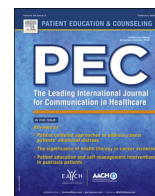


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Parent-to-parent peer support for parents of children with a disability: A mixed method study[☆]



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ABSTRACT

Objectives: This paper will report on the findings of a study which investigated the influence of a befriending (parent-to-parent peer support) scheme on parents whose children have a disability or additional need. The scheme operated from an acute children's tertiary setting in the UK.

Methods: A prospective concurrent mixed method design collected interview (n = 70) and questionnaire (n = 68) data at two time-points from befrienders (n = 13) and befriendees (n = 26).

Results: The main qualitative findings of the study relate to the different degrees parents (befriendees and befrienders) moved from being lost, to finding and being a guide and getting to a better place. The quantitative findings demonstrate that parent-to-parent peer support has a positive influence on parents' levels of psychological distress and their ability to cope with being a parent of a child with a disability.

Conclusion: The befriending scheme acted as a catalyst for many parents to move towards a place where they could grow and begin to flourish and thrive.

Practice implications: Professionals should inform parents who have a child with a disability that peer-to-peer parenting support schemes are a valuable and appropriate source of support and help.

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1. Introduction

Being the parent of a disabled child or a child with a chronic lifelong health condition goes beyond 'ordinary' parenting [1] and can increase the risk of family relationship problems, stress and depression (Contact a Family www.cafamily.org.uk). Although having a disabled child will not inevitably lead to family difficulties [2], evidence suggests that parents experience exhaustion, stress [3], feelings of isolation, loneliness [4], disempowerment and social marginalisation [5,2].

The support for parents caring for a child with a disability or long term condition can concentrate on specific needs or medical treatment (Solomon et al. [2]). Parent-to-parent peer support has existed since the 1920s, and aims to offer holistic parent centred

support [6,7]. Peer support for parents can be of particular value during specific stressful health care episodes, for example, at diagnosis of a disability or chronic condition [8].

Shilling et al.'s [9] systematic review of the benefits of peer parenting support schemes on parents' health, well-being, impact on family, and economic and service implications concluded there were four consistent themes that influenced parent experiences: social identity; learning from the experiences of others; personal growth; and supporting others. Such parenting support schemes can promote emotional support (including sharing of feelings) [9], social and practical support [10,11,6,12], coping models, problem solving skills, and empathetic understanding [13,2]. These schemes also aim to facilitate the feeling of social companionship, belonging and community with other parents, reducing feelings of isolation [12], enabling the sharing of ideas and strategies to cope with common problems [4] and enhancing self-efficacy [2,14]. Apart from one study [15] which demonstrated significantly lower maternal stress, depression and anxiety in mothers of preterm babies who received parent-to-parent support compared with those who did not, Shilling et al. [9] highlight that there remains a lack of robust quantitative evidence on the psychological, emotional and other health outcomes of parent-to-parent support.

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Most parent-to-parent peer support occurs and has been studied within community-oriented settings, these evaluations demonstrate the parents' perceived benefits of such schemes [9]. There have been no studies aiming to quantify the influence of peer support schemes on parents of disabled children within an acute paediatric tertiary setting. The research question underpinning this investigation was what is the influence of the parent-to-parent peer support scheme on parents' wellbeing?

1.1. Background to the parent-to-parent peer support scheme

The parent-to-parent peer support scheme (Face 2 Face) is co-ordinated by Scope, a UK-based charity. The scheme aims, through sessions of peer support, to help parents of disabled children understand their feelings about their child's disability, make positive changes to their own and their family's lives and promote parental mental health and wellbeing. Parent volunteers (befrienders) undertake 8 sessions of training which include non-verbal communication, body language, how to build trust in the befriending relationship, boundaries and visiting procedures, keeping themselves safe and being aware of difficult feelings. The befrienders then engage in six to eight, one-to-one support sessions (often spread over 3–5 months) with their allocated befriender (parent seeking support). The sessions occur in the befriender's home setting although some befrienders choose a venue outside of their home. The parent (befriender) is supported to talk through their feelings, reflect on their strengths, identify challenges and search for solutions. The trained befrienders are supported by a regional co-ordinator and attend regular group meetings during the timeframe they are befriending a parent. Scope runs peer-to-peer parent support schemes in community based settings in different geographical areas across the UK; prior to this project the scheme had not operated within an acute paediatric tertiary setting.

2. Methods

2.1. Research aim

The study aimed to examine the influence of the parent-to-parent peer support scheme on parents' (befriender and befriender) wellbeing and their ability to deal with the day-to-day circumstances experienced when parenting a disabled child.

2.2. Design

A prospective concurrent mixed method study design [16] was adopted with baseline and follow-up data collected to assess any

changes occurring over the course of the scheme. Qualitative interview data and quantitative questionnaire data aimed to provide different but complementary sources of evidence with all sources of data being afforded equal priority in the collection and analysis process [17].

Data were collected at the beginning of the scheme (TP1) (several weeks before the befriending commenced), and within several weeks of the parents finishing their befriending experience or the point at which they left the scheme early (e.g., unable to continue with sessions due to change in circumstances) (TP2).

2.2.1. Questionnaires

Care was taken when selecting the questionnaires not to overburden parents. Three validated self-completion questionnaires were administered to parents (befrienders and befriender) at the beginning and end of their befriending relationship: the Pediatric Inventory for Parents (PIP) [18]; the Peds QL™ Family Impact Module [19]; and the General Health Questionnaire-12 (GHQ-12) [20] (see Table 1 for further information)

The researcher was present during completion of the questionnaires, but was not normally involved in administering the tools. If the parent needed help the researcher read the questions and available responses to them in a clear and non-directive manner and their verbal responses were documented.

2.2.2. Interviews

Qualitative, audio-recorded semi-structured interviews, conducted within the parents' home or at an agreed setting, were conducted at the beginning and end of the scheme. The interview conducted at the beginning of the scheme explored befriender and befriender's prior experiences of support, why they had chosen to engage in the befriending scheme and their expectations of befriending. The second interview examined the befriender's and befriender's experiences of the befriending process, the logistics of meeting with their paired parent, perceived influence of the befriending and what could have worked better (see Table 2 for further detail).

2.3. Sampling and recruitment

All parents (befrienders and befriender) who engaged in the scheme were invited to participate and given a research pack by the scheme co-ordinator, which included the contact details of the research team. The research team did not have access to any parent's details until they contacted the team to express an interest in taking part in the study.

Table 1
Summary of questionnaires used in the study.

Name and purpose of measure	Author(s)	Number of domains (items)	Format of measure	Questionnaire Scoring
General Health Questionnaire-12 (GHQ-12) Assesses psychological distress and parental mental wellbeing.	Goldberg & Williams [20]	(12)	Likert scale questionnaire.	Scores range 0–36. Higher scores equate to higher psychological distress.
Pediatric Inventory for Parents (PIP) Assesses parental stress related to caring for their child with an illness.	Streisand et al. [18]	4(42)	Likert scale questionnaire. Four domains: communication; emotional distress; medical care; and role function.	Scores range 42–210. Higher scores indicating a characteristic is more frequent (PIP-F) and more difficult (PIP-D).
Peds QL™ Family Impact Module Assesses Health Related Quality of Life and Family Functioning.	Varni et al. [19]	5(36)	Likert scale questionnaire. Five domains: physical functioning; emotional functioning; social functioning; cognitive functioning and family functioning.	Scores range 1–100. Lower scores identify a characteristic is more problematic.

Table 2

Questions asked during semi-structured interviews at TP1 and TP2.

Key interview questions	Befrienders	Befriendees
TP1: Before befriending	<ul style="list-style-type: none"> • What made you volunteer to become a befriender? • Have you ever done anything like befriending before? • Have you ever been befriended or wished to have someone like a befriender? • What do you expect being a befriender will involve/be like? • What are you most excited/worried about in terms of being a befriender? 	<ul style="list-style-type: none"> • Have you ever received any other similar sort of support? • What made you join the befriending scheme? • How much information have you had about the scheme? • What do you expect from the befriending relationship?
TP2: After befriending	<ul style="list-style-type: none"> • Tell me about your befriending experience. • What sort of things were you feeling when you were with your befriender? • What were the highs and lows of the befriending? • Did you feel prepared for befriending? • Did befriending match your expectations? • What, if anything, do you think you could have done differently? • How has befriending this parent made a difference to you? 	<ul style="list-style-type: none"> • Tell me about your befriending experience. • What sort of things were you feeling when you were with your befriender? • What were the highs and lows of the befriending? • Did befriending match your expectations? • What, if anything, could have been done differently? • Do you think that being befriended has made a difference to you and your family. If so, how? • Would you recommend the scheme to another parent?

2.4. Ethical considerations

Ethics approval was obtained from the West of Scotland Research Ethics Service (12/WS/0065) and research approval was granted by the recruiting NHS Foundation Trust Research and Development Department. All participation was voluntary. Written consent was obtained at the start of participation and reaffirmed at every point of contact. A 'Research Concerns Protocol' was developed in partnership with the psychology department at the tertiary centre to identify concerns and appropriate actions to be taken by the researchers (e.g. concern raised by parents; high GHQ-12 score).

2.5. Analysis

In line with the concurrent mixed method design, the interview and questionnaire data were initially analysed as separate sources of evidence before being compared, contrasted and synthesised during the process of data interpretation. Interpretation was an iterative and collective process engaging each member of the research team. The interviews were interpretively thematically analysed [21] by all members of the research team. The data were coded inductively line-by-line, then labels were ascribed to segments of text. Four researchers (LB, KK, CS, BC) independently coded five transcripts line-by-line (20 in total) before meeting as a

team to discuss and gain some consistency of the codes. Each of the remaining transcripts was coded independently by two members of the team. The codes and ascribed labels were discussed and debated between the research team to reach consensus and consistency prior to the development of the three main themes. The questionnaires were coded, inputted and analysed using descriptive and inferential statistics within a statistical package (SPSS).

3. Results

The scheme ran between May 2012–June 2014; 70 interviews (lasting 10–80 min) were conducted and 68 sets of questionnaires completed (see Fig. 1). The scheme trained 13 parent befrienders (12 mothers; 1 father) who all engaged in the research project. Due to personal circumstances only 12 befrienders went on to befriend a parent and were interviewed at the end of their befriending experience. Thirty-four befriendees engaged in the scheme and 26 (24 mothers; 2 fathers) participated in the research study. The number of sessions held between a befriender and their befriender ranged from 2 to 12; the number of sessions was intended to be flexible and responsive to the individual needs of each befriender.

The children of the befriendees and befrienders had a range of conditions and disabilities (Table 3). Although we asked the parents for their child's main diagnosis, we did not request more

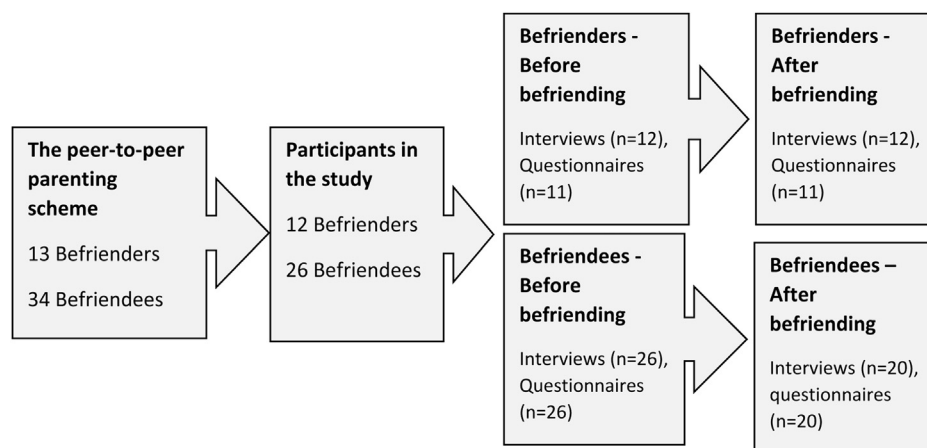
**Fig. 1.** Flow chart of participants and data collection.

Table 3
Diagnoses of children of parents engaging in the befriending scheme.

Main diagnosis of the children of the Befriendeds' (n=26)	Main diagnosis of the children of the Befrienders' (n=13)
Autistic Spectrum Disorder (n=12), Down's syndrome (n=4), Cerebral palsy (n=3), Attention Deficit Hyperactivity Disorder (n=1), Microcephaly (n=1), Fragile X (n=1), Foetal alcohol syndrome (n=1) Genetic disorders (n=3).	Autistic Spectrum Disorder (n=5), Down's syndrome (n=5), Spina bifida (n=1), Cerebral palsy (n=1) Congenital muscular dystrophy (n=1).

detail about their child's condition such as length of time since diagnosis or other demographic data as our focus was on the befriending relationship, regardless of the child's condition.

The findings will be presented in two sections; the qualitative findings and the quantitative findings.

3.1. Qualitative findings

The qualitative data are presented within the three themes of 'being lost and not knowing which way to turn', 'finding or being a guide' and 'getting to a better place'. These three themes were developed based on our iterative interpretation of the data and the sense of a journey (before-during-after befriending) that was evident in the stories the befrienders and befriendeds recounted. The codes and how these relate to the themes and the points of engagement with parents are presented in Table 4.

3.1.1. Being lost and not knowing which way to turn

This theme was dominated by the befriendeds' accounts, although befrienders often began their interviews recalling their own stories of feeling lost and the personal impact of their child's diagnosis. The following befriender reflected back on her emotional reaction to hearing her son's diagnosis

"I was in a lot of pain and it felt like physical pain to me because I felt like someone had punched me in the face or ripped my heart out or like picked my world up and shoved it upside down, rolled it around a few times and went – 'Here you are'" (Befriender 8, before befriending)

Many of the befriendeds were early in their journey of understanding their child's condition, some still awaited a definite

diagnosis, and many described themselves as having reached "rock bottom", "being in darkness", "not knowing which way to turn" and not being able to see the "light at the end of the tunnel".

While many parents felt supported by health professionals, both befrienders and befriendeds described how professionals focus on providing physiological information. Parents consciously presented themselves as being "fine" during these interactions as they feared the consequences of being judged as "unable to cope". The following mother discussed the risk she believed was inherent in being open with professionals;

"There are times when you feel overwhelmed by it. You feel that when the attention is on you, when they say to you – 'how are you getting on?' you've got to go 'I'm fine' because if you don't say 'I'm fine' what are they going to say next?" (Befriended M, before befriending)

Acting "being fine" meant that parents who needed support, did not reveal this, further reinforcing their isolation. Although many had supportive families and friends, they were often guarded about sharing sensitive or upsetting information with them. One mother expressed how her family had exacerbated her fears of losing her children if she admitted struggling.

"My mum is very old school, very sort of 'don't air your dirty laundry' you know – 'if you start telling people you are worried . . . you'll have social services involved and they'll take the children off you" (Befriended O, before befriending)

Befriendeds' concerns about the dangers of "letting down their guard" reinforced the idea that they should just try and "get on with it" and not openly acknowledge that they needed help or support.

Table 4
Qualitative themes and related codes.

	Being lost and not knowing which way to turn (evident in the interviews before befriending, TP1)	Finding or being a guide (evident in interviews before and after befriending, TP1 & 2)	Getting to a better place (evident in the interviews after befriending, TP2)
Befrienders	<ul style="list-style-type: none"> Emotional journey to getting a diagnosis Looking back at hitting rock bottom Ongoing battles with services Needing to portray 'being fine' to professionals 	<ul style="list-style-type: none"> Feeling I can help someone else Wanting to give something back Not wanting someone else to go through what I did Feeling ready to do and be more 	<ul style="list-style-type: none"> Gaining a sense of accomplishment and purpose Gaining skills and future prospects Feeling less isolated It has raised my ambitions Still having good and bad days, but more good than bad
Befriendeds	<ul style="list-style-type: none"> Emotional journey to getting a diagnosis Hitting rock bottom Not knowing where to go to for help Trying to get through one day at a time Not able to see the light at the end of the tunnel Ongoing battles with services The need to portray 'being fine' to professionals Keep your troubles to yourself and not 'airing your dirty laundry' Just trying to get on with it 	<ul style="list-style-type: none"> Feeling ready to talk about it It is the right time now Something for me I know I need help I can't go on like this I didn't want to burden my family and friends with my troubles Finding someone neutral Talking to someone who has been there Wanting to be stronger 	<ul style="list-style-type: none"> Being inspired that I can get through this Becoming more confident Now I can 'see the light at the end of the tunnel' Feeling less isolated The load was lifted by talking to someone for the first time Seeing a possible way forward Feeling ready to get back out there Being lifted up from a low

3.1.2. Finding or being a guide

3.1.2.1. Being a guide. Despite heartache persisting in the lives of some of the befrienders, they discussed how they had learnt strategies to cope and overcome daily challenges. They were able – in most cases – to look back and see where they “had come from” and the journey they had taken. Several befrienders hoped that by sharing their experiences they would be able to help other parents navigate the emotionally difficult times that can be associated with being a parent to a disabled child. As one mother explained:

“ . . . when you go to that mum’s house and you say to them ‘I’ve been where you’ve been’ and they look at you and think ‘well you’re normal, you’re just a normal person and if you can do it, I can’. And that inspires that mum to think, ‘well if that person can do it, I can do that, you know I can achieve that’”. (Befriender 8, after befriending)

Befrienders recognised that they needed to be “in a positive, strong place to be able to support someone else” as hearing other parents’ worries and fears sometimes emphasised the issues they were continuing to experience. They noted befriending “makes you assess your befriender’s world but also your own” (Befriender 7, after befriending).

3.1.2.2. Finding a guide. The need to talk to someone who had “been there” was the most frequently cited reason that befriendeds had sought support and chosen to engage in the scheme. Several of the befriendeds described this mutual support as lifting them through periods of feeling very low, for example:

“I was just so low you know at that point and having someone there really pulled me through. When I think back now how low I was, because we weren’t leaving the house even, and I wasn’t really getting any support from my family or friends, they couldn’t really understand.” (Befriender AF, after befriending)

Befriendeds had to find time in their busy lives to meet with their befriender and this was challenging especially when trying to balance other commitments such as work, shopping, cleaning and child care responsibilities. One befriender, who discontinued befriending after several sessions, discussed how she had struggled to make time to meet with her befriender:

“I had too much going on. I’ve got nurses coming from LD [learning disability] every week, speech and language some, he’s in school three hours and I’ve got housework to do and shopping so I just didn’t have the time to do it.” (Befriender I, after befriending)

3.1.3. Being in a better place

Many of the befriendeds’ accounts following befriending included descriptions of how they felt that they had reached a “better place”. Although many continued to experience high levels of distress and difficulty they described they had “moved forwards” and “come out the other end of the tunnel”. Being able to honestly share experiences and emotions encouraged one mother to explore positive aspects of her life and how she could move forward towards having a “good life”:

“Because at first you start thinking that your life’s over and ‘oh God it’s awful’ but that’s what I mean it helped me talking to her because I realised well no, you can still have a good life and have relationships and get out to places and things like that”. (Befriender F, after befriending)

One befriender described passionately the difference she had witnessed in one of the parents she had supported:

“To see her from the start she’s a completely different woman. When I found her she was on the floor and by the time I finished she was a completely different woman and it was amazing to see Because that’s all I want to do, put her in a better place than what she is when we find her”. (Befriender 8, after befriending)

As a result of engagement in the scheme many befrienders expressed a sense of fulfilment and achievement in their role, as described by the following mother:

“Yes I feel good about it, I feel like I’m doing something you know, because I had closed myself off. I feel I have accomplished a helluva lot through doing the Face 2 Face” (Befriender 4, after befriending)

The majority of befriending relationships which ran to completion met more than the expected six to eight meetings, as this proposed limit was felt to be “not enough” to really move a befriender “forward”. Befrienders suggested their befriender was not in a “good enough place” to be left unsupported at the proposed exit point. Many in the scheme continued to meet beyond the formal befriending experience, sometimes offering reciprocal guidance and support and with both being in a “better place” than which they started.

3.2. Quantitative findings

This section presents the quantitative data from the three questionnaires administered to parents (befrienders and befriendeds) before the start and at the end of befriending.

Table 5
Summary of scores from the questionnaires at the beginning and end of the befriending experience.

	GHQ ^a			PIP ^b			Peds QL Parent Health-Related Quality of Life summary score ^c		
	TP1 Mean (SD)	TP2 Mean (SD)	t-test	TP1 Mean (SD)	TP2 Mean (SD)	t-test	TP1 Mean (SD)	TP2 Mean (SD)	t-test
Befriendeds	20.15 (6.18)	13.75 (8.99)	2.656**	126.73 (19.67)	102.30 (33.01)	2.190**	34.83 (13.58)	44.64 (16.26)	ns
Befrienders	12.50 (6.64)	9.82 (5.67)	2.041*	115.20 (39.47)	81.00 (33.68)	3.654**	48.75 (26.09)	54.58 (27.82)	ns

* $p < 0.10$.

** $p < 0.05$.

^a Higher scores equate to higher psychological distress.

^b Higher scores indicate a characteristic is more frequent and more difficult.

^c Lower scores identify that the characteristic is more problematic.

3.2.1. GHQ-12

For both befriendees and befrienders, there was an improvement in GHQ-12 scores between TP1 (before the befriending scheme commenced) and TP2 (at the end of the befriending scheme). The GHQ-12 assessed parents' psychological distress and mental wellbeing.

As shown in Table 5, data from the GHQ-12 collected before befriending indicated that the befriendees were living with high levels of psychological distress (mean = 20.15, SD = 6.18). There was an improvement in the average GHQ-12 score of the befriendees from TP1 (M = 20.15, SD = 6.18) to TP2 (M = 13.75, SD = 8.99) and this difference was statistically significant: $t(19) = 2.656, p = 0.016$. Some befriendees continued to experience challenging personal circumstances relating to relationships with partners and family and housing difficulties and these parents continued to score very high on the GHQ-12 for psychological distress.

The befrienders average GHQ-12 scores likewise improved from TP1 (M = 12.50, SD = 6.64) to time point 2 (M = 9.82, SD = 5.67), and this difference was marginally significant ($t(9) = 2.041, p = 0.072$).

3.2.2. PIP

For both befriendees and befrienders, PIP-D and PIP-F scores lowered over the course of the befriending scheme. The PIP assesses parents' stress related to caring for their child with an illness.

The befriendees PIP-D scores were higher before the befriending scheme began at TP1 (M = 126.73, SD = 19.67) compared to their score when the befriending scheme had ended at TP2 (M = 102.30, SD = 33.01). The difference in scores between the two time-points was statistically significant: $t(19) = 2.190, p = 0.041$. Likewise, the befrienders PIP-D scores were significantly higher at TP1 (M = 115.20, SD = 39.47) compared to TP2 (M = 81.00, SD = 33.68) ($t(9) = 3.654, p = 0.005$).

PIP-F scores likewise decreased over time for both befriendees and befrienders. For befriendees, the difference in scores between TP1 (M = 124.42, SD = 23.61) and TP2 (M = 105.30, SD = 29.84) was not statistically significant: $t(19) = 1.49, p = 0.152$. However, for befrienders, the difference in scores between TP 1 (M = 111.30, SD = 32.84) and TP2 (M = 86.82, SD = 30.21) was statistically significant: $t(9) = 2.667, p = 0.026$.

3.2.3. Peds QL family impact module

The summary score for the HRQoL element of the Peds QL was examined as the main metric from the Peds QL scale. For both befriendees and befrienders, scores improved between TP1 and TP2. The Peds QL Family Impact Module assessed Health Related Quality of Life and Family Functioning.

Befriendees scores improved from TP1 (M = 34.83, SD = 13.58) to TP2 (M = 44.64, SD = 16.26), although this difference was not statistically significant ($t(19) = -1.675, p = 0.110$). For befrienders, scores likewise improved from TP1 (M = 48.75, SD = 26.09) to TP2 (M = 54.58, SD = 27.82), and again this difference was not statistically significant ($t(9) = -0.800, p = 0.44$).

4. Discussion and conclusion

4.1. Discussion

The findings from the qualitative and quantitative data led the research team to examine concepts underpinning parents' personal growth and journeying through adversity from 'being lost', 'being or finding a guide' and 'getting to a better place'. These inductively derived themes are explored in this discussion by being framed within a surviving and thriving trajectory; this trajectory facilitates the examination of how people cope and respond to challenging circumstances and life transitions [22,23]. The parents

in this study (both befriendees and befrienders) faced many challenges and life transitions including dealing with their child's diagnosis, managing day-to-day with a child with a disability or additional need, maintaining family life and work commitments, and dealing with unexpected changes to their child's condition and family circumstances. We will discuss how the befriendees and befrienders in this study presented surviving and thriving as part of a nuanced and complex journey.

Before befriending, many of the befriendees could be seen to be 'just' surviving and were experiencing high levels of psychological distress and difficulty. Isolation, personal struggles, feeling 'stuck' and not knowing where to turn for help were reinforced by the perceived need to present themselves as 'being fine' to family, friends and professionals. Although these parents were surviving, they seemed to be diminished by their experiences and the challenges they faced; in some cases they described their ongoing journey as insurmountable as they could not envisage an end to their struggles. These descriptions reflect Bergland and Kirkevold's [22] notion of 'surviving' where a person is impaired as a result of exposure to stress or adversity. The parents who were described being 'lost not knowing which way to turn' reflected key 'surviving' traits identified in the literature as 'managing to continue to live and exist' [24] whilst 'struggling to cope' [22]. Not all the befriendees experienced the same levels of adversity as there was variation of emotional and psychological wellbeing scores pre-befriending (TP1). However, most befriendees talked in terms of 'living less than a full life'.

Despite many of the befriender parents describing how they managed to 'just get on with it' and survive day-by-day, they contacted the peer parenting support scheme as they endeavoured to improve their circumstances. The befriendees who engaged in the scheme were guided by their befriender to look beyond day-to-day survival, to consider what may be acting as barriers for them in changing or coping better in their lives and begin to see opportunities to overcome and face these challenges. Despite many of their life circumstances remaining the same, the befriendees began to see possibilities for how they could flourish, grow and thrive. The concept of thriving [22] reflects 'growth and greater well-being' [25] and indicates a person feeling able to 'flourish' [23] following exposure to stress, suffering or challenging circumstance(s). The befrienders also thrived, flourished and developed through their interactions with the scheme, despite many continuing to experience difficult circumstances. Becoming a befriender seemed to open up further opportunities for continued growth, personal fulfilment and could be described as 'fully thriving' [23] in that they were functioning well in the face of adversity whilst at the same time pursuing meaningful life opportunities.

The ability of parents to share their feelings, worries and anxieties with another parent who had travelled a similar journey and had 'been there' was described as the most important characteristic of the support scheme. Befriending facilitated and fostered the befriendees' growth and they were able to thrive through the supportive meaningful relationships which Feeney & Collins describe as a key element in promoting thriving [23,26]. Within our study the befrienders nurtured the befriendees' desire for growth and their ability to see life's opportunities. In this way they acted as a relational catalyst [23], as identified within Feeney & Collins model of thriving. The social connections developed during befriending enabled both the befrienders and befriendees to discuss the affirmative aspects of parenting a child with a disability with someone who could understand through first-hand experience what that means. Other studies show that this ability to focus on the positives in life can directly reduce maternal stress [27,28] and this seemed to be true for befriendees who valued their support when reflecting on the positive aspects of their lives.

Through becoming a befriender or befriendee the parents embarked on a journey. For those who engaged fully in the process this most often resulted in them ending up in 'a better place', emotionally and psychosocially. The experience was not a linear move from one place (surviving) to another (thriving) but was multi-layered and complex, and subject to good and bad days. Our findings reflect Benson and Scale's [29] work that suggests thriving is not a fixed state, but a 'work in progress'. All parents are on a journey with their child but the parents in this study faced additional life challenges and their engagement with the peer-to-peer befriending scheme helped those who were lost to find a guide, for those who could guide to find reward in supporting someone else and for many of them to reach a 'better place'.

The collection of qualitative and quantitative data complemented each other and enabled a broad and deep understanding of the influence of the befriending scheme on parents' (befriendee and befriender) well-being. However, the sample sizes were small and parents' responses to the questionnaires may have been influenced by other aspects of their lives, therefore statistical significance should be treated with caution.

4.2. Conclusion

The peer-to-peer parenting support scheme was generative, it helped create supportive meaningful relationships for befriendees to embrace opportunities to flourish, grow and thrive. Bfrienders also flourished and thrived as a result of their engagement in the scheme; through training, connecting to others and seeing possibilities for the future. The qualitative findings are supported through the quantitative evidence demonstrating improvements in emotional and psychosocial well-being. This shift from surviving to thriving was enabled by the scheme supporting befriendees to move from a position of 'being lost' and 'struggling day by day' towards a 'better place'. In this way the parents in our study were facilitated to face and start to embrace the key components of a thriving person; to become future orientated, develop strong connections with others [30] and, after adversity, to surpass their past levels of functioning [22].

4.3. Practice implications

There is a need to address and support the emotional and psychological wellbeing of parents of disabled children. Peer-to-peer parent support (befriending) provides opportunities for parents to share and explore their feelings and experiences with someone who has 'been there' and who is non-judgmental. Peer-to-peer parenting support acts as a valuable catalyst for both bfrienders and befriendees to grow and begin to flourish. Professionals should inform parents of such schemes as an appropriate source of support and help.

We confirm all personal identifiers have been removed or disguised so the person(s) described are not identifiable and cannot be identified through the details of the story.

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