

‘Different things at different times’: Wellbeing strategies and processes identified by parents of children who have an intellectual disability or who are autistic, or both

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Abstract

Background: Most parents of children with an intellectual disability or who are autistic identify positives in their family life and their own wellbeing, in addition to reported mental health challenges. Several models and interventions have been developed in relation to parent carer wellbeing. Few studies have asked parent carers how they support their own wellbeing.

Method: Adopting an interpretive phenomenological approach this study utilised semi-structured interviews. Seventeen parent carers were asked what supported their emotional wellbeing. Template Analysis was applied to develop themes.

Results: All participants identified factors that supported their wellbeing. Themes included strategies that countered stress (time for themselves, relaxation, ‘parking’ difficulties) and broader wellbeing strategies (finding meaningful life direction, greater understanding of child). An ongoing process of supporting wellbeing by ‘*Reorienting and Finding Balance*’ appeared central.

Conclusions: Self-identified, multi-dimensional strategies benefit parents’ emotional wellbeing and should be considered in the context of support provided to families.

KEYWORDS

autism, emotional wellbeing, intellectual disability, mental health, parent carers

1 | INTRODUCTION

Research commonly suggests that relative to other parents, parent carers of children with an intellectual disability, who are autistic, or both, are at increased risk of mental health difficulties (Hayes & Watson, 2013; Rydzewska et al., 2021). Despite these risks, and the challenges and stressors experienced by parent carers, many also identify positive aspects (e.g., personal growth, putting things into perspective) of parenting a child with additional developmental needs (Hastings, 2016; Jess et al., 2017). Factors that influence parent carer wellbeing have been drawn out across several lines of research. First,

social support for parent carers, such as family support and friends/peers (Shilling et al., 2014), as well as availability of resources and services (Stanford et al., 2020) have been found as beneficial to parent carer wellbeing. Second, parent carer coping strategies in relation to psychological wellbeing have been the focus of some studies. Here, a broad array of coping strategies and their relationship with mental health have been explored using different methods. For example, a longitudinal study found that psychological reframing was positive for wellbeing (Benson, 2014). Another study, using parent-completed questionnaires, suggested an association between active-avoidance coping and poorer maternal mental health (Adams et al., 2018).

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Further studies have applied different coping models, including the Double ABCX Model of Adjustment and Adaptation (McCubbin & Patterson, 1983) to ascertain relevance to parent carers (Weiss et al., 2013). There has also been consideration of differences in coping strategies by gender (Langley et al., 2020).

Different paradigms and theoretical concepts that attempt to account for the emotional experiences of parent carers have been described in the literature. Concepts include post traumatic growth (Calhoun & Tedeschi, 2010; Young et al., 2019), meaning making and finding benefit (McConnell et al., 2015; Pakenham, 2011), meaning-focused coping (Beighton & Wills, 2017), personal growth (Woodman & Hauser-Cram, 2013) and positive psychology (Seligman, 2011). The scope of these studies suggest that emotional wellbeing may be broader and more proactive than merely a response to a stressor. Indeed, a number of studies critique the suggestion that parent carers' adaptive strategies (e.g., identifying benefits) represent a cognitive 'artefact' of coping (i.e., a strategy to protect against stressful events and improve mood) and instead view them as 'transformational' growth (i.e., a fundamental change in their life perspective and values) (Beighton & Wills, 2017; McConnell et al., 2015).

Finally, some studies have reflected on the complexity and oscillating nature of emotional responses (Sheehan & Guerin, 2017) and others have noted that adaptation is not necessarily the 'absence of stress or other negative feelings' (Hastings & Taunt, 2002, p. 119). Interestingly, a study that explored the concept of 're-goaling' [the ability to relinquish unattainable goals for more realistic ones] in parents of children with serious medical illness (Hill et al., 2014) noted that parents who showed a mix of positive and negative emotions not only demonstrated greater wellbeing, but were closer to being ready to discuss new life goals.

A variety of programmes that correspond to these models have also been developed to support parent carers. These include mindfulness, acceptance and commitment approaches (Flynn et al., 2020; Reid et al., 2016), as well as programmes based on the principles of cognitive behavioural therapy (Feinberg et al., 2014) and positive psychology (Dykens et al., 2014). A small number of other programmes have combined wellbeing support for carers with support that focuses on the developmental needs of their child (e.g., Gore et al., 2022).

Parent carers are not a homogenous group and there is likely considerable variation in their needs and experiences. Families will be diverse in terms of their child's primary needs (Totsika et al., 2011), socio-economic status (Minnes et al., 2015), ethnicity (National Autistic Society, 2014) and access to support (Sapiets et al., 2020). It is therefore unlikely there will be a one-size-fits-all wellbeing approach. Given the complexity of the concepts identified in the literature, and the suggestion, more broadly, that coping is context-dependent (i.e., how a person responds depends on their situation) (Aldwin, 2011), *a potential way to gain further understanding of these issues is to ask parent carers themselves.*

The primary aim of this study therefore was to explore how parent carers identify and apply strategies that support their wellbeing. Furthermore, within the broader context of working with, and learning from, lived experience (Borek et al., 2018) it is beneficial to work with parent carers. The first author, in addition to being a psychologist working in

the field of disability and families, is also a parent carer and therefore well placed to harness the benefits of insider research (Berger, 2015; Finefter-Rosenbluh, 2017). It has been suggested that insider research can support rapport with participants, providing additional insight and nuanced understanding (Finlay, 2020). Furthermore, in being open about the first author's position as a parent carer the inherent power imbalance in research (Hesse-Biber, 2011) may be somewhat redressed. A 'them and us' stance, which is often experienced as unhelpful by parent carers (Stanford et al., 2020) in relation to professionals, may be avoided. Given this context an insider approach was adopted to explore parent carers' emotional wellbeing and supportive strategies. This study was conducted as part of the first author's doctoral thesis in the UK.

1.1 | Ethical approval

Ethical approval was granted by the Ethics Committee at the first author's institution.

2 | METHOD

2.1 | Participants

Seventeen parent carers (14 mothers and 3 fathers) of children (aged 2–16) with an intellectual disability, who are autistic, or both were recruited. Criteria included at least 2 years' post-child diagnosis to lessen likelihood of being in crisis and increase opportunities for participants to have identified factors that supported their wellbeing.

The majority of parents (8) were aged 40–49. Four participants were aged between 50 and 59, three between 30 and 39, one between 20 and 29 and one was 60+. Self-reported ethnicity of participants were White British/European (13), Black African (1), Arabic (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).

There were a range of relationship statuses, the largest being married or cohabiting (11) and 5 were separated or divorced. Two participants were cohabiting with a partner who was not the biological parent of the disabled child including one who was in a same sex relationship. All children lived at home with their parent apart from one, who had recently moved to residential accommodation. Regarding socio-economic status, 12 out of the 17 earned over the median wage for the UK (£29, 900) (Office for National Statistics, 2020). Five were also health, education or social care professionals. There was variability with regards the type and extent of wellbeing support parents had previously accessed. During the course of the interviews 5 participants reported having received psychological therapy and 11 had received formal peer support (e.g., a group of parent carers generally focused on the child). Other support was more informal, such as from family, friends and peers via social media. The diagnoses of the participants' children were intellectual disability (35%), autism (30%) or both (35%). Eleven of the children were male and 6 female. Characteristics of participants' children are provided in Table 1.

TABLE 1 Participant's child details

Participant	Age and gender of child	Diagnosis/es (self-reported)
1. Mother	15, Male	Autism and moderate learning disability
2. Mother	10, Male	Autism, dyspraxia, and hypermobile syndrome
3. Mother	9, Male	Autism spectrum disorder with severe emotional and behavioural needs
4. Mother	10, Male	Autism
5. Mother	10 & 12 ^a , Male	Fragile X syndrome
6. Mother	10, Female	Learning disability
7. Mother	11 & 14 ^a , Male	Global developmental delay, autism
8. Mother	7, Female	Profound learning disability
9. Mother	12, Male	Phelan Mcdermid Syndrome 22.13q (chromosome deletion)
10. Mother	4, Female	Cerebral palsy and severe epilepsy
11. Father	16, Male	Autism spectrum disorder and intellectual disability
12. Mother	11, Female	Down syndrome and autism
13. Mother	8, Female	Learning disability
14. Mother	12, Male	Autism, global developmental delay and sensory processing disorder
15. Mother	10, Male	Autism
16. Father	14, Male	Severe autism, non-verbal and profound learning disability
17. Father	11, Female	Battens disease and learning disability

^aMore than one child with a diagnosis.

2.2 | Procedure

Participants were recruited via various means (charities, online forums and peer networks) and contacted the first author for further information. Those who wished to take part completed and returned a consent form prior to the interviews with the first author. Interviews took place, between July 2019 and February 2020, in various locations as best suited participants, including community settings, the participants' home and online using Zoom. Interviews were recorded and transcribed in anonymous form.

2.3 | Semi-structured interview

Semi-structured interviews were conducted by the first author to explore participants' experiences of emotional wellbeing. Questions were included on social support and personal psychological strategies with probes and follow up questions to allow further variables to arise. Given the varied ways of defining and understanding the topic in the literature, participants

TABLE 2 Interview questions—sample of the questions participants were asked

1. Can you tell me how you understand 'emotional wellbeing' and what that means or looks like for you in your life?
2. What has helped or helps you to look after your emotional wellbeing as a parent of a disabled child?
3. Are there types of formal support that have helped/help? What is it about doing X that supports your wellbeing?
4. Are there types of informal support that have helped/help? What is it about doing X that supports your wellbeing?
5. Is there a time in the past you can think back to when things have been difficult for you (in relation to your disabled child) and reflect on what helped your emotional wellbeing at that point in time?

were asked about their personal understanding of emotional wellbeing as well as how it was to take part in the research process. A list of example interview questions is included in Table 2. Interview length varied from 42 min to 1 h 56 min with the average time of 1 h 28 min.

2.4 | Analysis

A broadly interpretive phenomenological (IP) approach (Heidegger, 1962; Langdrige, 2007) was adopted for this study to guide individual interviews. IP embraces interpretive engagement with the data and, as well as seeking themes, acknowledges that phenomena are only ever experienced through our own subjective lens. IP has been implemented effectively in prior studies exploring the experience of carers (Benner, 1994) and supports exploration of rich, personal meanings in participants' lived experience (Langdrige, 2004; Van Manen, 2014).

Analysis was undertaken by the first author (interviewer) using Template Analysis (TeA) (King, 2004). In this study, TeA began by developing a coding template to identify tentative a priori (before interview collection) themes. Documenting the interviewer's understanding, knowledge and position in this way supports reflexivity (Etherington, 2016) and provides an 'audit-trail' (King et al., 2019, p. 203) to demonstrate transparency in theme development.

A posteriori (post interview) analysis began as interviews were transcribed comparing patterns and key topics identified in the interviews with the a priori template. An iterative process of coding and adaptation of themes occurred until the final template (number 13) was generated where no further themes were identified by the researcher. While some of the sub-themes and topics included in the a priori template remained, the overall organisation, main themes and identification of an integrative theme were different, thus adhering to King's (2004) view that a priori knowledge is held as tentative and open to change.

Throughout the process, the first author interacted with the data, theory and their lived experience in a reflexive manner. For example, on occasion, participants described 'down-playing' difficulties, or 'parking' problems as helpful. Such strategies are typically conceived as 'avoidance coping' and presented in the literature as unhelpful. The potential for these strategies to be helpful in certain situations did however resonate with the author's lived experience. Critically

reflecting on this within the context of the first author's insider perspective therefore allowed an openness to what participants were describing and supported an inductive approach. Reflexivity was enhanced through the use of a researcher journal (Finlay, 2020) and ongoing consultation with peer research network (Etherington, 2016). In addition, 'respondent feedback' (King et al., 2019, p. 216) was sought for both interview transcripts and during theme development and minor amendments made. Quality assurance included collating all examples of each theme and sub-theme (across-case and within-case) and discussing with colleagues, thereby enhancing transparency, coherence and rigour (Yardley, 2000).

3 | RESULTS

Participants identified myriad ways they supported their own emotional wellbeing. Utilising the participants' own definitions of wellbeing provided a useful framework for exploring the themes further. All names of participants have been changed.

First, wellbeing involved being 'able to deal with the highs and lows of life' (Irena) and 'not letting things get too overwhelming and doing things to stop it becoming so' (Samantha) (Coping strategies: countering stress). Second, wellbeing encompassed feelings of sense-making and of 'being the architect of your own destiny' (Alan), so that participants could 'keep moving forward' (Katherine) and 'enjoy my life and the journey' (Leila) (Wellbeing strategies: meaningful and purposeful life journey). A third theme, Reorienting and Finding Balance, describes a phenomenon commonly identified by participants; the process of changing their perspective, values and behaviours in line with their new family situation and captured the ongoing, dynamic nature of wellbeing.

3.1 | Coping strategies: Countering stress

Participants reported specific strategies that helped counter stress. This included protecting 'time that is mine' (Katherine) for different purposes, including time 'without the children' (Irena), time off from being 'on edge' (Eva) and their caring responsibilities.

Being outside, breathing and giving myself time to think and walk, I find that really helpful (Ruth).

There were activities and psychological strategies that helped. Francesca reported that 'a bit of mindfulness, I quite like that. I might take the dogs and pick some blackberries and just notice what's around me'. At certain times Ruth used relaxation techniques 'If I get a shitty letter in the post, I'll read it, put it down, do a bit of breathing, and then think about what I'm going to do about it'. Sally commented that 'I play in a band. And that's been a huge support... when you are playing the music you just get lost in it and this is the only time I don't think about learning disability. Because it was so absorbing'.

Other supportive strategies included venting, crying and downplaying difficulties (in the early stages)

I downplayed it [child's diagnosis] a lot to my family...it did help me deal with it. It takes time to get to that point where you are like, okay, I accept this is going on...I think I was delaying it [so I could] cope. (Michaela).

Participants identified the ability to 'park' (Sally) problems as helpful; particularly in relation to worries about the future. Ruth commented 'I was thinking "what's going to happen when I'm 80"...it can be quite overwhelming. [I] try and be mindful of, that's not happening right now, she's six...and think about it when it feels less overwhelming'.

Connecting to positive other people, including their partner, family, friends and professionals, was reported as helpful to participants' wellbeing. The value of talking to people who 'get it' and provide a non-judgemental space was identified across all participants. 'What you say is safe because the person understands just how difficult it is'. (Katherine).

In contrast, a number of participants spoke about how, in times of trauma (such as the shock of an unexpected diagnosis or their child undergoing medical interventions), social withdrawal was helpful. Sally remembered the day her daughter was diagnosed:

I was meant to go to work [instead] I bought this duvet and just sat under it...I followed my guts... go into a cave and process it.

Greater emotional awareness enabled participants to recognise when they needed to engage in different regulatory activities to support their wellbeing. Ruth noted that 'I'm getting better at noticing when I'm starting to sink a bit and... I know why I'm feeling like this and once I get some sleep, I'll be better'.

3.2 | Wellbeing strategies: Meaningful and purposeful life journey

In addition to the coping strategies, there were broader aspects to wellbeing that appeared to be more than just countering stress.

Participants identified ways in which they had found purpose in their life (e.g., through work or their family) and made sense of their experience which, in turn, supported their wellbeing. John reflected that 'first you go through that 'why me?' phase and then the answer we came to is because we're better equipped to deal with this than a lot of other people would be' illustrating how he had created meaning from his experience. Thirteen of the participants in the study identified helping others, particularly other parent carers, as being meaningful in their life. Greta commented that 'what makes me tick is feeling like I'm contributing something' reflecting another comment that 'part of my purpose is to not just help myself [but] to help everybody'. (Katherine).

As well as offering a safe space to talk (identified in the previous theme) positive other people could also provide a sense of belonging

and shared norms which enhanced wellbeing. This could even be through non-direct contact such as awareness of social justice movements (e.g., disability activism), by shifting the parental perspective of their child and family away from a negative narrative. Greta reflected that 'the neurodiversity movement was so positive... Once I realised that being autistic does not mean you are not able to be happy...that was probably the turning point'. Other participants talked of the importance of 'finding your tribe' (Francesca).

Finding ways to empower themselves positively affected participants' wellbeing, including having 'learnt to say no' (Eva) and 'grown a thick skin' (Francesca). As well as their increased assertiveness, greater knowledge and familiarity with the system around their child, including the law, policies and terminology helped

the thing that helps me most is feeling more competent and having a language that is much less emotional and more factual than it was five years ago when the SENCO [Special Educational Needs Coordinator] would constantly... make it about me being over-anxious, whereas now I have a clearer way of saying 'these are her needs' ... And that gives me emotional wellbeing because I feel confident that I can be her advocate. (Sally)

Increased confidence could also lead to participants challenging social norms. Greta reported that with time '[I gained] the confidence as a parent to pick and choose my battles so instead of choosing battles that society was telling me were really important, I could focus more on his [son] emotional need... Rather than making him like a parrot to say hello when he meets people'.

A connected theme was the development of greater awareness of 'the way that our children understand the world' (Sally). By enhancing their perspective taking skills, parents had a greater understanding of their child's needs and viewpoint and this supported their own wellbeing. Katherine reflected that her eyes had been opened and '[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?" The phenomenon involved greater parental knowledge and empathy. In turn, they felt closer to their child, better able to support them and to avoid taking things personally. John noted that over time 'I've found the key to him [son]' which had helped him understand what his son was communicating through certain behaviours. Participants noted that this awareness could take time to develop.

3.3 | Reorienting and finding balance

The integrative theme, reorienting and finding balance, describes a phenomenon commonly identified in participant interviews; the process of changing their perspective, values and behaviours in line with their new family situation. Adopting nomenclature used by one participant, the term '*reorienting*' (Alan), was used to describe this process which supported their own wellbeing. Participants reflected that it took time to go through this process.

If I could, I would go back to me, when [daughter] was born, say, 'I know that you're really scared, other parents have this too and these are the emotions you are going to feel and you're allowed to be like that', that would have been really helpful. You will get through it. It's normal and these are the processes you will go through. (Eva).

Participants reported that their perspective had changed due to having a disabled child. Ruth was 'more appreciative of smaller things', Alan's 'values have changed' and Yasmina stated 'I'm not judgemental anymore. I think I have sympathy and I understand people more.' Katherine reflected that 'the most important thing is that my children have the best life and that comes before my own needs and that's pretty much why I gave up everything and changed my own goals'. Bolanle noticed that '... a few years back everything had to be within my control and [now]...I don't have control of the situation but I'm in control of how I respond to that situation. Which is a bigger thing than being able to control something'.

Participants commented that they lived 'in a completely different world now' (Sally) which had led to more realistic expectations. As Greta reflected 'I don't even try and shoot for normal anymore...I used to try and aim for it and then fall short for it and then that would be a bad mental loop, whereas now I'm much more accepting'. Comparisons with other families with non-disabled children could be distressing but the adjustment process involved embracing what suited them as a family 'Once I stopped looking at typical children going "Really? Can a two year old do that? Oh my God," I felt less out of kilter'. (Sally).

This change had also led some participants to adjust their parenting style including rejecting the way they had been brought up; 'I was expecting compliance because I'm the adult and they're the child, that's how I was brought up and it worked [but] it didn't'. (Francesca). One father reflected on how his previous views on being an authoritative dad had to be abandoned; '...any kind of male ideas of 'you will obey' that's gone out the window, so you've got to find your own balance'. (John)

The process of reorienting often involved mixed emotions. Irena commented 'One day you deal with it fine and then the next day you feel low and then I think "I'm doing the best I can."' Yasmina felt that 'I'm stronger than I was but I'm not as happy' and Sally noted that 'I don't relish all the challenges that I will face but I think it's given me such a broad understanding'. Furthermore, Reorienting and Finding Balance appeared to be an ongoing process rather than an endpoint. Participants spoke of new challenges and periods of adaptation that would occur across the life span of the child.

You have to just accept what's happening and then with each step you have to unpick it and put it back together again... It's a real work-in-progress all the time, you can be plodding along, really happily, for six months and then something will happen and you have got to process it again. (Ruth).

Over time, I was like okay he's autistic and then you see it all written down again [in an application for Disability Living Allowance] and there's another period of adjustment. It takes time. (Greta).

Due to the ongoing nature of stressors Greta commented on the need to create a 'buffer' by protecting 'a little bit of spare capacity' in order to face additional challenges as they arose.

3.4 | 'I trusted you'

Participants considered it a positive to be interviewed by another parent carer and referred to increased trust, understanding and authenticity.

I know that you understand a lot of it, if it was someone who doesn't have [special needs child], just doing the research, one wouldn't open so much...it's not the same, I wouldn't do it with someone who doesn't know. (Sally)

Kevin reflected 'you share a lot of the passion that I share about things and I genuinely care about family caregiver emotions, so I'm always willing to [talk]' and Alan stated that 'I trusted you to handle it well'.

4 | DISCUSSION

Reflecting the primary aim of this study, participants were able to identify factors that supported their emotional wellbeing. There were a wide range of responses and these were conceptualised as coping strategies to counter stress, as well as deeper shifts in perspective to find meaning and purpose in life (wellbeing strategies). Strategies that countered stress included protecting time for the parent, relaxation techniques, 'parking' problems, downplaying difficulties as well as sharing difficulties with other parent carers. The wellbeing theme included finding purpose and meaning (e.g., work, their child or helping others), becoming empowered and gaining greater understanding of their child over time. A third theme, Reorienting and finding balance described the phenomenon of participants changing their perspective and adjusting expectations to better suit their family situation. This process involved mixed emotions (i.e., both positive and negative) and was seen as ongoing.

Rather than a one-size fits all, different strategies helped in different contexts. At times the same theme (e.g., positive other people) could be both a coping and wellbeing strategy. For example, connecting with other people could counter stress by sharing difficult experiences (including 'venting' or 'crying') as well as providing a broader sense of purpose and belonging. The latter may relate to the idea of 'social capital' (Furstenberg & Kaplan, 2007) and its well-recognised benefits on wellbeing. Conversely at times of trauma a number of participants reported needing to withdraw socially. This suggested

variance in not only how strategies were utilised but also that they could change over time. Down-playing difficulties was reported as helpful to wellbeing in the early stages of the child's diagnosis reflecting other studies focused on mothers of children with intellectual disabilities (Woodman & Hauser-Cram, 2013). However, over time this could prevent parent carers seeking appropriate support and connecting with others. The concept of being able to prioritise competing worries (i.e., 'park' concerns in the short term) was described as helpful at times of heightened stress, reflecting other studies on managing a life situation over which one has little, or no, control (Aldwin, 2011). Although at other times difficult situations needed to be faced and action taken. Venting, particularly with other parent carers, helped participants to get worries 'off their chest', as opposed to escalating negative emotions as suggested in some general literature (Larsen & Prizmic, 2008). However, over time this could possibly become negative rumination if people became 'stuck'.

The findings support the view that wellbeing is complex and multi-dimensional (Dodge et al., 2012) and possibly suggests why such a variety of models/concepts have been applied to parent carers. The breadth, and conceptualisation (e.g., coping and wellbeing strategies), of themes may reflect Aristotle's distinction between hedonism (i.e., a state of feeling happy in the moment) and eudaimonia (i.e., a well-lived purposeful life and connected to human flourishing). Interestingly, given the focus of this study was on what supported participants' emotional wellbeing a significant amount of each interview was taken up with negatives in the participants' life. This reflects other similar studies (Beighton & Wills, 2017). Despite the negatives, participants were managing to find ways to support their wellbeing which reflects the suggestion that wellbeing and stress are on different dimensions (Hastings & Taunt, 2002). This study reiterates the relevance to this cohort of psychological models which represent the complex, oscillation of emotions (i.e., Sheehan & Guerin, 2017).

The process of change appeared key in participants' interviews and of particular significance. When life involves adversity, or an unexpected event, there is inevitably a period of adaptation and as new challenges appear the adjustment continues. Whilst the extant literature reflects different terminology and conceptualisations of change (e.g., reframing, re-goaling, and growth) the authors propose that the term 'reorienting' potentially provides a broad inclusive description (identified by parent carers themselves) of this phenomenon and highlights integral elements to the process, namely, its ongoing nature and the importance of acknowledging mixed emotions. Of note, was how vital connection to positive other people was for reorienting. For example, connecting with social justice movements (e.g., neurodiversity) represented an alternative narrative which in turn, empowered parents to reject social expectations that did not suit their family.

With regards to the use of insider research in this study participants reported that the first author's position as a parent carer led to them: (i) being more willing to take part and (ii) feeling more comfortable to share their experiences. This reflects findings from the broader literature on insider research and its benefits (Berger, 2015; Finefter-Rosenbluh, 2017). Here it is possible that, just knowing the interviewer is a parent carer, rather than any particular words

spoken, was key to ensuring authenticity, trust and understanding, enabling participants to speak openly.

4.1 | Implications

This study suggests that it is beneficial for services to offer a range of wellbeing strategies offered at different points in parent carers' lives. Peer support was clearly evidenced as helpful therefore providing a 'safe space' for parent carers to connect would be helpful, ensuring parents can discuss the entirety of their emotional experiences (e.g., both positive and negative). In addition, the ease with which participants described strategies suggests that services and professionals can work with parent carers to develop support. Further research could explore in greater detail how processes of change and wellbeing strategies influence one another.

4.2 | Limitations

Defining wellbeing is a complex endeavour with differing viewpoints, and the distinction between coping and wellbeing strategies and processes is not always clearcut. As this study suggests, the meaning and purpose of certain strategies can change due to time and context thereby making it difficult to fully capture participants' experiences. Further, given the interpretive nature of the methodology the researcher can overly influence the findings, including the use of insider research. However, mitigations to this were outlined above and insider research brings advantages as well as potential limitations.

The study's small sample means that the findings are not necessarily generalisable to the wider population of parent carers. It is of note that the majority of participants were from a higher socio-economic status and a number were also professionals. This might have meant participants had greater access to supportive strategies and resources.

5 | CONCLUSION

Participants in this study identified strategies that supported their emotional wellbeing. These were often personalised and context-dependent. The findings provide nuanced description of the some of the complex processes involved in parent carer wellbeing. This may have implications for developing services, policy and research as different strategies may help at different times and in different ways. Furthermore, parent carers could be a useful resource in identifying what strategies are helpful for supporting wellbeing in parent carers more broadly.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

Research data are not shared.

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