"Right now I feel ok but more so that I am surviving not thriving": Experiences of sharing the parenting with a person diagnosed with Borderline Personality Disorder

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This report is submitted in partial fulfilment of the degree of Master of Psychology (Clinical)

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Declaration

This dissertation contains no material which has been accepted for the award of any other degree or diploma in any University, and, to the best of my knowledge, this thesis contains no material previously published except where due reference is made.

I give permission for the digital version of this thesis to be made available on the web, via the University of Adelaide's digital thesis repository, the Library Search and through web search engines, unless permission has been granted by the School to restrict access for a period of time.

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November, 2023

Contribution Statement

My research supervisors conceived the initial idea and design for this project. I then contributed to the research design, including developing the interview questions. The ethics application was completed by myself and one of my supervisors, with assistance from my other supervisors. My supervisors and I all promoted the research to potential participants. I scheduled and conducted all interviews; one supervisor assisted with two pilot interviews before I conducted the remainder of the interviews and data collection alone. I transcribed the interviews and analysed the data, discussing the case series and emerging and final themes with my supervisors who provided guidance, refined and verified the themes as is typical of qualitative research. I wrote up the thesis.

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Author Note: This article is intended for submission to the journal *Current Psychology* which requires the article to be no more than 10,000 words excluding references, tables and figures. The article has been written to satisfy the Master of Psychology (Clinical) thesis requirement of 6,000-8,000 words, which aligns with the journal word limits.

Abstract

Parenting with a diagnosis of borderline personality disorder (BPD) has been described as both a challenging and rewarding experience. Characteristics of BPD include difficulties in interpersonal relationships, inconsistent behavioural responses to stress and mentalizing, which can lead to challenging relational environments. Family members of people with BPD can experience increased burden, grief, and their own mental health concerns, including anxiety and depression. Despite this, little research exists regarding the experiences of individuals who share the parenting role with someone who has a diagnosis of BPD. This study aimed to explore parents' experiences of sharing parenting with an individual with a diagnosis of BPD to gain insight into their wellbeing and support needs. Parents' experiences were gathered through semi-structured interviews and a qualitative online survey. Reflexive thematic analysis of interviews and surveys resulted in five themes: (1) '*Increased Responsibility'*, (2) '*Self-care Suffers'*, (3) '*Information and Supports are Lacking or Self-initiated'*, (4) '*Relational Challenges'* and (5) '*Importance of Love, Connection, Understanding and Acceptance*'. This study contributes valuable information about families parenting in the context of BPD and hopes to inform future research and service provision to optimise appropriate support and facilitate positive outcomes for families.

Key words. Borderline Personality Disorder; parenting; wellbeing; support; case study; thematic analysis

Introduction

Overview

Borderline Personality Disorder (BPD) is defined in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V) as a “pervasive pattern of instability of interpersonal relationships, self-image and affects, and marked impulsivity beginning by early adulthood and present in a variety of contexts” (American Psychiatric Association, 2013, pp. 1772). The Biopsychosocial Model (Engel, 1977) acknowledges that a combination of biological factors, including genetic heritability, high sensitivity, and psychosocial experiences like abuse, trauma and neglect, may contribute to the development of BPD (Bailey & Grenyer, 2013). Across the general population, the prevalence of personality disorders is estimated to be between 6-6.5% (Lewis et al., 2018). In Australian populations, 26% of emergency mental health presentations and 25% of inpatient mental health admissions consist of individuals who meet the criteria for a personality disorder (Broadbear et al., 2022). Research conducted in South Australia reveals that a high proportion of mothers (23.1%) admitted to an inpatient mother-baby unit had a primary or co-morbid diagnosis of BPD (Yelland et al., 2015), suggesting parenting is a challenging experience for those experiencing BPD.

Mothers receiving combined treatment for BPD and support with parenting have noted the lack of treatment provided for their parenting partner or other family members, and stated that this involvement would allow carers to be better equipped to be supportive in the family context (Francis et al., 2020). Research suggests that caring for an individual with BPD is associated with higher levels of burnout and emotional distress than caring for a family member with other mental illnesses (Bailey & Grenyer, 2013). Despite this, there is limited research on the wellbeing of those sharing the parenting alongside an individual with BPD. Similarly, limited research to date has examined the support services or preferences of individuals in these roles. Therefore, this study aims to explore the experiences of parents who share the parenting role with an individual with a diagnosis of BPD. Uncovering the role's impact on their wellbeing, understanding their support needs and preferences and, importantly, expanding upon the limited literature in this area with the aim to provide valuable insights to assist families in the context of parenting with an individual with a diagnosis of BPD.

Parenting with a diagnosis of Borderline Personality Disorder

While parenthood can bring excitement, happiness and love, becoming a parent is a major life transition which can also precipitate emotional distress, including worry, sadness, exhaustion and stress (Gillis et al., 2019). These findings reflect what it is like to parent with BPD, with parents describing their experience as both challenging and rewarding (Bartsch et al., 2016). However, characteristics of BPD, including problems managing interpersonal relationships, inconsistent behavioural responses to stress and difficulties in mentalizing may intensify the challenges experienced by parents with this diagnosis (Sved Williams et al., 2018). Parents with a diagnosis of BPD report particularly high levels of parental stress and low levels of competency, self-efficacy, and reward in their role (Dunn et al., 2020). Mothers with BPD have reported feeling less satisfied and confident with their parenting compared to healthy mothers; however, findings show their knowledge of good parenting is equivalent, suggesting symptom severity may result in reduced parenting self-efficacy (Eyden et al., 2023).

Maternal BPD has been shown to increase the risk of insensitive parenting and disrupted attachment relationships (Geerling et al., 2019). Research has shown that children of mothers with BPD are more likely to experience disruptive and unstable households (Feldman et al., 1995). A growing body of research highlights that parenting with BPD can place children at greater risk of experiencing adverse outcomes, including behavioural and mental health concerns (Dunn et al., 2020). The outcomes for children are noted from infancy, with young infants of mothers with BPD being less likely to smile and vocalise and appearing less responsive to attempts at engagement from their mothers (Petfield et al., 2015). Systematic reviews of the literature have indicated that children of parents with a diagnosis of BPD demonstrate poorer mental health outcomes, including depression and attention deficit disorder, during adolescence, even compared to children in control groups who had parents with other significant mental health difficulties (Petfield et al., 2015). Other adverse outcomes for children include BPD symptoms, insecure attachment, and emotional dysregulation, with such vulnerabilities partly due to maladaptive parenting and maternal emotional dysfunction (Eyden et al., 2016).

Based on clinician report, factors that may protect children of parents with BPD from developing emotional or behavioural problems include supportive and consistent role models, social support networks, therapeutic intervention and particular child and parent characteristics such as having a calm temperament, intellectual and social skills (Bartsch et al., 2015a). Social support has also been found to moderate the effects of parental mental illness and problematic parenting behaviour, playing an important role for the wellbeing of children of parents with mental health difficulties (Seeger et al., 2022). Research with first time mothers and fathers from a general community sample has identified that partner support is associated with improved relationship quality, couple interactions, and co-parenting practices and parenting styles (Gillis et al., 2019). This may be particularly challenging for parents with a diagnosis of BPD and their partners given relational difficulties are core to the diagnosis (O'Leary et al., 2023). There is a lack of research exploring relational challenges for couples where one parent has a diagnosis of BPD during the perinatal period. Identifying and supporting people who provide care and support to a person with a diagnosis of BPD, in the context of parenting, may assist in strengthening protective factors for children.

Family/Carer Experiences

Bailey and Grenyer's (2013) systematic review highlighted that research examining carer burnout/wellbeing is overrepresented by female parental caregivers of individuals with BPD. This finding highlights the need for future research to explore the impact of the caring/supporting role on family members other than the individual with a diagnosis of BPD's parents, i.e., partners, carers and other family members, to understand their experiences, minimise emotional distress and prevent individuals with BPD from losing valuable sources of support (Greer & Cohen, 2018). Carers have shared their concerns about their lack of inclusion in therapeutic care, lack of experienced empathy, inconsistent or contradictory advice, and poor communication from health professionals and services (Bailey & Grenyer, 2013). Research also suggested that carers (primarily parents) of individuals with BPD reported greater levels of burden (family disruption, emotional distress) and grief (loss of the life a person could have had) than carers of inpatients with other mental illnesses, such as mood, substance and psychotic disorders (Bailey & Grenyer, 2013). Additionally, family members, partners and carers of a person diagnosed with a personality disorder may experience their own mental health concerns, including depression and anxiety (Bailey & Grenyer, 2013).

Contemporary models of personality disorders, such as the DSM-V alternative model and the International Classification of Disease 11th Revision (ICD-11; World Health Organisation, 2022), conceptualise the core difficulties within personality disorders as an impairment of self and interpersonal functioning (Bach & First, 2018). These core difficulties with interpersonal challenges and conflict commonly result in difficulties within the family relational environment. Symptoms of BPD, such as impulsive anger, self-harm and affective instability, are likely to adversely affect relationships, particularly with family members, partners and carers (Bailey & Grenyer, 2013). These challenges are taxing for the person diagnosed with BPD and can lead to distress and burden within the family system. Despite these findings, carers continue to report limited engagement with services and supports (Dunne & Rogers, 2013).

Results from a focus group reveal that carers (parents, partners and siblings) of individuals with a diagnosis of BPD experience a lack of access to appropriate services/information, lack of access to financial support and respite, minimal engagement with service providers and overall challenges with their wellbeing as a result of their role (Dunne & Rogers, 2013). Additional research via survey results found that when seeking support regarding their caring role, partners/spouses were largely unrecognised, and their needs remained unmet (Lawn & McMahon, 2015). Alongside these adverse experiences, carers express wanting to access support for themselves; however, many feel it is unavailable or difficult to access (Barr et al., 2020).

Existing research on the childhood experiences of those diagnosed with BPD found that there were higher rates of childhood adversity, including trauma, abuse and neglect within their family environment, in comparison to their same-aged peers (Temes et al., 2017). These findings led to carer stigmatisation and perceptions that family members and carers were ‘toxic’, creating greater difficulties in the recovery process (Bailey & Grenyer, 2013). However, more is now known about the development of BPD, and there has been a shift away from hospital-based care toward community-based treatment, with carers assuming greater responsibilities and now viewed as an important part of recovery (Bailey & Grenyer, 2013). In the context of parenting, partners and families are often a key source of support for mothers in the perinatal period. Mothers experiencing perinatal distress seek emotional, tangible and social support from their partners (Fletcher, 2023). Consistent with this, research has shown that mothers with a diagnosis of BPD have expressed interest in having their partner involved in therapy to support development of a shared understanding of BPD (Francis et al., 2020). This suggestion has been emphasised by programs for mothers with BPD, recommending that future interventions include psychoeducational interventions for partners and family members (Sved Williams et al., 2018).

Research has demonstrated that structured group programs for carers effectively reduce emotional distress and improve family empowerment and dyadic relationships between carers and individuals with BPD (Grenyer et al., 2019). More recently, brief peer-based interventions have improved stress levels, knowledge, and attitudes toward BPD, with carers feeling supported, valued and heard (Brown et al., 2022). Further, involving family members and carers in therapy has been shown to reduce emotional burnout, feelings of pain and guilt, depression and anxiety and improve relationship skills within the family system (Guillen et al., 2021). Researchers suggest that these interventions help families and carers better relate to the person they care for and feel better equipped to respond to crises (Guillen et al., 2021).

Research also highlights the importance of considering both parents' experiences of parenthood and discusses the protective role that partner support can play in reducing parental distress (Gilles et al., 2019). In contrast, many parents with BPD highlight concerns about feeling isolated and under-supported and have difficulties navigating and accessing support (Dunn et al., 2020). Similarly, fathers who are supporting their partner during perinatal mental distress, report a limited knowledge of suitable sources of assistance or not reaching out for support in fear of judgement or stigma (Fletcher, 2023). Qualitative research about family members' experiences sheds light on fathers feeling as though they have had to adopt joint roles of the father and mother and how this impairs their ability to care for themselves (Kay et al., 2018). Similarly, romantic partners report feeling as though they have adopted the dual roles of a romantic partner and a caregiving/therapeutic figure (Greer & Cohen, 2018). Parents who provide care to a child with a BPD diagnosis report a perceived increase in responsibility ‘above and beyond’ what is expected of other parents, whereas partners describe that there is an element of ‘choice’ in their role (Dunne & Rogers, 2013).

This study aims to explore parents’ experiences of sharing the parenting role with an individual with a diagnosis of BPD to gain insight into their experiences, wellbeing, and support needs. Understanding parents’ experiences and support needs may address a knowledge gap, increase awareness of their experiences, and inform future service provision to optimise appropriate support and facilitate better outcomes for parents and children.

Method

Design

A qualitative case series, where data were gathered using semi-structured interviews and a qualitative survey. The University of Adelaide Human Research Ethics Committee approved this research (HREC-2023-042).

Participants

Participants consisted of four Australian parents, aged over 18 years old, fluent in English, who had a child/ren of primary school age or younger, and who were sharing parenting with an individual with a diagnosis of BPD. Further demographic characteristics are provided below in the case series.

Procedure

Between March and August 2023, over 40 Australian organisations that provide therapeutic support to individuals with BPD or their carers/families were approached via email to share information about the research with their networks (e.g., Australian BPD Foundation, Sanctuary Carers Group SA, National Education Alliance for BPD (NEA BPD), Project Air, Lived Experience Australia, SMS 4 Dads etc). These organisations shared information about the research on their social media and/or via their e-newsletters. Recruitment also occurred through advertisements shared on social media (i.e., Facebook, LinkedIn) by the researchers and via passive snowballing.

During initial recruitment, participants were invited to engage in a semi-structured interview; those interested initiated contact with the researchers and provided consent prior to the interview. Semi-structured interviews used a topic guide with questions developed based on existing literature and clinical experience (see Supplementary Table 1). Demographic data was collected along with participants' experiences of parenting with an individual with a diagnosis of BPD and their support needs/preferences and wellbeing. The first non-demographic question, "Can you start by describing your experiences of parenting with someone who has a diagnosis of BPD?" was intentionally broad to enable parents to share the information they felt comfortable sharing. Following this, more focused questions explored information/supports/services available or accessed, wellbeing, and ways to optimise parental wellbeing. Example questions included "What supports, if any, have you accessed for yourself to help you share the parenting role with someone who has BPD?" and "Can you describe your overall level of wellbeing?".

To assess the suitability of the proposed interview schedule, the researcher and one of the research supervisors (a registered psychologist) conducted two pilot interviews in May 2023. Following pilot interviews, one additional question was added to obtain information about what advice participants would give to others in the same situation. The researcher then conducted the third interview independently.

Interviews were conducted via teleconferencing (Zoom) and ranged from 30 min to 1h and 35min (*M* = 53.33 min, SD = 36.17). All interviews were transcribed verbatim. As per standards for excellence in qualitative research (Tracey, 2010), an audit trail was maintained, and participants were sent their transcripts for verification and emerging themes for 'member reflections’, to enhance the accuracy of the themes identified. All participants confirmed their transcripts. All participants were sent a copy of the emerging findings and invited to provide feedback. No participants provided feedback on the themes; one participant provided information about their partner's response to new treatment.

Following significant difficulties recruiting participants for interviews, despite considerable effort, ethics approval was granted to also allow data collection through an online qualitative survey hosted on Qualtrics. This data collection method was added to maximise recruitment by providing an option that allowed for anonymity and flexibility for parents who may have limited time and increased caring responsibilities that hampered their ability to participate in an interview. Questions in the online qualitative survey reflected those asked in interviews. Information about the online survey was distributed to the organisations contacted previously and left open for engagement for three and a half months. Data collection continued until all parents who expressed their interest could complete an interview, and the survey was closed in October 2023.

Data Analysis

The analysis is reported as a series of case studies with comparative data analysed using reflexive thematic analysis, in which participants’ responses were interpreted to reflect their lived experience (Braun & Clark, 2022). The analysis followed the six-step process outlined by Braun and Clark (2022): (a) data familiarisation through transcription and repeated reading; (b) generating initial codes from; (c) searching for themes; (d) reviewing themes; (e) defining and naming themes; and (f) writing up the final results. The primary researcher developed the themes, which were reviewed and refined in collaboration with supervisors. All researchers agreed on the final themes.

Results

Case Study 1

The first interviewee was a woman in her 30's sharing the parenting of four-year-old children with her ex-partner with a diagnosis of BPD. This participant described her experience as *"chaotic"* and emphasised that she took on a large proportion of the parental responsibility. She stated: *"I was never able to fully check out of parenting…it kind of felt like I had three children".* Furthermore, she spoke about the challenges associated with her ex-partner's emotional lability and how seemingly small issues resulted in *"big blow ups".* The interviewee further expressed concern for her children's attachment relationships with their other parent and spoke to the challenges of managing communication regarding the children's shared care. The participant acknowledged that seeking help at this time would have been helpful due to being in a *"permanent state of anxiety and stress".*

The interviewee described having a comprehensive understanding of BPD and what this meant. She had attained knowledge through attending psychiatry appointments with her ex-partner, self-initiated online research and contact with BPD carer support groups. She said this information helped her to *"step back…from taking everything personally".* While this participant had access to comprehensive information and informal support from her new partner, she described having limited professional support until eventually seeking private psychological therapy. Given the complex nature of her past relationship, the interviewee acknowledged that accessing formal support earlier, particularly while making decisions about ending the relationship, would have been beneficial. She noted: *"I really should have had more wrap around supports than just the informal ones that I had".* While this interviewee did not desire access to specific support services at the time of the interview, she spoke about how contributing to lived experience/peer support groups made her experience feel like it was *"worth something"* and provided her with a sense of validation and connection. Before separation, the interviewee provided her partner with a lot of support, including managing her medication and appointments with her mental health professionals. She described the co-morbid diagnoses and associated pharmacotherapy recommended by the psychiatrist as complicating factors to her ex-partner's recovery and expressed that she thought a Dialectical Behaviour Therapy (DBT) approach would have been more beneficial.

With respect to her own wellbeing, she described a significant improvement after leaving the relationship. She emphasised: *"At the moment, great…at the time when we were co-parenting, I would say incredibly poor".* The interviewee was still consulting a psychologist; however, the nature of the sessions shifted as her needs changed. Regarding her children, the interviewee indicated there was limited information available about the impact of maternal BPD on short- and long-term outcomes for children. Finally, the interviewee highlighted the need for services to take a family-based approach and for families managing BPD to have access to affordable services specifically targeted at those in parenting roles.

Case Study 2

The second interviewee was a man in his 40's living with his partner who had a diagnosis of BPD and parenting their 1-year-old son together. The participant described his experience as *"emotionally draining…mentally draining"* and *"time-consuming".* He further reported that his partner experiences a range of emotions, often unexpected, that were difficult to regulate, leading to a *"conflicting priority"* whilst also trying to care for his young child. The interviewee emphasised that the love, support, care and shared goals he and his partner upheld contributed to the success of their ongoing relationship.

The interviewee had access to his own psychologist, had attended joint sessions with his partner's psychologist, attended a free skills-based carer group and had self-initiated online reading and research about BPD. Additionally, he and his partner had support through a local community health service sleep training program and a perinatal mental health inpatient service, which both supported the mother-infant dyad and relationship building. The interviewee most valued a skills-based carer program offered by the National Educational Alliance for BPD. He appreciated the knowledge, understanding and tools that this program provided and was eager to complete the course again. He shared*: "…it's targeting communication between you and the person with BPD, and it was incredibly powerful, I think everyone was impressed…realising that they could do something very significant to change the impact on their lives."*. He emphasised that learning about BPD was a process that occurred over time and that one service led him to the next, he stated: *"…it's that process of understanding is a journey in itself, you can't just go from 0 to 100% knowledge in one go…".* While accessing joint sessions with his partner's psychologist did not occur early on in her therapeutic journey, once his partner felt comfortable with him attending several sessions, he reported that this had provided him with perspective and a sense of closeness. Despite having access to valuable services, the interviewee highlighted the lack of access to evidence-based treatments for BPD, such as DBT. He stated: *"…they are on waiting lists for years to get DBT"*. He acknowledged this as true in their experience and for many others in the NEA BPD peer-based program.

With regard to his wellbeing, despite having access to services, the interviewee emphasised that with competing demands, he had limited time for self-care. He described having minimal sleep and no time to exercise like he used to. He expressed: *"…I guess I'm managing or I'm coping at the moment, rather than actually thriving…".* The interviewee re-emphasised that his love for his family and his resilience maintained his wellbeing.

Case Study 3

The third interviewee was a man in his 40's sharing the parenting of his 5-year-old daughter with his wife, who has a diagnosis of BPD and co-morbid attention deficit hyperactivity disorder (ADHD). This participant began by referring to their experience as a *"roller coaster"*. When sharing that his wife tended to make decisions on a "*whim*", without rationality, he stated: *"...you just never know where the roller coaster is going*". The participant emphasised the changeable nature of their day-to-day experiences describing *"...some days are good, a lot more of, you know aren't quite so good"*. Another factor leading to challenges within their family dynamic was differences in their thinking and coping styles, for which he had done a lot of work trying to understand his wife's point of view. He reported feeling as though he was taking on the larger parental responsibility for his daughter, which, at times, he finds "*exhausting*". He explained "*I do most of the housework... it doesn't get seen, it just becomes invisible, and the fairies do it, that being me*". Later in the interview he shared "*I started doing the mothering role… essentially when she came out* [after birth] *and then I just got used to that*". The "*ups and downs*" over the years of their relationship and the extra responsibilities from his work have led to varying levels of empathy and understanding and a notable impact on his emotional capacity. On the other hand, the interviewee described a reciprocity within their relationship that helped to bring about a sense of balance and connectedness.

The interviewee described having read literature about BPD to enhance his understanding of the diagnosis and had attended several sessions of a peer-led support group, which provided him with a sense of reassurance, validation, and connectedness. He communicated: "*... hearing their stories made mine a lot easier to understand*." After experiencing a couple of "*downward spirals*", he stopped engaging with the group due to a lack of availability. The books or articles he had read reportedly helped him to evaluate his expectations of his wife and enhance their communication. The importance of communication was emphasised several times throughout the interview as an important tool in their relationship; he shared: "*… she often sends me... things like... 'this is how I'm doing' ... so I know the mood for when I get home…*". The interviewee highlighted a tendency to neglect his wellbeing, sharing, "*I have never really tended to look for support, I just continue doing until I collapse in a big pile...*". Recognising a need for change, the interviewee established individual support from a counsellor and in-home supports for practical help and respite. He and his partner had also participated in a parenting program (Circle of Security) and group-based Cognitive Behavioural Therapy. Most of this interviewee's engagement with support services was established through his wife's knowledge of available programs due to her engagement with a range of community-based services. The interviewee acknowledged that ensuring his wife remained engaged with her support services helped them to manage "*the highs and lows*" and ensure that their lives "*run a lot smoother*".

With respect to his wellbeing, he described a changeable experience with periods of contentment and exhaustion. With increased responsibilities and limited time, he reflected on the challenges of prioritising his eating habits; he stated: "*I tend to just grab what I can in between disasters*". Despite he and his wife knowing that he needs time for self-care, he shared: "*If things are going to hell in a handbasket, that tends to go to the wayside*". Overall, he attributed his maintained wellbeing to their well-established daily routine.

The interviewee expressed that knowing about BPD and how it can influence relationships and parenting was key to maintaining relationships and wellbeing. He communicated a desire for a "*dummy's guide*" to BPD that is free of jargon and full of practical information about navigating the parenting journey with someone with a diagnosis of BPD to be established. Beyond knowledge, he highlighted the value of practical (in-home) and peer-based supports.

Through lived experience and navigating many challenges, the interviewee provided advice for individuals in a similar position. He highlighted the importance of communication, patience, empathy, and intentional active listening. Beyond the support offered to one's partner, he spoke about the importance of self-validation ("*giving yourself permission to* *feel*"), making space for the complexity of feelings, and not neglecting self-care. He explained: "*...that's why they tell you on aeroplanes to put your mask on first, because if you are passed out, then you can't help anybody else.*".

Case Study 4

The final participant, with data obtained through the qualitative survey, was a woman in her 30's sharing the parenting of two children (7 and 4 years old) with her husband, who had a diagnosis of BPD. From her written responses, it was understood that her husband becomes less present during a crisis and often "*catastrophises*", making it difficult to hold an open perspective. During these times, the participant assumed extra responsibilities to ensure that her husband can focus on self-care, putting her needs last. She described:

> *I feel that I take on a lot of extra duties to accommodate for him, I ensure that he always has enough time to himself, time to work on himself, mediate, journal etc, but often find that to do that, I put myself last.*

Despite these challenges, the participant reported her husband being "*dedicated to self-improvement and self-awareness*", having a comprehensive understanding of his mental health and having strong connections with their children. Having been raised by a mother with a diagnosis of BPD herself, this participant had greater experience understanding the potential challenges of BPD. Whilst she had listened to podcasts and read some articles, she had not considered that there would be information available specifically for parents in her position. The participant described reaching her "*caretaking capacity*" several months ago, which led to her being referred to a private psychologist; however, due to cost, she could not access this support.

The participant described having a close support network of friends and family and an optimistic outlook. While managing multiple roles as a part-time student, wife and mother she stated: "*Right now I feel ok but more so that I am surviving not thriving*". With her many roles, particularly the caretaker role she has adopted throughout her life, she expressed difficulty being "*a support person*" to her husband and finding it challenging to prioritise her physical and mental health. Finally, she wrote about accepting her position and attempting to manage it the best she could.

Themes

Five themes labelled (1) 'Increased Responsibility', (2) 'Self-care Suffers', (3) 'Information and supports are lacking or self-initiated', (4) 'Relational Challenges' and (5) 'Importance of love, connection, understanding and acceptance' were developed and are described below.

Theme 1: Increased Responsibility

All participants referred to the increased responsibility they held within their relationship dynamic. They emphasised that they provided most of the care to their child/ren, above what would be expected of a typical parenting role where the responsibility may be shared.

> *I always knew that I held the bigger responsibility, um so it never really felt like it was a co-parenting relationship…I had to do a lot of the organising a lot of the stepping in and picking up the slack, and just making myself available on a whim when she decided it was too much*. (Participant 1)

The interviews shed light on other day-to-day responsibilities for which participants held most responsibility. For example, taking over domestic tasks to ensure the everyday housework duties were maintained: "*I do most of the housework, I do most of the everything else*." (Participant 3).

Participants described taking on additional caregiver duties to ensure that the parent diagnosed with BPD felt supported to manage their health and wellbeing. Additional caregiving duties included managing the other parent's appointments and medications and supporting them to regulate their emotions.

> *I managed all of her appointments…I also assisted with all of her medication…I very much stayed on top of ensuring she was functioning at her best and had the support that she needed to be able to co-parent with me in our relationship*. (Participant 1).

They indicated this could be burdensome as they assumed caring responsibilities and practical management for multiple family members. "*I have two of them [partner and child] that I have to, you know, try and organise and get around*." (Participant 3).

Participants largely provided these descriptions when asked to share their experiences and the challenging aspects of their role. They also explained how this level of increased responsibility adversely impacts their ability to prioritise their own wellbeing and self-care.

Theme 2: Self-care Suffers

Participants described how increased responsibility, limited time, and a lack of resources and supports adversely impacted their ability to engage in self-care. Throughout the interviews, it was evident that participants prioritised the needs of their child and the other parent over their own. Whilst there are elements to these experiences that resemble the responsibilities of parenthood more generally, the additional element of caring for a partner (or ex-partner) complicated their ability to care for themselves.

> *I don't get a lot of sleep…I don't really get to exercise…part of that is obviously just having a child and some of that is giving up time for your job but a big part of it is also just the time taken away from things that happen with my partner and the amount of time that consumes. Um my overall health; definitely subpar*. (Participant 2).

A sense of determination and resiliency was reflected within the interviews, demonstrating the lengths the parents went to ensure their family's health and wellbeing, even if this was to their detriment. The aftermath of this increased responsibility was made evident: "*... I just give, give, give, until I fall down…*" (Participant 3).

The implications of caring for others, affected the prioritisation of many aspects of health: *"I find it hard to prioritise my own physical and mental health because I have been a caretaker for my whole life*." (Participant 4).

While acknowledging that self-care suffers when supporting their child and the other parent with BPD, parents were also in need of information and supports.

Theme 3: Information and Supports are Often Lacking or Self-initiated

Barriers and a need for self-motivation and initiative often hamper access to information and supports. Participant 4 explained that they "*…never thought there would be any information to access around parenting with someone with BPD*." Whereas others described that if they had attempted to find information about the impacts that parenting with a BPD diagnosis had on the family system, it was limited.

> *…there's not a lot of information out there, not a lot of formal information about the impacts that this particular diagnosis has on children and has on parents…I think we're just a little behind in understanding what it actually means long term for people*. (Participant 1).

A pattern of self-initiated help-seeking was evident when participants described how they obtained information or engaged services to support them in their role. For example, when discussing how Participant 2 became aware of the NEA BPD group program and sought private psychological support he shared: "*Just through my own want I guess, to find information*".

Similarly, other participants referred to utilising social media as a source of information rather than through official support providers in the community: "*I found one or two things just scrolling through Facebook…*" (Participant 3).

When formal supports were discussed, participants described that accessing formal supports such as a private psychologist, was difficult due to availability and financial stressors: *"…I know that there's a huge cohort of carers who just can't, either financially or with the time that they have available, mostly financially, access formal supports*" (Participant 1).

Parents who share the parenting role with an individual with a diagnosis of BPD require self-determination, motivation, knowledge, time, and access to affordable services that may provide practical and emotional support to sustain their long-term mental health and wellbeing. They must also learn how to effectively navigate relational challenges.

Theme 4: Relational Challenges

Several participants alluded to the interpersonal challenges within their current relationship or with their ex-partner. Challenges included identifying that they had different communication approaches to their partner and how improving communication was crucial in de-escalating further conflict. Additionally, participants emphasised the importance of acknowledging that each person had a different thinking style and approach to problem-solving: "*Yeah, we think very differently, she's very emotional and that influences a lot…I'm very pragmatic.*" (Participant 3).

Participant 3 also elaborated further that understanding their partner's perspective helped to enhance their level of understanding and acceptance:

> *…try and put yourself in their shoes, you may vehemently disagree and go 'no I don't think it should be done this way' but having that empathy and having*

> *that understanding of where they're coming from and how they're seeing things gives you a lot…* (Participant 3).

The importance of communication was highlighted by all participants, with differences observed depending on the relationship dynamic. For Participant 1, who was no longer in a romantic relationship with the other parent with a diagnosis of BPD, "*limiting communication*" was important. In contrast, for participants still currently in relationships with a partner with a diagnosis of BPD, enhancing their communication was expressed to be an important protective factor: *"…I've always been told; communication, communication, communication and have always brushed it off...but it is phenomenally important…*" (Participant 3).

Participants highlighted relational challenges, with communication seen as an important means to assist such challenges. While relational challenges were articulated, participants also spoke of the importance of positive feelings, understanding and acceptance.

Theme 5: Importance of Love, Connection, Understanding and Acceptance

With limited time for self-care, ongoing relational challenges and increased caregiving responsibilities, participants still in a romantic relationship with an individual with a diagnosis of BPD highlighted the factors that contributed to their relationship's longevity, including love, connection, understanding and acceptance:

> *… I have a lot of love for my partner… and I know my partner has a lot of love for me as well, so I think they are the things that are keeping me going*.
>
> (Participant 2).

Another participant emphasised the importance of making space for his own feelings, truly understanding his partner, and acknowledging the ongoing love for his partner: "*Because you know they are gonna drive you crazy. And that's just part of who they are, and it doesn't mean that you love them any less.*" (Participant 3.)

While acceptance was framed positively "*… it is what it is, and we just have to go around and make things work*" (Participant 3); it is acknowledged that this may also reflect unhealthy accommodation which may be difficult to sustain in a relationship long-term "*I've always just thought that this is my situation and I deal with it the best I can*." (Participant 4).

Discussion

Overview

This study aimed to explore the experiences of parents who share the parenting role with an individual with a diagnosis of BPD to gain insight into their experiences, wellbeing, and support needs. Data were summarised using a series of case studies and reflexive thematic analysis described similarities in participants' experiences.

The findings indicated that people who share the parenting role with an individual with a diagnosis of BPD may take on increased responsibilities in several life domains, including parenting, domestic duties and supporting the other parent to manage their wellbeing. Prioritising time for self-care was difficult, and in many cases, unachievable. Most participants had self-initiated the search for information about BPD and how it may influence parenting. Similarly, participants described actively seeking desired or needed supports. With interpersonal difficulties being core to a BPD diagnosis, it was unsurprising that participants reported relational difficulties. All participants, regardless of relationship status, highlighted the importance of communication. Where participants were still in a relationship with the person with a BPD diagnosis, communication was portrayed as a powerful tool to increase understanding. In contrast, for the participant who was no longer in a relationship, limits to communication were seen as crucial to sustaining appropriate boundaries. Whilst participants described several challenges, they also emphasised the role of love, understanding and connection in contributing to relationship satisfaction and longevity.

Summary of Findings

Parenting with a person with a diagnosis of BPD was associated with increased parental, domestic and caregiver responsibilities. Participants emphasised that this was often to allow the other parent space to maintain their wellbeing or to prevent dysregulation/conflict. This finding is consistent with past research, where partners felt they held dual roles as a romantic partner and a caretaker (Greer & Cohen, 2018), and parents emphasised the need to adopt joint roles of mother and father to support their children's needs (Kay et al., 2018). Indeed, one participant referred to themselves as a 'caregiver' rather than a 'mother' or 'wife'. Additionally, like Dunne and Rogers (2013), participants emphasised that they held larger responsibilities, 'above and beyond', what would usually be expected when parenting. Most participants referenced maintaining these responsibilities to reduce the likelihood of tasks being incomplete or to maintain relationship cohesion. Bailey and Grenyer (2013) also found that carers ensured the individual with BPD was supported/stable, which positively impacted carers' emotional state. These findings raise questions regarding carer overinvolvement, which has positive effects for individuals with BPD in the short-term as their needs are met; however, adverse impacts for family and carer mental health due to increased burden (Seigerman et al., 2020).

The current study found that increased parenting and caregiving responsibilities adversely impacted parents' self-care and wellbeing. Past research has shown the importance of acknowledging the 'silent carers' whose wellbeing is often overlooked (Dunne & Rogers, 2013) and demonstrated that carers of individuals with BPD may experience anxiety and depression (Bailey & Grenyer, 2013). While only one participant explicitly described their own mental health challenges, all participants spoke about their role's impact on their wellbeing, resulting in them seeking professional support. While they struggled to engage in self-care, parents recognised the importance of caring for themselves in order to then care for their families. Other carers (Dunne & Rogers, 2013) and fathers who support a partner with BPD and care for their child/ren (Kay et al., 2018) have recognised self-care as an important factor in being able to maintain their role. Treatment guidelines acknowledge the importance of considering carer wellbeing and burnout and recommend that families and carers are involved in BPD treatment and access mental health supports outside of group programs (Grenyer et al., 2019). Recent research has demonstrated the importance of carers developing social supports within and outside treatment programs to enhance positive mental wellbeing (Hayes et al., 2023). It appears that whilst carers are aware of the importance of maintaining their wellbeing, it is complicated and, in some cases, unachievable due to limited time, capacity, and resources. Therefore, routine screening and service provision for parents sharing the parenting with a person diagnosed with BPD is an important consideration for family wellbeing.

Participants also desired information and support specific to sharing the parenting role with someone with a diagnosis of BPD but indicated that it had to be self-sought, requiring motivation, knowledge, time, and financial resources. Whilst two of the participants accessed support alongside their partner, either in a group-based program or individual therapy, most participants didn’t appear to be offered supports as a package alongside their partners support. This was a consistent experience amongst participants, with concerns raised about having limited access to knowledge and information concerning how to best manage their situation (Kay et al., 2018). The current findings can be compared to carers’ experiences, including partners supporting an individual with a BPD diagnosis, whereby carers remain ‘invisible’, experiencing limited recognition for their needs from service providers (Lawn & McMahon, 2015). Other research has demonstrated that mental health services rely on carers to support people with BPD through crises; despite this, they often neglect to reduce carer burnout by providing carers with practical and emotional support (Dunne & Rogers, 2013).

Previous research reports a similar self-help seeking pattern amongst carers whereby they accessed most information about BPD through books or the ‘internet’ (Dunne & Rogers, 2013). Participants in the current study utilised social media as a source of information about BPD and associated services. Whilst social media is a powerful platform for advertising services, the information sought on such platforms may be biased or stigmatising (Bizzotto et al., 2023). There is a clear need for targeted, affordable and accessible evidence-based resources for this population of parents.

As well as increased responsibilities, reduced capacity for self-care and difficulties accessing information, participants described relational difficulties. Partners, carers and family members are likely to be affected by the experiences of a loved one diagnosed with BPD due to symptoms such as impulsive anger, self-harm and affective instability (Bailey & Grenyer, 2013). Within couples where one person has a diagnosis of BPD, high rates of maladaptive communication styles, particularly during stress and conflict, have been observed (O’Leary et al., 2023). Couples have shared that effective communication has been essential in navigating relational stressors, and others have shared how attending therapy to improve their communication skills has also helped their relationships (O’Leary et al., 2023). Within the current study, participants highlighted how communication was essential in understanding their partner’s experiences. One participant described how attending his partner’s therapy allowed him to see things from his partner’s perspective and how having a third party facilitate this, prevented things from escalating. Treatment guidelines for carers that incorporate skills targeted at relationships, communication and validation have seen positive treatment outcomes, including improvement in dyadic relations and family empowerment (Grenyer et al., 2019).

Despite the many challenges associated with sharing the parenting role with an individual with a diagnosis of BPD, for participants who were still partnered, love, connection and understanding were attributes that contributed to relationship satisfaction and longevity. In comparison to other personality disorders, BPD is associated with decreased romantic relationship quality, satisfaction and stability (O'Leary et al., 2023). Romantic partners who are accepting and nurturing, however, can support the stabilisation of BPD symptoms (O'Leary et al., 2023). Other factors that contribute to adaptive dyadic relationships include external resources such as seeking therapy (couple and individual), accessing information on BPD and internal factors, including emotional attunement, commitment to growth and externalising the diagnosis from the individual (O'Leary et al., 2023). Participants in the current study described similar features, highlighting the importance of love, empathy, shared goals and understanding. This idea of 'acceptance' has been described in other research, with partners being more satisfied in their role once they accepted that their role as a partner was not purely romantic but also to care for the individual with BPD symptoms (Greer & Cohen, 2018). Other researchers have reflected on this concept of 'choice', whereby carers felt responsible for managing challenges after having 'chosen' to be partner with an individual with a diagnosis of BPD (Dunne & Rogers, 2013).

Limitations and Future Research

Carers and family members can be crucial supports for people with a diagnosis of BPD, and sharing parenting with a person with a diagnosis of BPD is an important role. The current study contributes meaningful insights about this parenting role but should be considered in light of limitations. Despite significant recruitment efforts, only four participants were obtained. Although the sample contained feedback from both men and women, the findings may not represent the experiences of all people sharing the parenting role with an individual diagnosed with BPD, including those from different cultures or rural areas. Further research to explore the shared parenting experiences of individuals from diverse cultural backgrounds and different relationship dynamics beyond a biological parent (i.e., step-parents, foster parents, and grandparents) would be beneficial.

Research Challenges and Clinical Implications

Recruiting participants for this study was challenging. Considering the factors that may have contributed to low recruitment rates may guide future researchers in enhancing engagement. Initially, the study sought parents who had a child/ren aged 0-5 and used the term ‘co-parenting’. Changes were subsequently made to expand the age range and to use the term ‘sharing the parenting role’ as stakeholders advised the researchers that the term ‘co-parenting’ was confusing and may deter parents who were still in a relationship as they may incorrectly assume they were ineligible. Additionally, low recruitment rates in BPD-related research is common and may stem from stigma associated with the diagnosis (Woo et al., 2021) and potential fears of intervention from child protective services (Bartsch et al., 2015b). Moreover, recruiting partners or spouses is more difficult than recruiting carers who are a parent to an individual diagnosed with BPD. This difficulty may be due to the relationship being ‘intimate’ and ‘chosen’ (Grenyer et al., 2019). Strategies to enhance future recruitment may include broad inclusion criteria, inclusive language, and offering participation through multiple platforms (interview/survey), within and outside of business hours, to optimise availability and flexibility.

With respect to clinical practice, it is apparent that this cohort of parents require accurate, easily accessible information about how a BPD diagnosis may influence an individual’s parenting role and what supports are available to families. Further to this, with concerns arising for how the broader family system (children and extended family) may be impacted, parents may benefit from information about outcomes for children of parents with BPD and how to maximise protective factors. Services should aim to engage families and carers early, even prior to childbirth, offering free or low-cost services, at flexible times with content specifically targeted at parenting with an individual with BPD. Resources and services should be evaluated to ascertain their appropriateness and effectiveness. Front-line health practitioners, including General Practitioner's and associated mental health services, should continue to consider the role of the family and what supports they may require to optimise wellbeing.

Conclusion

This study adds to the limited knowledge and insight into the experiences of parents who are sharing the parenting role with an individual with a diagnosis of BPD. Parents take on increased responsibilities within their parenting and caregiver role, have difficulty maintaining self-care and wellbeing, and are required to self-initiate accessing information and supports despite the many relational challenges they experience that impact their wellbeing. Further, this cohort encountered several barriers to accessing supports, including limited knowledge of services, challenges with availability and financial barriers. Despite the challenges experienced, the importance of love, connection, understanding, and acceptance stood out as key factors in relationship satisfaction and longevity. While this study provides useful insights, future research would be beneficial to provide further information that may help to optimise the wellbeing of parents and families parenting in the context of BPD.

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Appendix A

Supplementary Table 1.

Interview Topic Guide

Questions

1. Can you start by describing your experiences of parenting with someone who has a diagnosis of BPD?
    - What, if anything, works well?
    - What, if anything, have you found challenging?
2. What information, if any, have you accessed to gain an understanding of the other parent’s mental health condition and how this might influence their parenting? (examples: online information, brochures, readings, videos online, podcasts, websites).
3. What supports, if any, have you accessed for yourself, to help you share the parenting role with someone who has BPD? (e.g., individual supports either formal or informal)
4. What supports, if any, have you accessed to help your child’s other parent to manage their health and parent effectively? (examples: individual therapy, joint therapy, support groups, FB pages, online groups, peer support programs)
5. Can you describe your overall level of wellbeing?
6. What, if anything, do you think could be done to help optimise the wellbeing of parents like yourself, who are sharing the parenting role with someone with a diagnosis of BPD?
7. Finally, based on your experience, what advice, if any would you give to someone in your position?

Appendix B

Instructions for Authors

Article Types

Regular Article: This article type is limited to a maximum of 10,000 words, not including references, tables, and figures. There should be a maximum of 3-4 figures, 3-4 tables, and 40-45 references. The abstract should be between 150 and 250 words, and the manuscript should include 4-6 keywords.

Brief Report: This article type is limited to 1,000 words. The abstract should be no longer than 150 words. There should be a maximum of two figures or tables and 20 references.

Classifications Required for Submission

Including Classifications with submission of your manuscript is required for this journal. When submitting your manuscript, please enter all of the manuscript's relevant areas of research when prompted. This will ensure that the initial submission and peer review process runs smoothly.

Editorial procedure

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This journal follows a double-blind reviewing procedure. This means that the author will remain anonymous to the reviewers throughout peer review. It is the responsibility of the author to anonymize the manuscript and any associated materials.

- Author names, affiliations and any other potentially identifying information should be removed from the manuscript text and any accompanying files (such as figures of supplementary material);

- A separate Title Page should be submitted, containing title, author names, affiliations, and the contact information of the corresponding author. Any acknowledgements, disclosures, or funding information should also be included on this page;
- Authors should avoid citing their own work in a way that could reveal their identity.

This journal also publishes special/guest-edited issues. The peer review process for these articles is the same as the peer review process of the journal in general.

Additionally, if a guest editor authors an article in their issue/collection, they will not handle the peer review process.

Manuscript Submission

Manuscript Submission

Submission of a manuscript implies: that the work described has not been published before; that it is not under consideration for publication anywhere else; that its publication has been approved by all co-authors, if any, as well as by the responsible authorities – tacitly or explicitly – at the institute where the work has been carried out. The publisher will not be held legally responsible should there be any claims for compensation.

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Online Submission

Please follow the hyperlink "Submit manuscript" and upload all of your manuscript files following the instructions given on the screen.

Source Files

Please ensure you provide all relevant editable source files at every submission and revision. Failing to submit a complete set of editable source files will result in your article not being considered for review. For your manuscript text please always submit in common word processing formats such as .docx or LaTeX.

Title Page

Please make sure your title page contains the following information.

Title

The title should be concise and informative.

Author information

- The name(s) of the author(s)
- The affiliation(s) of the author(s), i.e. institution, (department), city, (state), country
- A clear indication and an active e-mail address of the corresponding author
- If available, the 16-digit ORCID of the author(s)

If address information is provided with the affiliation(s) it will also be published.

For authors that are (temporarily) unaffiliated we will only capture their city and country of residence, not their e-mail address unless specifically requested.

Large Language Models (LLMs), such as ChatGPT, do not currently satisfy our authorship criteria. Notably an attribution of authorship carries with it accountability for the work, which cannot be effectively applied to LLMs. Use of an LLM should be properly documented in the Methods section (and if a Methods section is not available, in a suitable alternative part) of the manuscript.

Abstract

Please provide an abstract of 150 to 250 words. The abstract should not contain any undefined abbreviations or unspecified references.

For life science journals only (when applicable)

- Trial registration number and date of registration for prospectively registered trials
- Trial registration number and date of registration, followed by "retrospectively registered", for retrospectively registered trials

Keywords

Please provide 4 to 6 keywords which can be used for indexing purposes.

Statements and Declarations

The following statements should be included under the heading "Statements and Declarations" for inclusion in the published paper. Please note that submissions that do not include relevant declarations will be returned as incomplete.

- **Competing Interests:** Authors are required to disclose financial or non-financial interests that are directly or indirectly related to the work submitted for publication. Please refer to "Competing Interests and Funding" below for more information on how to complete this section.

Please see the relevant sections in the submission guidelines for further information as well as various examples of wording. Please revise/customize the sample statements according to your own needs.

Text

Text Formatting

Manuscripts should be submitted in Word.

- Use a normal, plain font (e.g., 10-point Times Roman) for text.
- Use italics for emphasis.
- Use the automatic page numbering function to number the pages.
- Do not use field functions.
- Use tab stops or other commands for indents, not the space bar.
- Use the table function, not spreadsheets, to make tables.
- Use the equation editor or MathType for equations.
- Save your file in docx format (Word 2007 or higher) or doc format (older Word versions).

Manuscripts with mathematical content can also be submitted in LaTeX. We recommend using Springer Nature’s LaTeX template.

Headings

Please use no more than three levels of displayed headings.

Abbreviations

Abbreviations should be defined at first mention and used consistently thereafter.

Footnotes

Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes.

Acknowledgments

Acknowledgments of people, grants, funds, etc. should be placed in a separate section on the title page. The names of funding organizations should be written in full.

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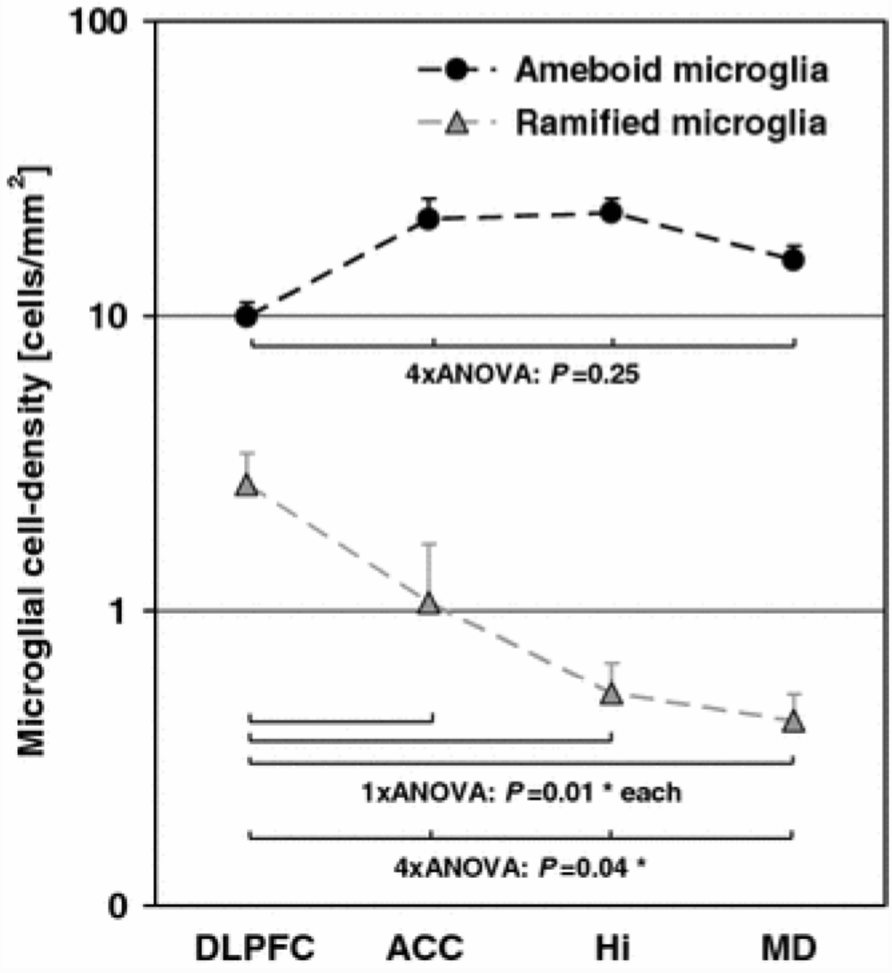

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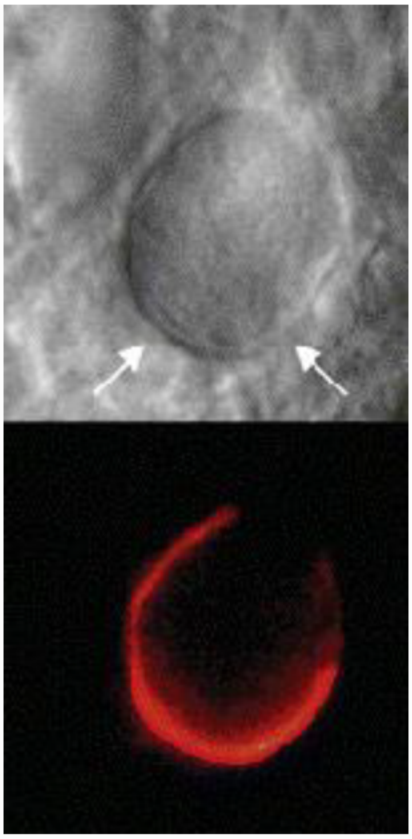

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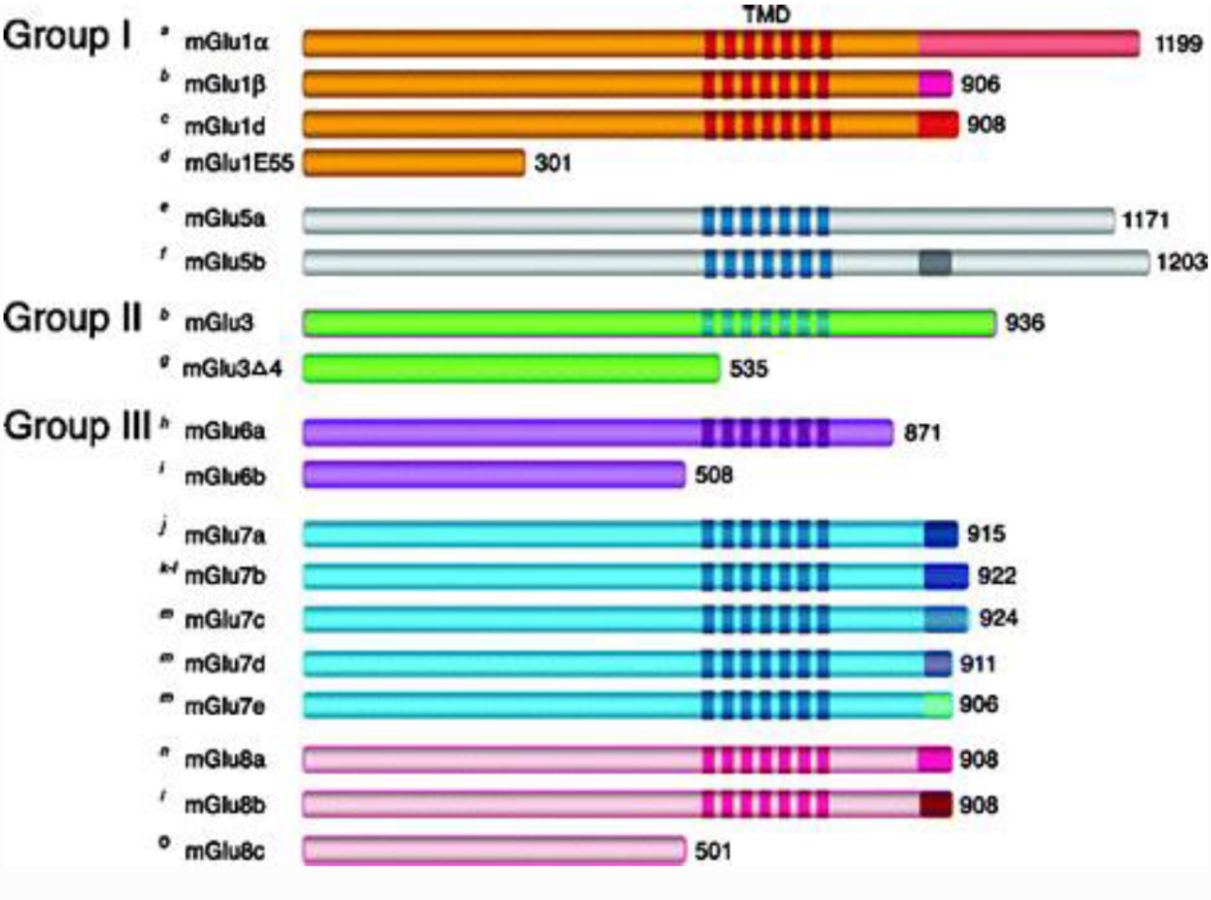

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Case reports require ethics approval. Most institutions will have specific policies on this subject. Authors should check with their institution to make sure they are complying with the specific requirements of their institution and seek ethics approval where needed. Authors should be aware to secure informed consent from the individual (or parent or guardian if the participant is a minor or incapable) See also section on **Informed Consent**.

Cell lines

If human cells are used, authors must declare in the manuscript: what cell lines were used by describing the source of the cell line, including when and from where it was obtained, whether the cell line has recently been authenticated and by what method. If cells were bought from a life science company the following need to be given in the manuscript: name of company (that provided the cells), cell type, number of cell line, and batch of cells.

It is recommended that authors check the NCBI database for misidentification and contamination of human cell lines. This step will alert authors to possible problems with the cell line and may save considerable time and effort.

Further information is available from the International Cell Line Authentication Committee (ICLAC).

Authors should include a statement that confirms that an institutional or independent ethics committee (including the name of the ethics committee) approved the study and that informed consent was obtained from the donor or next of kin.

Research Resource Identifiers (RRID)

Research Resource Identifiers (RRID) are persistent unique identifiers (effectively similar to a DOI) for research resources. This journal encourages authors to adopt RRIDs when reporting key biological resources (antibodies, cell lines, model organisms and tools) in their manuscripts.

Examples:

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Plasmid: mRuby3 plasmid **RRID:Addgene_104005**

Software: ImageJ Version 1.2.4 **RRID:SCR_003070**

RRIDs are provided by the Resource Identification Portal. Many commonly used research resources already have designated RRIDs. The portal also provides authors links so that they can quickly register a new resource and obtain an RRID.

Clinical Trial Registration

The World Health Organization (WHO) definition of a clinical trial is "any research study that prospectively assigns human participants or groups of humans to one or more health-related interventions to evaluate the effects on health outcomes". The WHO defines health interventions as “A health intervention is an act performed for, with or on behalf of a person or population whose purpose is to assess, improve, maintain, promote or modify health, functioning or health conditions" and a health-related outcome is generally defined as a change in the health of a person or population as a result of an intervention.

To ensure the integrity of the reporting of patient-centered trials, authors must register prospective clinical trials (phase II to IV trials) in suitable publicly available repositories. For example www.clinicaltrials.gov or any of the primary registries that participate in the WHO International Clinical Trials Registry Platform.

The trial registration number (TRN) and date of registration should be included as the last line of the manuscript abstract.

For clinical trials that have not been registered prospectively, authors are encouraged to register retrospectively to ensure the complete publication of all results. The trial registration number (TRN), date of registration and the words 'retrospectively registered' should be included as the last line of the manuscript abstract.

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Springer Nature advocates complete and transparent reporting of biomedical and biological research and research with biological applications. Authors are recommended to adhere to the minimum reporting guidelines hosted by the EQUATOR Network when preparing their manuscript.

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Checklists are available for a number of study designs, including:

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Observational studies (STROBE)

Systematic reviews and meta-analyses (PRISMA) and protocols (Prisma-P)

Diagnostic/prognostic studies (STARD) and (TRIPOD)

Case reports (CARE)

Clinical practice guidelines (AGREE) and (RIGHT)

Qualitative research (SRQR) and (COREQ)

Animal pre-clinical studies (ARRIVE)

Quality improvement studies (SQUIRE)

Economic evaluations (CHEERS)

Summary of requirements

The above should be summarized in a statement and placed in a ‘Declarations’ section before the reference list under a heading of ‘Ethics approval’.

Examples of statements to be used when ethics approval has been obtained:

- All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The study was approved by the Bioethics Committee of the Medical University of A (No. ...).

- This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Ethics Committee of University B (Date.../No. ...).

- Approval was obtained from the ethics committee of University C. The procedures used in this study adhere to the tenets of the Declaration of Helsinki.

- The questionnaire and methodology for this study was approved by the Human Research Ethics committee of the University of D (Ethics approval number: ...).

Examples of statements to be used for a retrospective study:

- Ethical approval was waived by the local Ethics Committee of University A in view of the retrospective nature of the study and all the procedures being performed were part of the routine care.

- This research study was conducted retrospectively from data obtained for clinical purposes. We consulted extensively with the IRB of XYZ who determined that our study did not need ethical approval. An IRB official waiver of ethical approval was granted from the IRB of XYZ.

- This retrospective chart review study involving human participants was in accordance with the ethical standards of the institutional and national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The Human Investigation Committee (IRB) of University B approved this study.

Examples of statements to be used when no ethical approval is required/exemption granted:

- This is an observational study. The XYZ Research Ethics Committee has confirmed that no ethical approval is required.

- The data reproduced from Article X utilized human tissue that was procured via our Biobank AB, which provides de-identified samples. This study was reviewed and deemed exempt by our XYZ Institutional Review Board. The BioBank protocols are in accordance with the ethical standards of our institution and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Authors are responsible for correctness of the statements provided in the manuscript. See also Authorship Principles. The Editor-in-Chief reserves the right to reject submissions that do not meet the guidelines described in this section.

Informed consent

All individuals have individual rights that are not to be infringed. Individual participants in studies have, for example, the right to decide what happens to the (identifiable) personal data gathered, to what they have said during a study or an interview, as well as to any photograph that was taken. This is especially true concerning images of vulnerable people (e.g. minors, patients, refugees, etc) or the use of images in sensitive contexts. In many instances authors will need to secure written consent before including images.

Identifying details (names, dates of birth, identity numbers, biometrical characteristics (such as facial features, fingerprint, writing style, voice pattern, DNA or other distinguishing characteristic) and other information) of the participants that were studied should not be published in written descriptions, photographs, and genetic profiles unless the information is essential for scholarly purposes and the participant (or parent/guardian if the participant is a minor or incapable or legal representative) gave written informed consent for publication. Complete anonymity is difficult to achieve in some cases. Detailed descriptions of individual participants, whether of their whole bodies or of body sections, may lead to disclosure of their identity. Under certain circumstances consent is not required as long as information is anonymized and the submission does not include images that may identify the person.

Informed consent for publication should be obtained if there is any doubt. For example, masking the eye region in photographs of participants is inadequate protection of anonymity. If identifying characteristics are altered to protect anonymity, such as in genetic profiles, authors should provide assurance that alterations do not distort meaning.

Exceptions where it is not necessary to obtain consent:

- Images such as x rays, laparoscopic images, ultrasound images, brain scans, pathology slides unless there is a concern about identifying information in which case, authors should ensure that consent is obtained.

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Regardless of whether material is collected from living or dead patients, they (family or guardian if the deceased has not made a pre-mortem decision) must have given prior written consent. The aspect of confidentiality as well as any wishes from the deceased should be respected.

Data protection, confidentiality and privacy

When biological material is donated for or data is generated as part of a research project authors should ensure, as part of the informed consent procedure, that the participants are made aware what kind of (personal) data will be processed, how it will be used and for what purpose. In case of data acquired via a biobank/biorepository, it is possible they apply a broad consent which allows research participants to consent to a broad range of uses of their data and samples which is regarded by research ethics committees as specific enough to be considered “informed”. However, authors should always check the specific biobank/biorepository policies or any other type of data provider policies (in case of non-bio research) to be sure that this is the case.

Consent to Participate

For all research involving human subjects, freely-given, informed consent to participate in the study must be obtained from participants (or their parent or legal guardian in the case of children under 16) and a statement to this effect should appear in the manuscript. In the case of articles describing human transplantation studies, authors must include a statement declaring that no organs/tissues were obtained from prisoners and must also name the institution(s)/clinic(s)/department(s) via which organs/tissues were obtained. For manuscripts reporting studies involving vulnerable groups where there is the potential for coercion or where consent may not have been fully informed, extra care will be taken by the editor and may be referred to the Springer Nature Research Integrity Group.

Consent to Publish

Individuals may consent to participate in a study, but object to having their data published in a journal article. Authors should make sure to also seek consent from individuals to publish their data prior to submitting their paper to a journal. This is in particular applicable to case studies. A consent to publish form can be found here. (Download docx, 36 kB)

Summary of requirements

The above should be summarized in a statement and placed in a ‘Declarations’ section before the reference list under a heading of ‘Consent to participate’ and/or ‘Consent to publish’. Other declarations include Funding, Competing interests, Ethics approval, Consent, Data and/or Code availability and Authors’ contribution statements.

Please see the various examples of wording below and revise/customize the sample statements according to your own needs.

Sample statements for **"Consent to participate"**:

Informed consent was obtained from all individual participants included in the study.

Informed consent was obtained from legal guardians.

Written informed consent was obtained from the parents.

Verbal informed consent was obtained prior to the interview.

Sample statements for **“Consent to publish”**:

The authors affirm that human research participants provided informed consent for publication of the images in Figure(s) 1a, 1b and 1c.

The participant has consented to the submission of the case report to the journal.

Patients signed informed consent regarding publishing their data and photographs.

Sample statements if identifying information about participants is available in the article:

Additional informed consent was obtained from all individual participants for whom identifying information is included in this article.

Authors are responsible for correctness of the statements provided in the manuscript. See also Authorship Principles. The Editor-in-Chief reserves the right to reject submissions that do not meet the guidelines described in this section.

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Data availability statements

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