

Feasibility of Parent-to-Parent Support in Recently Diagnosed Childhood Diabetes

The PLUS Study

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Acknowledgments: We gratefully acknowledge the support of our funders National Institute for Social Care and Health Research and Novo Nordisk UK Research Foundation, collaborators, members of staff in the participating centers, and especially the parents who generously gave their time, experiences, and commitment to make this project happen. This research was partly funded by a Clinical Research Fellowship for Sue Channon from National Institute for Social Care and Health Research and a supplementary clinical project grant from Novo Nordisk UK Research Foundation.

DOI: 10.1177/0145721716644673

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Purpose

The purpose of this study was to develop and test the feasibility of a parent-to-parent support intervention for parents whose child has recently been diagnosed with type 1 diabetes in the United Kingdom.

Methods

The research team conducted a formative evaluation, working with parents to design an individual-level parent-to-parent support intervention. Issues of recruitment, uptake, attrition, pattern of contact, and intervention acceptability were assessed.

Results

A US program was adapted in collaboration with a parents' advisory group. Of 19 parents nominated as potential mentors by their pediatric diabetes specialist nurses, 12 (63%) volunteered and 11 continued for the 12-month intervention period. Thirty-three children were diagnosed with diabetes in the study period, with 25 families eligible to participate as recipients of the intervention; 9 parents from 7 of those families participated, representing 28% of those eligible. Feedback from parents and clinic staff identified peer support as a welcome service. Lessons were learned about the nature of the supporting relationship (eg, proximity, connectedness, and managing endings) that will enhance the design of future peer support programs.

Conclusions

Parent-to-parent support in the context of newly diagnosed childhood diabetes in the United Kingdom is feasible to deliver, with good engagement of mentors and clinic staff. The program was acceptable to parents who chose to participate, although uptake by parents whose child had been recently diagnosed was lower than expected. The results merit further investigation, including exploration of parent preference in relation to peer support.

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A diagnosis of type 1 diabetes (T1DM) in childhood is a major life event for the child and family; parental and child adjustment to the diagnosis will have a significant long-term impact on the child's health. Poor initial adaptation by the child can be a risk factor for their future diabetes outcomes¹ and the development of psychological difficulties later in life.² Maternal adjustment shortly after diagnosis is a predictor of the mother's own long-term emotional well-being³ and their child's adjustment to the diagnosis.⁴ In a systematic review of parents' psychological adjustment to having a child diagnosed with T1DM,⁵ the prevalence of parental distress was high at diagnosis, and although distress decreases over time, significant levels of distress are still reported years later.⁶ Parental distress and other family factors are associated with a wide range of difficulties, both in terms of the child's psychological well-being (eg, low mood, stress, and quality of life) and the management of diabetes, particularly for adolescents.^{7,8}

Responsiveness to the psychosocial needs of children with diabetes and their families is an important component of the health care providers' role in achieving good clinical outcomes⁹⁻¹¹ and is integral to the delivery of person-centered care, a key principle of modern health care delivery.¹² However, challenges in delivering such support include limited resources,¹⁰ missing emotional needs in the midst of focus on glycemic control,⁶ and reticence by families and practitioners to address psychosocial concerns in routine encounters.¹³ To overcome these type of challenges, an increasingly common approach in adult services has been the involvement of lay health care workers,¹⁴ of which peer-led interventions, in which the supporter shares an experience with another person in similar circumstances, is one example.

Recognizing the potential benefits of peer support in health care and its global relevance, the World Health Organization convened a consultation on peer support¹⁵; subsequently, the organization "Peers for Progress" has been coordinating a range of research studies across the world based on the core principles of "harnessing the interpersonal relationship to activate intrapersonal change." In their 2014 report,¹⁶ the summary of evidence from the 22 studies in diabetes (primarily in adult services) concludes that peer support can offer significant benefit.

Peer-led interventions have also become increasingly common in child health settings, mostly involving parents but some including young people. Approaches range from structured, manualized programs for groups (eg, EPEC, a parenting program delivered by parents drawn from the local community)¹⁷ to those such as Scope's "Face to Face,"¹⁸ which trains parents who have had similar experiences (eg, parenting a child with a disability), who then act as befrienders in person, by phone, or email. Positive qualitative outcomes, as identified in a systematic review of peer support for parents of children with disabling conditions,¹⁹ include shared social identity, learning from the experiences of others, and personal growth. However, with evidence from the quantitative studies reviewed being equivocal, further work is needed to understand the impact of this type of intervention and consider the best way to manage peer support programs for parents.

In the Parents Listen Understand and Support (PLUS) study described in this article, a parent-to-parent support service for parents whose child had recently been diagnosed with T1DM was developed. It was closely based on work pioneered by the family-to-family network for families with children living with a lifelong condition.²⁰ Their particular model of informational, affirmational and emotional support has more recently been implemented specifically in the context of pediatric diabetes in the United States,^{21,22} and the PLUS study explored the feasibility of delivering the model in the UK health context.

Methods

Ethics/Research Governance

The study was granted approvals by South East Wales Research Ethics Committee, Cardiff and Vale, and Abertawe Bro Morgannwg University Health Boards.

Participants

All participants were parents of children with T1DM. There were 3 main groups of participants: the Parent Advisory Group (PAG), the mentors known as link parents (LPs), and the recipient parents (RPs), whose children had recently been diagnosed. All the LPs and RPs attended 1 of 3 small- to medium-sized pediatric diabetes services within 1 health board in South Wales and were recruited through 3 pediatric diabetes specialist nurses (PDSNs) who worked in those clinics. Exclusion criteria for all parents included learning difficulties, requiring an interpreter, or inclusion on the Social Services Department risk register. The parents in the PAG all had children who attended, or had previously attended, a clinic in a neighboring health board and were recruited via a local support group to help with the development of PLUS. Their children with T1DM ranged in age from infancy to adulthood and had been diagnosed for between 6 months and more than 10 years. The PDSNs worked with the LPs and RPs; they were guided in their selection of the LPs by the criteria and qualities identified by the PAG (see Table 1), including a minimum of 2 years since diagnosis, an optimistic realist approach, and confidence and flexibility in their management of T1DM.

Program Development

The program was developed in collaboration with the chief investigator on US studies using the parent mentor model (SSB) and then discussed with 8 parents in the PAG during 2 meetings and several email exchanges. As shown in Table 1, the PAG reviewed and refined aspects of the program.

Training

The LPs were approached initially by their PDSN and then either attended a group information session or were visited at home by a facilitator (S.C. or L.L.). Parents who agreed to participate received 6 hours of group training delivered across 2 sessions (see Table 2). The sessions were structured using the training handbook, which included practical information and covered governance protocols. The skills practice using role-play and practice interviews focused on enhancing active listening, reflection, and appropriate use of own experience to support others. Throughout the intervention phase, supervision groups were held bimonthly (1 daytime, 1 early evening) with individual phone contact in between sessions.

Model of Intervention

The intervention phase was 12 months (January 2013 to January 2014). The focus of the intervention (based on the STEP program²²) was to promote parental adjustment and coping by providing 3 types of support: informational (eg, providing contact information regarding support networks, common experiences of adjustment), affirmational (eg, identifying special qualities that the family have, enhancing parents' confidence in parenting, reassurance that their concerns are normal in context of the stress of diagnosis), and emotional support (eg, listening to concerns and experiences, conveying acceptance, and understanding). This support was delivered by the LPs individually or as couples (for recipient couples) for a maximum of 6 months per RP.

Recruitment of RPs

All eligible parents were given information about PLUS by their PDSN between 1 and 6 months postdiagnosis, with the exact timing left to the discretion of the PDSN. When the family contacted the chief investigator, a member of the research team arranged a visit to answer any questions, take consent, complete baseline questionnaires, and allocate a LP.

Measures

Four domains were selected for measurement based on the model of intervention, previous studies of parent-to-parent support, and guidance from the PAG: parental mental health (MHI-5),²³ experience of living with diabetes (Pediatric Inventory for Parents),²⁴ empowerment (Family Empowerment Scale),²⁵ and social support (single-item measure of social support).²⁶ The 4 questionnaires were administered at baseline and at the end of the intervention period by the research team. Individual interviews regarding the experience of participation, to address the acceptability and impact of the intervention, took place at the end of the intervention phase with participants and participating PDSNs.

Study Size

Based on training capacity, there was potential to train 18 LPs, 6 per clinic. Each LP could potentially support up to a maximum of 4 families (2 per 6 months of the intervention phase).

Table 1

Intervention Design Decisions Made in Collaboration With the Parents Advisory Group

Design Question	Decision
Name of mentor	Link parent
Time since diagnosis for link parents	Minimum 2 years Maximum: still within pediatric service
Qualities of link parent to guide pediatric diabetes specialist nurse selection	Reliable clinic attendance Child A1C consistently <86 mmol/mol (10%) Optimistic realist and balanced view of diabetes Reasonable confidence in managing diabetes Flexible attitude
Recruitment of link parents by clinic or across health board?	Each link parent to support parents within their own clinic
Timing and structure of training (eg, daytime, evening, weekends)	8-10 hours with ongoing training in supervision; training timetable to suit parents recruited
Training materials	Training manual from United States retained with minor modifications for clarity and for UK use
Modifications of US intervention guidelines from STEP ²² project	No children included in contacts Gender match if possible for individuals Couples supporting couples No group meetings
Number of parents to be supported by each link parent	Maximum of 2 at any one time
Time since diagnosis for recipient parents	Minimum 1 month; maximum 9 months
Age matching of children	Match children by current school phase (with exception of those diagnosed under 5 years when preferably paired with link parent whose own child diagnosed under 5)
Duration of support	Maximum 6 months
Likely pattern of contact (as guidance for information sheets)	Three face-to-face meetings in 6 months plus phone contact

Table 2

Training Outline

Session 1	Session 2
Program goals	Active listening skills practice
Model of support	Possible openers and how to get beyond "I'm fine"
Family patterns	Governance: what's ok, what's not ok, and what to do about it
What is supportive?	Paperwork and record keeping
Role of self-disclosure	Supervision
Main topics likely to come up	
Active listening skills practice	

Results

Recruitment of LPs

A total of 19 parents (3 fathers, 16 mothers) whose children had been diagnosed between 5 and 13 years ago were nominated by their PDSNs (see Table 3). Twelve parents (63%) attended the information sessions, all decided to take part, and all completed the training satisfactorily. One LP withdrew after the training because of ill-health, but the remaining 11 (2 fathers, 9 mothers) continued until the end of the study.

Recruitment of RPs

At the start of the intervention period, the clinics had a total caseload of 240 children younger than 16 years. Between June 2012 and August 2013, 33 children were diagnosed, with parents of 25 children eligible for inclusion. Seven families subsequently took part (including 2 couples, so 7 mothers and 2 fathers received the intervention; see Table 3).

Allocation of LP

Based on PAG advice, the evidence from research, and lessons learned as the study progressed, a combination of factors informed the allocation of LPs:

- The numbers of RPs each LP was supporting
- Locality, including clinic attended and school attended by the child
- Age of the child
- “Goodness of fit”; the views of PDSNs and the research team were combined to consider the best “fit” between parents if several options were available

Of the 11 LPs, 7 supported 1 new parent, 1 supported 2, and, because of the rate and locality of recruitment, 3 LPs did not support any new parents.

Patterns of Contact

The patterns of contact between each LP and RP varied widely in both type and frequency of contact. The minimum was 1 phone call and 2 text messages; the maximum contact was 4 face-to-face meetings combined with regular text messages and contact via social media. Of the 2 pairs who did not meet face to face, 1 had 1 phone call of 15 minutes, but the other pair had 4 phone

Table 3

Recruitment

Parent Group	Link Parents	Newly Diagnosed Families
<i>n</i> nominated	19	33
Eligible	19	25
Made contact with researchers	12	11
Recruited	12	7
Completed study (% of eligible)	11 (58%)	7 (28%)

calls lasting up to an hour each. Overall, the most common pattern of face-to-face contact was 1 or 2 meetings in the first month; of the 6 pairs who met in person, the longest single contact was 3 hours, but the meetings averaged 90 minutes. These were then most commonly followed by up to 2 phone calls ending with text messages from the LP to confirm availability to talk if the need arose. In terms of time commitment to mentoring (excluding social media contact, which is difficult to quantify), the range was 20 minutes to 12+ hours. The formal notification of the end of the 6-month contact was by letter from the research team.

Measures

Given the size and exploratory nature of the study, the questionnaires were included at baseline and the end of the intervention to determine their suitability as measures for any subsequent larger-scale study not to quantify change per se. The parents did not report any difficulties or concerns completing the questionnaires; 1 parent asked to complete the forms in their own time but did not return them.

Experiences of Participants and Staff

Participants were asked about their experiences and acceptability of the intervention at the end of the study in individual interviews. The LPs described their motivation arising from their experience of support (or lack of it) when their child was diagnosed and their wish to help others. They had a very positive response to the training, which enabled them to revisit their own experiences, gaining from the group process and also helping them

realize just how far they had come. The content of the mentoring ranged from specific queries (eg, managing on holiday) through to day-to-day life with diabetes and the adjustment process. For RPs, in general it provided welcome, personalized support; there were some insights from the LPs' experiences that did occasionally raise some anxieties about the future (eg, poor control), but the overall reports from them were positive. In a postintervention meeting with the PDSNs, they felt that PLUS had provided an additional support for parents, and from the nurses' perspective, knowing the LPs was an important contributory factor in their confidence in the intervention and hence in providing study information to newly diagnosed families.

Discussion

The purpose of this study was to adapt a parent-to-parent support program for parents whose children had recently been diagnosed with T1DM and to assess the feasibility of delivering that program in a UK context. Positive engagement with the program by parents involved in its delivery (PAG and LPs) and staff involved in recruitment led to its successful delivery. Based on their responses, this model of support has face validity for key stakeholders, and recruitment and retention of suitable mentors appears feasible in small- to medium-sized clinics. Given the retention rates of LPs and their feedback, it was clear that they valued the role. The parents who received support also provided positive feedback, describing PLUS as offering families something welcome that health professionals cannot provide. Overall, this is an approach that seems acceptable to the parents involved.

The rate of diagnosis during the recruitment phase was unusually low, meaning it was not possible to test the acceptability of the predetermined limit of 1 LP supporting 2 families at any one time. The recruitment rate of 28% of eligible new parents was lower than the participation rates of 77% and 51% in the 2 randomized controlled clinical trials in the United States.^{21,22} The main point of attrition was between the PDSN providing information and parents contacting the research team. It may well be that most felt they already had enough support, anecdotally reported by the PDSNs to be a common response from parents when they provided study information, but this was not systematically explored. It may also be that it was difficult for newly diagnosed parents to "cold call" the research team, particularly at a time

when they are feeling overwhelmed or stressed. This was the requirement for the research governance consenting process, but in a service context, the numbers of parents could potentially be higher if PDSNs were able to contact a project coordinator or an LP directly when a child was diagnosed. Cultural differences, either in help-seeking behavior or in general exposure to peer mentoring as a model of support, might have made UK parents more reticent about joining PLUS. It is not possible to calculate the numbers of these types of schemes available in different countries, but in a systematic review of parent-to-parent peer support, only 3 of the 17 studies included were from the United Kingdom, compared with 11 from the United States.¹⁹ The time since diagnosis may also have had an effect. This study provided support sooner after diagnosis than the United States studies, in which mentoring took place at least 1 year after diagnosis. The time frame in PLUS was guided by the PAG, who felt that the greatest need for the intervention was between 1 and 9 months after diagnosis, although with hindsight, this might have been too soon. This type of support is always going to be an optional addition to core services, so it will likely be delivered as a preference intervention. However, what determines whether a parent seeks out a peer support service and what factors might enhance the uptake are important areas for future studies.

The RPs used the support in very different ways, and each pairing created their own bespoke package. This clarified the importance of not creating a standard approach of a predetermined number of contacts via particular modalities. Similarly, it worked well to have some couples as LPs, happy to provide support as a couple or individually. The measures used were selected to determine their acceptability for use in any larger study to assess the impact of the intervention on the RPs. In the next study, it would also be of value to measure the impact of the training and mentoring role on the LPs.

Clinics may feel that they run something similar, linking parents on an ad hoc basis when it seems to make clinical sense. However, this informal approach does not provide support for the mentoring parent for whom it may raise significant issues (eg, unresolved grief), and it puts the parents in an uncertain relationship between friendship and professional support. The structure of PLUS provided a context for the relationship, provided the LPs with training, and offered support to all parties.

There were challenges encountered in delivering the program, primarily around the nature of the relationship,

which also provided learning opportunities to enhance the program. Initially, it was thought that local connections would be good to build on, but when children of LPs and RPs were, for example, attending the same school or the families were using the same local shops, it became apparent that this could prove problematic (eg, when the relationship was making significant demands on the LP, as there was no “down time,” and they did not have a professional identity to provide a necessary boundary). Conversely, in situations in which the bond between the pair was strong, the formal ending of the support relationship (via letter from the research team) left them unsure if they were “allowed” to remain friends. Governance concerns, in particular, making sure the volunteer parents were insured to carry out the work, took some time to resolve in a UK NHS context. Establishing the right level of support and supervision was also a dynamic process that needed some individualized tailoring for the LPs.

The level of involvement from the study leads with individual and group contact in training and supervision as well as matching the parents might affect replicability and scaling up the program. One option to be explored could be to support the PDSNs, who know the parents, to do the matching. However, bringing the peer support closer to the professional team needs to be done with care: from the report on peer support health workers in NHS England, the qualities that add value to the intervention get diluted if the intervention becomes more closely aligned with the formal structures.²⁷

Having established the feasibility of delivering peer support in one health board, the next step would be to implement the PLUS program on a wider scale, incorporating more clinics and implementing the quantitative measures to evaluate the impact of the intervention. There would also be value in considering extending the project beyond diabetes and also offering support for those further on from diagnosis. In this feasibility study, the sociodemographic characteristics of the participants were not explored, but in other domains (eg, parenting groups for socially disadvantaged families),¹⁶ peer-led approaches have value in increasing engagement with socially disadvantaged populations. Potentially a program such as this one, with careful matching, could enable greater support to be accessed by those families reluctant to engage with the diabetes team, thereby improving the support families receive early in their experience of diabetes.

Implications

This study demonstrated that it is feasible to recruit and retain parent mentors and deliver a parent-to-parent support service in small- to medium-sized clinics in the United Kingdom. The mentors valued taking part, and those parents of newly diagnosed children who elected to participate welcomed the support offered. There remain questions about the best timing, in terms of diagnosis, for peer support and the reasons why some parents might choose not to access it. These are important questions to address as peer support gains ground in different aspects of health care and we try to distill the active ingredients that make programs effective.

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