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Fictive Carers Perceptions of the Impact of Outcome-Focused Homecare with Older People Living Alone

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Abstract

Purpose: The aim of this paper is to discuss whether the use of outcome-focused homecare improves the subjective wellbeing of the fictive carers of older people living alone. It also discusses fictive carers' perception of whether this intervention has improved the well-being of their relative.

Design/methodology/approach: This study followed the fictive carers of 30 service users who were assessed as having high care needs and living alone over a six-week period. Semi-structured interviews were undertaken at three intervals during the six weeks. The carers were asked to assess their subjective well-being at the start, middle and end of the study.

Findings: The key findings were that all 30 fictive carers expressed an improvement in their subjective well-being and that of their older family member, who appeared more settled as a result of this model of care.

Originality/value: This study provides an insight into the impact of outcome-focused homecare with older people as perceived by their fictive carers. Previously, research has established that outcome-focused care increased the subjective well-being of the older person from their own perspective. This study also demonstrated that this model of outcome-focussed care also improved the subjective well-being of the fictive carers themselves. These findings will help healthcare practitioners consider the use of this model of homecare as a potential alternative to providing separate support packages for the fictive carers.

Keywords: Fictive carer; Older people; Outcome-focused home-care

Background and Introduction

As the life expectancy of people continues to increase in developed countries the burgeoning older population has generated increased pressure for the provision of health and social care by the state, private insurers and the families who have ageing relatives. Increasingly in western societies women are having their children later in life and are therefore having to cope with care demands of parenthood and the care demands of caring for older people. Various studies have shown that the additional burden of caring for older relatives can often leave friends and families feeling helpless and socially isolated by the loss of their own freedom and independence [1,2]. The pressure involved in caring for an older relative was the rationale for this study into outcome-focused care. Prior to the commencement of this study the older people had been receiving the standard model of care which is classified as the time and task model of homecare, which is define as:

"The division of assessed care needs into time allocated components and is measured by the completion of tasks rather than assessed outcomes" [3].

This care tended to be purchased from a number of providers and was allocated within set time limits of 15 minute slots.

The impact of outcome-focused care interventions on older service users has been reported in two previous papers (Quantitative study Gethin-Jones in 2012 and the subsequent qualitative follow up, [4]. These studies established that the older people receiving outcome-focused care appeared to have a significant improvement in their subjective well-being. The original model of outcome-focused care arose out of the initial research of the Social Policy Research Unit based at York University with the main authors being Qureshi and Henwood [5], whose studies were developed further by Glendinning [6]. Glendinning in her follow up studies defined outcome-focused as:

"Outcomes are defined as the impact, effect or consequences of a service or policy. Outcome-focused services are therefore those that meet the goals, aspirations or priorities of individual service users" [6].

For this definition of the outcome-focused care model to be applied, care and outcomes were agreed in consultation with the paid carer the older person and their family and was reviewed on a daily basis.

The concept of subjective well-being has been mainly studied in depth by Diener [7], which in particular, has focused on the concept of subjectivity as applied by the individual to their global assessment of their well-being at a given time. Dieners' work has built on the work of Shin and Johnson [8], who defined subjective well-being as "a global assessment of a person's quality of life according to their own chosen criteria" (p. 478). The measurement of subjective well-being has utilised both a multi and single items scale to measure an individuals' subjective well-being. A single item scale was used in this study to allow for a snapshot measurement of subjective well-being which is

particularly effective when measuring changes in well-being at different points in time.

Method

The data for this study followed the same framework as a previous study Gethin-Jones, by using two semi-structured interviews. One interview took place at the commencement of the use of outcome-focused care and another interview six months into the intervention. During the interview, the carers completed the individual Likert rating scales for their self-identified subjective well-being and also their ratings for the subjective well-being of their older relative receiving the outcome-focused model of care. The relatives were also asked to express the two main concerns they had about caring for their dependent relative or friend. These themes were then analysed by the use of thematic analysis.

Sample

The sample consisted of (n=30) participants. All 30 participants were recruited by a voluntary process and all had relatives of older people living on their own in the community and requiring home care to a degree that meant they would be unable to live independently without the support of paid carers in addition to their friends and family.

Gender and age distribution

The sample (n=30) was distributed as females (25) and males (5) all females were married with all having dependent children under the age of sixteen. The five males were also married but took on the main care responsibility for the older relative as they had the familial connection. All participants were in employment of more than 16 hours per week. The mean age of the sample was 54.

Carers concerns

The carers were asked to identify their two main concerns they had about their relative who was living on their own. They were all asked the following question. "In the last month what has caused you the most concern about caring for your relative? Could you please give me two, one that is your main concern and one that is secondary?"

The responses to the question were placed into 4 broad categories which are displayed in (Tables 1 and 2) below.

Categories	Descriptors for Concern 1	Number of Participants
Category 1	Inability to cope	16
Category 2	Feeling isolated	6
Category 3	Inability to get help	5
Category 4	Fear of harm coming to the sufferer	3

Table 1: Self-identified concerns 1.

The majority of the participants reported they were concerned about their ability to cope and the feeling that they were ultimately responsible for the coordination of the care of their relative, whilst trying to balance the care of their sometimes small children. These are some of the responses given by the participants when talking about their relatives support prior to the use of outcome-focused care;

"I get really frustrated when mum rings to tell me she has not had her visit or that the care she received wasn't very good. It means I have to go and fill in the gaps."

"The worry never goes away so many different people (formal Carers) visit mum trying to sort any problems out takes a lot of time that I simply do not have."

Categories	Descriptors for Concern 2	Number of Participants
Category 1	Inability to cope	9
Category 2	Feeling isolated	18
Category 3	Inability to get help	3
Category 4	Fear of harm coming to the sufferer	0

Table 2: Self-identified concern 2.

These comments were typical of the responses of the carers interviewed; it was the ambient stress that was constantly around them and especially the need to balance work and numerous care commitments. This was particularly the case for the female participants who, in addition to the responsibility they felt themselves, also felt that that the male members of the family expected that they should be responsible for the older relative and the childcare. The minority of male respondents were concerned about the impact of taking time off work had on their careers, as the majority of their child care was covered by their partners, which they reported to be putting stress on their relationships.

The sense of isolation and also additional pressure expressed by the participants came over very strongly in the interviews. Fictive carers felt that they were isolated as they had all the responsibility and in their eyes and potentially all the blame when things went wrong. They had a very distant relationship from the formal planning of care which in most cases was done at the point of discharge from hospital. Once they were in the community they had a variety of different agencies involved in the care and they felt they had little control over what was happening with regard to the older relative's care. This sense of isolation is summed up quite effectively in the following responses:

"The care over the last month has been chaotic, there are three different homecare agencies the General Practioner and the district nurse; nobody seems to talk to each other and no one is clear on who is responsible for what. I find it really stressful."

"Just feel so overwhelmed I just do not know what to do sometimes."

What came across was their sense of disconnection from the care package and how things were done, over which they had little control or even consultation. This sense of powerlessness impacted upon the carers' own sense of control and led them to feel helpless and unable to control events. This sense of disconnect was also experienced by the service users in a previous study that looked at the delivery of the time/task model of homecare [3], which was the model that had been delivered to the older relatives up until the start of this study.

The last two concerns; the inability to get help and the fear of harm coming to the older relative were quite closely linked in the interviews

to the main themes and is a common theme throughout reports into the care of older people. This was caused by the fact that the majority of care given by the formal carers was in the working day. As the Fictive carers were working, they had little opportunity to meet with the care agencies or deal with any issues. This meant that issues had to be dealt with either out of hours or by taking time out of their employment.

Participant's subjective well-being

Subjective wellbeing scales were completed on two occasions one prior to the new model of intervention and one six weeks into the intervention. The participants were provided with an explanation prior to them being asked the question as to what was meant by the use of the term subjective well-being. The participants were all asked the following question;

"In the last week how would you rate the impact of your caring responsibilities on your subjective well-being?"

The participants' subjective well-being responses were self-recorded on a Likert scale which offered the following response options:

(Table 3) below shows their scores with 1 having no impact to 5 having major and distressing impact.

Self -reported subjective Well-being Score	First Interview Number of responses	Six Month Interview Number of Responses	Overall Change =/-
As good as it gets	0	0	0
Very good	0	2	+2
Good	3	14	+11
Neither good nor bad	5	10	+5
Poor	10	2	-8
As bad as it gets	12	2	-10

Table 3: Subjective well-being response.

We can see from Table 3 above that the major move has been into the categories of very good and good placing the overall response between the good category and the neither good nor bad category. Therefore there does appear to have been an improvement in the carers' self-reported subjective well-being, six weeks into the intervention. These findings were followed up in the interviews to ascertain what had changed for the respondents; these were some of the responses:

"It the fact is that you know who is going to call. The same staff delivers they update me and I also know their names."

"Mum now knows who is calling next and, she has gotten to know them by their first names now, it makes me feel so much happier seeing mum less agitated."

"Communication, I have their mobile numbers and I can ring them to check up or sometimes they text me you just feel that your involved rather than it being done around you."

The sense of being involved was themed throughout most of the interviews and seemed to be the major contributory factor to the improvement in the fictive carer's sense of subjective well-being. The fact that the care process was a continual negotiation meant that the care had continuity and flexibility and this assisted the carers in feeling more supported and provided them with a sense of involvement.

The carers were asked to rate their perception of their relatives' subjective well-being at the commencement of the study and also at the 6-week stage. Table 4 below shows their scores with 1 having no impact to 5 having major and distressing impact.

Self -Reported subjective Well-being Score	First Interview Number of responses	Six Month Interview Number of Responses	Overall Change =/-
As good as it gets	0	0	0
Very good	0	0	0
Good	0	7	+7
Neither good nor bad	2	12	+ 10
Poor	17	6	-11
As bad as it gets	11	5	-6

Table 4: Subjective well-being response.

These findings are based on the fictive carer's perspective of their relative and it is therefore accepted they are subjective. As can be seen from Table 4 above, the measurements demonstrates that the fictive carers believed that in their opinion the older person own subjective well-being had improved significantly. However the improvement was still not deemed sufficient enough for the majority of the older relatives to be moved into the good plus category. This was considered in the follow up interviews and it became apparent that as the older relative had chronic and ongoing deterioration in their health, that the Fictive carers believed this would continue to have a negative impact upon the older relative regardless of which model of care was involved in meeting the older relative's needs.

Key findings from this paper

The major elements and themes established in this study is the need to have good communication between the formal and Fictive carers. By its design outcome –focused care, is delivered within a process of ongoing dialogue, between all the individuals and agencies involved in the older relatives care. However the most significant factor is that the older person has a consistent care team that has allowed for the development of informal micro-relationships of care.

Limitations of the current study

This current study was of only a small sample group and therefore the ability to generalise these findings is very limited. This study was also undertaken in a predominantly white Caucasian neighbourhood within the United Kingdom and does not take into account the impact of different cultural backgrounds on the effectiveness of outcome-focused.

Key themes to be developed

A wider evaluation of the effectiveness of outcome-focused over a longer period of time and with a larger sample size.

The need to evaluate the importance of consistent and regular paid care staff for carers as well as service users.

The need to measure if a possible cost reduction could be gained from the use of outcome-focused care as opposed to paying for carers to receive support outside of the care package.

Conclusion and Recommendations

This research study has focused on a further exploration of the effectiveness of outcome-focused care as a care model with older people, and in this particular case study with the carers of older people. It has established the effectiveness of outcome–focused care in improving the subjective well-being of the carers and their perceived improvement in the well-being of their relative. In line with previous studies it has shown that it is the consistency of the care provision combined with the ability to form relationship between carers, paid care staff and the older person experiencing dementia that has the greatest impact. Consistent with previous studies Gethin-Jones, outcome-focused care provided connectivity in the delivery of care to those in receipt of it.

Limitations to the clinical applications of outcome–focused homecare

Outcome-focused care needs the development of small care teams who would require additional training of how to implement the model in their practice. It is also more resource intensive and cost approximately 17 per cent more to deliver than the existing time focused model of care.

Implications for practice

The need to consider the use of outcome-focused care as an intervention strategy for older people living alone in the community.

The need to provide supportive environments for the carers of older people with dementia to limit their sense of isolation.

The prioritising of outcome-focused care in the most complex and chaotic cases.

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