Project title

Improving the health and wellbeing of parent carers of disabled children: systematic and iterative development and evaluation of a peer-led group-based programme

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Plain Language Summary

Why did we do this research

Parent carers of disabled children are at risk of poor mental and physical health. Healthy Parent Carers is an online or in-person health promotion programme led by facilitators who are also parent carers.

Health promotion programmes for parent carers need to be easy to access and engage with and their effects need to be measured in ways that matter to parent carers.

What we did

Parent carers helped design and deliver this research.

We interviewed parent carers about their views and experiences. Some had participated in the Healthy Parent Carers programme, but others had not. There were two studies.

Study 1: we asked parent carers how they think about their health and wellbeing. We showed them a questionnaire that is often used to measure mental wellbeing in research and asked what they thought about it.

Study 2: we interviewed parent carers from diverse backgrounds and asked them about what would help them engage with health promotion programmes.

What we found

Study 1: three main themes captured how parent carers thought about health: ‘self, identity and beliefs’; ‘social connections and support’; and ‘health-promoting practices and outcomes.’

Study 2: parent carers from different backgrounds helped identify five ways of making it easier to access and engage with programmes:

- wider ways to advertise.
- making sure people delivering the programme seem trustworthy.
- helping potential participants see this as possibly important for them.
- addressing worries about taking part.
- tailoring the programme to fit different people.

What we learnt

The questionnaires often used for measuring outcomes may not assess mental wellbeing in ways that parent carers think most important.

People designing and evaluating programmes for parent carers need to engage with them from the beginning and think about the needs of people from all types of communities.

Scientific abstract

Background

Parent carers of disabled children are at increased risk of mental and physical health problems. We co-created the Healthy Parent Carers (HPC) programme, a peer-led, group-based intervention that encourages actions associated with health and wellbeing using established behaviour change techniques.

In Study 1, we sought to explore what are appropriate health and wellbeing outcomes to assess for the parent carer population to inform selections of an appropriate outcome measure to evaluate HPC or similar programmes. Separately, we want to ensure HPC is accessible and acceptable to parent carers from diverse backgrounds to reduce the risk of the intervention potentially reinforcing health inequalities. Therefore, in Study 2, we investigated which personal and contextual factors might influence engagement with the HPC or similar programmes, and how we might mitigate them.

Methods

We completed two qualitative interview studies, with purposively sampled parent carers who had been participants or facilitators or not experienced the HPC programme. Additionally, for Study 2, we purposively sampled parent carers who self-identified as being from minority ethnic groups, whose children were educated other than at school, with sensory impairments or neurodiversity, and fathers. Participants were recruited through local and national organisations and parent carer networks. Data collection involved semi-structured remote interviews, which were transcribed verbatim and analysed thematically. For Study 1, we utilised items from the commonly used Warwick-Edinburgh Measure of Mental Wellbeing (WEMWBS) to prompt discussion and inform analysis.

Results

Parent carers with intersecting characteristics across the sampled backgrounds participated (30 in Study 1, 36 in Study 2).

In Study 1, three themes described how parent carers perceived health outcomes: ‘self, identity and beliefs’; ‘social connections and support’; and ‘health-promoting practices and outcomes.’ Parent carers agreed the concepts included in the WEMWBS corresponded to aspects of health and wellbeing that they care about. Nevertheless, participants raised questions about the appropriateness or interpretations of some items for the parent carer population. Responses suggested issues regarding the face and content validity for parent carers and indicated that the WEMWBS lacks responsiveness and precision among this population.

In Study 2, we identified five themes relating to finding out about, attending and/or engaging with health programmes, and strategies to consider: (i) Reach – targeted and universal advertising; (ii) Credibility – trustworthiness of those advertising and/or delivering the programme; (iii) Opportunity – ensuring that the programme is seen as fulfilling an important perceived need; (iv) Reservations – addressing any reticence to participate; (v) Optimisation – tailoring to improve the inclusivity of the programme delivery.

Conclusion

Our findings suggest WEMWBS may not capture in an appropriate way the most salient and specific aspects of health and wellbeing for parent carers. Consequently, there is a need to develop a patient-reported outcome measure with, and specifically for, parent carers.

We identified modifiable factors that impede members of some social groups from engaging with health promotion programmes, and potential solutions. We advocate a multifaceted approach is required from outreach to delivery, tailored to be mindful of diverse needs of parent carers in underserved communities.

Keywords

Qualitative; Health promotion; Carers; Caregivers; Outcome measures; Equity; Health inequality; Wellbeing

Summary of Research Findings

Background

There are more than one million children with special educational needs or disability (SEND) in the UK.[1] SEND is the terminology for children with learning or any disability enshrined legally by The Children and Families Act 2014. It encompasses a range of difficulties, but many children have developmental or life-limiting conditions requiring complex care. Parent carer is the preferred term for the person aged over 18 years who is the primary caregiver with parental responsibility.

Parent carers of disabled children are at increased risk of poor health and wellbeing outcomes.[2 3] Population-based studies suggest the health problems persist and may worsen over time.[4] Myriad individual, family and environmental factors affect parent carers' health. Social disadvantage, gender, ethnicity, sexual orientation and/or other personal factors may intersect to exacerbate health problems.[5]

A health and wellbeing promotion programme uses systematic design and actions to empower individuals and communities to address amenable health determinants with the aim of improving health and wellbeing.[6] A range of parent carer-focused health programmes have been developed to improve health outcomes for parent carers and their children.[7-9] Although different in their design and approach, they have a shared challenge of reaching underserved parent carers who would benefit from such interventions.

We co-created Healthy Parent Carers (HPC) as a community-based programme that aims to improve the health and wellbeing of parents of disabled children by encouraging engagement in health-promoting behaviours.[10-13] There are eight categories of health-promoting behaviours under the acronym 'CLANGERS': Connect, keep Learning, be Active, Notice, Give, Eat Well, Relax and Sleep. The HPC programme is predominantly delivered by licensed partner organisations. Third-sector organisations are those outside of the state or market, incorporating diverse groups such as charities, non-governmental organisations and social enterprises. Within the UK, third-sector organisations are often commissioned to deliver health programmes.

Following a feasibility randomised controlled trial of the HPC programme, qualitative research findings indicated strongly that HPC was perceived by participants to be beneficial and impactful.[12] However, analysis of the distribution of responses to items in the patient-reported outcome measures [Patient Health Questionnaire (PHQ-9), Warwick-Edinburgh Mental Well-being Scale (WEMWBS), and EQ-5D] indicated a potential lack of sensitivity to the benefits articulated by participants.[10] This suggested that parent carers may have a particular experience of health and wellbeing that is not easily captured using items in these generic and dimension-specific measures, warranting further investigation.

Outcomes that researchers have measured have not always been those participants regard as most relevant, leading to avoidable waste in research and misleading interpretations about effectiveness of interventions.[14] This highlights the key criterion of 'appropriateness' when selecting patient-reported outcome measures (PROMs) for trials, alongside reliability, validity, responsiveness, precision, interpretability, acceptability and feasibility.[15] Appropriateness in this context requires consideration of the match of a PROM to the specific purpose and questions of a trial.[15]

A systematic review of self-report measures identified 99 questionnaires measuring 196 discrete dimensions of wellbeing.[16] Therefore, our first aim was to elucidate which dimensions of health and wellbeing are perceived by parent carers as being most important

to them, thereby identifying which dimensions should be measured when evaluating parent carer focused interventions.

Despite good intentions, there is a risk that interventions might reproduce or worsen inequalities by primarily favouring individuals with greater advantages.[17] Therefore, investigating how interpersonal (e.g. family), social (e.g. ethnicity) and wider contextual factors influence health behaviour change interventions is critical to informing programme design and delivery to promote equity.[18-20] Accessibility and acceptability may also be unequal for some groups compared to others, which has implications for participant recruitment and intervention evaluation.[21]

Some health promotion and behaviour change interventions have shown promise at reducing inequity through contextual adaptation at individual and community levels with different groups.[22-24] However, there are notable research gaps; (i) in understanding how to reach and engage underserved groups in health research and; (ii) in accounting for how social determinants influence interventions and outcomes across different social contexts. Therefore, a second aim of our study was to identify how to help ensure equitable access and engagement for socially and ethnically diverse parents of disabled children to benefit from parent carer focused health programmes.

Aims and Objectives

Study 1: Exploring views on important outcomes for parent carer focused interventions:

- How do parent carers think about health and wellbeing, and what are important outcomes when evaluating parent carer focused interventions?

Study 2: Exploring acceptability and accessibility of programmes to ensure equity:

- What personal and contextual factors, and to what extent, likely influence participants', and prospective participants', engagement with health promotion programmes?
- How can we ensure equitable access to, and ability to benefit from, the programme among parent carers under-represented and under-served in past research and service provision?

Methods

We completed two parallel qualitative studies using broadly similar methodology.

Participant sampling

All participants were parent carers of disabled children living in the UK. Sampling for both studies was informed by our Patient and Public Involvement (PPI) group with parent carers from diverse backgrounds, as well as by UK national guidance on reducing healthcare inequalities. We used purposive maximum variation sampling for parent carers who had experience of the HPC programme either as facilitators or participants, or no experience.

For Study 2 particularly, we focused on groups who would provide insight into different aspects of inequity in this area, including: ethnically diverse, fathers, parents with sensory impairments or identifying as neurodiverse, and parents whose children are educated at home. This latter group includes parents of children Educated Other Than At School (EOTAS) and those who are Electively Home Educated. We recorded relevant intersecting

demographic characteristics, including area deprivation using Indices of Multiple Deprivation, educational status, single/co-parenting status and child history. While we were cognisant of intersectionality as important in equity research,[25] sampling of all potentially possible intersectional permutations was unfeasible.

As we analysed data and recruited participants concurrently, we identified specific groups who continued to provide novel insights even after our initial analysis. Therefore, we sampled proportionately more participants from ethnically diverse backgrounds.

Recruitment strategy

We posted adverts on social media platforms with invitations including a link to the study website with participant information and an online expression of interest form. The expression of interest form asked potential participants about their characteristics to allow for purposive sampling. All potential participants who had expressed their interest were contacted by telephone or e-mail and screened. Eligibility was assessed against the basic parent carer information and the fit with the target sample groups. We informed those who were ineligible by email or phone.

To ensure recruitment from potentially underserved groups, we took additional steps. Ethnically diverse members of our PPI group approached parent carers within their communities about the study. We collaborated with local and national third-sector organisations for the target sample groups, who shared the study adverts across their networks. In four cases during the recruitment process, prospective participants were offered a chaperone while being interviewed. In cases where this offer was accepted, a chaperone was identified. In three cases the chaperone was a female member of our PPI group; she was from a Pakistani background and was known to the participants. In the fourth case, a parent carer with a visual impairment requested a representative from a national charity to support them as a chaperone because they had a pre-existing working relationship.

Data collection

We conducted one-to-one semi-structured in-depth interviews via video conference calls from September 2023 to February 2024. Interviews were conducted by one of two researchers and lasted approximately one hour. A semi-structured topic guide was created and piloted with the PPI group for each study.

For Study 1, the first section of the topic guide included open-ended questions about health and wellbeing. The second section invited interviewees to examine fourteen health and wellbeing categories based on the WEMWBS. During this phase of the interview participants were asked to complete an elicitation activity. The fourteen concepts making up the WEMWBS were represented by individual words or phrases, such as "loved", "relaxed", and "dealing with problems well". The participants were then asked questions such as: "Which concepts most closely relate to your health and mental wellbeing, and why?"

For Study 2, the topic guide included open questions, followed by more specific prompts, about accessing and engaging with the HPC and/or other health programmes. Within the framing of their social identity (e.g. ‘as a father …’), we encouraged participants to reflect on factors that enabled or impeded their access and engagement with such programmes. Interviewees who had attended the HPC programme were asked to reflect on these factors both before and after joining the course and facilitators in relation to its delivery. Interviewees who had no experience of HPC were asked to consider factors relevant to them and their community when thinking about other hypothetical or experienced parent-carer programmes.

Interviews were audio-recorded and transcribed verbatim. All participants provided consent and received a £35 voucher following interview.

Data analysis

We used reflexive thematic analysis methods.[26] Drawing on rapid qualitative analysis techniques, brief written summaries of each interview were reviewed during weekly team discussions alongside data collection to enable a responsive approach to subsequent recruitment, interview probing and analysis.[27] Verbatim transcripts were uploaded to NVivo v.14 software for coding. To develop codebooks, three researchers independently coded the same sub-sample of transcripts. Each researcher arranged the codes into candidate categories. The categories and codes were compared and discussed and integrated into one combined codebook. It was then used in subsequent analyses of transcripts. Where new and relevant phenomena were observed, additional discussions supported the further development of the coding framework. Findings were regularly reviewed with the research team and periodically with the study PPI and stakeholder groups.

For Study 1, the initial phase of our analysis was an inductive thematic analysis. In a subsequent deductive analysis, we used a framework of health and wellbeing domains and dimensions to help with further analysis and interpretation.[16] This framework is a synthesis of 99 generic measures of wellbeing. It comprises 196 wellbeing dimensions grouped into seven themes: 'mental wellbeing', 'social wellbeing', 'physical wellbeing', 'spiritual wellbeing', 'personal circumstances', 'activities and functioning', and ‘wellbeing overall’.[16]

For Study 2, we were mindful that researchers conducting the analysis included two white males and a white female from diverse professional and academic backgrounds (educational psychology, physiotherapy and sociology). To remain cognisant of our positionality during interviews and within the analysis and ensure rigour, we used reflexive practices such as writing memos, (peer) supervision and discussing differences in coding interpretations. In addition, triangulation was vital with the PPI and stakeholder groups, which included those from underserved groups, to increase the validity of findings.[28 29]

Ethics approval

The study procedures were approved by the University of Exeter Medical School Research Ethics Committee (UEMS REC ID: 525009).

Findings/Discussion

Both studies were completed successfully. Parent carers with intersecting characteristics across the sampled backgrounds participated in both studies (30 in Study 1, 36 in Study 2).

Study 1: Exploring views on important outcomes for parent carer focused interventions

In Study 1, parent carers generally viewed health and wellbeing in terms of overcoming the specific challenges they face as a group. They described how carrying out the parent carer role means that their physical and psychological needs often go unmet. Three themes captured how parent carers perceived important health outcomes: ‘self, identity and beliefs’; ‘social connections and support’; and ‘health-promoting practices and outcomes.’

Parent carers agreed the concepts included in the WEMWBS corresponded to aspects of health and wellbeing that they care about. Nevertheless, participants raised questions about the appropriateness, or interpretations, of some items for the parent carer population.

Responses suggested issues regarding the face and content validity for parent carers and indicated that the WEMWBS lack responsiveness and precision among this population.

We found support in our data for all domains of wellbeing in the framework. Nevertheless, within domains, some dimensions appeared to be more resonant for parent carers:

- Mental Wellbeing: Stress reaction, Anxiety/ Depression, Acceptance, Autonomy, Self-esteem, Cognition and Mental functions.
- Activities and Functioning: Achievement, Interests and hobbies, Learning.
- Social Wellbeing: Need for relatedness.
- Physical Wellbeing: Relaxation, Sleep, Fitness-exercise / Physical activity.
- Spiritual Wellbeing: Life purpose and satisfaction.

Outcome measures including these dimensions would be most likely to meet the criterion of 'appropriateness' in the selection of patient reported outcome measures to evaluate the effectiveness of parent carer focused interventions to improve health and wellbeing.

The WEMWBS items focus on positive aspects of mental health. Participants in our research hold a strong social identity as parents of disabled children, and they discussed health and wellbeing almost exclusively from their experiences as parent carers. Not measuring a reduction in 'negative' constructs might risk missing some of the important changes. For example, it might be more meaningful for parent carers to describe how often "I feel stressed" as opposed to how often "I feel relaxed." Including parent carers in the formation of an instrument from its inception could potentially resolve these issues.

A strength of Study 1 is a robust thematic analysis, based upon consensus between multiple researchers and triangulation with other parent carers through the study PPI group. We compared findings across HPC facilitators, previous HPC participants and HPC nonparticipants, finding that they were consistent across these groups. The findings are therefore likely to have resonance and transferability to a variety of groups working in this field.

Limitations to Study 1 include that two-thirds of our participants were parents of children with autism, though we did seek to recruit more parents of children with physical disabilities. Four-fifths of our participants in Study 1 were white British, meaning that the nuanced ways in which ethnic-cultural characteristics might influence attitudes and beliefs about health and wellbeing are less prevalent in our findings. Nevertheless, the four parent carers in our sample from a British Asian background advocated that, while differences might exist in perspectives around health and wellbeing in their communities, the core challenges facing parent carers were likely common across each ethnic group.

Study 2: Exploring acceptability and accessibility of programmes to ensure equity

In Study 2, we identified five themes relating to finding out about, attending and/or engaging with health programmes, and strategies to consider: (i) Reach – targeted and universal advertising; (ii) Credibility – trustworthiness of those advertising and/or delivering the programme; (iii) Opportunity – ensuring that the programme is seen as fulfilling an important perceived need; (iv) Reservations – addressing any reticence to participate; (v) Optimisation – tailoring to improve the inclusivity of the programme delivery.

Our study identifies and builds an understanding of the challenges and barriers that some parent carers might experience to accessing and engaging with parent carer focused programmes. Within our UK context, we focused on potentially underserved parent carer social groups: Global Majority communities, fathers, parents of children EOTAS, those with

sensory impairment, and identifying as neurodiverse. We identified challenges and also strategies that may help improve the access and engagement of some underrepresented groups of parent carers.

A key challenge is to include parent carers who are less connected with SEND or parent carer networks and may be less aware of support available for their child or themselves. Cultural factors, language barriers, and social norms further complicate access to parent carer programmes, because these factors constrain some people's interpretation of their own health needs and/or how to address them.

Strategies likely to improve reach include targeted outreach efforts, community partnerships, and leveraging trusted messengers within underserved communities. The credibility of the messenger advertising a programme is crucial, with trust built through authentic engagement and understanding of community needs. The opportunity for attendance must be presented clearly and resonate with the audience, addressing linguistic, cultural, and social barriers.

Strategies to address reservations and cultivating readiness for engaging in a programme include scheduling, addressing socioemotional concerns, and providing practical support. Tailoring delivery for inclusivity involves considering group composition, adapting materials for diverse needs, and alternative options for online and in-person groups.

Overall, addressing barriers to access and engagement requires a comprehensive approach, from publicising to programme delivery, tailored to the diverse needs of parent carers in potentially underserved communities. Although we focused on a parent carer programme, similar strategies have been advocated across different types of interventions and populations, indicating that our findings might also be transferrable to other contexts. For example, working with community partners is vital to recognise and align with cultural and religious values in developing sensitive and resonant communication.[30] Equally, understanding the specific needs of target populations is critical to create more relevant and impactful health interventions.[24]

Strengths of Study 2 include that we involved a diverse PPI group and recruited a diverse sample of participants. To ensure that parents from underserved groups were enabled to participate, we worked with key gatekeepers within different communities and partnered with chaperones. Our analysis and interpretation were challenged and strengthened by the critical contributions and triangulation with the PPI group and other stakeholders.

A potential limitation was the educational status in our sample, which leant towards more highly educated individuals, and this may have reduced the diversity of perspectives overall. Some participants were second-generation immigrants with higher education, whereas typically first-generation immigrants with lower socioeconomic and educational status might be more likely to adhere to more "traditional" religious/cultural beliefs and norms.

Conclusions

Our findings suggest that commonly used generic and dimension-specific measures of health and wellbeing may not capture the salient and specific aspects of health and wellbeing for parent carers with sufficient granularity. Consequently, there is a pressing need to develop a patient-reported outcome measure specifically for parent carers, capturing areas of health and wellbeing most salient to them.

We identified modifiable factors that impede members of some social groups from engaging with, and benefiting from, health promotion programmes, and potential solutions. We

advocate a multifaceted approach is required from outreach to delivery, tailored to be mindful of extant diverse needs of parent carers in underserved communities.

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Patient and Public Involvement

We carried out Patient and Public Involvement (PPI) with members of our PenCRU Family Faculty group facilitated by a Family Involvement Co-ordinator, who is herself a parent carer.

The Family Faculty comprises parent carers of disabled children who are interested to be involved in research. We convened a study-specific working group with volunteers from members of the Family Faculty from diverse backgrounds, many of whom had experience of the Healthy Parent Carers (HPC) programme through its co-design process, or as participants. The Guidance for Reporting Involvement of Patients and the Public short form describes the collaboration with our PPI group for this study.

Aims

Our diverse working group were encouraged to bring their lived experience and expertise with the aims to:

- Provide focus on the most meaningful aspects/factors of equity in parent carer focused health programmes,
- Inform the sampling strategy by identifying and prioritising target groups of parent carers who might experience inequity,
- Provide practical support for the recruitment strategy,
- Pilot and feedback on the interview topic guides,
- Support sharing of findings

Methods

Eight people were involved in Study 1 meetings and ten in Study 2 meetings. PPI group members were from diverse ethnic backgrounds and lived in different urban and more rural settings across the UK; one member was a father. Some had participated in Healthy Parent Carers. Group meetings were co-designed and co-facilitated between two researchers and the Family Involvement Coordinator.

Six group meetings for Study 1 and five meetings for Study 2 were convened and focused on:

- Consensus discussions supported the prioritisation of target groups and sampling approach.
- Parents connected researchers to other organisations and networks of target underserved parent carers groups.
- One PPI group member adopted a chaperone role to parent carers from a Muslim background in three interviews.
- The interview topic guide was piloted and cognitively tested during one PPI meeting and feedback was given specifically relating to wording and interpretation of questions and areas for potential further probing.
- Emerging analysis was shared with the group for discussion through vignettes to sense-check and challenge the assumptions of the researchers to build a more robust interpretation.
- PPI members helped by discussing how to get the research findings into practice, for example suggesting key stakeholders to involve in the next stage of implementation.

PPI members were also involved outside of the group meetings in reviewing study documents, such as the participant information sheet, study advert and consent form and later in the development of the plain English summary of the findings for wider sharing.

Two further stakeholder meetings were held with twenty-seven HPC programme facilitators enabling further consideration of the implications of the findings for programme delivery and implementation.

Parallel engagement work was undertaken to support our awareness and the recruitment strategy, involving key organisations: The Fatherhood Institute, DadMatters, Look UK, Tower Hamlets Opportunity Group, The Esteem Team.

Results

PPI strengthened the study in multiple ways:

- Enabled recruitment from underserved communities, e.g., one member, a British Pakistani mother, invited eight potential participants, five of whom decided to take part.
- A PPI group member chaperoned for Muslim mothers, where requested, and supported some parents with low digital literacy to access the video conference call for interviews.
- The PPI group advised the researchers directly around cultural sensitivities when approaching and engaging with members of their ethnic community.
- Charities provided strategic advice relating to recruitment.
- The study topic guide was developed with the PPI group, who advised on the use of language and tested it through pilot group interviews.
- The emerging findings from analyses were presented and discussed with the PPI group acting as critical friends. Overall, they reported a resonance with the findings and felt they were sensitively developed.

Discussion and conclusions

PPI had a positive and direct influence on the study; specifically, it supported success around recruitment, the collection of rich data and the development of credible and resonant findings and identification of practical implications.

Reflections/ critical perspective

The data collection via interviews occurred online for feasibility and pragmatic reasons. When engaging with different communities, a multipronged approach was used to build trust and relationships. However, we had limitations on being able to go to meet with different groups face-to-face. Meeting face-to-face may have optimised relationship building in certain communities and the participation of more underserved parent carers. Nevertheless, our strategy did still enable effective involvement of many parent carers who we would not have been able to access otherwise.

Further engagement work will inform dissemination and implementation.

Data sharing agreement

Data may be shared on reasonable request by contacting christopher.morris@exeter.ac.uk

Disclaimer

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This project was carried out between March 2023 and September 2024. This final report has not been peer-reviewed. The report was examined by the Programme at the time of submission to assess completeness against the stated aims. These reports do not undergo a peer review process.