 'mediating role' between stress and illness (Gray, 2003)

ii) Different types of coping – problem, emotion and meaning-focused (Folkman, 2011). Emotional-focused coping styles – includes positive reappraisal (which improved isolation and spousal relationship difficulties). Escape-avoidance most likely to correspond to increased depression and isolation (Dunn et al., p. 49). However, other literature suggests it might be helpful for some situations. Can suppress or express emotions to cope. Denial – when situation is ambiguous – allows 'for reason for functioning'. (Lazarus & Folkman, 1984)

iii) Temporal aspects. What lasts? Coping – short term or longer-term transformation?

iv) Appraisal of situation key. Link to Positive perceptions which create buffer against stress. Overlap with meaning-focused coping.

Table 1: Section of the *a priori* template

Ensuring the *a priori* template was held 'tentatively' (King, 2004) enabled significant change to the thematic structure and terminology following analysis of the interviews.

In particular, I had struggled with theoretical discrepancies between types of coping and how these were interpreted, for example, what constituted an example of 'problem-focused coping' or 'emotion-focused coping'. Furthermore, there were differences in the conceptualisations of whether a wellbeing strategy was considered a short-term way to manage stress or a long-term, transformative process. There was overlap and contradictory views, and some assumptions made on the part of researchers. From the interviews in the current study, the data provided examples of lived experience that transcended and cut across the different theories. The themes therefore attempted to describe broad underlying meaning of what each activity/strategy provided for the participant rather than trying to shoehorn them into extant theories.

Reflexivity on my own position was key throughout this process, not only as a parent carer but also as a psychologist who had worked in the field for many years. For example, participants spoke about having an awareness of life's challenges and limits as well as developing a broader perspective on their life. During the initial analysis I described this as 'awareness of the human condition' which will inevitably have been influenced by my experience of being existentially trained. Finlay (2011) notes that 'care needs to be taken…when importing outside theories to do so *because the data invites it* rather than researchers playing with their pet theory' (p. 141). Discussions with my peer network and participants helped critique such developments in checking that the themes and codes were adequately capturing the participants' experiences.

Ethics

Ethical approval for this study was granted by the Ethics Committee at Middlesex University where the author undertook the research.

Considerable consideration was given to supporting the participants both prior, during and after the interviews. This involved checking in with participants following the interview, being clear about the interviewer's position as a parent carer and psychologist as well as offering short term emotional support (e.g., counselling with another therapist) if participants were upset due to the nature of the interviews. Participants also gave specific consent for use of anonymous quotes in outputs.

Recruitment

Participants were recruited via various means, including social media, charitable organisations and newsletters. After receiving further information on what the study would entail, those who wished to proceed provided written consent to take part. Part way through the recruitment process, purposive sampling was applied to fathers to take part as all participants up until that point were mothers.

Criteria included at least two years' post-child diagnosis to lessen likelihood of being in crisis and the potential for the interview to be overly distressing. This also increases the chances of parents having developed wellbeing strategies that work for them.

Participants (+ child's characteristics)

Seventeen parents of children with an intellectual disability, who are autistic, or both were recruited. Most of the participants (8) were aged 40-49. Four participants were aged between 50-59, three between 30-39, one between 20-29 and one was 60+. The self-reported ethnicity of participants was White British/European (13), Arabic (1), Black African (1), and Middle-eastern (Iranian) (1) and 1 ethnicity not reported. Participants' first language was predominantly English (13) as well as Yoruba (1), Czech (1), Arabic (1) and Farsi (1).

An overview of the participants' child's details are outlined in Table 2.

Participant	**Age of child**	**Diagnosis/es of child (Parent-reported)**	**Gender of child**
1 Mother	15	Autism and moderate learning disability	M
2 Mother	10	Autism, dyspraxia, hypermobile syndrome	M
3 Mother	9	Autism spectrum disorder	M
4 Mother	10	Autism	M
5 Mother	12 & 10*	Fragile X Syndrome	M
6 Mother	10	Learning disability	F
7 Mother	14 & 11*	Global Developmental Delay. Autism	M
8 Mother	7	Profound Learning Disability	F
9 Mother	12	Phelan Mcdermid Syndrome	M
10 Mother	4	Cerebral Palsy	F
11 Father	16	Autism Spectrum Disorder and intellectual disability	M
12 Mother	11	Down Syndrome & Autism	F
13 Mother	8	Learning disability	F
14 Mother	12	Autism, Global Developmental Delay	M
15 Mother	10	Autism	M
16 Father	14	Severe autism, Profound Learning Disability	M
17 Father	Not completed	Battens Disease	F

* More than one child with a disability

Table 2: Overview of the participants' child's details.

Semi-structured interviews

Participants took part in a semi-structured interview either face to face or online depending on the participants' preference.

Interview questions included asking how participants understood the term 'emotional wellbeing' and what formal or informal support had helped their emotional wellbeing. They were also asked how it was taking part in the research.

Immediately after the interview I made 'reflexive notes' (Finlay & Evans, 2009, p. 88) to try and capture 'cognitive and noncognitive meaning' (van Manen, 2014, p. 47) and spot any immediate responses or biases. Reflections were then shared with the author's supervisor and peer network where necessary.

Data collection

Interviews were recorded and transcribed by a transcriber. Interview length varied from 42 minutes to 1 hour 56 minutes with the average time of 1 hour 28 minutes. The word length of the interviews varied from 7,558-22,004 with an average of 13,257 words per interview.

Data analysis

Template analysis involves an initial *familiarisation* with the data as each interview happened instead of waiting for the full data set as analysis and developing the template is a joint ongoing activity (King, 2004). *Preliminary coding* noted recurrent and distinctive feature that may be categorised as a theme, as well as comparison with the 'soft' (King & Brooks, 2017, p. 28) *a priori* themes. Relevant extracts were then *clustered* into a separate Word document which formed the basis for several versions of the *post-data collection coding template*. *A posteriori* (interview-derived) and *a priori* (theoretically-derived) themes were compared, merged (or discarded) and clustered into groups. The template continued to be *developed* by applying it to small subsets of between three and five transcripts, amending where necessary in an iterative fashion. The full data set was then *applied* to the final template in an iterative fashion and minimal changes made to extracts. The final interpretation involved a thorough reflection on, and account of, the data coding and template, including reflexivity on patterns of themes in the data, ensuring relevance to the topic and connections between and across themes (King & Brooks, 2017).

Quality

Due to the interpretive nature of this study and my insider status it was of paramount importance that I maintain a reflexive stance (Etherington, 2017) throughout the research process. As well as using my Academic Advisor, Academic Consultant, critical friend and Peer Network Group I utilised a reflexive journal throughout the process (Bager-Charleson, 2012) to remain open to new interpretations. Moreover, the template development documents the process of analysis in an open and transparent manner.

Participants were given the option to review their transcript and the themes and check quotes before publication thereby ensuring interpretations were 'plausible and justified' (Finlay & Evans, 2009, p. 61). Respondent feedback also enables participants to 'share in meaning-making processes' (p. 169). Changes were made in light of feedback from participants. For example, the importance of sleep was mentioned several times by a small number of participants (those whose sleep was affected by their child). This was not surprising because of the general relationship between poor sleep and lower wellbeing. However, I recognised that I had missed the significance of this in earlier coding development and had included it only in a minimal way, rather than including it within a significant theme. Involving participants in the development of themes was an additional quality check.

Findings

All participants could identify strategies and processes which support their wellbeing. The myriad experiences were developed into three broad themes: i) Relationship with others ii) Protecting their sense of self, and iii) Managing the 'emotional rollercoaster' of parenting a disabled child. Furthermore, ways in which professionals supported participants and observations about the interviews are also noted.

1. Relationship with others: Acceptance, Understanding and Belonging

All participants identified other people in their lives who were supportive and reflected that this helped their own wellbeing. Positive others included partners, family and friends. They could also be other parent carers, including those with whom the participants only had virtual contact (i.e., social media forums and online support groups).

However, all participants were also able to candidly recount other people who had been unsupportive and the negative effect this could have on their wellbeing. Identifying the dichotomy helped to clarify the attributes of those they found supportive.

The key factors of those who were deemed supportive were people who 'got it' (e.g., they understood the context for parent carers or understood disability and neurodiversity) and provided acceptance and belonging.

> 'You end up finding your tribe I think… I'm a bit picky with friends… I think most of my close friends are either autistic or have got autistic children.' (1)

Participants found it particularly supportive when they were in a safe, non-judgemental place where they, and their child, could be themselves. Many participants also mentioned the importance, and value, of being able to 'vent', 'whinge' and 'offload' to others who understood.

> 'What you say is safe because the person… the other side of the coin understands just how difficult it is.' (3)

> [Connecting to others in a similar situation is] '… valuable that you know that you're not on your own but you know, that whatever it is is not out of place because sometimes you think, oh, this is really extreme, but then you hear other people, you gain another perspective, and that sometimes they give you their solution or maybe what they think might help or has helped them. You at least try, it gives you hope sometimes. And then it's just really therapeutic because you do that and you feel part of [something] and start to feel better.' (4)

As well as emotional support and understanding it was appreciated when others made practical efforts to be inclusive. Participants appreciated the gesture of being part of a group and not made to feel like a burden or a bother (which conversely some had experienced).

> '… things like if we were going to my NCT [National Childbirth Trust] friends whose house we'd meet at… I couldn't always get [daughter's] wheelchair into one of the

> houses, so it was like, 'well let's go to someone else's house', yes, simple.' (6)

Their Child

The Relationships with others theme also included the participants' child. The majority of participants talked of a deep bond with their child, despite there being challenges.

> 'my son, I love, I'm always going to love, difficult as it can be sometimes.' (11)

Participants reflected on the skills and awareness they had developed in order to 'learn the way that our children understand the world.' (12), particularly when this was seen as different from 'typical' development.

> '…now I've got these skills, [the behaviour] is less likely to [challenge], because I probably step in earlier and make it right quicker, so we're not having the unhappiness and I don't feel as anxious about the unhappiness because… I've got more of an idea where it's coming from.' (12)

Interestingly, this sub-theme developed the idea of acceptance, understanding and belonging (that participants found helpful from others) to the application of these values towards their child. Often, this enhanced perspective-taking, that participants recognised in themselves, had developed through contact with other people either in parent carer groups, training, professionals or from wider communities (e.g., neurodiversity or disability groups). The transition was relational. Furthermore, greater understanding, acceptance and sense of belonging was reported as having a positive ripple effect on the participants' wellbeing and that of their child. Not only did increased understanding help manage behaviours that challenged in their child it also served to broaden the participants' perspective.

> '[I] almost prefer my son's viewpoint on life, which is why do I have to be in this school play, if it doesn't suit me, and I don't want to dress up and I don't want to be a silly character, why do I have to?' (3)

Positive other relationships could also include professionals, and this theme is explored in in more detail in Theme 4.

2. Protecting their sense of self

The second theme comprises the participants' relationship with themselves, in particular, being more boundaried about protecting time for themselves, using their lived experience in meaningful ways and feeling more empowered.

This process often started with a recognition of the importance of looking after themselves.

> 'It's better to put myself first at times because if I don't put myself first then it's kind of like the foundations aren't there. And it might be locking myself in the loo for five minutes sometimes or it might be getting the dogs out for a walk, but you can't fill from an empty cup.' (1)

The need to protect 'time that is mine' in order to look after their wellbeing was frequently mentioned by participants.

> [On undertaking a course on neurolinguistic programming] 'I couldn't handle not having a sense of purpose that was predominantly mine and so it gave me one weekend a month I needed that gave me something back for me and that was really the only time that became mine.' (3)

Participants referred to the need to 'slow down' and allow some 'spare capacity' in their day-to-day life in order to help manage the demands of being a parent carer. There was a sense that these insights had developed over time and there could be a tension initially (or ongoing) between looking after oneself and being a carer for your child; taking time for themselves would often elicit feelings of guilt.

> 'I've realised I need time for myself, it's not just him, him, him [son]. So, yes, I just want to do little things like that, like, go and not feel guilty about it. (14)

> 'I get respite, I get seven hours a week help...before I was using that time to go shopping and go to the dump and do all the stuff I can't do [with daughter]… But I think actually I felt better in myself when I used it to go to lunch with my friend and sod the dump, it can be done another week.' (10)

Part of this theme included participants using their own lived experience to engage in the world in meaningful ways. For example, those who were involved in parent carer projects or charities emphasised how important it was to them that they could utilise their own experience in a purposeful way.

> 'I am very open…it's important to me that people know that the reason that I'm doing this is because I have a daughter with a genetic condition that has gone through all of these things. I don't keep that a secret…so most of my personal self I funnel into my public life and that's because my lived experience is a really important aspect of myself.' (17)

An interesting connection between the relationship with others and relationship with self was illustrated in the subtheme of 'helping other parent carers', which nearly all participants mentioned.

> 'I know there are people that have a harder life than me and I almost feel that part of my purpose is to not just help myself, is to help everybody. So, if a situation isn't right I want to make it right, not just for me, but for others.' (3)

As background, many participants talked about the difficulties of having control taken away from them in relation to decisions around their child or accessing the support they needed as a family.

> 'You have this group of people with all the power. Gate-keeping everything we need and you have a group of people who need something from that group of people. And the two never mix.' (12).

There was a sense that finding ways to use their own lived experience (in a meaningful, empowered way) enabled an element of taking back agency which positively impacted the wellbeing of participants; helping others also helped themselves.

Several participants reflected that becoming more empowered in the face of initial powerlessness could also transfer out to other areas of their life.

> 'I'm more confident now / I would never have questioned a doctor before… and they are just human and they make mistakes and actually you don't know everything…You need to be able to say no. Because these people are just doing their job, but this is your life.' (10)

> 'I'm not afraid of public speaking any more. That was a really big deal for me back then.' (17)

3. Managing the emotional rollercoaster: 'I just let myself feel how I need to feel and just let it be'

The third theme concerns the complex interaction between recognising the difficulties many participants faced on a daily basis and acknowledging the skills or insights they had developed to manage the 'emotional rollercoaster' of being a parent carer. Participants described how having greater emotional awareness supported their wellbeing, including their ability to recognise what they needed and when.

> 'I'm getting better at recognising when my mood is beginning to sink a bit and I know that it's either / it's normally lack of sleep or an upcoming family visit and I'm beginning to recognise that in myself now and I kind of pull myself / try and / if I can get more sleep / but at least / just recognising actually that I know why I'm feeling like this and once I get some sleep I'll be better.' (6)

> 'I think I just let myself feel how I need to feel and just let it be. I don't think that trying to minimise how I'm feeling is very healthy for me. I just let it come and then when the feeling goes it goes.' (8)

A number of participants spoke about their complex, layered emotions; a bittersweet feeling in relation to being a parent carer.

> 'you know my heart broke but I got a backbone.' (17),

> 'it changed me as a person, I'm mentally stronger but I'm not as happy as I was.' (15).

Whilst acknowledging that they felt 'stronger', which connects to the empowerment of the previous theme, the transformation was not something they had chosen for themselves, rather it had developed out of necessity in challenging circumstances.

The ways that participants supported wellbeing during the ups and downs of life were varied. These could involve specific practices (e.g., mindfulness or meditation), having a positive mindset, hobbies or sleep. The common factor was that they all served as a means of emotional regulation.

> 'It could be all manner of things, bath, yoga, you know, getting out of the house and whatever, just a change of environment, situation.' (9)

> 'Getting out with my dog, I find really important… getting out and getting some fresh air is really helpful. I try and not look at my phone when I go out, so I have to think and process my thoughts, just being with my own thoughts is really helpful. Just being out.' (8)

> 'Just having a positive mind set. So it is the 'nothing lasts forever', 'this too shall pass'…just being positive, using positivity. A bit of mindfulness, I quite like that' (1)

> 'the time I have off is the time I sleep' (12).

Interestingly, participants referred to expressing difficult emotions, such as crying and getting angry, as helpful at times. Some would also consciously disengage from thinking about things when they became overwhelming or use denial to support themselves in the early years.

> 'I do cry. I've literally just stood in the kitchen one evening trying to do dinner and I just burst into tears and the kids are like, why are you crying Mum, and I'm like just can't

> cope with everything, everything's just gone in my head all of a sudden…a build up of everything, like there must have been a problem at school, one of the boys, so you've got the teacher on the phone, or you've got [son] coming off the bus moody, because something has happened. It's just one big pressure.' (7)
>
> '… sometimes that would be the darkest of the darkest period for me and I didn't look after myself. I allowed myself to cry a lot. I allowed myself to get angry.' (4)
>
> '…the worry about her future… I try and park that and think, well, you know, if I tried guessing at 2 where we'd be at 11, I'd have been wrong, so there's no point guessing at 11 where she'll be at 20, because you'll probably be wrong, so let's just not.' (12)
>
> 'I kind of down-played it a lot to my family, to the point where they / no one was really sure. Because I was like it's okay, he's fine. Maybe it did help me deal with it, I guess, but / that's / I guess / when I say that out loud it feels like / it sounds like I just / it's acceptance, you just need to kind of / it's a horrible thing to have to accept when your child's sick or ill or not how they should be and you don't know why and it takes time to get to that point where you're like, okay, I accept this is going on. I think I was delaying it [so I could] cope.' (9)

All the approaches that participants referred to as helping their wellbeing acted as a way to re-calibrate or gain a sense of grounding in their lives. Whether this was by having a cry or thinking with a positive mindset the purpose was the same – to achieve equilibrium and balance for their sense of wellbeing.

In addition, some of the interviews captured a philosophical wisdom about the human condition more broadly (e.g., disability, difference and death) that had been honed by their experiences of being a parent carer. Adopting this stance helped the participants to deal with (and discuss in the interviews) some very difficult situations which were powerful and profound.

> 'The prognosis we were given was so exceptionally bleak … there was no expectation that she would survive essentially…[and] I think because what transpired was so so much better than we could have ever have imagined, you know, she was / she did so well and although she was in and out of hospital, we mostly were at home and she was here and we got to have her and love her and she was so smiley and so happy and it was sort of the gratitude I felt for that / just the / the bewildering joy of it.' (13)
>
> 'I think I probably have changed in the way that I am very open and aware of difference and disability and other kids with, not necessarily kids, just people. And how, you know, you go about your day and you can come across paths with people who are just very different.' (9)
>
> '… it made me realise life is not perfect.' (3)
>
> '… we have an expectation but we don't really have any control over life, it just happens doesn't it?' (8)
>
> 'I do find that there is something different about special needs parents. They just sort of more.. accepted something, more open about things. About life.' (5).

4. Professional support

As well as support from partners, family, friends, and other parent carers, the majority of participants also referred to professionals. In particular, where professional support combined emotional and practical elements this was found to be beneficial.

Participants' reflections are grouped under the sub-themes of i) time and space to talk, ii) flexibility in duration and type of support and iii) understanding the context.

i) Time and Space to talk

Providing a safe, non-judgemental space for participants to talk was helpful, as identified in the first theme, Relationship with others. Sometimes participants felt they had nowhere else to share their feelings which were often difficult to process.

> 'we did have counselling, which I think helped…it's just that time you know that outlet to go [deep sigh]' (9)
>
> 'For me / it's just getting it out there and just saying, these are all the things that are happening, because what I generally find is, because I talk non-stop, you can almost talk yourself into a solution when you're talking' (13)

Also noted (by the interviewer) during the research interviews was the process whereby participants would begin by discussing something challenging but naturally follow an arc to identifying more positive aspects. This mirrored a therapeutic session and interestingly, when asked about how it was to take part in the research, several participants found it useful to take time to stop and reflect on their experiences.

> '… just thinking about things, makes me realise that I've come a long way in the last couple of years and I have much healthier coping strategies these days.' (8)

ii) Flexibility in duration and type of support

Participants commented on the need for support to be flexible, such as longer term or ad-hoc sessions when needed. This reflects the rollercoaster of experiences that parent carers may go through across the lifespan and the support required at different points.

> 'I needed counselling at the very beginning…To get me past the shock. And then I do think you need it again. Because after you come to terms with what's happened, there's other feelings that you need to make sense of, …I think you shouldn't be left, you need to be checked on.' (10)

> 'So when [daughter] was first diagnosed the GP offered me six sessions [of counselling] and then she kind of did me a bit of a favour actually, she…kept me on, but I just sort of saw her ad hoc, so maybe even once a year, or twice / I would ring and go, "I feel I need a couple of sessions".' (6)

It was also found to be helpful when there was flexibility in the type of support (i.e., delivered online, being family rather than child-centred as well as practical help).

> 'I think probably you could offer some of it online. I think often if you've met for the first time, if you've established a kind of rapport, I think you can then move to an online kind of thing. I think that would suit parents more and be even more flexible.' (5)

> 'We went to an NHS child psychologist and she was really helpful because although we came with our son, a lot of it would be talking to us rather than him…[and] I could just phone up / a drop-in session, and I would say look I don't know how to handle this, what's the best way and that was really helpful to be able to talk to somebody…although it was a child psychologist, she was very good about helping the family / because…she didn't talk specifically always to my son.' (10)

iii) Understanding the context for parent carers

Throughout the interviews all participants referenced the difficulties with services and having to fight for limited support. This could have a negative impact on their own wellbeing.

> 'If parents just had services come to them as needed, they probably wouldn't have that many problems.' (12)

Where professionals understood the holistic situation for parent carers this was helpful.

> 'She [therapeutic support] got the autism but she also got the parent exhaustion' (1)

The need for respite was mentioned several times and the potential (but often inaccessible) positive impact this could have on their lives.

> 'if I knew there was a respite, which I know is unaffordable /If I knew it was there, set up, every first weekend in the month, that would make a difference to my wellbeing, I could have a mini-break, [rather than] feel like this house is like a prison, especially during the holidays'. (5)

Although practitioners may not feel comfortable or confident to access practical support on behalf of their client, where there was at least an awareness of what was available or the struggles to access support, this could be received as helpful.

Discussion

This study explored the lived experience of parent carer emotional wellbeing. Participants identified numerous strategies and processes that supported their emotional wellbeing. By utilising the expertise of participants, it is hoped a broader understanding of parent carer wellbeing can be brought to research and practice.

Although the strategies are varied and personal and different things may help at different times, three broad, and inter-related, themes were developed: i) Relationship with Others ii) Protecting their sense of self and iii) Managing the emotional rollercoaster. In addition, participants were also clear about ways in which professionals could best support them.

Within each theme there could be a range of phenomena. For example, Relationship with Others could include partners, family, parent carers and friends. It could also involve the loving relationship with their child, which had a positive impact on their own wellbeing. Participants discussed the new skills and understanding they had developed through their love of, and support for, their child. Although many acknowledged the challenges they had experienced, or were still experiencing, they reflected on their enhanced perspective taking which helped in their parent carer role.

It was interesting that in the interviews identifying what was helpful was often pre-empted by reflections on what had not been helpful, for example, relationships that had been rejecting, and negating of their experience. Participants talked of lost friendships and unsupportive wider family members and the distress this had caused them. In the literature it is recognised that parents may come to hold 'views about disability that are different from dominant societal views' (Woolfson, 2004, p. 11). This may involve challenging prejudice and discrimination and developing the ability to withstand the way other people look at them, which is 'often stigmatizing and guilt-inducing' (Pelchat et al., 2009, p. 251). Stigma is described by Goffman (1968) as the phenomenon whereby society rejects an individual due to a particular attribute that is deeply discredited. Ryan (2020) develops Goffman's idea of 'the wise' who become allies to the 'othered' group (i.e. those who are disabled): 'parents can harden to the public scrutiny and feel more confident about fronting it, which can be, in itself, liberating.' (Ryan, 2020, p. 83).

The contrast in attitudes served to emphasise the appreciation for those positive other people who provided safe non-judgemental space, a sense of belonging and practical support where necessary. Although participants mainly mentioned close family members or other parent carers this support could also be provided by sensitive and compassionate friends. It was the quality of the relationships that were key to supporting the participants' wellbeing.

In the theme 'Protecting their sense of self' there was an ongoing tension reflected in the participants' accounts of how they attempted to maintain a sense of 'self' while also being a carer for their child. Finding time without feelings of guilt was key. Several participants discussed the struggle they had experienced in finding (and protecting) time for themselves, although most had come to a point of carving out time or activities that worked for them. This may be because of the recruitment criteria of participants needing to be at least 2 years post their child's diagnosis. It can be a process to find ways to protect time for self which may be more of a struggle during the early years. Although this exclusion criteria limits the research focus to a particular experience it is an important ethical consideration that those taking part had managed to identify ways to support themselves.

In this second theme there was also a clear dichotomy in participants' experiences of disempowerment/ empowerment. All interviews mentioned frustrations with services and the wider context. Finding ways to counter this disempowerment was seen as necessary to protect against becoming overwhelmed as well as achieving the best support for their family. Feeling empowered was key to wellbeing, although this could take time for participants to develop. Many reflected on their increased assertiveness or confidence transferring out across other aspects of their life.

This finding mirrors other literature which highlights the importance of empowering parent carers particularly when in contact with services (Stanford et al., 2020; Reeder & Morris, 2021). When services take a family-centred approach and develop a partnership between parent and professional this had a beneficial effect on parent carer wellbeing.

Helping other parent carers was mentioned by nearly *all* participants. The use of their lived experience appeared incredibly meaningful to participants, which relates to the theory of feeling that your life has significance and coherence (Martela & Steger, 2016). As well as having an altruistic element to it and wishing to share the knowledge they had developed and curated over many years, this experience may also be an attempt to counter the 'learned helplessness' that the system can sometimes elicit. After being de-skilled and disempowered, people seek ways to re-empower themselves. This reflects ideas around empowerment and the use of lived experience in research and services in other areas, such as the disability field (Shakespeare, 2022).

The third theme, 'Managing the emotional rollercoaster' acknowledged the ongoing flux and ups and downs of being a parent carer, and of life in general. Participants reflected on the need to constantly 're-calibrate' when new challenges came along. Part of this ongoing balancing act overlapped with their changed relationship to self and other, for example, feeling more confident to ask for time alone, challenging professionals' opinions and a transformed insight into the nature of being human.

Activities that supported their wellbeing across the 'rollercoaster' could be varied and meet different needs but all with the aim of replenishing and recalibrating the parent to help maintain their emotional wellbeing. This was one of the most challenging aspects of tying together the prior literature as 'coping strategies' per se were sometimes presented in limited ways, such as short-term v. long-term coping, or problem v. emotion-focused coping. Focusing on the participants' experiences, and how they benefitted from the activity or strategy, rather than trying to rigidly define the type of activity/strategy helped capture something more latent and meaningful. Therefore, mindfulness, going for a walk or helping others could all serve the same purpose, whether this was deemed a short or long term solution would depend on the person and the context. It is for the participant, rather than a theoretical approach, to decide what works for them and the way in which it works.

There were also examples of psychological flexibility where participants had transformed their perceptions of, and responses to, their situation and developed greater adaptability towards life stressors. Bridges defines transitions as the 'start of letting go of what no longer fits or is adequate to the life stage you are in.' (2019, p. 132) which appears relevant to this process. Participants had to develop new strategies in the face of their transformed life situation.

Several participants used language that captured the complex emotions they would experience, often at the same time, such as 'my heart broke but I got a backbone.' (17), 'I'm mentally stronger but I'm not as happy as I was.' (15). Research into emotions indicates that identifying the granularity of emotions can be helpful in preventing them from becoming overwhelming (Feldman Barrett, 2017). These findings also reflect the paradox of emotions detailed in Larson's study (1998). Practitioners can support parents while they find the words that help make sense of their complex lived experiences.

Interestingly, participants' recognition that they need to look after themselves (without guilt), adopt a position of acceptance towards their emotions while also recognising their own humanity are all tenets of compassion focused therapy (CFT) (Gilbert, 2013). A study that utilised ACT (including compassion-based therapy) was noted in the literature (Reid et al., 2016) and the findings of this study suggest that self-compassion may be an important part of supporting emotional wellbeing in parent carers. However, the variety of strategies and processes that supported parent carers in the current study suggests that CFT may be only one part of the support that helps. An integrative approach using myriad strategies may be more beneficial (this is considered further below).

Implications for practice

This study highlights a number of ways in which therapeutic practitioners can support parent carers including i) providing time and space to help parent carers reflect on their experiences and find their own answers ii) flexibility in the duration and type of support (e.g., ad hoc sessions, online) and iii) an understanding of the context for parent carers.

A key role for professionals is to provide a safe, non-judgemental space for parent carers to reflect and identify what support they need. Additionally, flexibility in the support provided can be useful. It is well recognised that the shift in identity for any new parent can be challenging and flexibility in their counselling appointments may be required (Arnold-Baker, 2019). For parent carers, this transition can continue for longer and be outside the typical development stage in the life span of the child (e.g., still overseeing care for one's adult-child). Offering online appointments, ad-hoc appointments at difficult times (e.g., transitions, child's surgery) and embracing a broader remit (e.g., referring for respite; liaison with other professionals; co-ordinating appointments) are some ways parent carers reported that counselling could become more accessible and beneficial for them.

It was particularly helpful when professionals were knowledgeable of the world of disability and neurodiversity. Understanding different services, the limited resources for families and the ongoing (and sometimes exhausting) nature of caring can ensure pragmatic and tailored support for parent carers, rather than a one-size fits all. For example, there may be times when parental lack of sleep is not solved by changing their sleep routine or medication but by them having a break (therefore it may be better to focus energy on applying to social services for respite).

Participants commonly described the difficulties they had navigating, and fighting, the systems around them which could elicit feelings of powerlessness. A positive relationship with a psychotherapist/counsellor may be the first time they feel on 'an equitable footing' with a professional.

In addition, this study illustrates that participants utilised many different strategies, therefore, an integrative professional approach may be helpful for parent carers. For example, support could employ relaxation/mindfulness techniques, tenets from compassion-focused therapy/increasing self-compassion as well as encouraging connection with others in a similar situation (for example, signposting to disabled children's groups or the Local Authority Local Offer). Different aspects may be required at different points on the rollercoaster.

Implications for theory

Purely theoretical approaches to parent carer emotional wellbeing may lack some of the nuance of lived experience. Interestingly, some strategies identified in this study may not immediately be viewed as 'adaptive coping' including anger and disengaging from problems at certain point in time.

In relation to anger, a small number of participants were very clear about their anger and how this could be helpful when fighting for support. This mirrors Kashdan and Rottenberg (2010) view that 'righteous indignation can be considered "positive" in terms of promoting progress toward desirable goals'. Dunn et al. (2001) also supports this view, describing how confrontative coping can help parent carers, for example 'fighting for what is wanted, expressing anger to the cause of the problem, letting feelings out somehow.' (p. 50).

The strategy of disengaging and prioritising concerns involved participants' avoidance of thinking about difficult things when they were upsetting or uncertain (e.g., their child's future) or when other activities (such as sleep) needed to take precedence. They referred to making a conscious choice to wait until they were ready, or had more resources available, to deal with a difficult issue.

Interestingly Woodman and Hauser-Cram's study (2013) highlighted the frequent use of denial and suppression of competing activities in participants in their study (mothers of children with disabilities). They note that 'The preference for denial found within this sample is inconsistent with prior research on coping among mothers of children with disabilities.' (p. 525). The current study contributes further understanding of this phenomenon and supports the suggestion that there may be specific strategies which parent carers find helpful that are not always recognised as 'adaptive' in the wider literature. Furthermore, this finding supports Kashdan and Rottenberg's (2010) view that 'we should be wary of simple, universal strategies' (p. 867), refuting the idea that some strategies (such as cognitive reappraisal) are always better than others (e.g. suppression).

Participants in the current study noted that anger and disengagement from problems, *in certain circumstances*, were helpful. This suggests that professionals need to keep an open-mind as to the parents' strategies. The key appears to be having flexibility in one's responses and a broad toolkit from which to choose, given a particular situation.

Implications for future research

Of note, the interventions discussed in the introduction may not generally include (or encourage) certain forms of 'coping' that were identified in this study (i.e., expressing anger or disengaging from problems). This raises the importance of involving people with relevant lived experience when designing interventions for parent carers. Feedback from participants who took part in other interventions (where parent carers were involved in its development) have reported such co-production as beneficial (Apanasionok et al., 2025; Sutherland et al., 2025).

In addition, it would be interesting to see if using a mixture of different approaches, rather than solely focusing on one, had greater benefit for parent carers.

Strengths and limitations

A strength of this study is the small sample size, enabling an in-depth understanding of participants' reflections on their own emotional wellbeing. As the author is also a parent carer lived experience was at the forefront of the study.

A criticism of TeA is that if the researcher is too committed to *a priori* themes they may 'not allow new insights to emerge' (Willig, 2013, p. 65). As noted in the methodology, from an interpretive phenomenological perspective it may be viewed as 'contentious' (Brooks et al., 2015) to use 'top down' *a priori* themes, however, it is also acknowledged that we all carry biases and assumptions. As long as these are held tentatively, TeA offers a transparent way to document the pre-understandings which allows greater scrutiny during the reflexive process with peer network and participants.

While TeA does not necessarily provide a 'holistic understanding in relation to individual accounts' (Brooks et al., 2015) it does offer a systematic yet flexible approach for qualitative research across a number of participants. Moreover, conducting analysis both across and within interviews can help maintain the anonymity of participants (and their children).

Future studies could interview a larger number of parent carers or utilise quantitative methods (i.e., a survey) to ascertain the relevance of the themes to a wider audience.

Conclusion

Parent carers can be at risk of poorer mental health and several different wellbeing interventions have been applied to this group. This study utilised lived experience to explore what supported their emotional wellbeing and parent carers identified strategies and processes that were beneficial. Findings were developed into three broad themes i) Relationship with others, ii) Protecting their sense of self and iii) Managing the emotional rollercoaster. In addition, participants were clear about how professionals can support them. This paper summarises some of the key factors that participants found useful for their wellbeing and aims to add to a greater understanding for practitioners and researchers to consider further.

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