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Exploring feasibility of clinical psychology as a model of care for families affected by congenital cytomegalovirus

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Abstract

Objectives: Congenital cytomegalovirus (cCMV) is the leading infectious cause of hearing loss and neurodevelopmental impairment in children, yet the psychosocial impact has only recently begun to be explored. The objectives of this study were to describe the experiences of children and families affected by cCMV, and examine the use of clinical psychology as a model of care.

Methods: Thirty-four families were recruited from a specialist cCMV clinic and invited to access developmental assessment and individual formulation-based clinical psychology intervention, including facilitated parent peer support.

Results: Birth mothers were significantly more stressed than fathers, and poorer parental well-being was associated with negative perception of life changes following cCMV diagnosis, but not related to disease severity. Following clinical psychology intervention, parents reported significant improvements in understanding and confidence in managing their child's needs. However, well-being remained varied, which may reflect the ongoing prognostic uncertainty of having a child with cCMV. Thematic analysis of parental experiences identified five themes: (1) processing the experience of cCMV, (2) disrupted newborn phase, (3) relationship to healthcare, (4) lack of shared experiences, and (5) raising awareness.

Conclusion: Clinical psychology was positively received as a protected space to explore and validate the emotional impact of cCMV, and facilitate connection with others who share personal experience of cCMV. The findings support the use of embedded clinical psychology provision for families affected by cCMV, and the importance of increasing cCMV awareness to improve pathways of care and reduce psychological distress.

Keywords: congenital cytomegalovirus (cCMV), caregiver psychosocial functioning, deafness and hearing loss, psychosocial intervention, peer support.

Congenital cytomegalovirus (cCMV) affects 0.67% of infants worldwide, 10% of whom have severe manifestations at birth (Ssentongo et al., 2021). cCMV is the leading infectious cause of hearing loss in children and is associated with a wide range of neurologic and neuro-cognitive consequences, including microcephaly, Cerebral Palsy, epilepsy, visual impairment, language delay, developmental delay, autism spectrum disorder (ASD), and attention-deficit/hyperactivity disorder (ADHD) (e.g., Cannon et al., 2014; Korndewal et al., 2017; Pesch et al., 2024a, 2024b; Topham et al., 2019). Cytomegalovirus (CMV) transmits through close contact with urine and saliva, and is prevalent among young children (Balegamire et al., 2022), whereas cCMV results from transplacental transmission during pregnancy (e.g., Pass & Anderson, 2014). Risk reduction includes hand hygiene, especially when caring for young children (e.g., Balegamire et al., 2022; Revello et al., 2015). Severity of infection is associated with poorer outcomes (Alarcon et al., 2016; Korndewal et al., 2017; Noyola et al., 2001); however, up to 15% of infants asymptomatic at birth have late-onset neurocognitive sequelae and/or hearing loss (Boppana et al., 2013). Antiviral treatment with valganciclovir can mitigate and limit progressive and late-onset manifestations (Kimberlin et al., 2015). In the United Kingdom, the absence of a universal screening program results in delayed or missed diagnoses for up to 75% infants due to having no, or nonspecific, symptoms at birth (Alifieraki et al., 2022).

Parents of children with developmental disabilities, chronic illness, or whom are Deaf or Hard of Hearing (DHH) are more likely to experience stress, anxiety, and depression (e.g., Cohn et al., 2020; Hoffman et al., 2023; Scherer et al., 2019). Nonetheless, the experience of parenting a child with cCMV has only recently been explored. cCMV is associated with parental guilt for infection during pregnancy, developmental uncertainty, and anticipatory grief (Vandrevala et al., 2020; Zappas et al., 2023); parental distress is exacerbated

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by diagnostic delays and poor professional knowledge of cCMV (Vandrevala et al., 2020). Lack of public health awareness prevents engagement in risk reduction strategies and poses a barrier to accessing social support (Vandrevala et al., 2020). Through comparisons with other chronic conditions, the wider impact of cCMV is hypothesized to result from parental resources being diverted away from their own health needs, those of siblings, and other social relationships (Zappas et al., 2023). Further research is needed to better understand the specific impact of cCMV, and the variables that contribute to differences in well-being and adjustment to diagnosis.

Psychological support is increasingly indicated for parents and caregivers in pediatric settings (e.g., Dovey-Pearce & Flannery, 2021; Irwin et al., 2019; Salley et al., 2024), and has become a national standard of care for many chronic conditions including perinatally acquired human immunodeficiency virus infection (PaHIV), which is also associated with parental guilt and developmental consequences (Children's HIV Association, 2017). Timely psychological support following identification of hearing loss is considered imperative (Scarinci et al., 2018), and embedded psychological provision in pediatric DHH settings is advocated (Hoffman et al., 2023); for example, targeted parent–child intervention, and support for parents and caregivers to overcome shock and grief, which are also common in the cCMV population.

Despite emerging evidence and parallels with other conditions, to date, there are no known studies evaluating clinical psychology for families affected by cCMV. This paper aims to describe the psychosocial impact of cCMV and to examine the use of clinical psychology as a model of care.

Methods

Design

This feasibility study uses a pre-post design. TREND checklist is available as Supplementary File S1. Ethical approval was granted by the National Health Service (NHS) London—Central Research Ethics Committee (REC; Reference number: 22/PR/0895).

Positionality

The authors are a group of English- and German-speaking women of White British and White Other backgrounds. None of the authors have personal experience of cCMV; however, we have extensive combined clinical experience of working with children and families living with cCMV in pediatric infectious diseases, and neonatal and pediatric psychology. We hold doctoral degrees in Clinical Psychology (C.C. and R.H.) and postgraduate degrees in medicine (H.L., H.P., S.J., & I.B.). We have experience in qualitative and quantitative methodologies, and our group includes the academic ranks of Research Fellow (H.P.) and Professor (H.L.). We acknowledge that our interpretations of the data will be influenced by our personal and professional characteristics.

Patient and public involvement

Study design was informed by focus groups exploring universal screening for cCMV. Six members of the public, recruited via a PPI group at University College London (UCL), discussed the importance of identifying the specific needs of families affected by cCMV. A second group of three parents of children diagnosed with cCMV, organized by CMV Action Charity, highlighted the importance of psychological support for affected families. Proposed measures were shared with a convenience sample of two parents of children diagnosed with cCMV, known to H.L., to establish their suitability. Parental views, alongside feedback from REC, resulted in modifications to ensure that the language used was more appropriate and sensitive for families of newborns and children diagnosed with cCMV.

Measures

Adaptive Behaviour Assessment System, 3rd Edition

The ABAS-3 (Harrison & Oakland, 2015) is a parent-report questionnaire that assesses a child's adaptive functioning. The ABAS-3 demonstrates reliability and validity from birth to adulthood, and is norm-referenced and standardized. General Adaptive Composite (GAC) standard scores were used for demographic comparisons, and individual analysis of adaptive functioning was used, as required, to inform intervention.

Perceived Stress Scale-10

The PSS-10 (Cohen et al., 1983; contact information and permission to use: Mapi Research Trust, Lyon, France, https://eprovide.mapi-trust.org) is a 10-item self-report questionnaire that produces scores between 0 and 40; higher scores indicate higher perceived stress. It demonstrates good internal consistency and concurrent validity in adult populations (Lee, 2012).

World Health Organization Well-Being Index

The WHO-5 (World Health Organization [WHO], 1998) is a five-item self-report measure of well-being. Higher percentage scores indicate better well-being, with those below 50 reflecting poor well-being (WHO, 1998). The WHO-5 demonstrates good validity, and high sensitivity and specificity when used as a screening tool for major depressive disorder (MDD), indicated by scores below 28 (Topp et al., 2015). A modified version of the WHO-5 was used (see Table 1). Reliability of the modified WHO-5 in the current sample was good ($\alpha = .76$), and convergent validity was good, demonstrating an inverse relationship with the PSS-10 ($r = -.67$, $p < .01$).

Sheffield Learning Disability Outcome Measure Part 1

The SLDOM-1 (Girgis, 2013) is an eight-item self-report measure of parental coping and perceptions of their child's sequelae that produces scores between 8 and 40; higher scores are favorable, and those above 25 are considered "positive." The SLDOM-1 is recommended for use for parents of children aged 3–16 years (Girgis, 2013), although the psychometric properties are not reported for any population or age group. The SLDOM-1 provides clinically useful

Table 1. Modified WHO-5 questionnaire items.

Original questionnaire items	Modified questionnaire items
I feel cheerful in good spirits	I have felt happy
I have felt calm and relaxed	I have felt calm
I have felt active and vigorous	I have felt active
I woke up feeling fresh and rested	I woke up feeling rested

Note. WHO-5 = World Health Organization Well-Being Index.

Table 2. cCMV impact.

Subtest	Questionnaire item
Support	I have sought psychological/counselling support since my child was born, and it has helped me with some of the issues I had[a]
	I have sought support from a self-help group or charity such as CMV Action and it has helped[a]
Home	Our home life has changed since the diagnosis of cCMV in my child[b]
Relationships	Our family enjoy spending time together[a]
	I have one-to-one time with significant others[c]
	I enjoy one-to-one time with significant others[a]
	I feel supported with the daily challenges of my life[a]
	The diagnosis of cCMV has changed my relationships with family[b]
	The diagnosis of cCMV has changed my relationships with friends[b]
Siblings	I feel that I can adequately address the needs of my child's siblings[a]
	I enjoy one-to-one time with my child's siblings[a]
School or nursery	I worry about my child at school/nursery[c]
	I can communicate effectively with my child's teacher[a]
	I feel able to support my child's learning needs[a]
	I feel capable to support my child developing friendships[a]
	I feel that the diagnosis of cCMV affects my relationships with other parents in my child's class[b]
Work	I am satisfied with my career status[a]
	My child's cCMV diagnosis affects my ability to fulfil my job roles and responsibilities[a]
	My child's cCMV diagnosis currently, or will, put financial stress on our family[a]
	My career status has changed since the diagnosis of cCMV[b]

Note. cCMV = congenital cytomegalovirus; CMV = cytomegalovirus.
[a] 5-point Likert scale from *strongly disagree* to *strongly agree*.
[b] 5-point scale (*strongly agree*—negative change; *agree*—negative change; *neither agree/disagree*; *agree*—positive change; *strongly agree*—positive change).
[c] Frequency.

information regarding parental experiences not otherwise included in traditional symptom-count measures, including understanding of the child's needs, parent–child relationship, familial coping, hopefulness for the future, and confidence interacting with services (Girgis, 2013). Given the long-term effects of cCMV, including neurodevelopmental sequelae, we determined that this measure had acceptable validity for our sample. Reliability in our sample was also acceptable ($\alpha = .62$). There was a borderline negative correlation between PSS-10 and SLDOM-1 scores ($r = -.35$, $p = .02$) and a positive correlation between SLDOM-1 and modified WHO-5 scores ($r = .40$, $p < .01$).

cCMV Impact

The authors compiled additional questions to facilitate description of the psychosocial impact specific to cCMV (see Table 2). Each item was scored on a 5-point scale of agreement or frequency, and higher scores were indicative of greater challenge and/or perceived impact of cCMV.

SLDOM Parts 2 & 3

The SLDOM-2 and SLDOM-3 (Girgis, 2013) were used to evaluate participants' experience of accessing a clinical psychology service. The SLDOM-2 is a 10-item measure that evaluates the experience of service. It produces scores from 10 to 50; positive experiences are attributed to scores of 30 or above. The SLDOM-3 is a free-text form for respondents to describe what helped and suggest improvements.

Procedure

The procedure is outlined in Figure 1. Families were recruited from the U.K.'s largest specialist cCMV clinic. Eligible families had a child under the age of 16 years old who received a virologically confirmed cCMV diagnosis within 21 days of life. Since H.L. and H.P. had clinical relationships with potential participants, C.C., who was seconded to the team, led recruitment to help mitigate the inherent power imbalance in medical research. Potential participants were made aware that participation was voluntary, and nonparticipation would not affect future medical care.

Psychological support was predominantly provided by C.C. (Clinical Psychologist), supervised by R.H. (Consultant Clinical Psychologist). Five appointments (3.52%) were conducted by Z.R.-W. (final year Trainee Clinical Psychologist), supervised by C.C. Co-created goal-based intervention based on individualized clinical formulation (British Psychological Society, 2011) was considered appropriate for this feasibility study, given the wide-ranging consequences of cCMV; clinical psychologists are trained to integrate different therapeutic modalities and consequently provide holistic support (e.g., Kinderman & Tai, 2007). Facilitated peer support groups were offered alongside individual sessions or as a stand-alone intervention, as there is evidence to suggest they improve the well-being and quality of life of parents of children with additional developmental needs and/or chronic health conditions (Lancaster et al., 2023). The groups were facilitated by C.C., with Z.R.-W. co-facilitating two sessions.

Finally, focus groups were used for evaluation and to support service development. To support mitigation of feedback bias, the first group was facilitated by Z.R.-W. A second group was held for families who had enrolled within a month of their child's cCMV diagnosis, as their views were not represented in the first group. Due to clinician availability, this group was facilitated by C.C.; potential feedback bias was considered during data analysis.

Data analysis

Demographic and baseline data were summarized using descriptive statistics. Participant postcodes were used to determine the English Index of Multiple Deprivation (Ministry of Housing, Communities & Local Government, 2019) decile scores, with lower scores indicative of higher

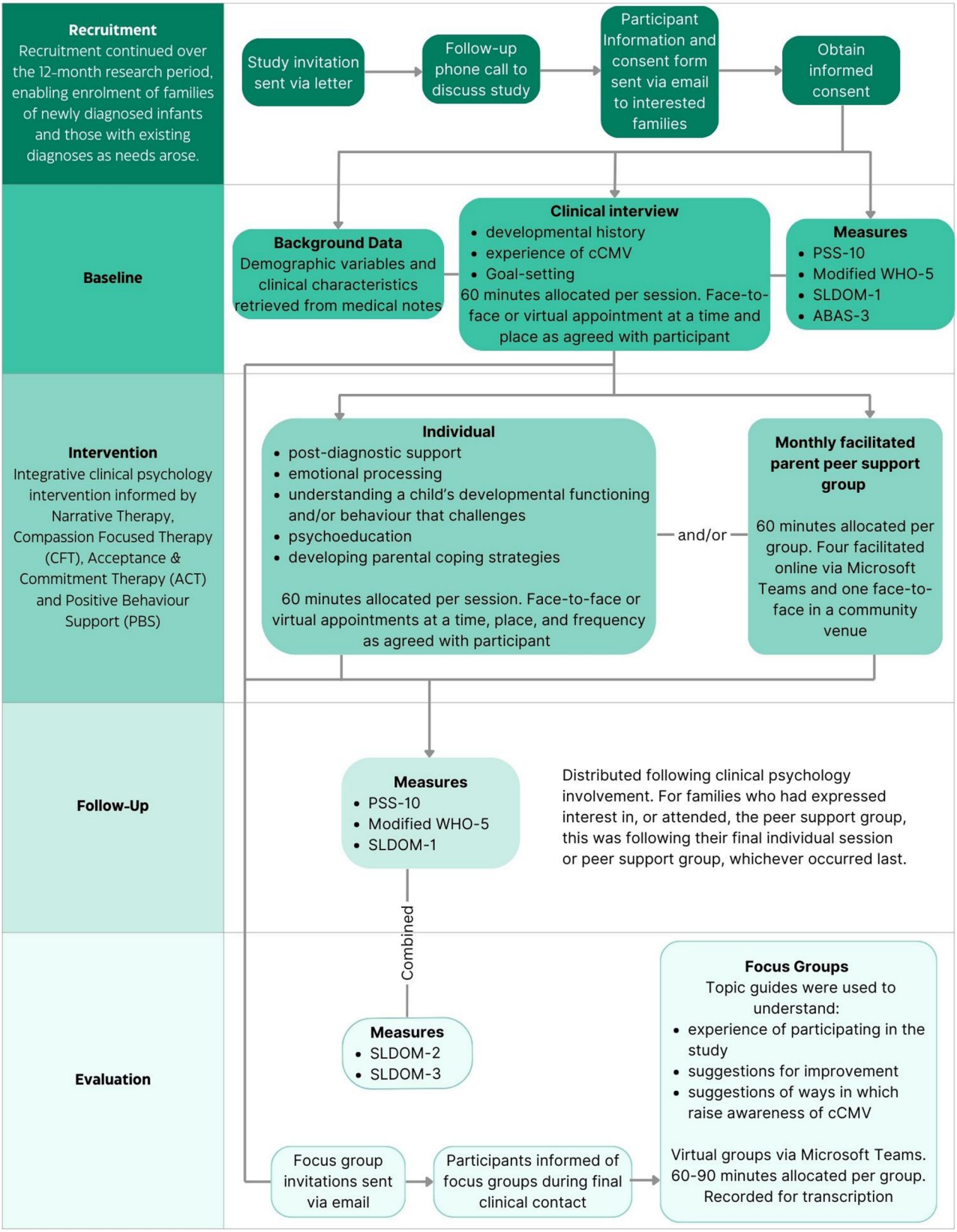

Figure 1. Procedure.

deprivation. Systematic differences between demographics of participants, non-participants, and non-respondents were explored using Kruskal–Wallis tests; available data were limited to maternal demographics in medical notes. One-way ANOVA and Pearson's chi-squared were used to explore systematic differences between enrolled participants at different

time-points throughout the study. Pearson's R correlation coefficients and *t*-tests were used to explore relationships between demographic and clinical variables and parental well-being. Paired *t*-tests were used to examine the impact of psychological intervention upon well-being. Analyses were conducted in Stata 16.1 and R. Data available upon request.

Qualitative data from SLDOM-3 and anonymized focus group transcripts were analyzed using thematic analysis (TA; Braun & Clarke, 2006). All data were read and re-read before being coded by C.C.. Coding was inductive, including both semantic and latent codes. To mitigate potential bias, 25% of qualitative data were randomly selected to be independently re-coded by P.M. (Practitioner Psychologist in Paediatrics). Theme development was explored in consultation with R.H., H.L., and H.P. Themes were cross-referenced with session summary notes to ascertain reliability across the sample. Following refinement, themes were named. Verbatim participant quotations from focus group transcripts and SLDOM-3 forms are presented to provide evidence of our interpretations. Participants were given a summary of themes via a participant feedback leaflet.

Results

Participants

Of 123 families invited to participate, 95 (77%) responded to the invitation; 37 (39%) enrolled in the study, 28 (29%) made an informed decision to decline, and 30 (32%) expressed interest but did not enroll. Reasons for nonparticipation, where shared, were lack of time ($n = 8$), no perceived need for support ($n = 6$), already accessing support ($n = 3$), and preferring not to participate in research ($n = 1$).

Families of White, Mixed, or Asian maternal ethnicity were more likely to have enrolled than those of Black or Other maternal ethnicities, Fisher's exact test (two-tailed) ($p = .04$). 81% ($n = 13$) of families of Black maternal ethnicity declined, whereas decline rates were 38%–50% for all other maternal ethnicities. Mothers of Other maternal ethnicity had the highest non-response rate of (47%, $n = 7$). There were no significant differences between maternal age at childbirth or deprivation indices when comparing enrolled and non-enrolled families.

Three families withdrew prior to participation; two cited lack of time, and one didn't give a reason. Demographic variables and clinical characteristics of 34 participating families are summarized in Table 3. There were no statistically significant differences between clinical characteristics or demographic variables across time-points.

Most children were from English-speaking families (94.59%, $n = 35$). Language data were not routinely collected for English-proficient families. Available data indicated that four families had at least one parent for whom English was an additional language. The primary languages spoken in these families were Polish ($n = 2$), Arabic ($n = 1$), and Urdu ($n = 1$). Two children were from Gujarati-speaking families, and an interpreter was used throughout their participation.

Baseline measures

The mean PSS-10 score was 18.10 ($SD = 6.14$, range = 4–33). The mean modified WHO-5 score was 57.96 ($SD = 17.64$, range = 8–92); 14 parents (31%) had scores indicative of poor well-being, and one met the threshold for MDD. The mean SLDOM-1 score was 31.70 ($SD = 3.88$, range = 21–40); most ($n = 42$, 93%) were positive. PSS-10 scores were significantly higher for birth mothers ($M = 19.39$, $SD = 5.96$, range = 4–33) than for fathers ($M = 15.53$, $SD = 5.85$, range = 4–26); $t(43) = 2.06$, $p = .05$, $d = 0.65$. Although U.K. normative data are currently unavailable, female participants were significantly more stressed than females in the United States (for comparison, data were taken from Cohen & Janicki-Deverts, 2012); $t(1060) = 2.33$, $p = .02$, $d = 0.48$, whereas males were not, $t(981) = 0.005$, $p = 1.00$, $d < 0.05$. Modified WHO-5 and SLDOM-1 scores did not differ significantly when grouped by parental role. PSS-10, modified WHO-5, and SLDOM-1 scores were not significantly correlated with gestational age, birth weight, child's age at enrollment, adaptive functioning, age of treatment onset, or number of services involved. Furthermore, there were no statistically significant differences in baseline measures when grouped by severity of cCMV or presence of clinical characteristics (foetal abnormalities, sensorineural hearing loss, brain MRI abnormalities).

Children with cCMV accessed an average of three specialist services ($SD = 2.68$, range = 1–9), including audiovestibular (100%, $n = 34$), speech and language (41%, $n = 14$), and child development services (38%, $n = 13$). Eleven parents reported having sought psychological support since the birth of their child; eight described this as helpful, while three were ambivalent. Fourteen parents had sought support from a self-help group or charity; six described this as unhelpful, five as helpful, and three were ambivalent.

Forty-four percent ($n = 20$) of parents agreed that cCMV had, or will, put financial stress upon the family. Thirty-seven percent ($n = 17$) described a negative change to home life following their child's cCMV diagnosis, while 24% ($n = 11$) reported negative changes to relationships with friends, 22% ($n = 10$) described a negative change to their employment status, and 15% ($n = 7$) reported negative changes to family relationships.

SLDOM-1 scores were significantly lower for parents reporting a financial consequence of cCMV, $t(42) = 2.72$, $p < .01$, $d = 0.83$, negative changes to home life, $t(42) = 3.35$, $p < .01$, $d = 1.07$, negative changes to family relationships, $t(42) = 2.22$, $p = .03$, $d = 0.97$, negative changes to friendships, $t(42) = 2.56$, $p = .01$, $d = 0.92$, and career dissatisfaction, $t(42) = 3.97$, $p < .01$, $d = 1.43$. Negative changes to family relationships were also associated with significantly higher levels of perceived stress; $t(43) = -2.42$, $p = .02$, $d = -0.10$.

Intervention

Thirty-three families attended at least one individual appointment; due to competing life stressors, one family only returned baseline measures. On average, families attended four appointments ($SD = 2.94$, range = 1–11).

Thirty-two families were offered facilitated peer support; one family was not eligible as the groups occurred prior to their enrollment. A third of eligible families ($n = 11$) attended at least one group. On average, participants attended two groups ($SD = 1.13$, range = 1–4). Mean attendance per group was eight parents ($SD = 0.89$, range = 7–9).

Follow-up measures

Baseline measures for respondents and non-respondents at follow-up did not significantly differ. Nonetheless, pre- and post-comparisons were made from complete data sets. The

Table 3. Participant demographics.

Characteristics	Whole sample Child with cCMV ($n = 34$)	Baseline Child with cCMV ($n = 30$)	Follow-up Child with cCMV ($n = 19$)	Focus group Child with cCMV ($n = 4$)	Significance
Mean age at enrolment (months)	34.59 ($SD = 31.40$)	34.63 ($SD = 27.67$)	28.89 ($SD = 26.80$)	16.5 ($SD = 20.17$)	0.60[a]
Sex					
Male	19 (56)	18 (60)	11 (58)	3 (75)	0.95[b]
Female	15 (44)	12 (40)	8 (42)	1 (25)	
Mean gestational age (weeks)	37.81 ($SD = 2.52$)	37.8 ($SD = 2.52$)	37.84 ($SD = 2.99$)	37.5 ($SD = 0.58$)	1.00[a]
Mean birth weight (grams)	2714.74 ($SD = 734.02$)	2764.18 ($SD = 733.54$)	2691.29 ($SD = 883.25$)	3142 ($SD = 556.04$)	0.74[a]
Mean age at diagnosis (days)	13.45 ($SD = 24.29$)	14.43 ($SD = 25.29$)	19.11 ($SD = 29.70$)	28.00 ($SD = 34.50$)	0.68[a]
Fetal abnormalities (%)	22 (65)	18 (60)	11 (58)	1 (25)	0.56[b]
Baseline brain MRI abnormalities (%)	24 (71)	22 (73)	13 (68)	3 (75)	0.98[b]
SNHL (%)	17 (50)	15 (50)	8 (42)	2 (50)	0.96[b]
Treatment (%)	31 (91)	29 (97)	18 (95)	4 (100)	0.87[b]
Mean treatment onset (days)	26.83 ($SD = 34.20$)	27.10 ($SD = 34.77$)	28.33 ($SD = 34.73$)	33.5 ($SD = 36.06$)	0.99[a]
Mean treatment duration (weeks)	23.35 ($SD = 7.22$)	23.93 ($SD = 6.89$)	22.33 ($SD = 4.96$)	24.00 ($SD = 0$)	0.87[a]
Mean General Adaptive Composite (GAC) score at enrolment	89.10 ($SD = 23.94$)	89.12 ($SD = 24.37$)	91.47 ($SD = 22.98$)	86.75 ($SD = 27.93$)	0.98[a]
	Parents ($n = 49$)	**Parents ($n = 45$)**	**Parents ($n = 28$)**	**Parents ($n = 6$)**	
Parental role					
Birth mother	34 (69)	30 (67)	19 (68)	4 (67)	0.99[b]
Father	15 (31)	15 (33)	9 (32)	2 (33)	
Parent age (years)					
16–25	3 (6)	3 (7)	0	0	0.74[b]
26–35	16 (33)	13 (29)	11 (39)	3 (50)	
36–45	15 (31)	15 (33)	12 (43)	3 (50)	
46–55	1 (2)	1 (2)	1 (4)	0	
Not stated	14 (29)	13 (29)	4 (14)	0	
Ethnicity of parent					
White British	27 (55)	26 (58)	16 (57)	2 (33)	0.95[b]
Asian or Asian British	6 (12)	4 (9)	4 (14)	1 (17)	
White Other	9 (18)	9 (20)	4 (14)	2 (33)	
Other ethnic group	4 (8)	4 (9)	2 (7)	0	
Black African or British	2 (4)	1 (2)	1 (4)	0	
Multiracial	1 (2)	1 (2)	1 (4)	1 (17)	
Employment status					
Full-time	16 (33)	16 (36)	10 (36)	3 (50)	1.00[b]
Part-time	9 (18)	9 (20)	5 (18)	0	
Parental leave	6 (12)	6 (13)	4 (14)	2 (33)	
Homemaker	4 (8)	4 (9)	3 (11)	1 (17)	
Long-term sick	1 (2)	1 (2)	1 (4)	0	
Full-time carer	1 (2)	1 (2)	1 (4)	0	
Student	1 (2)	1 (2)	1 (4)	0	
Not stated	11 (22)	7 (16)	3 (11)	0	
Mean deprivation scores					
Multiple deprivation decile	6.69 ($SD = 2.43$)	7.05 ($SD = 2.25$)	7.33 ($SD = 1.90$)	8.50 ($SD = 1.12$)	0.24[a]
Income decile	6.59 ($SD = 2.33$)	6.91 ($SD = 2.18$)	7.22 ($SD = 1.97$)	8.67 ($SD = 1.63$)	0.14[a]
Employment decile	7.24 ($SD = 2.38$)	7.57 ($SD = 2.24$)	7.89 ($SD = 1.91$)	9.50 ($SD = 0.56$)	0.10[a]
Education decile	7.49 ($SD = 2.29$)	7.77 ($SD = 2.14$)	7.96 ($SD = 2.11$)	9.17 ($SD = 2.04$)	0.34[a]
Health/disability decile	8.12 ($SD = 2.32$)	8.27 ($SD = 2.25$)	8.48 ($SD = 1.63$)	9.83 ($SD = 0.41$)	0.29[a]

Note. cCMV = congenital cytomegalovirus.
[a] One-way ANOVA (two-tailed).
[b] Fisher's exact test (two-tailed).

mean PSS-10 score reduced from 17.32 ($SD = 6.82$, range = 4–40) to 15.82 ($SD = 5.28$, range = 6–26); however, the difference was not significant. The mean modified WHO-5 score increased from 57.86 ($SD = 16.20$, range = 32–92) to 60.71 ($SD = 16.66$, range = 12–84); however, the difference was not significant. The mean SLDOM-1 score increased significantly from 31.12 ($SD = 4.14$, range = 21–39) to 33.62 ($SD = 3.63$, range = 28–40); $t(25) = 3.90$, $p < .01$, $d = -0.64$.

The mean SLDOM-2 score was 39.52 ($SD = 8.27$, range = 17–50, $n = 21$). 95% ($n = 19$) were positive. The two scores below 50 resulted from respondents rating some items as "Not Applicable," excluding these from scoring.

Qualitative analysis

Twenty-two SLDOM-3 forms and two focus group transcripts were analyzed. Five main themes and 15 subthemes were identified (see Figure 2).

Processing the experience of cCMV

Coming to terms with cCMV diagnosis was rarely described as linear and often confounded by prognostic ambiguity. Parents described the shock of their child receiving a diagnosis which they had largely never heard of before, requiring them to both learn about the condition and its possible implications for their child, while navigating parenthood. For example, "we knew so little with regards to what the

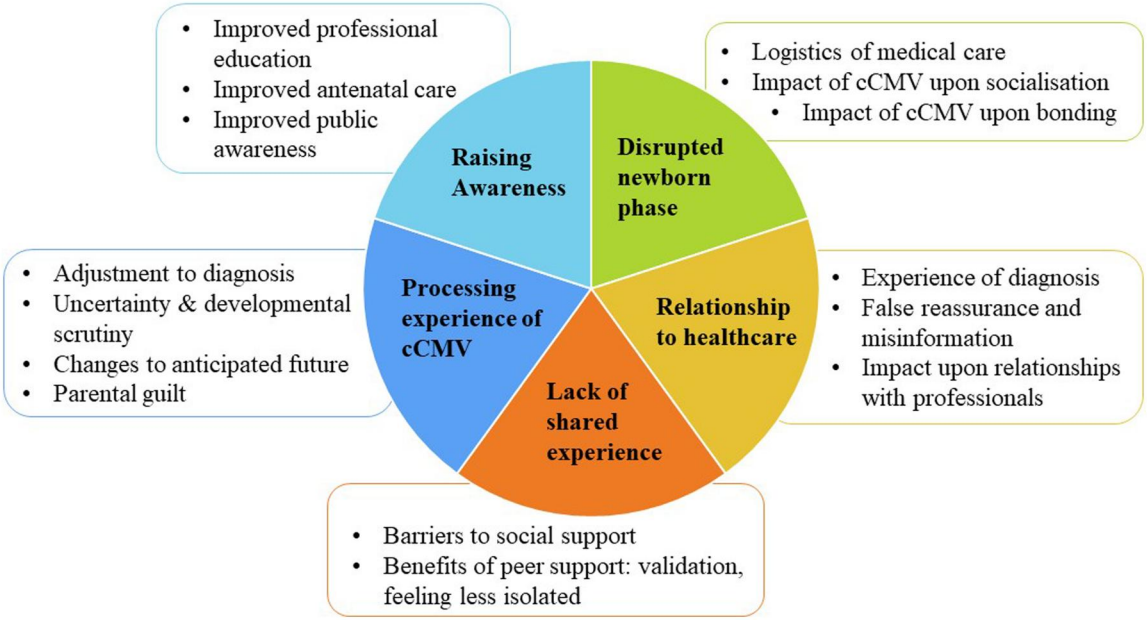

Figure 2. Summary of qualitative themes.

outcomes of cCMV . . . would be, as well as knowing so little as new parents" (P19), and:

> Telling you your child is not going to be able to do everything you imagined them to be able to do . . . just the simplest of things like sit up . . . and all of a sudden that is just taken within a few minutes. (P22)

The possibility of late-onset or progressive sequelae resulted in developmental scrutiny, with parents noticing that they frequently assumed that variations in typical development were associated with cCMV. Often, this was coupled with preemptive anxiety about the identification of further sequelae during medical review or developmental assessment. Many parents described increased concern for their child with cCMV, even if a sibling presented similarly.

Birth mothers felt guilty for their infant acquiring cCMV even though they had little or no antenatal information on reducing their risk of CMV during pregnancy. Guilt appeared to inflate developmental scrutiny, with birth mothers describing feeling responsible for identifying developmental sequelae and ensuring access to early intervention.

For some, emotional responses to cCMV remained intense, even years after their child was diagnosed. Often parents acknowledged they hadn't prioritized time to process their experiences, and benefits of doing so within the study included "having the time and guidance of the team has helped me start to process the feelings I had around our child's diagnosis, in particular the traumatic early days and ongoing uncertainty of the condition" (P14), and "it has been helpful talking about my experience and making me feel it is okay to feel the way that I do" (P11).

Parents valued being supported to focus on their baby as a developing individual rather than the cCMV diagnosis. Some recognized that making comparisons with their previously anticipated future resulted in distress and described feeling empowered by focusing upon their child's strengths.

Families requested longer-term psychology and advocated for "continued support throughout your journey as a parent with a child with cCMV" (P26), with provision from the point of diagnosis and regularly thereafter to support different phases of adjustment, including to late onset or progressive sequelae, or developmental and medical needs that become apparent over time. Similarly, parents anticipated that children, and their siblings, may benefit from support in navigating cCMV as they become older and more aware of the condition.

Disrupted newborn phase

Parents described disruption to the newborn phase due to post-diagnostic challenges, including navigating medical care, which often involved multiple hospital visits and potentially distressing procedures, such as blood tests. Appointments were often lengthy, and specialist clinics were not always local. For infants receiving antiviral treatment, twice-daily medication was administered for an average of 24 weeks. For some, the requirement for refrigerating medication posed a barrier to leisure activities and/or socialization. Birth mothers tended to experience the burden of medical appointments, as they were more likely to have taken parental leave from employment.

Some parents described the impact on the parent–infant relationship, for example, "he was treated like he was this infectious disaster basically, and it really made it difficult as well to bond with him to begin with" (P24).

Competing healthcare demands often resulted in reduced access to community groups, health visiting clinics, and children's centers. Transmission fears resulted in some parents avoiding shared spaces occupied by children or pregnant women.

Relationship to healthcare

Most parents described poor experiences of receiving cCMV diagnosis, including by telephone, in waiting rooms, or via clinicians who were unable to answer their questions.

Resources were described as limited, and parents often advised not to undertake independent research, which had the inverse consequence of them doing so; the majority of accessible online information was reported to relate to more severely affected infants.

Some experienced diagnostic delays due to nonspecific symptoms and/or disjointed care pathways. They described frustration at the incongruence between cCMV guidance recommending treatment initiation within the first month of life and lack of consistent proactive testing for cCMV, for example, upon a failed newborn hearing screening. Families also felt angry that diagnostic delays had potentially denied their infants the opportunity for protective treatment.

Barriers to help-seeking resulted from lack of knowledge of cCMV, and trivialization and/or exaggeration of its effects:

> Even the GP didn't know about CMV [*sic*] … he sort of shrugged it off and it made me so angry … I'll never forget when we had the first midwife appointment after [child] had come home from special care … and she went "Oh! He actually looks quite normal" I was just like horrified at that sort of reaction from a professional. (P24)

Parents were reassured and more hopeful once under the care of a specialist cCMV clinic. Psychological support was considered to be enhanced by clinicians' specialist cCMV knowledge; benefits of participation included "open and honest discussions about the impact of CMV [*sic*] with someone who actually knows what it is, and its complexities" (P21).

Accessing support proved challenging due to difficulty navigating systems, lack of awareness of available support, and competing demands. For some parents, embedded support enhanced acceptability and accessibility, permitting them to acknowledge the psychosocial impact without increasing feelings of guilt. Advantages included, "I think the fact that [psychology] was immediately in place … because you know if you're given something like 'if you need any help here's a pamphlet', the pamphlet goes to the bottom of your bag" (P19) and:

> Often those [medical] appointments were coupled with the psychological appointments and that was a huge help in terms of debriefing and understanding what was happening with [child] at the time as well as dealing with our emotions as a family. (P20)

One parent described difficulty in knowing how best to utilize psychology and suggested that sessions or groups focused on common themes may benefit families with limited or no prior experience of psychological support. Another recommended specific support for fathers to increase their uptake.

Lack of shared experiences

Parents shared that "no-one has really heard of cCMV" (P17) and explained how limited understanding of cCMV became a barrier to accessing social support as the impact was often hidden, particularly when newborn. One parent shared, "he was like any other newborn really but as they're meant to start hitting their milestones … that's when people suddenly sort of thought oh, ok, this is actually something more" (P25).

Disclosure was challenging due to perceived stigma and the emotional burden of being seen as a cCMV expert, leading to internalization and/or avoidance. Consequently, facilitated peer support was highly valued, and described benefits included "knowing there are others with similar experiences" (P41) and "talking to other people going through similar journeys … made us realise we are not alone" (P25).

Many parents accessed CMV Action charity and/or social media for support. Some found it difficult to relate to other parents' stories; perceiving them as too negative or unrelated to their own experiences. Attending facilitated peer support groups promoted an acknowledgement that "all the children are affected differently but all our stories seem to be very similar" (P25). Parents were comforted by shared experiences of diagnosis and psychosocial impact, even if their children presented with different types or severity of cCMV sequelae; this highlights the importance of opportunities for reciprocal interaction in developing connections and finding commonality in shared experience.

For many, facilitated peer support groups offered their first opportunity to meet other parents of children with cCMV, and helped reduce isolation and guilt. For example, "it also helped me to not feel [guilt] like *I* didn't see it … just knowing it wasn't individual, it's a collective experience" (P19). Increased access to peer support was requested, including opportunities outside working hours.

Raising awareness

Parents were passionate about raising awareness of cCMV. They advocated for cCMV to be discussed during antenatal appointments: "you don't need to scare people, we're all told about all the other things that we could possibly catch or that could impact a pregnancy so I don't see why CMV [*sic*] shouldn't be included in that" (P24). Parents discussed the universal benefits of risk reduction strategies, for example, "it's just making smart choices and understanding why you're going to do things. I think a lot of the CMV [*sic*] prevention is good practice anyway while you're pregnant" (P19).

Parents hypothesized that increased professional knowledge would improve pathways to care and experience of diagnosis, reducing misinformation and treatment delays. Parents also discussed raising awareness among groups more likely to be affected by cCMV, including childcare workers. Raising public awareness via broadcast, digital, and social media was supported.

Discussion

This paper describes the psychosocial impact of cCMV for 34 families and explores the use of clinical psychology as a model of care. The wide-ranging psychosocial impact of cCMV is consistent with both previous cCMV research (Vandrevala et al., 2020) and studies exploring the well-being of parents of a child with a chronic health condition, developmental disability, and/or deafness (Cohn et al., 2020; Hoffman et al., 2023; Scherer et al., 2019). Positive SLDOM-1 scores supports the hypothesis that parents prioritize resources for their child with cCMV (Zappas et al., 2023).

Birth mothers' stress appeared to be exacerbated by guilt, and being burdened by medical appointments due to being more likely to have taken parental leave or working part-time. This is consistent with previous cCMV research that highlights the weight of parental guilt and the impact of navigating healthcare systems (Vandrevala et al., 2020; Zappas

et al., 2023). Similarly, parents of DHH children experience difficulties navigating healthcare systems (Young & Tattersall, 2005).

Higher PSS-10 and lower SLDOM-1 scores were associated with perceiving negative changes across life domains following diagnosis, rather than clinical characteristics or severity. Therefore, the impact of the diagnosis should be discussed regularly in medical appointments, particularly as parents may neglect their own emotional well-being (Zappas et al., 2023). Universal access to psychology would mitigate difficulty predicting which parents are more likely to experience emotional distress, and embedding psychological provision supports acceptability; uptake would be expected to increase if provision were fully embedded within clinical care.

The significant increase in SLDOM-1 scores suggests that psychological intervention may help improve parental coping and relationship with cCMV. Comparisons with a nonintervention control group would strengthen inferences; however, the lack of significant correlation between SLDOM-1 scores and age of child at enrollment suggests that improvement may not occur independently. While changes to PSS-10 and modified WHO-5 scores were limited, this is consistent with the ongoing assessment, intervention, and prognostic ambiguity that can be associated with cCMV.

The experience of clinical psychology was overwhelmingly positive. Psychological support appears to help mitigate the effect of lack of information and awareness of cCMV as a barrier to receiving professional and social support. Improving professional education, streamlining pathways of care, and raising public awareness of cCMV may further support parents, as deficits in these areas contribute to psychological distress (e.g., Vandrevala et al., 2020; Young & Tattershall, 2005). Facilitated peer support was particularly well-received; parents described reduced isolation and parental guilt through normalizing shared experience and validating emotional responses. This clearly demonstrates the role of psychological support in helping families adjust to a diagnosis of cCMV. Such improvements are consistent with existing research exploring peer support as a model of care for parents of children with additional developmental needs (Lancaster et al., 2023).

Increasing the sample size would improve statistical power and enable further exploration of the relationship between demographic, clinical, and psychosocial variables. Identifying systematic differences between participants and nonparticipants would enhance understanding of barriers to uptake. Including wider ethnic representation would enable increased understanding of the varying needs of diverse populations, and improve generalizability of findings; language and cultural factors may affect the extent to which meaningful comparisons can be made on outcome measures, both due to cultural norms and the impact of translating questionnaire items. Research would be enhanced by collecting data on participant language profiles, including use of British Sign Language (BSL) or Makaton. Psychological services should ensure that models of care reflect the diverse needs of their communities; the efficacy of different interventions should be explored.

This feasibility study emphasizes the wide-ranging psychosocial impact of cCMV and supports clinical psychology as a model of care for parents of children affected by cCMV. We highlight the need to raise public and professional awareness to enable earlier diagnosis and more timely initiation of treatment to improve clinical outcomes, thereby reducing parental distress and optimizing family well-being.

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Supplementary material

Supplementary material is available online at *Journal of Pediatric Psychology* (http://jpepsy.oxfordjournals.org/).

Author contributions

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