Patient and befriender experiences of participating in a befriending programme for adults with psychosis: A qualitative study.

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Abstract

Background

Befriending is a popular form of volunteering in health care, and research suggests that it can be beneficial for people with mental illness. This study aimed to explore the experiences of a large sample of volunteer befrienders and patients who participated in the same befriending programme for individuals with psychosis.

Methods

A series of semi-structured interviews were conducted with 34 befrienders and 28 participating patients. All participants who had participated in at least one befriending session were invited to take part in an ending interview about their experiences. This aimed to include a wide range of views, including those who had withdrawn from the befriending programme. The data was analysed using Thematic Analysis.

Results

Four broad themes were developed from the analysis of the befriender and patient interviews: 1) Bridging the gap, 2) A genuine relationship that developed over time, 3) A big commitment, 4) A flexible approach.

Conclusions

The results indicate that a befriending programme for individuals with psychosis can be a worthwhile experience for both befrienders and patients. However it also requires perseverance, flexibility and patience. Different factors have to be considered in the development and management of a befriending programme to provide effective support to both befrienders and patients.

Declaration of conflicting interests

None

Background

Befriending is a common form of volunteering generally involving supportive one-to-one companionship with a non-professional over a regular period of time (1,2). Commonly the focus of the befriending relationship is for the befriender and befriendee to engage in meaningful social and leisure activities (3,4). Befriending has shown to have benefits for people with both mental and physical illnesses, such as a reduction in symptoms (5), social isolation (6,7) and improved patient reported outcomes, including well-being and quality of life (8).

Previous research has predominantly focused on assessing the benefits of befriending opposed to exploring the experiences of participating in these programmes, and then largely this is from the befrienders' viewpoint (9). A systematic review by Hallett and colleagues (4) and updated by Toner and

colleagues (10) synthesised the experience of befrienders, who were participating in befriending programmes for individuals with severe mental illness. Befrienders reported a largely positive experience of befriending. However data was synthesised from heterogeneous programmes with varied structure, including the duration of the programme and the level of training and supervision offered. Research exploring both the perspectives of befrienders and patients is limited to a handful of studies, and the majority of which include data collated from multiple befriending programmes. These studies however indicate that befriending is predominantly a positive experience for both participant groups, but state that there are some challenges including confusion about the role of a befriender, and the level of commitment required (3,9,11).

The benefits of befriending is thought to be particularly relevant for individuals with psychosis, who experience higher levels of social isolation than the general population (12,13). Recent research has aimed to establish the effectiveness of befriending in this population, and which showed positive gains in social outcomes despite variable implementation of the programme (7). However, to our knowledge, there has been no research that has explored the specific experiences of participating in befriending programmes for people living with psychosis.

The present study therefore aims to explore the experiences of a large sample of befrienders and patients who participated within the same structured befriending programme for individuals with psychosis.

Method

Sample

Interviewees were recruited from a larger sample of people participating in the VOLUME Trial, a randomised controlled trial testing the efficacy of a befriending intervention for people diagnosed with a psychotic disorder conducted across ten community services in East London (7). The full protocol and findings of this trial has been published elsewhere (14). Briefly, befriending pairs were encouraged to meet for one hour on a weekly basis, over the period of one year, and the focus was on encouraging the patient to engage in more activities outside of the home. To do this befriending pairs were given an activity booklet, detailing inexpensive activities in the local area and during the year, patients and befrienders were invited to monthly socials (such as ice skating, picnics etc.) as an opportunity to meet and interact as a group. Once the programme was formally finished (i.e. after the year), patients and befrienders could continue the relationship if both chose to, although support from the programme was discontinued.

Patients were eligible to participate in the programme if they were between 18–65 years, had a diagnosis of schizophrenia or a related disorder (ICD: 10 F20-29), had capacity to provide written consent, and had sufficient command of the English language to participate in the programme. Befrienders were eligible to participate if they were over 18 years of age, had sufficient command of English, had no criminal record and were not currently receiving secondary mental health care.

All participants who had participated in at least one befriending session were invited to an ending interview. This ensured a varied range of demographic characteristics and included both participants who had withdrawn from the intervention as well as those who completed the full programme. Ethical approval was received from Camden and Kings Cross Research Ethics Committee (15/LO0674).

Procedure

The semi-structured interview schedule was developed in collaboration with a panel formed of people with lived experience, who also contributed to the development of the befriending programme. The interview schedule was designed to be open-ended with the participants guiding the direction of the interview, but including topics such as motivations for and experiences of participating in the programme, including what worked well, and any challenges that were faced.

The befriender and patient interviews were conducted by four female graduate researchers. Interviews were conducted in a variety of locations based on participant preference, including community mental health premises or participants' own homes if a quiet and private space was available.

Data analysis

Interviews were audio-recorded, transcribed verbatim by an external transcription company, and checked by the research team to ensure accuracy. Anonymised transcripts were uploaded to NVivo version 11 and inductive Thematic Analysis was used to analyse the data, following the steps outlined by Braun and Clarke (15).

All analysts were female psychology post-graduates and researchers trained in qualitative analysis. Despite the themes being developed inductively, from the content of the transcripts, it is likely that due to the analysts' backgrounds in mental health research the interpretation of the data was to some extent shaped by this previous experience.

The befrienders' and patients' experiences of the befriending programme were analysed separately to account for the variation in the different roles and experiences that both were likely to have had. Despite being analysed separately, both followed the same process. Firstly, all analysts read the full set of transcripts to familiarise themselves with the data. Ten transcripts from each set of interviews were then selected for line-by-line analysis, which was completed independently by two analysts (patient analysis: ML & AC and befriender analysis: EB & AC).

In the second stage of analysis, the analysts developed a coding framework, based on discussion surrounding the initial codes, including resolution of any discrepancies and agreement on how the codes may be interlinked. The coding framework was then applied to the remaining patient and befriender transcripts by the lead analysts, ML and EB respectively. During this process any new codes that were not captured by the original framework were discussed with the larger research team, and where necessary

the coding framework was modified. In the final stage of the analysis, the analysts examined how the codes could be interlinked and modified to develop the overarching themes of the data.

Results

In total, thirty-four befrienders and twenty-eight patients, 66% and 57% respectively who had participated in at least one befriending session, agreed to an interview at the end of the 12 month intervention. The remaining befrienders and patients either declined to be interviewed or were lost to follow-up. Interviews ranged in length from 20 minutes to 2 hours. Demographics of the participants are presented in Table 1.

Table 1

Socio-demographic characteristics of patients and befrienders

Patient characteristics (n = 28)	
Gender (n, %): Female Male	12 (42.9%) 16 (57.1%)
Age (Mean, SD)	43 (10.3)
Ethnicity (n, %) White Black / Black British – African Black / Black British – Caribbean Bangladeshi Other	7 (25%) 6 (21.4%) 5 (17.9%) 5 (17.9%) 5 (17.9%)
Years since diagnosis (Mean, SD)	25.52 (11.30)
Employment status (n, %) Paid employment Full time education or training Retired Unemployed Withdrew from the scheme (n, %)	1 (3.6%) 1 (3.6%) 1 (3.6%) 25 (89.3%) 4 (14.3%)
Befriender characteristics (n = 34)	
Gender (n, %): Female Male	24 (70.6%) 10 (29.4%)
Age (Mean, SD)	29.24 (9.95)
Ethnicity (n, %) White Black / Black British – African Black / Black British – Caribbean Bangladeshi Indian Pakistani Other	17 (50%) 6 (17.6%) 1 (2.9%) 2 (5.9%) 1 (2.9%) 1 (2.9%) 6 (17.6%) 12 (35.3%)
Employment status (n, %) Full time employment Part time employment Full time student Unemployed Retired Other Did not disclose	8 (23.5%) 4 (11.8%) 4 (11.8%) 1 (2.9%) 3 (8.8%) 2 (5.9%) 24 (70.6%) 10 (29.4%)
Previous experience of volunteering (n, %) Yes No Withdrew from the scheme (n, %)	6 (17.6%)

Four overarching themes were developed from the data and are presented along with their subthemes in Table 2. These were: 1) Bridging the gap, 2) A genuine relationship that developed over time, 3) A big commitment, 4) A flexible approach.

Table 2
Themes

Main Theme	Sub-themes patient	Sub-themes befriender
Bridging the gap	Normalising schizophrenia Is the gap too big to bridge?	Changing perceptions of schizophrenia My match was an easy one
A genuine relationship that developed over time	Developing a genuine and reciprocal friendship	Attuning to my match Befriending can be emotional
A big commitment	It doesn't feel like they have time for me Befriending is a voluntary role	Befriending is a bigger commitment than I originally thought It's volunteering so there is no obligation
A flexible approach	The scheme needs to be flexible to differing needs Achieving goals vs. having someone to talk to	The balance between pushing and patronising

1. Bridging the gap

Some patients expressed feeling isolated from society due to having psychosis. As members of the community, befrienders were viewed by patients as being in a good position to bridge this perceived gap between mental illness and society. For some this was simply the notion that the befriender, as a so-called 'normal' member of society wanted to spend time with them.

"That's what was helpful, being treated like I was normal and worthy of respect by a member of society who was considered to be a normal respectable member of society. In that respect, that makes you feel you fit in, you know." (Patient 131)

For some patients, however, the differences between the befriender and themselves were felt to be too large, with some feeling judged by their befriender.

"She was arrogant. […] because she was at college and that, because I never went to college, she asked about my college and school, and started asking all personal questions. I don't like that." (Patient 15)

Many befrienders admitted to being initially influenced by false preconceptions of psychosis, common throughout society and depicted in the media. This in turn affected how nervous they were when joining

the scheme. As a result of taking part in the befriending programme many befrienders reported that their perspective changed, and they developed a better understanding of the reality of psychosis.

“My mother thinks that schizophrenic people go around killing people on the streets of London and that’s what most people think and that’s what potentially I may have had a slight thought about before doing this scheme and then meeting someone like [patient] and realising that she isn’t harmful to no one.” (Befriender 23)

Nevertheless, this changed perception of psychosis was not always generalised beyond their own befriending match. Some befrienders felt that they had been lucky to befriend an ‘easy match’, and that other patients in the programme were more challenging, expressing behaviours more in line with their initial perceptions of psychosis.

“To be able to see especially for those social events because there were people different from [patient] and [patient]’s a mild situation. You can’t differentiate her from anyone else. She looks completely normal. And I was fortunate.” (Befriender 53)

2. A genuine relationship that developed over time

To make a new friend and find companionship was one of the key motivators for many patients to join the scheme as they often expressed feeling lonely and isolated, with few, if any social contacts. For many this was achieved, with patient feeling that the befriending relationship developed into a friendship over the course of the programme.

“Because even for me I really value the friendship that me and her have made now, It’s always nice to make new friends, so I think having her in my life now, I do see us being friends for a long time.” (Patient 103)

Befrienders and patients spoke about how having certain commonalities, such as cultural background and mutual interests, enabled a friendship to develop between them. For some, the befriender opening up about their own life or even discussing their own difficulties also aided the development of a real friendship with reciprocal support.

“I do discuss my personal issues with her. She discuss[es] her own personal issues with me and she does ask me where I’m needing advice for some certain things she does advise me. And when she did advise, I did advise her, we became close.” (Patient 17)

Many befrienders stated that over time as the relationship developed they could attune to their match, which enabled them to pick up on subtle signals to understand how they were feeling.

“Like if there was a really busy place that we’d been to, like I say, I could see the change in her body language and needing to just leave. So, when we had the social where it was at a football stadium it was

really busy and as we got out of the station, because it was really loads of people, I could tell she was like shutting down a bit." (Befriender 31)

Whilst being able to relate to their match was viewed as important, with many befrienders reflecting that empathy was vital for the role, this also had a downside in that they could become too emotionally invested.

"I think one of the reasons I could do it and I was quite good I think at befriending him, is about empathy and emotional availability but I think if you have those things it can also be quite painful and quite intense and quite emotionally distressing." (Befriender 39)

This became especially poignant towards the end of the scheme where several befrienders felt that terminating the relationship could be cruel for the match who had become used to receiving social support from a befriender.

"I think that it's quite cruel that it cuts off after a year and you then perhaps don't have any contact with the person again. I do feel it's quite harsh, that they have somebody once a week every week and then they have a social once a month and then that's gone." (Befriender 60)

3. A big commitment

Befriending often felt like a big commitment to befrienders, and often a larger commitment than was originally expected. This was often due to unforeseen lifestyle changes for the befriender, competing commitments and the additional impact of travelling to and from befriending appointments, particularly when the befriendee did not live close by.

"I had to try and coordinate having my own life, my family and I've got a boyfriend [...], so it did get at points some weekends where I was thinking, I'd love to spend it with my boyfriend or I've love to go away with my friends but I haven't seen [patient] for a week and I need to see her." (Befriender 23)

Many befrienders felt unable to meet their match on a weekly basis, which sometimes led to infrequent meetings, or having to cancel appointments last minute due to competing demands.

"I think as the year progressed because I was becoming a little bit more busy and I was finding the commitment a bit hard but I didn't kind of want to let go of the commitment altogether especially because we'd built a good bond." (Befriender 62)

However, some befrienders felt that as the programme was voluntary there was not the same obligation to be consistent within the role as there would be for a paid job. Some spoke about being attracted to this voluntary role in particular, because of the flexibility, and freedom to negotiate the timing and location of meetings.

“Like obviously it’s volunteering, so it’s nothing that you have to do every week, it’s something if you can make time and if your match has time then it’s nice to meet up.” (Befriender 35)

Patients had different views on the level of commitment they expected from their befriender. Some felt that the befriender could not provide the time that they felt they ought to give, whilst others expressed awareness that their befriender was a volunteer, and therefore understood that they had other commitments and priorities.

“She works ‘n all and she hasn’t got time for me most of the time […] she doesn’t have time for me and I don’t have time for her.” (Patient 45)

“She was a student, so she couldn't always give me time. Plus she had exams, so I kind of understand she couldn't always make time for me. But when she did make time, it was really enjoyable.” (Patient 46)

4. A flexible approach

Both befrienders and patients agreed that both the role of the befriender and the befriending programme needed to be flexible in acknowledging that every person is individual in terms of their needs. Patients appreciated a flexible approach to befriending, where they could be supported to achieve their goals, or to just have someone there to talk to.

“Each day is different; each day is a different battle. On a good day I will challenge myself. On a bad day I will hibernate, sleep.” (Patient 94)

“You might look at an activity as a befriender, yes, somebody to do things with, but sometimes people are so stressed they just need somebody to talk to.” (Patient 30)

Some befrienders were mindful of the need to encourage their match without appearing patronising; therefore finding a balance in achieving this as well as the difficulty in achieving that balance. Other times it felt necessary to gently push their match outside of their comfort zone and that this in hindsight was appreciated.

“There’s a feeling for me of I feel like it’s really delicate not to be the apparently well person coming into help the unwell person do things they should really be doing. I really didn’t want to do that. […] I didn’t want to be pushing him out of his life.” (Befriender 39)

“When we first met, he’d be like […] “I’m feeling really tired today,” or, “I’m feeling really unwell,” and then at the end when we were leaving […] he’d just say, “I’m really glad I came out today, it did sort of help.” (Befriender 33)

Discussion

Four broad themes largely capture the experiences of both befrienders and patients who participated in the same befriending programme for individuals with psychosis. The first theme ‘Bridging the gap’ indicates that befriending can be a means of normalising psychosis within society. For patients, it was empowering to have access to a non-judgemental and supportive segment of society, and the volunteers noted that through exposure to someone with psychosis they became aware of any misconceptions they may have held prior to volunteering. However, this change in attitude may not have always extended beyond the befriending pair. The second theme ‘A genuine relationship that developed over time’ explores the relationship that developed between the befriending pairs over the period of a year that they were participating in the scheme. Many of the participants felt that a genuine and authentic relationship had been able to develop between them. Some befrienders however reflected that through developing a relationship with their match they became too emotionally invested. In the third theme ‘A big commitment’ the befrienders highlighted the reality that befriending can be a big commitment, and that balancing regular meetings with the patient and other commitments, such as work, family and social life, could be challenging in a voluntary role. Befrienders differed on the level of commitment that they were willing to invest, but the general consensus was that meeting once per week was too much. Similarly, patients differed on the level of commitment that they expected from their befrienders. In the final theme ‘A flexible approach’ participants iterated that the befriending programme needs to be flexible, and not too rigid in its approach to support the differing needs and goals of the participants. It was felt that the focus of the programme therefore should not only be about encouraging the patients to engage in activities, but should also be providing someone to talk to. Befrienders reported that they sometimes struggled with this balance, and were unaware how much it was appropriate to push their match.

Strengths And Limitations

This is the first known study to evaluate both patients’ and befrienders’ experiences of participating in a structured befriending programme specifically designed for individuals with psychosis. Therefore, these findings enrich the understanding of the factors that may affect the uptake and acceptability of befriending programmes in this population. This may be helpful in the design of future programmes.

A major strength of this study is the large sample size, and to date this is the largest known study exploring both the experiences of befrienders and patients who have participated in befriending programmes for individuals with mental illness (3,9,11). Secondly, an advantage of this study is that all participants participated in the same structured befriending programme, and therefore the participants’ perspectives were not affected by variation in the structure or design of different befriending programmes. Furthermore, we used a broad sampling strategy by inviting every participant who had participated in at least one befriending session. This ensured that we got a varied range of opinions and experiences, and included those who had withdrawn from the programme to aim to understand what influences ‘drop-out’.

There were several limitations to this study; firstly, participants were recruited only from community services across three East London boroughs (Newham, Tower Hamlets, City & Hackney). This is an urban and multicultural area marked by specific challenges, including a high deprivation index and a transient population. It is therefore unknown whether the accounts provided by the volunteers and patients in this study would be reflective of befriending programmes conducted in different locations, including semi-urban and rural locales.

Additionally, despite all participants coming from the same befriending programme there was large variation in how often they met their match (between 1–48 meetings). The experiences of the participants who met their match less frequently are likely to vary substantially from those who met their match more often as many of the benefits that were discussed within this study appeared to become more apparent over time. Furthermore, the sample of befrienders who participated in this study were on average much younger than befrienders reported in previous befriending studies (10,11,16) and were often younger than the patients they were matched with. It is possible that some of the challenges and benefits that were discussed by participants in this study may be more specific to the different demographic of befrienders observed in this study.

Comparison With The Literature

The benefits and challenges of befriending people with psychosis appear to be non-specific to the benefits and challenges of befriending individuals with mental illnesses in general. The findings from this study are consistent with previous literature indicating that befriending programmes for people with mental illness can provide numerous benefits for both the befrienders and patients, but concurrently can also be challenging (3,4,9,11).

A benefit of befriending that was explored within the present study suggests that befriending might be a means of challenging prevailing negative perceptions towards mental illness in society due to increased exposure and familiarity. A study by Toner and colleagues (16) found that befrienders had less desire for social distance than the general population, however a degree of social distance still remains. Interestingly in this present study, the befrienders change in attitude towards psychosis was not always generalised past their own match, which could suggest some desire for social distance still remains.

Many of the challenges that were identified in this study, such as the level of commitment required to participate were not insurmountable to the overall success of the programme. Furthermore, many of the challenges that were experienced could be addressed through flexibility on the part of the befriender and the befriending programme. It has been suggested that there is not a one-size-fits all approach to befriending individuals with mental illness, as there is a limited consensus on a range of befriending options including the variability and longevity of the programme, as well as the type of the relationship that is developed with the befriender (9,17).

Similarly, being too rigid in the objectives of the befriending programme can create confusion over the role of the befriender. In a review of how befriending has been conceptualised in previous literature, Thompson and colleagues (1) found that there was a spectrum of different befriending practices. On one side befriending was conceptualised as more of a professional relationship, which is characterised as being more boundaried and goal-focused. On the other side of the spectrum befriending has been likened to the development of a more natural friendship, which in turn has been linked to a greater risk of emotional turmoil (1). Both the befrienders and patients in this present study largely conceptualised the role of a befriender as closer to a genuine friend as opposed to a more professional relationship. This could have caused some role ambiguity for the befriender, who may have felt pulled in different directions by the needs of the patient and the requirements of the programme, which were more goal-focused in encouraging the patients to engage in more activities. Toner and colleagues (17) found that the majority of patients who were surveyed about their preferences for a befriending programme, favoured having someone to listen to and support them over doing more activities, which might reflect some the discomfort that befrienders felt in trying to push their match to achieve specifics goals which were sometimes met with resistance.

Implications

Befriending has shown to be a valuable resource in the care of individuals living with mental illness, and this study indicates that the benefits and challenges of befriending individuals with psychosis are similar to befriending individuals with mental illness in general. Understanding the experiences of befrienders and patients has implications for the design and implementation of future befriending programmes to fully optimise befriending as a resource. For example, befriending programmes that are too rigid in their design may be unhelpful. This seems particularly pertinent when befriending programmes are too prescriptive in their aim, e.g. the focus solely being on achieving goals as opposed to just providing someone to talk to. The development and implementation of more flexible programmes would allow participant preference to be accommodated, particularly in the type of befriending relationship that is formed as well as the longevity and variability of the programme. Furthermore, there are also implications for the training and supervision of befrienders, which must acknowledge that befriending can be demanding and emotional. This should include both training and ongoing support for a range of issues faced by befrienders, including role ambiguity and managing relationships ending.

Conclusion

Befriending is a valuable resource in mental health care that has shown to be beneficial for both patients and befrienders themselves; at the same time befriending can also be challenging. Some of these challenges can be alleviated through encouraging a more flexible approach to befriending, which takes into account individual participant preferences and is less prescriptive in the role of the befriender and the duration and variability of the programme. Participant preference needs to be taken into account in both

the design of befriending programmes and in the support provided to befrienders and patients during participation in a befriending programme to maximise the benefits that can be provided by befriending.

Declarations

Ethics approval and consent to participate

A positive ethical opinion was received from The National Research Ethics Service (NRES) Committee London—Camden & Kings Cross (reference 15/LO/0674). Written informed consent to participate was obtained from participants.

Consent for publication

Not applicable

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author upon reasonable request.

Competing interests

None to declare

Author Contributions

EB wrote the first draft, and AC, ML and SP contributed to its revisions. SP led the original study design and its development. EB, AC and ML conducted the analysis.

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