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Evidence, messages, learning



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Introduction

Currently, 820,000 people in Britain are thought to suffer from dementia – a severe and life-changing condition which affects their ability to cope with everyday activities and relationships. Young Onset Dementia especially, poses a diagnostic challenge. Sufferers can encounter delays in getting an accurate diagnosis and face difficulties accessing support.

Learning from what we do, capturing evidence, sharing ideas and finding better ways to help change lives through gardening, is all part of the way we work at Thrive.

Through this project we sought to discover if gardening activities could help younger people with dementia. Although a small sample, the findings are very positive as this report shows.

Research project team

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using gardening to change lives

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Thrive is a small national charity that uses gardening to change the lives of disabled people.

Thrive is registered in the UK as The Society for Horticultural Therapy.
Thrive is a registered charity number 277570 and a limited company number 1415700.

Does A Structured Gardening Programme Improve Well-Being In Young-Onset Dementia?

A Pilot Study

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Abstract

Young onset dementia (YOD) affects about 1 in 1,500 people aged under 65 years in the UK. It is associated with loss of employment, independence and an increase in psychological distress. This project set out to identify the benefits of a brief (2 hours/week) structured activity programme for people with YOD. Over a one year period the carers of the people with YOD found that the project had given participants a renewed sense of purpose and increased well-being while cognitive functioning declined. This study suggests that a meaningful guided activity programme can maintain or improve well-being in the presence of cognitive deterioration

Keywords: Young onset dementia, gardening, health and well-being outcomes, dementia interventions

Dementia is a chronic condition that results in a progressive decline in a person's ability to think, remember and reason (WHO, 1992). Young onset dementia (YOD) refers to the onset of symptoms before the age 65 years (ICD 10) and has an estimated prevalence of between 67 and 81 per 100,000 in the 45 to 65 year old age group (Ratnavalli et al., 2002; Harvey et al., 2003). People who develop the condition are therefore likely to be in work at the time of diagnosis, be physically active and may find it difficult to rationalise losing skills at such a young age. This poses particular issues for affected individuals, their families and the care services provided.

In an overview of the social aspects of YOD, Werner et al. (2009) stated that people with the condition experience a loss of independence as a result of reduced ability to carry out daily tasks. This loss of independence affects the relationships of the individual with peers and family members as roles and self-identities change (Haase, 2005; Harris & Keady, 2009). If it leads to the loss of employment, then this has been shown to impact on individual's self esteem and self-worth as well as contributing towards a feeling of a lack of meaningful occupation (Harris, 2002). Harris & Keady (2009) identified through narratives that feelings of loss, fear and abandonment are prevalent in the lives of people with YOD as individuals and their families often have limited access to external help and support.

YOD also has distinctive clinical characteristics. Symptoms include loss of short term memory, depression and anxiety (Ferran et al., 1996; Werner et al., 2009). Harvey et al. (1998) found that the most prevalent symptoms among people with YOD were non-cognitive and behavioural symptoms such as aggressive behaviour (61%), delusions (53%) and hallucinations (44%). Perhaps not surprisingly, the unique clinical and social aspects of YOD cause the impact of the condition on family members and caregivers to differ from those experienced by people affected by dementia as older adults. 66% of carers experience high levels of stress (Williams et al., 2001). High stress levels may be caused by a lack of structured support and/or care duration (Arai et al 2007). As YOD is less common, care givers may feel more socially isolated and excluded (Freyne et al., 1999).

Although there is a growing body of evidence highlighting the unique social and clinical nature of YOD as well as its prevalence, there are relatively few specialist services available for this patient group and those that do exist are often combined with services available for older people Chaston et al., 2004; Coombes et al., 2004; Freyne et al, 1999; Haase, 2005; Alzheimer's Society 2007, National Audit Office, 2007). Behavioural interventions can result in improved quality of life for individuals with dementia and subsequently their caregivers (Gigliotti et al. 2004), and the development of tailored provision for service users aged between late forties and late fifties is one of the priorities listed in a recent government report (National Dementia strategy, 2009). Harris (2002) argues that specialist

services providing peer socialisation that allow individuals to engage in meaningful and productive activity are needed to help people with YOD and their families. Such a group would enable individuals to generate a sense of meaningful occupation, as well as helping to build relationships with peers in a supportive environment.

Parr (2007) identified community gardens as one such meaningful activity, helping individuals to be recognised as active, capable and useful. The productive nature of horticultural therapy offers its participants the opportunity to feel a sense of accomplishment and success, something that Beuttner (1999) suggested is important to help maximise the benefits of meaningful activity for people with dementia. Such benefits include enhanced mental state (including reduced depression), reduced behavioural problems and improved quality of life – three aspects that are prevalent among patients with YOD. Diamant and Waterhouse (2010) found that social and therapeutic horticulture facilitates health & well-being through belonging, a term defined as the interpersonal connection of people to each other as they engage in occupation. This sense of belonging may help to combat the feelings of abandonment and isolation that Harris and Keady (2009) identified as central to the experience of people with YOD. Additionally, an increased sense of belonging may allow the development of self-efficacy, further facilitating positive well-being (Robiero, 2001). Horticultural Therapy has the added benefit of a large capacity for adapting activities to suit the abilities of group members. This allows for groups to include members at varying stages of their dementia, while still facilitating both the rehabilitation and development of skills (Sarno & Chambers, 1997). Provision of appropriate occupations has been shown to have a positive impact on the psychological, social and cognitive well-being of people with dementia (Pool, 2007).

The aim of this pilot project was to identify possible benefits of a structured group gardening programme for people with YOD. The primary objective was to identify potential changes in the well-being of group members. In addition, the mental state of participants and the perceptions of carers of the group were also measured. The perceived benefits of the activities were assessed qualitatively and quantitatively in an effort to capture the particular aspects that make horticultural therapy effective. The study also aimed to identify useful assessment scales and group activities as part of a feasibility pilot to inform a larger research project. The project was carried out by the Berkshire NHS Foundation Trust in partnership with Thrive, an organisation that aims to utilise the beneficial effects of gardening to improve the quality of life of people with a range of disabilities. Thrive has many years experience of running gardening activities for older people with dementia and was well placed to develop a structured intervention programme for younger, more physically active people with dementia.

Method

The study was carried out in 2 community sites: the Thrive Trunkwell Garden Project, Berkshire, a site developed for horticultural therapy for people with physical disabilities, learning difficulties and older people with dementia; and Barkham Day Hospital garden, a purpose designed garden for people with dementia set in the grounds of Wokingham Community Hospital, Berkshire. The study was given ethical approval by the Berkshire Local Research Ethical Committee (ref. 09/H0505/7).

Participants

Potential participants were referred by local dementia services in the west of Berkshire and relevant support groups such as Alzheimer's society and Crossroads. The project was also advertised on the local YOD website and the principal researcher attended a YOD Forum to talk about the project. Those potential participants with YOD and their carers who expressed an interest were discussed with the main clinician involved in their care to determine their appropriateness for the study. They were then sent information about the project and inviting them to express an interest. For those interested, carer and potential participant interviews were arranged to discuss the project in more detail. Written consent was gained from participants with capacity to give consent, otherwise written consent was given by carers and assent by the participants. The participants chose to attend on either one of the 2 sites.

The inclusion criteria for the study were:

- Confirmed diagnosis of dementia, based upon neuropsychometric testing, brain scan and clinical opinion, with onset of symptoms below 65 years.
- Still physically active and interested in engaging in gardening sessions
- Carer available who was in contact with the person with dementia on at least a weekly basis
- Access to transport to attend weekly sessions

12 people were recruited to the project, 4 male and 8 female. 14 people were initially approached having expressed interest, 2 of whom declined because of transport difficulties. Of the 12 recruited, 9 were diagnosed with Alzheimer's disease, 1 with Frontotemporal dementia, 1 with mixed Alzheimer's/vascular dementia and 1 with dementia with Lewy bodies. The mean age was 58.6 years and the age range was 43 – 65 years.

Two of the participants dropped out of the study shortly after it began. One of these stopped attending out of choice, while the other was felt unsuitable for the project as they did not want to engage in the gardening tasks once they arrived at the site. A third participant sadly died after attending for several months.

Intervention

The project ran from 12th May 2009 until to 10th May 2010. Participants attended for 2 hours once per week for 46 sessions. Each session followed a specific format and routine. Participants attended a group meeting enabling them to socialise and to help plan the session. This was followed by 1 hour of structured gardening tasks targeted to each person's abilities. To match tasks to abilities the Pool Activity Level (PAL) instrument for occupational profiling was used in conjunction with the Large Allen Cognitive Level Screen (LACLS). Options were given where possible so that participants could engage in specifically tailored activity whilst maintaining choice and autonomy. A flexible and adaptable approach was adopted throughout the programme based upon positive reinforcement. Examples of tasks included digging and planting a bed with spring flowering bulbs or a one-step task such as sweeping leaves or sensory activities. Participants then regrouped after the gardening to reflect on the activities, discuss progress and promote group belonging. A communication book for the participant and their relative/carer was recorded in after each session to include written information and photos. Staff met after the participants left to discuss the group collectively before filling out the relevant outcome measures outlined below. This process was designed to aid staff communication and to improve inter-rater reliability on the scales.

Measures

Family members or carers were interviewed at the start of the study and were asked to complete these questionnaires anonymously at both the beginning and the end of the project:

- Bristol Activities of Daily Living Scale (BADLS) (Bucks, Ashworth, Wilcock & Siegfried, 1996) is a carer completed scale with 20 items of daily living activities to assess the participants level of functioning.
- A short questionnaire was developed by one of the research team to measure any perceived benefits of the gardening programme and was given to carers to fill out anonymously at the mid way and end point of the study.

Participants were asked to complete the following assessments before and after the study.

- Mini Mental State Examination (MMSE) (Folstein et al., 1976)
- Large Allen Cognitive Level Screen (LACLS) where appropriate, (Allen, 1996) was administered to individuals to assess cognition and to help predict the complexity of task participant would be able to manage.

The MMSE was also completed at the midway point of the study.

The Bradford Well Being Profile (University of Bradford 2008) and the Thrive Behavioural Checklist (available from the corresponding author) was recorded by staff members each week immediately after the group had taken place.

Results

The analysis that we report here consists of two parts: first an analysis of observer results; second, a qualitative analysis of the interviews with carers.

Well-being profile

Figure 1 illustrates the mean weekly well-being scores using the well-being profile 1 outcome measure for participants from the first group session on the 11/05/09 to the session on the 28/09/09. An increase in the mean well-being score can be seen for the first 8 sessions of the group, followed by leveling off of the scores. From 28/09/09 a new measure of well-being was introduced as staff members felt that after a period scores did not necessarily reflect their opinion of the participant's well-being accurately. Scores hit a ceiling value as there were no options on the outcome measure that referred directly to indicators of negative well-being (that would potentially lower the overall well-being score). The University of Bradford had themselves realised this limitation and made available an amended version of the well-being profile. This version was adopted from 05/10/09 and the mean scores for this outcome measure can be seen in figure 2. Results from well-being profile 1 therefore need to be interpreted with caution, but still serve to illustrate the positive indicators of well-being. Weeks without a mean score value highlight occasions where no group took place due to either bank holidays or holiday periods in which there were either insufficient numbers of participants or staff to run an effective group.

Figure 2 shows the mean weekly well-being scores using the well-being profile 2 outcome measure from 05/10/09 to the last session on the 10/05/10. Although the range in scores for the two well-being profile's is similar (well-being profile 1 range = 4.6; well-being profile 2 range = 5.5) the difference in scores on a week by week basis for the well-being profile 2 is visibly greater. The trend in mean well-being scores for profile 2 is steady fluctuation in scores around the overall mean score for this profile of 11.58.

Cognitive functioning

Figure 3 shows the MMSE scores for participants at 6 month intervals through the gardening project. The difference between the beginning of the project and the 6 month measurement point does not reach statistical significance (paired $t(7) = 1.99$, NS) but it showed a statistically significant decline by 12 months (paired $t(5) = 3.88$, $p=0.012$).

Semi structured interviews with carers

Questionnaires were sent to the carers at the midway and end points of the gardening project. Semi-structured interviews were carried out by one of the researchers at both the midway and end points. 7 out of 8 people provided completed sets of answers.. Themes were identified if at least 3 out of the 7 respondents gave similar responses. They were analysed using grounded theory methods.

The findings at 6 months.

Carers were asked what difference (if any) has the gardening group made? The main themes which they commented on were:

- i) Self Identity – An example of this was “gives her a purpose”
- ii) Companionship – “Gives her a talking point when she is with other people”
- iii) Orientation – “Helped with orientation, he usually seems to know when it is a Friday and his visit to Thrive.” (This is unusual as normally his time and day orientation is poor).

In response to the question “What difference has the gardening group meant for you personally?” carers identified:

- i) Respite/independence for participant. “Opportunity to attend an activity which their spouse could carry out independently of them and that they seemed to enjoy ”
- ii) Safe physical activity and knowing a loved one was being looked after” it is as far removed from a ‘Day Centre’, ‘hospitalised’ environment as is feasibly possible. I don’t feel guilty about him attending this group, as I do with other activities he attends which I don’t feel fully meet his needs (particularly with regards to his age).”

Findings at end of project

Carers were asked what difference (if any) has the gardening group made? Main themes that were commented on:

- i) Enjoyment
 - ii) Independence
 - iii) Feeling useful, having achievement
 - iv) Feeling valued
 - v) Reduced anxiety – “Small size of group led to reduced anxiety for participant and carer.”
- 2 reported no difference.

Carers were asked to rate whether they had noticed improvement, no change or worsening in mood, confidence, sociability, memory, concentration and willingness to garden at home or go out more.

The results are shown in Figure 4.

Discussion

The present study served as a pilot to inform a future research project investigating the potential benefits of a structured gardening group for people with YOD. There was no control group, so no inferences can be made about the relationship between the observed outcomes and the gardening group. The study does allow us to speculate about potential trends and to use the information gathered to identify aspects of the group that warrant further investigation for the future project. It also enables the practical issues surrounding both the running of the group and the use of outcome measures to be discussed and evaluated.

Well-being

Results from the first well-being profile that was used for the initial 4½ months of the pilot show a gradual increase in the positive indicators of well-being for this period. Although these results need to be interpreted with caution as they did not include the negative indicators, the second well-being profile did include them and showed that well-being levels were maintained. This outcome measure was used for the remaining 7 months and demonstrated greater sensitivity, as fluctuations in well-being scores were greater from week to week. The future research project may wish to include a measure of inter-rater reliability however, as perceptions of well-being and interpretations of behaviours differed among staff members during the post group meetings.

Cognitive screen

The maintenance in well-being as observed in this study becomes more significant when it is viewed in the context of scores on cognitive screening tests. Over the 12 month period of the study, the mean score on the Mini Mental State Examination (MMSE) dropped by 1.13 points. Over the same time scale, ¾ of those who were able to complete a LACS assessment showed a deterioration in score. These findings suggest that participation in structured group gardening tasks may help to maintain well-being despite the presence of a cognitive deterioration. In addition to this, the mean drop in MMSE scores over the 12 months in this study was lower than might be expected, with prevalence studies predicting loss of 2.7 points (Roselli et al., 2008) to 3.2 points at MMSE = 17 (Mendonado et al., 2000) over 12 months for all ages and a more rapid deterioration in younger people. This may reflect a beneficial impact of the group on cognition, although this may be due to the addition of another group member at 6 months who's MMSE score was above the mean. Another variable that may have impacted on this observed outcome was the prescription of acetylcholinesterase inhibitors for 8 participants, although none began this course of treatment immediately before or during the study.

Carer feedback

At both mid point and end stages of the study the most common themes that emerged from interviews with the carers were ones centred on self-identity, purposeful activity and mood. Comments regarding improved self-identity suggested that the opportunity for participants to attend a group in a non-hospitalised environment with peers was important. A sense of group belonging may in part explain the feedback of increased confidence and sociability with some participants. The benefits of the peer group as a key theme provides evidence to support Diamant and Waterhouse's (2010) notion that horticulture facilitates health & well-being through belonging. Another point that was emphasised was the significance of attending the group independent of family members. This again may have contributed to a sense of autonomy and self identity that is challenged in many ways by YOD (Haase,

2005; Harris & Keady, 2009), with the added benefit of providing valuable carer respite.

Purposeful activity was also identified as an important aspect of the gardening group. Feedback from the carer questionnaires included statements that participants felt useful, valued and had a sense of achievement. Interestingly, one carer wrote that this contrasted with the occupations available at a local day centre which "don't fully meet their needs, particularly with regards to their age". These comments provide support for Parr's (2008) recognition of gardening as a meaningful activity, which has been shown to be beneficial for people with YOD (Beuttner, 2001).

The final theme to emerge from the carer interviews was mood. Approximately half of the respondents felt that participant's mood had improved since attending the gardening project, while the remainder felt that there had been no change. Improved self-identity, sense of group belonging and/or meaningful occupation may have had a beneficial effect on the mood of participants. This was not assessed formally during the pilot but the inclusion of this as an additional outcome measure for the future research project may provide support for this finding.

Carers were also invited to suggest any ways in which the group could be improved. Two respondents felt that improved communication between staff members and the carers may help them to reinforce the skills that participants learnt or maintained in the home environment. Although a memory book was completed at the end of each session for participants to take home with them, once of the carers stated that the information within them was often vague and difficult to interpret. Improved communication would also allow carers to feel more involved with the project while still maintaining participant independence when they attend the group. One potential limitation with this information was the structure of the questionnaire, which may have resulted in a bias towards positive feedback. The use of a Likert scale in the future project may reduce this possibility. It may also be helpful to include questions that focus specifically on well-being, so that a contrast can be made between the observed well-being of participants in the group by staff and in their home environment by their carers. The inclusion of questions around self-identity, meaningful activity and mood will be valuable for further investigating the trends observed in this study.

Practical issues

There are several practical issues that need to be considered when conducting a research project in this area. The present pilot study had a small sample size which reduces the reliability of the findings. The catchment area for a future research project may need to be larger in order that a control group can be included along with big enough groups to improve experimental reliability and the possibility of statistical significance. This in itself creates difficulties as the

running of these groups is staff intensive. Careful thought needs to be given to ways of increasing staff efficiency while maintaining the therapeutic benefits of the group.

Concluding comments

Initial findings from this pilot study suggest that structured gardening may have a positive impact on the well-being, cognition and mood of people with YOD. The use of a carefully constructed control group would enable the benefits of structured gardening to be compared with those obtained from group activity in general. Of particular interest is the relationship between the well-being of participants and their cognition, as results from this study suggest that well-being can be maintained despite the presence of a cognitive deterioration. Future projects may wish to explore the potential feelings of isolation and abandonment that have been identified as central to the experience of people with YOD (Harris & Keady, 2009) and their relationship with the development of group belonging and meaningful occupation. This might be more effectively captured by interviews with the participant in addition to the carer. Research in this area is critical to the development of effective interventions and specialist services that meet the needs of people with YOD. Preliminary findings suggest that structured gardening groups for young and active people with dementia may be one such intervention.

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Appendix

Table 1

Table of MMSE scores over time

Baseline MMSE score	6 month MMSE score	12 month MMSE score
17	16	15.87

Figure 1. Mean well-being score over the first 21 sessions of the intervention

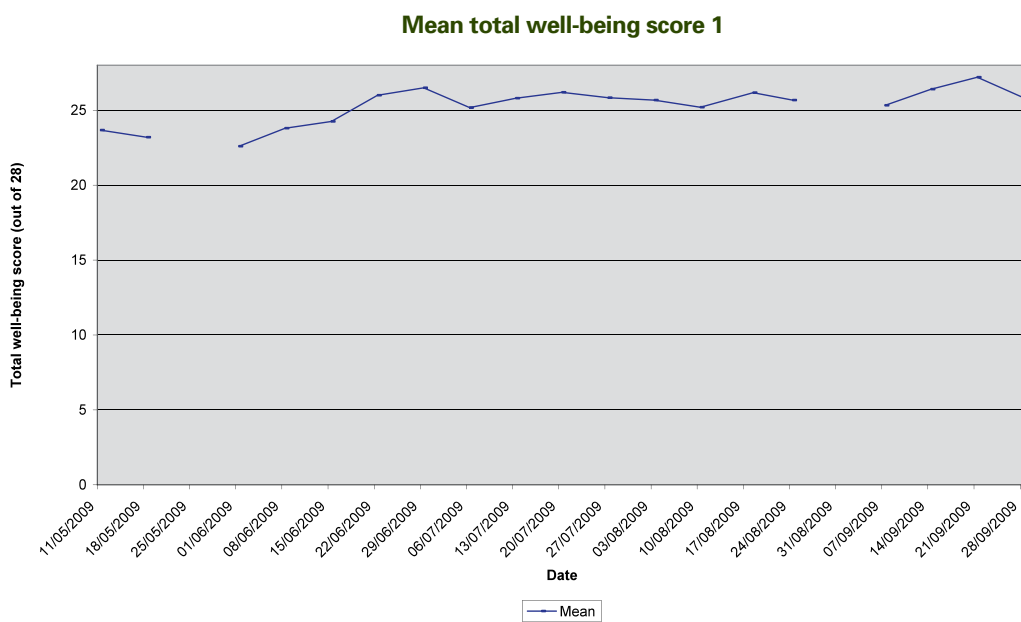


Figure 2. Mean well-being score sessions 22-46

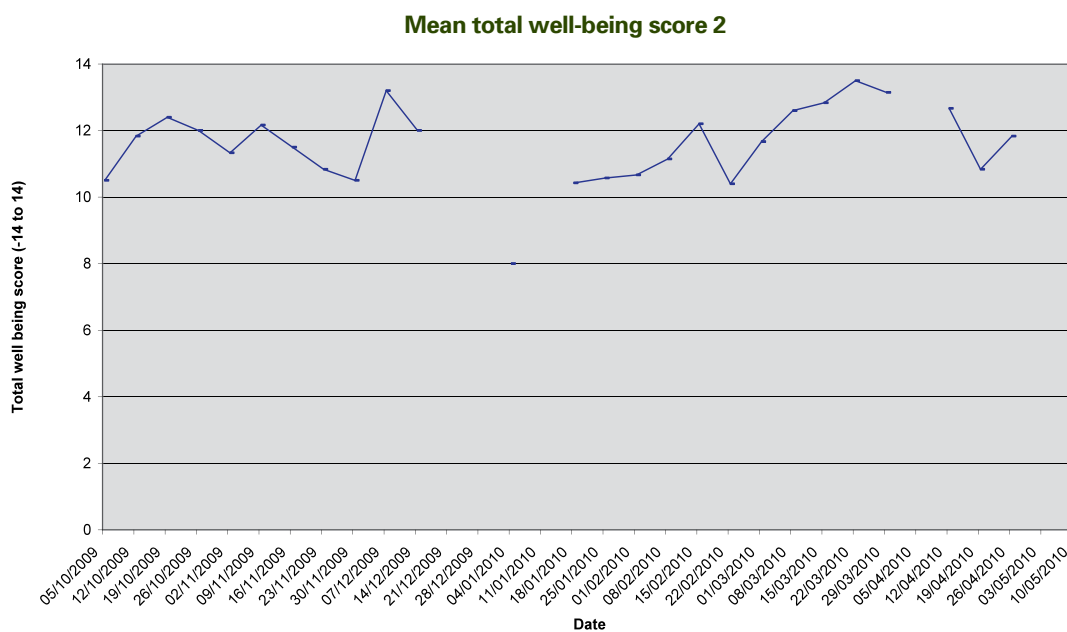


Figure 3. MMSE Scores

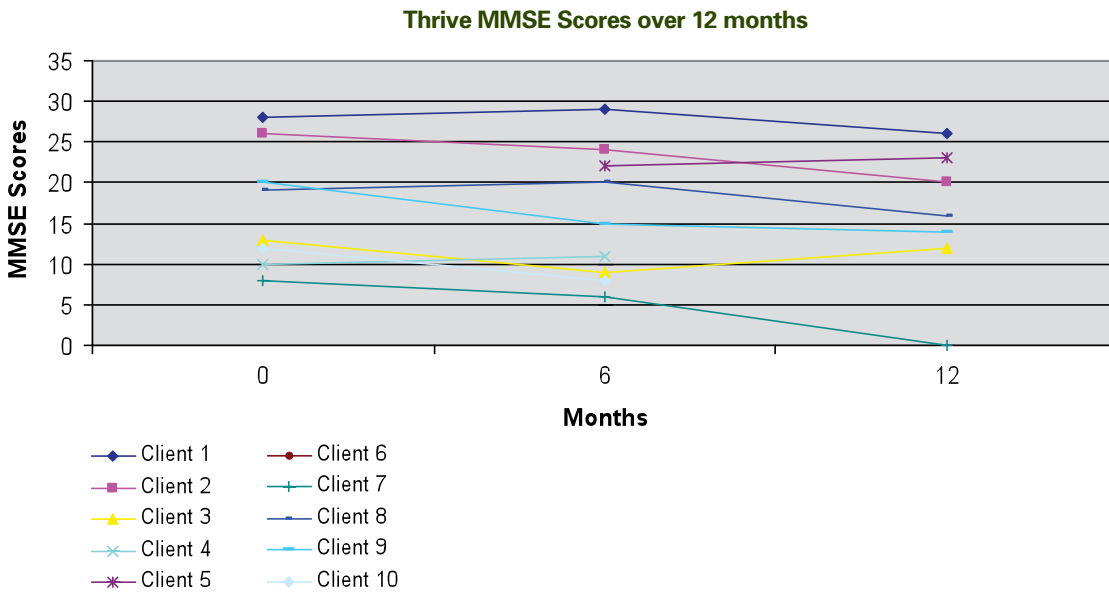
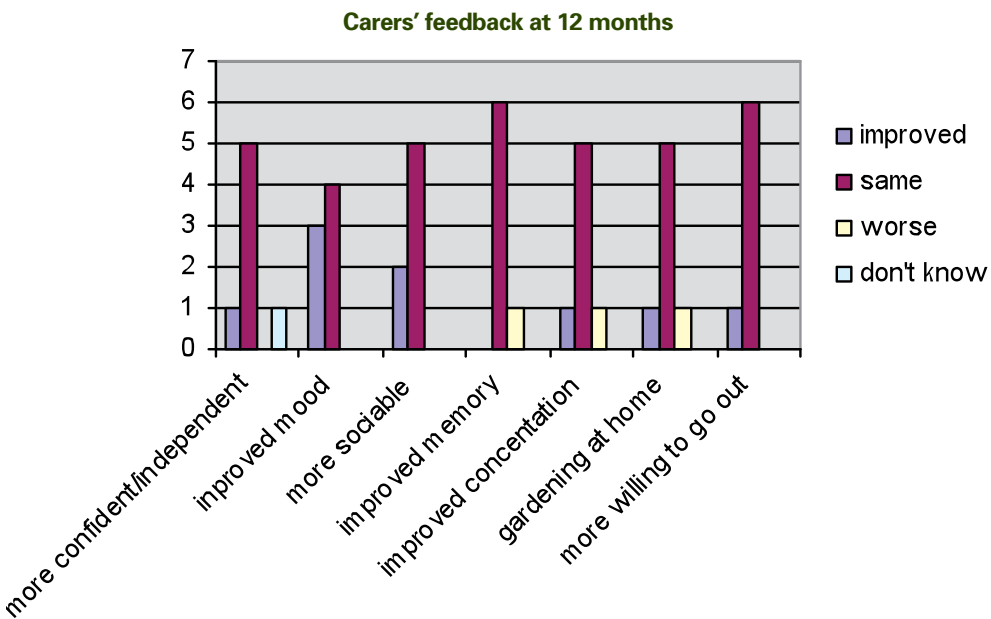


Figure 4. Carers' feedback at 12 months





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