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The impact of volunteer befriending services for older people at the end of life: mechanisms supporting wellbeing.

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Abstract

Introduction: Older people at the end of life are particularly vulnerable to social isolation and loneliness, the associated health effects of which are significant. Increasingly, charitable organisations are offering befriending services for people at the end of life. However, there is little research evidence around the mechanisms by which befriending facilitates wellbeing at the end of life. The aim of the study was to explore the mechanisms by which befriending facilitates wellbeing in older people at the end of life.

Methods: Semi-structured interviews were held with 12 recipients and family of a UK befriending service for older people at the end of life. Interviews explored experience of the befriending service, and the impact on wellbeing. Interviews were analysed using a process of thematic analysis.

Results: The data indicate that the befriending service had a multi-dimensional impact on a range of outcomes including emotional and psychological wellbeing, and reduced social isolation. Other outcomes included practical support, and family carer support.

Discussion: The mechanisms by which befriending facilitates wellbeing in older people at the end of life are complex. The unique issues faced by people approaching the end of life mean further research is required to explore dimensions of befriending in more depth and further develop theory.

Keywords: Older people; Palliative care; End of life care; Social Isolation; Ageing; Befriending

BACKGROUND

It has been estimated that approximately 10% of people over the age of 65 are lonely all or most of the time, with rates rising to 50% amongst those over 80.[1] Older people at the end of life are particularly vulnerable to social isolation and loneliness due to loss of mobility, deteriorating health,

reduced functional capacity, and reduced social contacts due to the deaths of partners and friends.[2] Loneliness and social isolation are major health problems for older adults living in the community, and are associated with numerous detrimental health effects including increased risk for all-cause mortality [3], increased risk for re-hospitalization [4], and an increased number of falls.[5]

The importance of tackling social isolation and loneliness is increasingly being recognised in international policy [6]; befriending interventions have been suggested as one way of addressing this policy priority. Befriending can be defined as "a relationship between two or more individuals which is initiated, supported and monitored by an agency that has defined one or more parties as likely to benefit" .[7] A recent Demos Think-Tank report on services provided to people at the end of life recommended the use of volunteer befriending networks to improve end of life care by reducing social isolation and facilitating psychological and emotional wellbeing.[8] Whilst increasing numbers of organisations such as hospices and charities are offering befriending services for people at the end of life (e.g. Macmillan Cancer Support)[9], the evidence base on the effectiveness of such interventions is weak. Findings are often contradictory, which reflects current lack of understanding of the mechanisms by which befriending facilitates wellbeing .[10,11,12]

No overarching theory of how befriending facilitates wellbeing currently exists, and there are no theoretical frameworks relating to befriending for people at the end of life. However, theoretical insights into the relationship between social networks and health provide us with a basic conceptual model from which to develop theory. For example, Cohen and colleagues (2004) influential model on social relationships and health suggests that different social variables (social support, social integration, and negative interaction) influence health through different, probably independent pathways.[13] Berkman et al (2000) incorporated influential earlier work by Émile Durkeim to propose a more complex multilevel, multidimensional model of how social networks impact on health.[14] They proposed a cascading causal process beginning with the macro-social and leading to psychobiological processes, these processes are dynamically linked together to form the processes by which social

integration affects health. These are undoubtedly useful frameworks for helping explore the mechanisms of befriending. However, the unique issues faced by those approaching the end of life are likely to mean new theoretical developments are required. Increasing levels of dependency, psychological morbidity, and existential concerns have all been reported as significant concerns for those approaching the end of life [15], however these issues are not adequately addressed by existing models of social engagement and befriending.

Therefore, the aim of this exploratory study was to explore the mechanisms by which befriending facilitates wellbeing in older people at the end of life, and gain theoretical insights into models of befriending.

METHODS

A qualitative research design using semi-structured interviews was adopted. Interviews are recognised as an appropriate method for developing and identifying theory in complex interventions such as befriending .[16] The sample for the study comprised recipients of a volunteer delivered befriending service for older people at the end of life. The befriending network was established by Age UK in 2010 in a region of Southern England comprising a large urban centre and its surrounding rural/semi-rural districts. The befriending service is aimed at supporting socially isolated older people with life limiting conditions. The service provides befriending recipients (BR's) with a minimum of a 3 hour weekly visit from a trained volunteer. Older people are eligible for referral if they are registered on an NHS End of Life Care Register, and are carefully matched with volunteers on the basis of mutual interests and life history.

Twenty five current BR's were approached by their volunteer and invited to participate. Ten BR's agreed to participate in addition to the wife of one recipient, and the daughter of a recipient who passed away during the time of the evaluation. The sampling strategy aimed to achieve participant

diversity across a range of key characteristics including age, gender, diagnosis, and length of time accessing the befriending service. Sampling aimed to recruit between six and twelve participants in line with literature indicating saturation is usually achieved within 6-12 interviews .[17] Recipients who were believed to be close to death at the time of the evaluation were excluded. An interview guide was developed with the aim of identifying key outcomes of the service, both positive and negative (table 1).

Interviews were conducted in early 2013 by CG and SB, were digitally recorded and transcribed verbatim. The data were analysed using the principles of thematic analysis [18], with the assistance of the computer software programme NVivo9. To ensure rigour and trustworthiness transcripts were read by both authors and core themes were identified. An inductive approach to coding was used where themes identified were strongly linked to the data themselves. Themes were initially identified at the semantic level, further coding at the latent level began to identify underlying ideas, assumptions, and conceptualizations shaping the semantic content of the data .[18] A coding framework was developed by consensus, themes and sub-themes were reviewed in relation to coded extracts and ongoing analysis refined the specifics and definitions of each theme. Ethical approval was granted by the University of Sheffield Ethics Committee.

[insert table 1 here]

[insert table 2 here]

RESULTS

Data were collected from 12 participants, about 11 befriending recipient/volunteer partnerships (table 2). Participants were able to identify a range of positive outcomes which they attributed to the befriending service, these were underpinned by a range of psycho-social and practical mechanisms.

Psycho-social mechanisms: meaningful interactions

Participants accounts of the impact of the service often centred around changes in psychological wellbeing and quality of life. This impact was most often mediated through the knowledge that someone *'cared'* about them, rather than through someone undertaking specific tasks or roles.

Interviewer (I): "What do you think is the best thing about the befriending network?

Befriending Recipient (BR): "The very fact that, I think, it shows that people care. They can't always provide you exactly what you want or need, but the point is that they care about you and they're unselfish enough to offer their time".

The knowledge that someone was *'thinking about them'* appeared to manifest in improved psychological functioning and enhanced quality of life, which were not contingent upon direct contact, and were apparent even when the befriender was not physically present. One participant noted the 'life changing' impact of the service which resulted from improvements in psycho-social health, directly attributed to the caring role of the befriender.

I: "What kind of impact has the befriending network had on your quality of life?"

BR: "Oh tremendous. Absolutely tremendous. There's no comparison. I mean, before I had them I was depressed, lonely and ... it's the very knowledge that people care. No, no it's changed my life."

A further facilitator of psychological wellbeing was social interaction under the role of friend or contemporary, rather than as a patient. One participant described how notions of reciprocity, humour, and conversational safety were key in allowing him to benefit from this relationship in ways he was unable to do from interactions with family and friends. The perceived mutual benefit of the relationship appeared to result in a more positive experience for the recipient.

BR: "Before erm I was stuck indoors and when friends or family came to visit they're all very well meant and very pleasant etc but in the great majority anybody that came felt it was their duty to sit down and talk at me, talk at me, talk at me, but I got that from the radio and the television you

know… and erm [befriending volunteer] is very prepared to listen, she even laughs at an old man's jokes and I like that very much (laughing) and er that's been most successful, it really has…..she gave me the space to open up and to talk you know and that was very, very nice".

Psycho-social mechanisms: connectedness, purpose and cognitive participation

The majority of participants who lived alone described a positive impact on social outcomes such as loneliness and social isolation. Participants' accounts varied in terms of the perceived mechanisms facilitating improved social outcomes, but notions of companionship and physical proximity appeared significant for all.

BR: "I don't have any relatives in [this town]. I speak to my sister nearly every day on the phone, but she doesn't live very close. So it's somebody that I can talk to."

For some participants, a visiting befriender engendered a renewed sense of purpose to life, which was synonymous with perceived social participation and connectedness. For housebound participants in particular, having something to look forward provided an external focus and an increased sense of self-efficacy.

BR: "Well it's had a lot [of impact] because you must have something in life to look forward to. And it was ... when she was coming on Fridays, it was something for us to look forward to and I got some cakes and tea all ready"

Other participants described the intellectual or cognitive stimulation provided by volunteer visits. The diffusion of influence and information not only provided opportunities for intellectual growth and cognitive participation, but also mediated social connectedness.

BR: "I've got something to look forward to every week. Not only that, but also he has taught me how to use an iPad. Oh yeah, it was his idea; I was frightened in the beginning but that's another story! He's taught me how to use it, but equally so he's taught me how to email and he emails me."

Maintenance of intellectual participation also appeared to support a sense of purpose, and widened participants' opportunities for meaningful engagement with other aspects of life.

BR: "Well as I say it's given me something to look forward to and it's just a totally different aspect of life. And as I say, he's got me interested in things that, you know, that I didn't know about before".

Practical mechanisms: resource use & access

For some participants, an unexpected benefit of the service was in aiding them, in a practical sense, to access other services and resources, for example citizen's advice, psychiatric support, or respite care. One family carer described how discussions with her husband's befriender had helped prompt her to access respite care.

Family member: "One big change that she's helped to instigate was (…) respite. The last 4 years I've had [respite], partly because of her discussions with [BR] and the realisation that I should get a break you know, should have some sort of respite."

Other BR's described how their volunteer provided practical support such as doing odd jobs, shopping or accompanying BR's to hospital appointments, thereby reducing the need for social services support and community transport services.

BR: "Next week she's taking me to the hospital for my consultant's appointment…which is a great, great step forward from patient transport."

BR: "And I think actually without the Befriending Network probably I would have started to become a burden"

Mechanisms of befriending: Impact on family members

In addition to the significant benefits reported by befriending recipients, positive outcomes were also noted by the families of some of those being befriended. Where a befriending recipient lived with a spouse or informal family carer, the service could provide as much support to the family member as to the recipient themselves. The impact on family members was often framed by their experience of caring and the resultant loss of individual purpose, and the lack of time or 'emotional space' for engaging in non-caring tasks.

> *Family member: "And I can get out and walk the dog or go shopping or do something, do things, and that has been a tremendous help and that has freed me up."*

The burden of caregiving re-defined the structure of the relationships and networks within which family members were embedded, with negative consequences for emotional wellbeing. Befriending offered a mechanism for supporting these family carers, through psycho-social and emotional pathways not dissimilar to those reported by recipients themselves.

> *Family member: "Yes she does, oh yes, yes she supports the two of us, she's a tremendous help but not physical help you know but mental you know, the ability to … when you're stuck on your own and caring all the time with somebody you can … it's a tremendous help to be able to unburden you know."*

DISCUSSION & CONCLUSIONS

This study aimed to explore the mechanisms by which befriending facilitates wellbeing in older people at the end of life, and identify preliminary theoretical insights. The data suggest that the befriending service had a multi-dimensional impact on a range of outcomes. Participant data indicate that the most significant benefits of the service were in the areas of emotional and psychological wellbeing, and reduced social isolation. This finding is in keeping with previous research on befriending interventions, which have primarily focused on emotional wellbeing outcomes such as depressive symptoms [12], mood and health related quality of life. [19] The

mechanisms by which befriending facilitates wellbeing appear more complex. Whilst authors such as Cohen (2004)[13] and Berkman et al. (2000)[14] have contributed much to the conceptualisation of how social networks influence health, there are as yet no overarching theories of how befriending influences health and wellbeing, either in a general population or amongst those at the end of life.[11] However, a key assumption underlying much work in this field is that providing individuals who have deficient social networks with additional 'enacted' support (such as a befriender) will increase their perceived social support.[20]

Our data suggest a key feature of successful befriending is social interaction as a contemporary or friend, rather than as a patient. This is a particular issue for patients nearing the end of life, for whom a growing dependence and unwavering role as a 'patient' can result in a loss of meaningful identity as end of life approaches.[21] The renewed sense of purpose offered by a befriending relationship is a further mechanism addressing existential concerns such as loss and purposelessness that often accompany dying. Whilst there remains a paucity of research as to how existential issues are managed and understood in palliative care, the experience of lack of meaning and feelings of loss of purpose are commonly reported amongst patients approaching the end of life.[15] Notions of reciprocity and mutual benefit also seem key in ensuring a successful social interaction. The work of Rook (1990 & 1992)[22,23] lends some support to these as dimensions of successful befriending, by pointing out that not all social relationships fall under the rubric of 'support', and inadequate social relationships may be associated with poorer health outcomes.

Intellectual stimulation and cognitive participation may further support a sense of purpose. Maintenance of intellectual challenge in the face of declining physical and mental health has been identified as an important coping mechanism for people with life limiting conditions; a study of patients with Amyotrophic Lateral Sclerosis (ALS) described how intellect being left intact was crucial for maintaining purpose as the end of life approached .[24] The intellectual stimulation provided by a visiting volunteer may mitigate the increasing total physical dependence, and provide a further

mechanism for providing purpose and reducing loneliness. There is some debate in the literature as to whether social support improves mental health by mitigating the psychological effects of stressful experiences (the 'stress buffering' hypothesis) or whether it is beneficial regardless of pre-existing stress (the 'main effect' hypothesis) .[13] Our research indicates that both of these mechanisms may be involved in improving health and wellbeing in older people who are recipients of befriending.

The importance of family caregivers has long been recognised within palliative care; however, the implications of undertaking a caring role have only recently begun to receive sustained research attention. Whilst a caring role can have significant rewards, caring can also bring about considerable physical, emotional, financial and practical costs which can adversely affect a family carers quality of life.[25] Lazarus' (1966) transactional model of stress can be used as a helpful framework for understanding the mechanisms through which befriending facilitates positive outcomes for family carers. According to Lazarus' model, stress or burden is only said to result when the demands of a situation exceed an individuals ability to respond effectively or cope.[26] Hence, carers may be able to cope effectively with the burden of caring if sufficient support is in place to buffer the demands placed upon them. This concept has been operationalised through initiatives such as carer respite [27]; befriending may offer an alternative and more cost-effective solution to mitigating the demands placed on carers and reducing carer burden and risk of carer breakdown.

The practical benefits of befriending should also be considered. Existing evidence on the economic impact and cost effectiveness of befriending interventions is limited and inconclusive.[12] However our data indicate that the potential impact of the service on resource use and subsequent economic outcomes warrant further attention, especially given concerns over the escalating costs of providing palliative and end of life care for growing numbers of older people. [28] It is also important to note that many of the identified benefits of befriending did not appear specific to people at the end of life, and may apply to any older person who is physically frail and socially isolated. Further research

should seek to identify the unique needs of older people at the end of life in order that befriending services can be tailored to their specific requirements.

CONCLUSION

Whilst this is a small exploratory study, the data provide some indications as to how befriending may facilitate wellbeing in a unique way in people approaching the end of life. Notions of meaningful interactions with capacity for reciprocal benefit; enhanced sense of purpose; and cognitive stimulation are potentially important dimensions of successful befriending at the end of life and should be considered as part of any conceptual framework development. The positive impact on family carers should also be considered, the stress buffering effects of befriending may be important mechanisms for supporting carers. A framework may be considered under the broad structure of Berkman and colleagues (2000)[14] model linking social networks to health, which reflects dimensions identified in this study including 'cognitive exercise' and 'reinforcement of meaningful social roles'. However, the unique issues faced by people approaching the end of life mean further research is required to explore dimensions of befriending in more depth and further develop theory. The findings also have implications for service development and highlight a need for effective interventions including (but not limited to) befriending which address issues of social isolation and loneliness amongst older people at the end of life. Such interventions should be integrated into service provision for older people as part of a comprehensive package of support at the end of life.

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CONTRIBUTION OF AUTHORS: CG and SB jointly conceived the study, undertook data collection and analysis. CG wrote the first draft, SB revised further drafts.

CONFLICT OF INTEREST: None declared

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TABLES

Background and use of service

- Can you tell me how you came to use the befriending service? (prompts: were you referred to the service? By whom?)
- Can you tell me about the things that you usually do with your befriending volunteer?
- Can you tell me how often you see your befriending volunteer and for how long?
- What do you think about how often you see your befriending volunteer? Would you like to see more or less of them?

Satisfaction with service

- How well do you think your befriending volunteer has been matched to you?
- What do you think about the sorts of activities that you do with your befriending volunteer? (prompts: Is there anything else you would like them to do?)
- How satisfied are you with the befriending network?
- In your opinion what is the best thing about the befriending network?
- In your opinion what is the worst thing about the befriending network?
- What could be done to improve the befriending network?

Training & information

- Do you feel that your volunteer had sufficient training to be able to provide the befriending support you require?
- Did you feel you received sufficient information about the befriending network, so that you could decide whether or not to be involved?

Impact of Service

- What kind of impact has the befriending network had on your quality of life? Social life?
- What kind of impact has the befriending service had on those around you? [prompts: carers, friends, family]
- How has your life changed since being involved in the befriending service?
- Is there anything else you would like to say about the befriending network?

Table 1: Interview guide

Gender	Male	3 (27.3%)

	Female	8 (72.7%)
Age	Mean Range	71 years 51 – 91 years
Diagnosis	Cancer Non-Cancer	3 (27.2%) 8 (72.7%)
Living arrangements	Lives alone Lives with others	8 (72.7%) 3 (27.2%)
Length of time with Befriending Network	Mean Range	44 months 4 months – 12 years

Table 2: Befriending recipients characteristics (n=11)