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The Authors declare that there is no conflict of interest.

Paradoxical and powerful: Volunteers’ experiences of befriending people with dementia

Abstract

This qualitative UK study explored the lived experiences of volunteer befrienders to people with dementia, using Interpretative Phenomenological Analysis. Individual semi-structured interviews were conducted with nine befrienders aged between 25 and 66 years. The relationship that developed between befriender and befriendee was at the heart of befrienders’ experiences. It comprised numerous paradoxical processes that generated issues of power, equality and boundaries, characterising befriending as a complex and unique phenomenon. Befriending was expressed as a deeply personal and human experience, often with emotional power and profound meaning. Befrienders’ personal learning included seeing past dementia stereotypes, challenging their own assumptions and boundaries, and reflecting on love, life and humanness. Dissemination of these findings could help to challenge the stigma around dementia, and enhance recruitment and support of dementia befrienders. Future research should consider befriendee experiences of the relationship, additional measures of befriending effectiveness, and exploration of befriender attrition and support.

Keywords

Befriender / Befriending, dementia, qualitative, relationship, volunteer.

Introduction

Dementia: Definition and prevalence

Dementia involves substantial progressive decline in one or more cognitive domains (memory, attention, language and perception); this decline (a) interferes with independence, (b) occurs outside a delirium context, and (c) is not primarily attributable to another mental disorder (American Psychiatric Association, 2013). In the United Kingdom (UK), it is estimated that dementia will affect one million people by 2025, as well as over 670,000 family carers (Alzheimer's Society, 2007; Carers Trust, 2013).

Social isolation and loneliness in dementia

Social isolation and loneliness are particular ongoing issues for people with dementia and their family carers in the UK (see Greenwood, Habibi, Mackenzie, Drennan, & Easton, 2013). Recent surveys of people with dementia report that 40% feel lonely and less than half feel a part of their community (Alzheimer's Society, 2013a, 2014). Loneliness has been linked with sleep dysfunction and cognitive decline, as well as increased risk of heart disease and early death (Cacioppo et al., 2002; Holt-Lunstad, Smith, Baker, Harris, & Stephenson, 2015; James, Wilson, Barnes, & Bennett, 2011; Ong, Rothstein, & Uchino, 2012; Wilson et al., 2007). Many carers also experience increasing social isolation, due to the stigma of dementia and the loss of their relationship with the person with dementia (see Charlesworth et al., 2008; Georges, 2008; Greenwood et al., 2013). In contrast, being a valued part of community life is one of seven outcomes that people with dementia and their families would like to see in their lives, according to the National Dementia Declaration 2010 (Dementia Action Alliance, 2014).

Befriending in dementia care

Befriending makes a ‘distinctive’ contribution to dementia services (Mental Health Foundation, 2007, p. 25) and is specifically recommended in order to reduce loneliness and improve quality of life (Alzheimer’s Society, 2013a; Audit Commission, 2002; National Audit Office, 2007). Befrienders provide a ‘non-judgemental, mutual, purposeful’ relationship that is ‘initiated, supported and monitored by an agency’ (Dean & Goodlad, 1998, p. 2).

People with dementia have reported that befrienders meet an emotional need for companionship, provide social and intellectual stimulation, and enhance their quality of life (Alzheimer’s Society, 2013a; Moyle et al., 2011; Preston, Marshall, & Bucks, 2007). Randomised controlled trials (RCTs) showed trends towards improved carer mood and quality of life for those who engaged (Charlesworth et al., 2008; Wilson et al., 2009). Furthermore, a qualitative study of carer peer support highlighted numerous gains including emotional support, enjoyment, and support to manage their situation (Greenwood et al., 2013). Befrienders have also been praised by General Practitioners, and both service evaluations and funding for RCTs have been set up, with further findings being awaited (Audit Commission, 2002; National Audit Office, 2007).

Volunteer involvement in dementia care

The voluntary sector is ‘uniquely placed to reach socially isolated people’ (Department of Health, 2012, p. 22) and voluntary organisations now play a central role in dementia service delivery (e.g. Care Service Improvement Partnership, 2005; Health Foundation, 2011; Department of Health, 2012; National Institute for Health and Clinical Excellence (NICE), 2006). Many dementia services are run by unpaid volunteers (Alzheimer’s Society, 2013b; Audit Commission, 2002) and virtually all befriending services are delivered by volunteers (Dean & Goodlad, 1998). The UK government has set up several organisations and invested £40 million to support volunteering, as well as launching the social action movement Dementia Friends to increase public support of people with dementia (HM Government, 2011; Department of Health, 2012). However, volunteering has reportedly ‘flat-lined’ in recent years (HM Government, 2011, p. 4). Services report a shortage of befrienders (Heslop & Robinson, 2004; N. Lavin, personal communication, October 25, 2013). Two-thirds of services report problems attracting befrienders and one third report high befriender turnover (Dean & Goodlad, 1998).

Research with volunteers

Research exploring the experiences of volunteers has been highlighted as important (Smith & Greenwood, 2013). Understanding workers’ experiences can help to identify appropriate support, which in turn can positively influence their satisfaction and wellbeing (e.g. Kristiansen, Hellzén, & Asplund, 2006; Stockwell-Smith, Jones, & Moyle, 2011).

Existing research with dementia volunteers has identified issues relating to a) volunteers' role, particularly regarding the need for role clarity, b) emotional experiences, including emotional reward, acceptance of their own experiences, fear of rejection and difficulties ending the relationship, c) personal development, such as increased empathy and appreciation of clients, and d) professional support in terms of the need for specific training (Chung, 2008; Greenwood et al., 2013; Guerra, Demain, Figueiredo & De Sousa, 2012; Pillemer, Landreneau, & Suitor, 1996; Tanner & Brett, 2014). Research has not yet explored volunteer befrienders in dementia, however.

Rationale for the current study

Befriending is both valued and clinically recommended in order to help address social isolation and loneliness for people with dementia and their family carers. Befriending services are typically provided by unpaid volunteers, yet there are problems with befriender recruitment and attrition, and a lack of clarity about factors contributing to this. Existing research in dementia services suggests that volunteering can be both rewarding and challenging, and that role definition and professional support are important.

Research into the lived experiences of dementia befrienders is justified at this early stage in order to understand the issues involved in providing dementia befriending. This could improve understanding of recruitment and attrition issues in dementia befriending, with implications for attracting volunteers to the role and providing any ongoing support they may need.

Research aim

This study aimed to gain an insider perspective into volunteers' lived experience of befriending people with dementia.

Method

Design

This study adopted a qualitative design using Interpretative Phenomenological Analysis (IPA), in order to explore individual lived experience. Semi-structured interviews were conducted with each participant.

Participants

Demographic characteristics. Participants were nine volunteer befrienders from two Age UK Dementia Befriending services (see Table 1). Ethnicity and first language have remained confidential to maintain anonymity. At the time of the interviews, Harriet was befriending two people and all remaining participants were befriending one person. All befriendees had a diagnosis of dementia and ranged in age from 66 to 89 years.

Table 1. Demographic characteristics of participants.

Pseudonym	**Gender**	**Age**	**Length of time befriending**
Alexander	Male	33	2 years 6 months
Bill	Male	66	4 years
Chris	Male	65	3 years
Daphne	Female	65	2 years 8 months
Elliott	Male	30	1 year 4 months
Fraser	Male	61	4 months
Gregory	Male	25	3 years 10 months
Harriet	Female	56	4 years 6 months
Janie	Female	26	10 weeks

Inclusion criteria. Participants met the following criteria:

- Volunteer (i.e. unpaid).
- Befriender (i.e. person providing company, support to maintain hobbies and assistance to access the local community).
- Supporting people with a diagnosis of dementia.
- Working for an Age UK Dementia Befriending Service. Age UK was an appropriate service as it has been highlighted in several governmental policies as a key initiator in planning and delivering local services (e.g. Audit Commission, 2002).
- Individual face-to-face contact for at least one hour per week.
- At least two 1-hour contacts (for sufficient experience for discussion).

Procedure

Ethical approval. The design was informed by the British Psychological Society Code of Human Research Ethics (2010) and approved by Coventry University Research Ethics Committee.

Materials. The interview schedule comprised five questions exploring the meaning of the befriender role, the lived experience of dementia befriending and professional support, as well as procedures regarding informed consent, interview set up, participant debrief and reflexive time (Smith & Osborn, 2003; Smith et al., 2009; Hugh-Jones, 2010). A demographic questionnaire was also issued at the interview.

Recruitment. An information sheet was distributed via the Dementia Befriending Service Coordinators. Befrienders then opted in to the study either by contacting the researcher or via their Coordinator.

Interviews. Interviews took place between December 2013 and February 2014. Locations included an Age UK office (*n* = 4), an academic institution (*n* = 2), a public setting (*n* = 2) and the individual's home (*n* = 1). Interviews were digitally recorded and lasted between 70 and 120 minutes (average 90 minutes).

Data analysis

Procedure. Recordings were transcribed and identifying information was replaced or omitted. Written transcripts were analysed according to IPA as outlined by Smith, Flowers and Larkin (2009). The researcher kept a written record of each stage of analysis, so that the process can be retraced.

Validity. Steps to enhance validity included: (a) a bracketing interview, (b) independent analysis of one transcript section by an IPA researcher, (c) review of preliminary codes and themes by members of the research team, (d) reference to original transcripts throughout analysis, and (e) reflexive notes throughout the research process.

Results

Two main themes encompassed these befrienders' experiences (Table 2). Firstly, befrienders saw the key to befriending as building a relationship with their befriendee. This was a special and complex relationship that was difficult for them to define, comprising paradoxical intricacies relating to role, power and equality. Secondly, befriending was a powerful experience. Befrienders sought to make a positive difference to their befriendees and shared experiences that felt deeply meaningful. This generated emotional rewards and challenges, and befrienders often felt that they had learned in profound ways from their experiences.

Table 2. Master table of themes for the group.

Theme 1: A paradoxical relationship	Theme 1a: Comparable but indescribable
	Theme 1b: Two-way but not equal
Theme 2: A powerful experience	Theme 2a: Making a difference matters
	Theme 2b: Emotional involvement
	Theme 2c: Profound learning

Theme 1: A paradoxical relationship

The relationship between befriender and befriendee was the foundation of befriending. It was special yet complex, being difficult for befrienders to define and comprising numerous paradoxical processes that made the relationship distinctive.

Theme 1a: Comparable but indescribable. As Gregory expressed (line 388), it felt almost ‘impossible’ for any befriender to satisfactorily describe their relationship with their befriendee. The qualities of the relationship made it both like and unlike other relationships, so words used to describe other relationships did not seem to fit. This often left the befrienders at a loss for words, as Elliott found:

> It’s not like a relationship I would have with a friend, it’s not a kind of relationship I would have within the family [pause] I mean it’s certainly professional in a *way* [...] I can’t really explain that kind of relationship. (519-524)

Furthermore, befrienders and befriendees took a multitude of roles within the relationship. This made it difficult to describe their relationship in a single word and indicated that befriender and befriendee played a unique role in each others’ lives. Befrienders described taking on many roles, including carer, friend, lunch buddy and confidante. They saw their befriendees in many different ways, likening them to parents, grandparents, partners, friends and educators. The closest likeness was a friend, despite this not being a totally satisfactory descriptor; the exception was Daphne, who described her befriendee as her friend several times. Janie’s description of her role suggested giving time and attention that befriendees often did not get from others, implying that befriending provided a unique space:

> *She's* got a visitor *just* for her just to come and talk to *her* and take an interest in her, and you sort of get a sense that this is actually really unusual. (Janie, 83-85)

Janie's mention of a 'sense' also indicated something intuitive about the relationship, which may partly explain its indescribable nature. It seemed to have an intangible and indefinable quality, which several other befrienders mentioned. For example, Gregory highlighted that there was an element of 'chance' in the befriending relationship, that befriending was based on 'random' matching of befriender and befriendee, and that their feelings for each other depended on the 'chemistry' between them (lines 676-687).

Indeed, befrienders expressed the personal element of the befriending relationship very strongly during interviews. The extent of their closeness with befriendees differed; for example Elliott said 'it's just a nice pleasant relaxed relationship' (line 514), whereas other befrienders shared parts of their personal life with their befriendee, like Bill who jokingly described his befriendee as a counsellor. Sharing personal topics meant that the relationship could feel quite 'intimate':

> She could tell me that she had the diarrhoea, that she was worried about it, what was happening [...] and to *me* that feels intimate, you know, *sharing* those sort of things, sharing some of the things she's told me about family life [...] they're just not things that, I'd expect someone would be telling you unless they really trusted you. (Harriet, 662-668)

Several befrienders voiced reluctance to articulate love, but many expressed feelings of love in the way they spoke about being there ‘unconditionally’ (Alexander, line 472), ‘treasuring’ their befriendee (Bill, line 681) and feeling ‘blessed to have her in my life’ (Harriet, line 164). Gregory was one of the befrienders who felt most able to articulate love in his befriending experience:

> I think it’s a strong word but I think there were elements of love there, definitely, in the relationship, cos I cared for her, and she was fond of the time we had together [...] it was an amazing experience, and a really beautiful relationship. (456-460)

In contrast, Chris felt that his befriendee was ‘self-censoring’ during their visits, in that his befriendee chose to reveal little about himself, and as a result Chris felt like ‘a stranger to him’ (lines 180-183). This impacted considerably on Chris:

> He’s just regarding me as some kind of [servant] [...] like some kind of lower-order being that’s been brought in to provide a service for him that he requires and, beyond being *polite* [pause] he doesn’t have to deal with me as a person and that made me angry. (231-235)

The lack of emotional closeness made Chris feel depersonalised, even dehumanised. Indeed when asked to describe his relationship with his befriendee, he replied, ‘it’s mechanical’ (line 274), indicating an absence of human emotion and connection with his befriendee. This made him question whether he could continue the relationship. These accounts suggested the importance of emotional closeness between befriender and befriendee, both in defining a befriender and in shaping experiences of befriending.

On the other hand, the personal element coincided with befrienders' status as a professional. This appeared to explain befrienders' difficulty in describing their relationship, as the personal element comprised one part of a multi-faceted professional role. Many befrienders identified themselves as an Age UK worker, with multiple functions including a) liaising with their befriendee's family, b) signposting to local services, such as advocacy, c) organising community outings, for example to the cinema or a snooker club, d) supporting befriendees to relearn skills, such as typing, and e) facilitating meaningful conversation. This sense of purpose and professionalism appeared to have a significant influence in defining the befriender role. Befrienders also shared a strong sense of commitment to the role as well as responsibility for their befriendee:

> When I get back to the house, I always make sure he's actually settled in properly, you know, I don't just leave him at the door, so it's a relationship of *friendship* but obviously a bit of the carer there as well, in terms of making sure he's looked after properly in the time I'm with him. (Fraser, 307-312)

His account suggested divides in the befriending role, with a comparison to a paid professional with 'proper' standards of care as well as someone providing friendship. Fraser also mentioned time, which all befrienders spoke about as a way of both defining and confining their role:

> She’s an important person in *my* life now, but it is a very *contained* section of my life it’s a Tuesday morning, and that’s a bit unique as well, coz your normal friendships obviously spread into all sorts of things, and your family spreads into all sorts of things, but this is a Tuesday morning relationship. (Harriet, 248-252)

Thus Harriet’s time restrictions made her befriending relationship ‘unique’ from her other relationships. The opposing concepts of containment and ‘spread’ implied that she chose to maintain boundaries around the befriending relationship. Daphne explained the importance of maintaining these boundaries:

> It’s self-*preservation* for me, and *also*, I mean when Age UK start you off on this, they give you very clear guidelines about what you can and cannot do [pause] which I think is helpful, because otherwise I suppose your instinct would be to step in and do more and then you actually would *not* be helping. (875-879)

Daphne described a clear awareness of her remit as a befriender, yet this could go against her ‘instinct’ at times. These accounts illustrated the complexity of the interaction between befrienders’ personal and professional elements, which contributed to difficulties defining the role.

Theme 1b: Two-way but not equal. Most befrienders felt that their relationship with their befriendee was two-way, in that both befriender and befriendee contributed to and benefited from the relationship. There were numerous caveats to this, however. For example, befriender and befriendee tended to ‘get very different things’ from the relationship (Harriet, line 1115), there was imbalance as ‘he does more of the talking than *I* do’ (Fraser, line 363), and there was a difference between theory and practice: ‘it *is* a two-way process but it’s not really a two-way process’ (Chris, lines 654-655). Indeed for Alexander, the relationship’s one-way nature was what set it apart from ‘real’ friendship:

> For me a friend in the real world is somebody who I can give something to and they give something back to me [...] that is not the case here I can’t say “Winston, you know what, I got fired, help me out” you know it’s not that sort of relationship [...] befriending is a real one-way thing, *I* am befriending *him*, it’s not a two-way thing. (229-234)

His account also revealed a power imbalance in the relationship. Indeed, there was a shared sense amongst befrienders that the relationship was unequal, and a common discomfort with that. Some befrienders like Bill consciously developed ways in which their befriendee could give to them, such as seeking their advice. Several befrienders like Daphne highlighted humour and teasing as a reflection of equality between befriender and befriendee. Ultimately, however, befrienders expected this imbalance to be part of the role, and at times they were even able to use it to their advantage. For example, all befrienders wanted their befriendee to feel happy during their time together and, in this professional capacity, they ‘let’ befriendees ‘lead’ the visits:

> It’s more important what’s happening for him than what’s happening for me, in other words, let him lead. (Bill, 542-544)

Bill's account reflected a shared desire amongst befrienders to put their befriendee first, as well as their conscious choice to do so. Chris' account vividly illustrated this power imbalance:

> He really wants to talk about these things he *really* wants to tell me this story again, and, I'm nice enough to let him do it, and then if I get really bored I'll take something out of him for, you know payment for that, I'll make him listen to something he doesn't want to listen to or something [laughs] and then we're quits. (746-750)

The concepts of 'letting', 'taking' and 'making' suggested that befrienders were in more of a position to control the interaction than the befriendees. Chris appeared to consciously use his power as a way of regaining some equality in the relationship, as well as a means of emotional self-support. Central to Elliott's account was the importance of his befriendee setting goals and having achievements, but he acknowledged that this purposeful approach 'works' for him as a befriender:

> For *me* I'm very goal-oriented, and I think it works better, for *me*, if I can say "this is what we've tried to achieve", and if we can look back and say [...] "we've come a long way". (147-150)

Daphne said that she and her befriendee developed a 'modus vivendi', which she described as:

> The way of living together. Or it could be modus operandi the way of operating together. You know, we've found a *way* of making it work. (821-822)

Her repetition of ‘way’ and ‘together’ suggested that, for befriending to truly ‘work’, some befrienders negotiated a relationship that gave them a sense of equality and reciprocity, even though they were aware that this was not necessarily the ‘reality’:

> Although I say I have a back and forth and it feels like I have an equal conversation with Nellie, it is *just* in the moment those glimpses of it [...] for five minutes it’ll feel like an equal relationship and then it’ll go back to me leading the conversation, and I value those five and that’s what I kind of take away from it, those are the memories I have but in reality I *am* leading it. (Janie, 1039-1044)

Janie’s account echoes Alexander’s and Chris’ earlier descriptions of what was ‘real’, a sense of a relationship that was experienced in the moment quite differently from how it may be described or perceived more widely by others.

Thus the befriending relationship was expressed as a complex and paradoxical interaction, one that did not easily fit into an existing cultural repertoire. The development of a personal connection within a professional context created issues of power and equality, as well as a fluid reality.

Theme 2: A powerful experience

It was important for befrienders to feel that they were making a difference to their befriendees. Befrienders often spoke about benefits in terms of mood, yet the relationship generated opportunities that had a deeper significance for them. In particular, existential matters created considerable emotional rewards and challenges for befrienders, and often prompted meaningful reflection and learning.

Theme 2a: Making a difference matters. Volunteers came into befriending from different routes. Some wanted to give back following family experiences of dementia, but most had not anticipated working in a dementia service. They spoke of feeling ’comfortable talking to older people’ (Janie, line 1015), a ‘*deep* feeling of compassion for people who are lonely’ (Bill, line 6) or desire to be ‘contributing’ (Daphne, line 413). Regardless, all befrienders expressed very strongly that they wanted to make their befriendee ‘happy’ during visits, and many hoped to provide mental stimulation through new conversation or activities. Many befrienders wanted to have a longer-lasting impact; for example Elliott spoke about building his befriendee’s confidence in the community and Gregory witnessed his befriendee’s improving ability to use a computer. For other befrienders, their role was slowing the progression of befriendees’ dementia, but there was a sense that this was idealistic:

> The *only* person he can just let these things loose to is *me*. So I think I *do perform* a service for him, whether it’s helping his condition [laughs] I don’t know. (Chris, 251-253)

For Chris, the value of befriending lay in enabling his befriendee to talk freely, and almost all the befrienders described being the ‘only person’ who provided this for their befriendee. While they questioned the long-term benefits of this, befrienders spoke in emotive ways about deep and meaningful experiences they had with their befriendees.

Befrienders spoke movingly about their befriendee’s intense isolation and loneliness. They shared a profound sadness at witnessing befriendees feeling separated from who they were and what was happening around them. It was therefore particularly powerful when befrienders described ways in which they could bring closer the things that truly mattered to befriendees. Alexander described a memorable visit with his befriendee, who used to be an actor:

> We put Laurence Olivier on YouTube, stuff like his favourite scene, and he played it again and again and again and at some points he was repeating it and he stood up, then he started crying and then he said “hey can we put more things on” and he couldn’t believe that I could operate that machine and knowing that I could operate it it’s amazing like videos of Laurence Olivier are online there’s the clip he was amazed he was like *wow* [...] he was *so* happy. (379-387)

Alexander enabled his befriendee to relive an important part of his life and it was evident from his befriendee’s amazement and tears that this experience was incredibly meaningful.

Many befrienders went into the community with their befriendees, explaining it was often the only time befriendees left their home. Daphne gave an empathic explanation of why this was so important:

> I’m sure if *I* was housebound, the only thing I would want to do is get out in the fresh air, and you know, go into a shop and feel part of the *wider* human race, you know go and *buy* something and *talk* to somebody, and *have* that interaction which you know, means you’re part of the community. (189-193)

Daphne saw her role as helping her befriendee reconnect with his community, perhaps even giving him a sense of belonging.

Several befrienders spoke about the importance of giving their befriendees choice, control and independence. This contrasted with befriendees' metaphorical 'prison' of their usual living situation (Alexander, line 15) and there was a strong sense of freedom in the way that befriending visits were described during interviews. For example, Harriet described a time when she and her befriendee 'broke out' of hospital and went to a cafe together (line 185), Alexander wanted his befriendee to 'feel free' to do whatever his befriendee wanted (line 519), and Chris felt that his visits gave his befriendees an 'opportunity to let loose' (line 103). This gave a sense of liberty to befrienders' experiences.

Ultimately, when befrienders spoke about the meaning of befriending, they expressed a powerful and profound account of what it means to be human and alive. Many befrienders described it as a fundamental human need to build relationships, to have friendship and to share experiences with other people. They emphasised that this was nothing to do with dementia but that as human beings, we all share a need for company and closeness. As Chris described, the befriending relationship therefore represented an essential human experience:

> There's just [pause] feeling the warmth of other people [...] knowing that you're two human beings, that understand each other and are [pause] trying to be nice to each other, and helping each other out a little bit. (630-634)

Chris' repetition of the phrase 'each other' indicated a reciprocity that he had not expressed in his earlier accounts. For befrienders, their befriendees were fellow human beings, a perspective that elicited their empathy, compassion and support.

Theme 2b: Emotional involvement. All befrienders described emotional gain from their visits, although the extent of this differed. For example, Fraser found befriending 'very *pleasant*' (line 267), Alexander described feeling 'satisfaction' (line 206) and Harriet found it 'really rewarding, really special' (line 169). In keeping with his desire to make a difference, Elliott found it 'uplifting' to see his positive impact on his befriendee:

> In the beginning […] he didn't have any facial expression, he didn't show anything, and he was always quiet, wouldn't put much effort, much time into his appearance [pause] so when we *do* go out he looks quite nice, he's smiling and he initiates conversation, it's a *big* change, and when he makes *me* laugh, that's a good thing, it's quite uplifting. (221-228)

Befrienders also experienced a range of difficult emotions. Some expressed anxiety and guilt that they were not doing enough for their befriendee. Others experienced unfamiliar situations where they felt out of their depth and unsure how to respond. In anticipation of this, Alexander felt too afraid to take his befriendee out of the 'safe environment' of the house, explaining 'I am his only port of call' (line 727). His words conveyed a sense of danger about being a lone worker and several befrienders described feeling isolated, particularly in comparison with their paid jobs. Despite assurance that their Befriending Coordinator was 'there in the background whenever I need her' (Alexander, line 877-878), many felt 'it's on your own hands really' (Gregory, line 728-729) and said they would value more contact with their peers.

Most commonly, befrienders spoke about predictability in their visits with their befriendee as a result of the dementia. Some like Fraser found that a particular topic of conversation would 'stick' for the duration of a visit (line 237), whereas for others it was 'almost like a scripted conversation' (Chris, line 35-36). This lack of variety could leave befrienders feeling tired, bored or frustrated, and even questioning their ability to 'go on', as Chris later explained:

> I've said a couple of times, I'm so bored now I don't think I can go on, but he obviously *misses* me when I don't go [pause] and I *know* he can't talk to his daughter the same way. (244-246)

Reminding himself of the benefits to his befriendee appeared to enable Chris to continue befriending. Indeed, many befrienders talked about the influence of their mindset in coping with the emotional challenges of the befriending role. They perceived difficulties like predictability as an inevitable part of the role and therefore saw themselves as responsible for managing their emotions:

> It's only tiring *if* I let it be, if I'm in the wrong mood, and that's down to me. Because he *is* constant. He's *exactly* the same every week [pause] and if I let that get to me then that's *my* problem, it's not him. (Daphne, 772-774)

This reflected befrienders' commitment to their role and to their befriendee. For some befrienders, however, their caring feelings for their befriendee raised the poignant issue of their befriendee's death. This was seen as an inevitable issue because of their befriendee's age and physical health, not just the dementia. Several befrienders expressed 'fear' of their befriendee dying:

> My biggest fear, probably, is that, if he dies on me […] that's my biggest fear, after having built this relationship then I lose him. (Alexander, 732-734)

Alexander feared the loss and hurt from the end of his relationship with his befriendee. Indeed, other befrienders spoke emotively about befriendees who died:

> It's difficult to reflect on it [...] I don't think I'm fully, like, able to detach myself, objectively, and say like this is what she meant to me because I still feel a bit, even maybe I shouldn't I don't know, but I do feel a little bit of guilt there still, that I didn't do more for her [...] if I could have in any way made her life better, then I'm really happy about that, and that's a huge life experience that I won't forget, and I'll always cherish. (Gregory, 430-488)

Gregory's hesitancy indicated he may not have come to terms yet with the loss of his befriendee, and may still struggle with feelings that he 'shouldn't'. Befrienders' accounts illustrated the intensity and complexity of the emotional challenges that they could experience.

Theme 2c: Profound learning. While many befrienders described a 'learning curve' (Janie, line 182) in terms of knowing what to do in their role, Gregory’s description of befriending as a ‘life experience’ reflected a shared experience of more profound learning.

Many acknowledged that befriending had challenged their own preconceptions about dementia, describing a shift from initial apprehension about the dementia element of their role (‘I heard the word “dementia” and took a gulp’; Fraser, line 595) to frustration about the dementia stereotype:

> People are too quick to just, you know “*that’s* the way you think, you’ve got dementia we’ll just have a very nice basic conversation with you” […] I think she *does* deserve more than that and she can *cope* with more than that. (Janie, 250-255)

Befrienders accounts suggested that the dementia label could take away people’s individuality and implied they were less able than they actually were. Befrienders shared concern that this negative stigma deterred other people from taking on the befriending role and many wanted to let people know that this was wrong, as Harriet expressed with warmth and passion:

> It’s lovely, you know, if anyone was thinking about doing it I’d just sort of say to them, “do you like *people*?” Really, it’s not people with dementia it’s *people*. (621-623)

All befrienders emphasised that befriendees were people in their own right with individual traits, strengths and values, as opposed to being a person with dementia. Fraser highlighted the valued roles that his befriendee still had, irrespective of dementia:

> He's still somebody's dad he's still somebody's granddad
> he's still somebody's great-granddad he's still somebody's friend. (564-565)

There was shared positive regard for befriendees, who were described as interesting, intelligent and capable people. Many befrienders' accounts contained a sense of admiration and respect for their befriendees; for example Elliott expressed appreciation of his befriendee's courage when finding situations 'difficult' (line 287). Befrienders' accounts suggested a shared experience of learning to see the person behind the dementia stereotype.

Another learning experience took the form of personal development, where befrienders reflected on their own character and personality. For example, Daphne felt that she was 'not a people person' (line 420) and was initially alarmed to discover that the role involved one-to-one contact:

> I thought this is *insane* this is not what I do! I don't have any skills for this […] I'm *really* not sure about this at *all*, *but* I've said I'll do it and I'll give it six months […] and that was over two years ago […] it wasn't *anything* I *ever* expected to end up doing, but having *said* that, I enjoy our outings. (428-442)

Daphne's experiences challenged her expectations about her own skills and limitations, suggesting a personal learning experience. Harriet decided to take on a particular befriendee in order to challenge herself:

> I thought, this person is going to stretch *my* boundaries, I like *rules* I like things *ordered*, I like things proper and she *doesn't*, she likes things *wild* and just 'go for it', sort of thing, and I thought this is quite an interesting person to have around. (353-356)

Both accounts contained some personal discomfort, yet both befrienders were willing to learn in personal ways from their befriending experience. Harriet later explained that she had learned from her befriendee in other ways too, about the universality of ageing for example:

> I know how important it is to her, her appearance […] *I* used to look at older people and think [that] you get to a stage where it doesn't matter anymore, and I realise […] that actually there's no such stage as that, that doesn't exist […] it never doesn't matter. (538-542)

The absence of a transition conveyed a strong sense of sharing values and relating to older people, as opposed to differentiating by age. Similarly, Gregory's account centred around learning from his befriendee in ways that transcended their individual relationship:

> I do think that [pause] having some sort of [pause] love in your life, and I think, not just with another person but in terms of loving *life*, loving *yourself*, and loving other *people* [pause] that is what happy is and that's not something that I would have said I'd say a few years ago, but [pause] I think *that* is what Norah valued, and I learned that from *her*, more than *anything*. (227-233)

These accounts contrast strongly with the concept of befriending as being a one-way relationship. Befrienders' expectations were often challenged and they learned from befriending in deeply personal and meaningful ways. Befriending was not conveyed as an experience of dementia, but as a personal, human and life experience.

Discussion

The relationship that developed between befriender and befriendee was at the heart of befrienders’ experiences. It comprised numerous paradoxical processes that generated issues of role, equality and power, characterising befriending as a complex and unique phenomenon. The relationship was felt to be a personal and human experience, which befrienders felt was deeply meaningful and emotionally powerful. Befrienders’ experiences with their befriendees often prompted learning, including seeing past dementia stereotypes, challenging their personal boundaries, and reflecting on existential matters of love and life.

The current findings highlighted the significance of the relationship in the experience of dementia befriending, with three particular aspects.

Firstly, the close, personal nature of the relationship between befriender and befriendee suggests that successful matching is an important part of befrienders’ experiences, and is consistent with the finding that matching is crucial to success in befriending (Dean and Goodlad, 1998). Secondly, the complexity within the befriending relationship for these befrienders was consistent with a) experiences of other-sector befrienders, b) descriptions of friendship by people with dementia, and c) characteristics of a therapeutic relationship (e.g. Dean & Goodlad, 1998; Elvins & Green 2008; Howgego, Yellowlees, Owen, Meldrum, & Dark, 2003; Sabat & Lee, 2011). Finally, befrienders’ experiences of emotional challenges are related to some experiences of other volunteers who expressed feeling demotivated and discouraged, particularly when they felt ineffective (e.g. King et al., 2009; Rath, 2008).

Befrienders' accounts raised a question about how befriending makes a difference to befriendees. The value of befriending is commonly discussed in relation to improving quality of life by reducing social isolation and loneliness (e.g. Age UK, 2010; Alzheimer's Society, 2013a). There is limited evidence of the emotional and social benefits of befriending (Age UK, 2010), but people with dementia and/or family carers have specifically reported value in relation to mood, self-esteem, memory and willingness to initiate conversation (Alzheimer's Society, 2013a), which were common themes in befrienders' accounts in this study.

Many befrienders supported their befriendees into the community. Engagement in community life was identified as important by 35% of people with dementia and is one of the key characteristics of a dementia friendly community (Alzheimer's Society, 2013c). It also reflects a citizenship perspective, as citizens are 'full members of a community' in both status and practice, and are considered equal in terms of rights and duties (see Bartlett & O'Connor, 2007, p. 111). This perspective has the potential to reduce discrimination, by perceiving and supporting the ability of people with dementia to be socially active and connected (Brannelly, 2011).

Similarly, true recognition of the 'other' as a person, rather than treating them as an object, reflects the concept of personhood (Kitwood, 1997). This influenced person-centred care, which means interactions and relationships that support the self (Fazio, 2013). Indeed in research interviews, people with dementia highlighted that promoting a continuation of self and normality was fundamental to their wellbeing (Edvardsson, Fetherstonhaugh, & Nay, 2010). Befrienders echoed this in their accounts of bringing closer things that matter to befriendees.

Finally, many befrienders made reference to core existential experiences in their accounts. Indeed, belonging, esteem, self-actualisation, and desires for emotional closeness and autonomy are fundamental to human wellbeing and motivation (e.g. Deci & Ryan, 2000; Maslow, 1970, as cited in Thielke et al., 2012; Pederson, 2004; Schüler, Brandstätter, & Sheldon, 2013; Sheldon & Gunz, 2009). Such humanistic principles are reflected in dementia guidelines and recommendations (e.g. NICE, 2006, Love & Pinkowitz, 2013) and are consistent with befrienders' emphasis on supporting befriendees' sense of agency, value and connectedness.

Limitations

Results cannot be considered representative of all dementia befrienders' experiences. As with other qualitative studies, the sample size was relatively small and although similar themes were identified amongst these participants, other themes could arguably have emerged from other participants. The sample was also self-selecting and befrienders' motives for participating could have influenced the topics discussed. In addition, interactions between participant and researcher will have impacted on the findings of this study. Results should therefore be considered suggestive rather than conclusive.

Interviewing at a single time point offers limited insight into the evolving nature of the befriending relationship. Repeated interviews or a study using grounded theory could explore issues such as changing befriendee needs, blurred boundaries between befriending and care, and how befriending relationships end. Similarly, results relate only to befrienders' experiences. Befriendees need approaching directly in order to understand their experiences of befriending.

Clinical implications

Befrienders' emphasis on the personal element of the befriending relationship suggests the value of a thoughtful and considered approach to matching befrienders and befriendees.

Findings regarding the complexity and significance of the befriending relationship could point to a role for a) befriender peer support, b) regular supervision, and c) clarity in training. This is in keeping with good practice guidelines for dementia befriending, with particular emphasis on befrienders' 'ability to enjoy the moment' (Befriending Network Scotland and Alzheimer Scotland, 2009-2016, p. 10).

In order to capture the full value of befriending, additional measures such as befriendees' sense of belonging and being part of community life could be considered, consistent with outcomes important to people with dementia and their families (Dementia Action Alliance, 2014).

Publicising befrienders' experiences of the personal and human aspects of befriending could help to address the stigma around dementia and potentially assist recruitment of future dementia befrienders. More generally, given the value of genuine and person-centred relationships, other workers such as dementia care staff could be supported to develop such relationships with their clients.

Suggestions for future research

Future research should explore befriendee experiences of befriending, to further understand the value of the role. Similarly, both befriender and befriendee perceptions of what makes a ‘good match’ should be explored, to inform the development of befriending as well as community-based dementia care.

Research with people who discontinued dementia befriending is also suggested, to gain insight into specific challenges and help to improve befriender support and retention. Using current findings to develop online questionnaires may enable wider-reaching investigation.

Exploring dementia befrienders’ experiences of bereavement and coping is recommended, given the progressive nature of dementia. Finally, exploring befrienders’ understanding of their role in relation to the progress of dementia could help to inform support and training regarding appropriate expectations.

Conclusion

Befrienders’ experiences centred on their relationship with their befriendee. This paradoxical relationship reflected the complexity of the befriending role, as well as the emotional and existential power of relating to others. Befriending was expressed as a deeply personal and human experience, which often prompted personal learning about assumptions and boundaries as well as profound reflection on love, life and humanness.

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The Authors declare that there is no conflict of interest.

List of Abbreviations

IPA	Interpretative Phenomenological Analysis
NICE	National Institute for Health and Clinical Excellence
UK	United Kingdom

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