

The Tailored Activity Program (TAP) to address behavioural disturbances in frontotemporal dementia: a feasibility and pilot study

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Abstract

Purpose: To explore the feasibility of implementing the Tailored Activity Program with a cohort of people with frontotemporal dementia and their carers (dyads).

Methods: The Tailored Activity Program is an occupational therapy based intervention that involves working collaboratively with family carers and prescribes personalised activities for behavioural management in people with dementia. Twenty dyads randomised into the study (Tailored Activity Program: n=9; Control: n=11) were assessed at baseline and 4-months. Qualitative analyses evaluated feasibility and acceptability of the program for the frontotemporal dementia cohort, and quantitative analyses (linear mixed model analyses, Spearman's rho correlations) measured the impact of the program on the dyads.

Results: The Tailored Activity Program was an acceptable intervention for the frontotemporal dementia dyads. Qualitative analyses identified 5 themes: "carer perceived benefits", "carer readiness to change", "strategies used by carer to engage person with dementia", "barriers to the Tailored Activity Program uptake/implementation", and "person with dementia engagement". Quantitative outcomes showed an overall reduction of behavioural symptoms ($F_{18.34} = 8.073, p = .011$) and maintenance of functional performance in the person with dementia ($F_{18.03} = 0.375, p = .548$).

Conclusions: This study demonstrates the potential for using an activity-based intervention such as the Tailored Activity Program in frontotemporal dementia. Service providers should recognise that while people with frontotemporal dementia present with challenging issues, tailored therapies may support their function and reduce their behavioural symptoms.

Key Words: frontotemporal dementia; dementia; Tailored Activity Program;
activities of daily living; behaviour; randomised-controlled trial

Introduction

Frontotemporal dementia (FTD), the second most common younger-onset dementia syndrome, causes devastating impairments in cognition, behaviour, and everyday function. Three clinical subtypes are generally recognised: behavioural variant frontotemporal dementia and two primary progressive aphasia, semantic variant and non-fluent variant. These FTD subtypes present differently in the early stages, and while all experience progressive declines, the patterns of cognitive, behavioural and functional decline differ [1-4]. The impact of FTD is not limited to the person diagnosed with dementia but also affects the informal carers. Indeed, research has shown carers of people with FTD tend to be more burdened and stressed than carers of individuals with Alzheimer's disease [5, 6]. The behavioural symptoms inherent in FTD are a key contributor to the high stress in carers and are also a predictor of institutionalisation [7-9]. It is no surprise then, that behaviours have been a major target of pharmacological intervention studies in FTD. While medications such as antidepressants or antipsychotics may offer benefits, evidence remains limited, and the potential for adverse effects is high [10]. Consequently the importance of developing effective non-pharmacological approaches for the management of behaviours in FTD is increasingly recognised [11].

A recent systematic review highlighted the lack of randomised controlled trials on the non-pharmacological management of FTD [12]. Studies to date have been un-blinded, and apart from three non-randomised clinical trials, have only included case reports, retrospective studies and expert opinion papers, and have focused on supporting family carers [12]. Carer education and enhancing carer skills have been major themes in FTD intervention work. Support groups and FTD-specific carer conferences have been reported to improve social support and knowledge of the disease, while a video-conferencing support group was also reported to reduce burden [13-15]. A more recent study involving a structured program providing education on cognitive appraisal, skills development and seeking support, found that carers were less burdened and less reactive to behaviours post intervention [16, 17].

The other focus of FTD intervention studies has been on behavioural management of the individuals with dementia. Single-case interventions have ranged from providing environmental and specific behavioural modification strategies, to an

FTD-specific day program, and active music therapy [18-21] and point towards a benefit of non-pharmacological interventions for behavioural management in FTD. An eight-week trial of lavender aromatherapy (n=20) found a reduction of behavioural symptoms during the intervention period [22].

While preliminary evidence for separate carer- and person-with-dementia-based interventions has shown promise, experts have suggested the importance of dyadic interventions that address the needs of and interactions between the person with dementia and their carer, as well as the need for more rigorous research designs [11, 23]. One method of achieving this, is providing dyadic interventions aimed at improving the functional capacity of the person with dementia by including combinations of behavioural management with carer education and support [24, 25]. Community-based, dyadic interventions have been trialled successfully in primarily later-onset dementia or Alzheimer's disease populations [26, 27], but not in FTD.

The Tailored Activity Program (TAP) is an occupational therapy intervention, which aims to directly impact the person with dementia, but also involves important carer education in a dyadic approach [28]. The US trial of TAP (n=60) targeting a later-onset dementia population showed reduced levels of behavioural symptoms overall, increased activity engagement, and improved carer management skills [26]. A recent case report of two participants from the Australian TAP pilot trial illustrated the potential benefit of the TAP intervention for this cohort [29].

FTD is a unique dementia syndrome with severe patterns of behavioural symptoms and functional impairments that differ from other dementias, and may respond differently to interventions designed for more common dementia cohorts such as Alzheimer's disease. This paper presents the results of the FTD sub-cohort involved in a pilot randomised-controlled trial of the TAP in Sydney, Australia. This exploratory study investigates the feasibility of implementing TAP with an FTD cohort. In particular, the following research questions were explored: (1) what is the acceptability and what are the experiences of the TAP intervention for individuals with FTD and their carers; (2) how does TAP impact on behavioural symptoms and activity engagement for this group; (3) how does TAP impact on the caregiving experience of FTD carers.

Methods

Study design

The FTD cohort included in this study was part of a larger pilot (n=66) randomised-controlled trial of the TAP program that was conducted in Sydney Australia (trial registration ACTRN12612001161819), with a two-group parallel design as described elsewhere [30]. This study uses a combination of qualitative and quantitative approaches to address the research questions. As with the larger trial, potential FTD participants were screened for eligibility, then completed the baseline assessment (by CO'C or a trained research assistant) before being randomised into either the TAP intervention group or the control group (figure 1). The randomisation allocation was generated by a researcher not involved with the recruitment or assessment processes, and concealed in opaque numbered envelopes. The therapist (CO'C) used these envelopes in numerical order to randomise participants as they were recruited into the study. All assessments collected at baseline were completed again post intervention (M=5.17 months, 95% confidence interval=4.75–5.58) by a research assistant blinded to group allocation.

Participants

Participants (dyads of individuals with dementia – carer) were either recruited via mail-outs through FRONTIER (@frontierbrainandmind), the frontotemporal dementia research group in Sydney, Australia (n=18), referral from a memory clinic based at a tertiary hospital in Sydney, Australia (n=1), or via an advertisement in the Alzheimer's Australia "In Touch" magazine (n=1). Participants were recruited between December 2012 and August 2015. Inclusion criteria for the individual with dementia were as follows: (1) a diagnosis of FTD (assigned by consensus of a multidisciplinary team after comprehensive clinical assessment) according to the current diagnostic criteria [31, 32]; (2) presence of behavioural disturbances over the past month as rated by the carer; (3) a score >3.31 on the Informant Questionnaire on Cognitive Decline for the Elderly; (4) able to participate in at least two basic activities of daily living (ADLs); (5) be on a stable dose of psychotropic medication for the past two months, and dementia medication for the past three months; and (6) have

conversational English. In addition, carers needed to meet the following conditions: (1) have conversational English; (2) be at least 18 years of age, and if not living with the person with dementia, have at least 7hr/week or 4days/week contact; (3) be accessible by phone; and (4) indicate their willingness to learn skills in using activities as an intervention. Both person with dementia and carer had to fulfil entry criteria. The University of Sydney Human Research Ethics Committee approved the study and written informed consent was obtained from each dyad randomised into the study. Nine dyads were randomised to TAP and 11 to the control group (figure 1).

Insert figure 1 about here

Intervention

The TAP intervention involves up to eight home-visits by a TAP-trained occupational therapist over a period of four-months, and involves three phases: (1) assessment; (2) implementation; and (3) generalisation and closure [28]. The assessment phase involves assessing the person with dementia's current abilities as well as his or her current and previous roles and interests. The Allen's Cognitive Levels are used to provide an indication of the person's level of functional cognition from which to appropriately tailor activities to their capabilities [33, 34]. This information is then used to generate three individualised activities, which are then provided sequentially in subsequent visits in the implementation phase. Also, in the implementation phase, the carer is provided with education about dementia and behaviours (e.g. behaviours are not intentional), learning skills in activity simplification and communication, and practising ways to effectively engage the person with dementia in activities. Each activity is reviewed with the carer, with any issues addressed through a problem-solving approach. Finally, phase three involves the occupational therapist helping the carers to generalise the skills learnt to other care challenges (e.g. bathing, dressing), and learning to recognise the inevitable declines in their family member and adapt strategies accordingly. For a detailed overview of the TAP intervention process, see Gitlin et al. [35] and O'Connor et al. [30].

In the control group, carers received three telephone calls over four months, which consisted of education sessions based around a book on general dementia-related matters such as legal issues and residential care. These sessions were conducted by the same occupational therapist who conducted the intervention sessions and were intended to control for the dementia-specific information and empathetic interaction received in the intervention group. Carers in both the intervention and control groups received a copy of the book on which the control sessions were based.

Measures – Clinical Information

Dementia stage

Dementia severity was measured using the Frontotemporal Dementia Rating Scale [36]. The Frontotemporal Dementia Rating Scale provides an overall score based on a combination of ADL functioning and behavioural symptoms over 30 items. A Rasch score is determined from the raw score, which provides an indication of stage in disease progression ranging from “very mild” to “profound”.

Person with dementia and carer cognition

General cognitive function was measured using the Montreal Cognitive Assessment [37], a brief 30-item measure which covers executive functioning, visuospatial abilities, language, memory, attention, concentration, and orientation. Carers were also evaluated with the Montreal Cognitive Assessment at each time point to determine carer capacity to participate in TAP.

Measures – Exploratory outcomes for TAP in FTD

QUALITATIVE OBSERVATIONAL DATA

TAP intervention acceptability and response to intervention

Qualitative data were generated from the therapist's case notes and reports, which were extensive and included the therapist's reflections, observations and noted quotes from TAP sessions. After each individual TAP session, the therapist completed these detailed case notes and a set of standardised survey questions developed from the original TAP trial [26] to record both the carer's and person with dementia's participation in and acceptability of the session. These survey questions drew on the therapist's observations and reflections on the acceptability of the intervention, such as communication/activity simplification skills of the carer, and engagement of the person with dementia (e.g. did the person with dementia show enjoyment when engaged in an activity?; how long did the person with dementia remain engaged in an activity for?). The in-depth case notes provided document data that supplemented these standardised questions; the therapist recorded her own observations and clinical reasoning throughout the TAP process. These case notes often included direct quotes taken from the carer or the person with dementia. Carer readiness to engage in the TAP intervention was assessed in the first or second session (phase one), and again in the last session (phase three) at the end of the intervention period. Readiness was rated by the therapist based on direct observation of the carer's interactions with the person with dementia and clinical interviews. Scores range from 1.0—"pre-contemplation type behaviours" suggesting the carer may not understand their family member has dementia, to 4.0—"Action/maintenance type behaviours" indicating the carer is actively implementing and generalising strategies learnt in the intervention [38]. In addition, case studies were prepared as brief reports and regularly presented at TAP team monthly meetings to discuss challenges and ensure treatment fidelity was maintained.

QUANTITATIVE EXPLORATORY DATA

Person with dementia behaviours

The revised Neuropsychiatric Inventory – Clinician rating scale (NPI-C) was used to assess behavioural frequency (0=never – 4=very frequently), severity (0=none – 3=marked), and carer distress related to behaviours (0=not distressing – 5=extremely) [39]. The NPI-C comprises 14 behavioural domains: delusions, hallucinations, agitation, aggression, dysphoria, anxiety, elation/euphoria,

apathy/indifference, disinhibition, irritability/lability, aberrant motor disturbance, sleep disorders, appetite and eating disorders, and aberrant vocalisations. The composite scores (frequency x severity) of four of these behavioural domains were analysed: apathy, agitation, disinhibition, and aberrant motor disturbance. These were selected on the basis that they are common and difficult to manage in FTD [9, 40, 41]. We also included a sum score of the total number of behaviours present at baseline and follow-up. A sum score of the presence/absence of behaviours has been previously used to measure the impact of the TAP intervention [26, 42] and as an outcome in a meta-analysis of non-pharmacological interventions to reduce neuropsychiatric symptoms of dementia [43]. The NPI-C was administered with all other quantitative measures at baseline and post intervention by a research assistant blinded to group allocation.

Person with dementia everyday function

As TAP involves a generalisation phase, we investigated if the intervention resulted in a change in the person's level of functioning in everyday activities. The Disability Assessment for Dementia (DAD) [44] is a proxy measure made up of 40 items with 17 items focusing on basic ADLs such as hygiene, dressing and continence, and 23 items on the more complex instrumental ADLs such as managing medications, meal preparation, and managing finances. The total DAD score is reported as a percentage to allow for any non-applicable questions (e.g. if a person has never managed the finances) to be excluded without biasing the result. In addition to the total DAD score, sub-scores of basic ADLs and instrumental ADLs were also included to provide a more detailed analysis of function. Higher DAD scores are indicative of better functioning in ADLs.

Health related quality of life

Health related quality of life of the person with dementia was measured using the EuroQol 5-D [45]. The EuroQol 5-D is a proxy measure based on how the carer believes their family member would respond to each question on their own health if they were able to articulate it. The measure consists of two parts: five general health

status questions rated by descriptive items (e.g. “no problems with personal care” or “some problems washing or dressing”), and a measure of overall health on a visual analogue scale which extends from 0–“worst imaginable health state” to 100–“best imaginable health state”. Scores from the visual analogue scale were analysed for the present study, with higher scores on the scale indicative of better overall health related quality of life of the person with dementia.

Carer vigilance

Carer time feeling “on duty” and actually “doing things” for the person, was measured using the Vigilance Items [46]; this was found to be a significant outcome in the original TAP trial, with TAP carers reporting less time both “doing things” and feeling “on duty” compared to control carers who reported more time over four months [26]. We used two items from this brief four-item scale, which require carers to estimate the amount of time in a 24-hour day spent in these specific tangible and non-tangible aspects of care. These two items showed positive outcomes in the original TAP trial [26]. A greater vigilance score indicates the greater amount of time the carer spends doing that item.

Data analysis

Qualitative analysis

Data from the case notes and case reports were analysed to provide insights into our findings. A combination of thematic [47] and content analyses [48] of these data were conducted which also provided triangulation with our quantitative results. Generated codes were systematically extracted from each of the TAP case files (n=9) through an inductive approach and grouped together into meaningful themes. Themes were reviewed and agreed upon by two authors (CO’C and LC), and supported by relevant extracts from the data.

Quantitative analysis

As this was an exploratory study, no power analyses were conducted to determine a prescribed sample size. To investigate the changes in measures between the TAP and control group over time, linear mixed-effect models were used. Fixed effects in the model included time, intervention group (TAP or control), and the interaction between time and intervention group. Individual variability between participants at baseline was the only random effect included; a random intercept was therefore included in each model. The variability of any estimated parameters was determined by both the random and fixed effects in the model. A linear first-order polynomial was used in the analysis due to the small sample size. A separate model was constructed for each of the dependent variables analysed: NPI-C behavioural domains present/absent, NPI-C apathy composite, NPI-C agitation composite, NPI-C disinhibition composite, NPI-C motor disturbance composite, DAD total, DAD basic ADLs, DAD instrumental ADLs, EuroQol 5-D health scale, Vigilance on duty, and Vigilance doing things. For each of the models, a change in the dependent variable over time would be indicated by a significant effect of time, and different changes in the dependent variable over time between the TAP and control group would be indicated by a significant interaction between time and intervention group.

Insert table 1 about here

Results

Of the 20 dyads, 65% (n=13) persons with dementia were male; 45% (n=9) had behavioural variant FTD, 30% (n=6) had semantic variant primary progressive aphasia, and 25% (n=5) had non-fluent variant primary progressive aphasia. Of the carers, 40% (n=8) were male, 90% (n=18) were the spouse of the person with dementia, 5% (n=1) an ex-spouse, and 5% (n=1) a daughter. All carers were living with the person with dementia, and 35% (n=7) participants had children residing in the same household. There was some variability in the baseline demographic variables between the TAP and control groups (table 1), which was accounted for by inclusion of this individual variability in the analysis as a random effect (49).

Insert figure 2 about here

Baseline

Nine dyads were randomised to the intervention group and 11 to the control group (figure 1). Participants overall exhibited an average of 7.2 (SD=1.5, range=3-10) behaviours, with the most frequently reported being: apathy and eating disorders (both, n=19, 95%), agitation (n=17, 85%), disinhibition (n=16, 80%) and anxiety (n=15, 75%) (figure 2).

TAP implementation and acceptability

TAP Visit Processes

Overall, participants had an average of 7.44 in-home treatment sessions each. Five participants had 8 sessions in home and three participants had one of the sessions via telephone. One participant moved to permanent residential care during TAP and had the final two sessions conducted in the care facility. Visits lasted an average of 73 minutes (SD=25.2 minutes), and telephone sessions an average of 30 minutes (SD=21.6 minutes). An average of \$46.01 AUD (range: \$0.00–108.69) was spent on activity materials per dyad. Examples of activity materials provided include: jigsaw puzzles, painting materials, music DVDs and word puzzle books. In some instances, activities such as gardening or photography meant that no new activity materials were required to be provided. Carers attempted to engage their family member in TAP activities an average of 4.01 times per week throughout the TAP intervention period. Each session of activity engagement lasted an average of 33.3 minutes.

Prescribed activities varied in type and complexity depending on the interests and abilities (cognitive and functional) of the person with dementia, as well as the acceptability to the carer who would be implementing the activity prescriptions with their family member between TAP visits. Table 2 provides an overview of the activities that were prescribed according to each person with dementia's level of functional cognition as assessed by the Allen's Cognitive Levels [33]. Higher functioning participants received prescriptions for more complex activities, while

participants with greater cognitive and functional impairments, received activities that could be easily broken down into fewer steps.

Insert table 2 about here

Acceptability of TAP

TAP was well accepted by all dyads, notably all carers were engaged with the process and were actively involved in implementing the intervention strategies. Similarly, all persons with dementia engaged in at least some of the prescribed activities. In total, 27 activities were prescribed of which 96.3% (n=26) were used at some point during TAP and 63.0% (n=17) were still being used when participants were in phase 3 (sessions seven and eight) of their intervention period. Average carer readiness to engage in the TAP intervention at baseline was 3.0 (range 2.5-3.5), indicating most carers were willing to listen and had an intention to take action. By the end of TAP this average had increased to 3.5 (range 2.5-4.0), suggesting most carers had moved closer to being ready to take action in terms of implementing TAP strategies (figure 3a).

Insert figure 3 about here

After each TAP session, the therapist completed survey questions rating their own observations of the level of effective communication skills and activity simplification skills demonstrated by the carer, and whether the carer was perceived to have found the contact useful. At the beginning of TAP, 77.8% of carers indicated that the contact from TAP visits was either “extremely” or “very much” useful, and 22.2% indicated it was “moderately” useful. By the end of TAP 100% of carers indicated the TAP visits were either “extremely” or “very much” useful. In terms of communication skills with the person with dementia, only 22.2% of carers demonstrated an “extremely” or “very much” effective communication style at the

beginning of TAP, but by the conclusion of the TAP sessions, an effective communication style was exhibited by 75.0% of carers. Similar gains were seen in activity simplification skills. At the beginning of TAP, 100% of carers exhibited only “a little” or “moderately” effective simplification skills, but by the end of TAP 87.5% of carers were demonstrating an “extremely” or “very much” effective approach to simplifying activities (figure 3b).

Qualitative outcomes

Five main themes were identified from the therapist notes taken after each TAP visit. Themes, which were labelled to best reflect the relationship between the sub-themes and the TAP process included: “carer perceived benefits”; “carer readiness to change”; “strategies used by the carer to engage person with dementia”; “barriers to TAP uptake/implementation”; and “person with dementia engagement”. Table 3 provides a summary of the themes and associated subthemes, and the frequency of which these appeared across the cases.

Insert table 3 about here

Carer perceived benefits from meaningful engagement

This theme conveyed a sense that the carers found TAP a beneficial experience for both themselves and their family member with dementia. Carers saw the benefit of the person being engaged in meaningful activities. One carer commented the activity of gardening for her husband became “*something for him to do...that takes time...and it’s his role.*” (Wife, 50yrs) The benefits of TAP for the carers themselves was also highlighted, as one carer discussed how this whole “*process is very positive*” (Wife, 50yrs) in helping her learn strategies to help her husband, and another carer discussed how she felt she was “*floundering*” (Wife, 59yrs), but once she was involved in TAP, she felt more in control. A number of carers commented on how engaging in the activity with the person with dementia facilitated a positive interaction. One carer (who was the daughter of the person with

dementia) said *“I remember when we coloured together and he did it exactly how he taught me as a kid. It was a nice moment, it made me feel like he was normal again.”* (Daughter, 26yrs) While another carer commented that doing a jigsaw puzzle with her husband *“was actually very relaxing and one of the few things we can connect with now...very therapeutic for everyone!”* (Wife, 66yrs)

Carer engagement in TAP

This theme emphasised the active role that carers took in engaging in the TAP process. Recognition by the carer of their important role in facilitating engagement for the person with dementia was pivotal to TAP, as one carer reflected it’s *“probably about changing my own behaviour.”* (Wife, 50yrs) A number of carers were particularly proactive in their approach to participating in TAP. For example, two carers had tried introducing the activities with the person with dementia before the therapist arrived with the actual activity prescriptions, while other carers introduced extra activities outside of the three specific activities selected as the focus for their TAP intervention.

Barriers to uptake/implementation

In contrast with the other themes, this theme focuses on the difficulties that were encountered regarding the implementation of TAP. Lack of time or reluctance to introduce activities were key barriers to carers implementing TAP activities (table 3); one carer commented that the process of introducing an activity was a *“massive obstacle in my head”* (Ex-husband, 69yrs). Low levels of readiness to engage in the TAP process as measured by the readiness to change scale also contributed as a barrier, as did being reserved or not wanting to consider future declines in the abilities of their family member with dementia. For instance, one carer was reluctant to discuss disease progression and struggled to link this with potential activity simplification strategies, saying: *“No way. There is no way to make that easier.”* (Wife, 62yrs) Another barrier to the implementation of TAP was when carers perceived activity engagement as *“unsuccessful”* (Husband, 53yrs). An example of this was when a carer overestimated the person’s abilities. This was highlighted where the therapist

reflected in the case notes that the “*carer admitted today that when they started TAP he was hoping for some ‘magic’ activity that would engage (the person with dementia) for 30–60 minutes at a time.*” (Husband, 53yrs)

Strategies used by carer to engage person with dementia

This theme reflected the range of strategies that was used by carers throughout TAP to engage their family members in activities. Table 3 outlines the most common strategies used by carers throughout TAP. These included: setting up activities, managing their own approach to interacting with the person with dementia including communication, prompting, understanding the person’s abilities and changing their expectations, and involving other family members. Some carers commented on specific strategies they found useful, as one carer commented, “*it’s like you said, you need to face him to talk and give instructions, rather than yelling from another room.*” (Wife, 50yrs) Other carers contemplated strategies they learnt through a process of trial and error. For example, one carer purchased a much more complex jigsaw puzzle than was originally introduced, which she reported “*didn’t work*” as her husband “*walked away from it*”. The carer then reflected, “*I realised what you said about needing to target things to him*” (Wife, 50yrs). A common theme in the therapist’s notes was the benefit of education around FTD and its impact on behaviour and function. One example from the notes reads: “*With her better understanding of the genesis of behaviours in FTD, (the carer) seems more calm in her management of his behaviours...and is now concerned that their daughter also needs to understand these as part of the disease process.*” (Therapist notes about a wife carer, 62yrs) Indeed, in a number of cases, the children of the person with dementia participated in some of the TAP sessions, and appeared to benefit from education on FTD.

Engagement of person with dementia in TAP engagement

The final theme underscored the level of engagement of the person with dementia in the prescribed TAP activities. Some of the positive indicators of engagement from the person with dementia included the person’s willingness to engage in the prescribed activities or being involved in choosing activities, sense of

achievement, and visible enjoyment (e.g. smiling). In fact, the majority of people with dementia outwardly showed enjoyment while engaged, for example, one person who usually had reduced verbal output began animatedly discussing their new jigsaw puzzle. In these situations, carers also reported benefit in that they could discuss the activity with their loved one in a conversation that felt “*almost like normal*” (Wife, 66). Even in people who did not show outward enjoyment, a level of engagement and concentration was achieved with the prescribed activities. A common sub-theme was from carers commenting on the positive impact of engaging in the activity for the person with dementia. One carer reported that her family member “*loved doing it*” (Wife, 50yrs), another said “*I could see he had a sense of achievement*” (Wife, 69yrs), while a third commented that she was “*so happy to see him.... he’s chatting, smiling and happy in his face.*” (Wife, 69yrs) The people with dementia themselves had positive feedback about engaging in the activities. When asked if he enjoyed working on a jigsaw puzzle, one person said, “*Oh crumbs yeah! You’ve started me on a roll with those.*” (Man with dementia, 68yrs) While another person commented at the end of baking her favourite biscuits “*I want to do more of this.*” (Woman with dementia, 61yrs)

Interventionist observations during and post TAP

Carer readiness to change was an important factor for how much carer engagement was achieved throughout the TAP process. That is, carers who had developed higher levels of readiness to change throughout TAP were more likely to have implemented effective communication ($r=.856$, $p<.01$) and activity simplification skills ($r=.817$, $p<.05$). Further to this, carers who had initially higher levels of confidence in using activities, reported less time feeling “on duty” ($r=-.756$, $p<.05$) and “doing things” ($r=-.868$, $p<.01$) for the person with dementia at the end of TAP.

Across the TAP participants in the present study, there was a relationship between person with dementia’s health and functioning with the length of engagement time that was achieved. Specifically, people who spent more time engaged in activities were those who were more independent in their instrumental ADLs (DAD; $r=.695$, $p<.05$) and had better health related quality of life as rated by their carer

(EuroQol 5-D; $r=.672$, $p<.05$) post TAP. At the end of TAP, five (55.6%) participants were still engaging in two or three of the prescribed TAP activities, one (11.1%) participant was still engaging in one of the activities, and three (33.3%) participants were no longer engaging in the prescribed activities. Of these three participants, one had moved into residential care, one of the carers was trying to organise professional carers to facilitate the activity engagement, and the other carer (the daughter) had recently moved out of the home and was no longer the primary carer.

Insert table 4 about here

Longitudinal changes from baseline to post intervention/control

Linear mixed-effect models were applied to examine changes over time between the TAP and control groups across the quantitative measures (table 4). Of the four primary behavioural outcomes, a significant interaction for agitation indicated that the TAP group worsened and the control group improved over time on the NPI-C agitation composite score (frequency x severity). None of the other three behaviours showed any changes between the groups. Looking at the sum score of the total number of behavioural symptoms overall (presence/absence of each behaviour on the NPI-C), a significant effect of time indicated the number of behaviours exhibited over time changed, and a significant interaction effect indicated that the TAP group declined in the number of behaviours exhibited from baseline to post intervention. In contrast, there was no change in the overall number of behaviours exhibited by the control group.

Regarding everyday function, a significant interaction effect indicated that the TAP group maintained or improved their baseline level of instrumental ADL functioning at the post intervention assessment (table 4). Conversely, the control group declined in their instrumental ADL abilities. No changes were found in overall ADL function or in basic ADLs between the groups.

Finally, quality of life for the persons with dementia did not change post intervention/control period. There were no significant differences in the EuroQol 5-D

health scale over time between the groups. Similarly, the amount of time (Vigilance) carers spent “doing things” for their family member with dementia, or feeling “on duty” did not change over time between the groups.

Discussion

To the best of our knowledge, this is the first randomised controlled study, albeit a pilot, to investigate a non-pharmacological intervention in an FTD cohort. Previous research on activity interventions has not included well-characterised FTD. This pilot study has demonstrated feasibility and acceptability of providing TAP to an FTD cohort. There was a high recruitment rate from dyads offered the program, and a zero per cent drop-out from participants randomised into the study, indicating FTD carers recognise a high need for intervention. Benefit was observed in carers, who had improved skills and confidence, which was specifically associated with reduced time on caring duties. Further to this, the individuals with dementia displayed a willingness to be involved and engaged in the prescribed activities.

The significant decline in the number of overall behaviours flagged at follow-up for the TAP group points to more universal positive changes to behaviours generated within the TAP group. Given that behavioural symptoms in FTD are marked and difficult to change [11, 32, 50, 51], this is a compelling finding, although the exact mechanism of this reduction in behavioural symptoms is unclear. In the original TAP study, it was postulated that the intervention reduced behaviours by addressing overstimulation and promoting a sense of self in the person with dementia [26]. This theory aligns with the concept of unmet needs, which is often outlined in the Alzheimer’s disease literature [52, 53]. The factors contributing to behavioural symptoms in FTD may be more complex than this however, given the inherent focal atrophy of the frontal and temporal lobes [54]. For example, atrophy of the anterior cingulate cortex has been associated with apathy in FTD, and right temporal lobe dysfunction with disinhibition [55, 56]. Therefore, results from this study suggesting that the TAP intervention may have a positive impact on the behavioural symptoms of people with FTD is an important finding which deserves further investigation. Looking at specific behaviours, we found a decline in carer-reported agitated behaviours from the control group, suggesting that even receiving general information

from a therapist via telephone has some benefit from this group of FTD carers who often feel isolated within conventional dementia services [11, 57].

People with dementia in the control group declined in their instrumental ADL function from baseline to post intervention/control assessment. This pattern was expected, given that functional decline is a feature of FTD, with instrumental ADLs in particular shown to decline earlier than basic ADLs [3, 4, 58]. Therefore, it was interesting to find that in contrast with the control group, the TAP group maintained their instrumental ADL function over the same time frame. This points to the benefits of activity engagement stretching beyond the moment of engagement itself, to impact on other areas of functional performance. In fact, the capacity for non-pharmacological interventions to delay functional decline in dementia has been shown previously [23, 59, 60]. The impact of activity-based intervention programs on ADL performance in FTD specifically is yet to be clarified [61, 62], but the potential for these interventions to delay functional decline deserves further investigation in future trials.

The thematic analysis conveyed the experience of the carers and the persons with dementia throughout the TAP process. For most of the carers, their experience was shaped by a combination of their readiness to change, how beneficial they perceived TAP to be, and any barriers that existed that may have impacted on their uptake of the TAP intervention. Education on the impact of FTD on cognition, function and behaviour emerged as an important subtheme to support carers in implementing a range of management strategies, reflecting previous reports [17, 29]. Carers learnt a range of strategies to support their family member's continued engagement in activities. The most common subthemes included setting up an activity, prompting, communication and activity simplification, which relate to the premise of the original TAP study of tailoring activities to the person's preserved capabilities and interests [26]. The identification of this theme emphasises that the implementation of TAP in the present study maintained fidelity with the original intervention. These themes also align closely with the occupational therapy concepts of meaningful occupation and task analysis [63, 64], which inform why these strategies are effective to facilitate activity engagement. In addition to support from the carer, engagement of the person with dementia in the TAP activities was also shaped by how keen the person themselves was to participate in the activities, whether

they were included in the decision around which activities to do, and whether the activities became amalgamated into their routine. This finding is congruous with earlier studies, which have highlighted the benefits of supporting consistent routines in FTD [19, 29].

An important theme generated in the thematic analysis was related to barriers to carer uptake and implementation of the TAP intervention. The most common barriers pertained to the carer feeling stressed, feeling like they don't have enough time for themselves, and difficulty finding the time to introduce the activities with their family member. A number of carers were still employed while participating in TAP, while others still had dependent children at home. These are common issues faced by families affected by young onset dementia, and are likely to impact on how much time carers are able to invest in implementing the intervention [65, 66]. Further to this, engaging with the TAP intervention requires a level of behaviour change from the carers themselves. This is an important barrier to address, as the literature on behaviour change shows that even if new behaviours are enacted with the introduction of an intervention, it is likely that the old behaviours or 'habits' will reappear over time [67, 68]. A factor that contributes to whether a new behaviour is maintained is if the benefits or outcomes are obvious to the person. While the outward engagement and enjoyment of the person with dementia with the TAP activities was clear, any impact on the person's function or behaviour was subtle. In addition to this, carers of people with FTD have been shown to experience worse stress when their family member is more impaired and when they themselves have dysfunctional coping strategies [69]. Therefore, if carers who were struggling to cope found it difficult to see how their family member's engagement in activities had any benefit for themselves, it may be likely that they lacked the motivation to continue with TAP implementation [67, 70].

While there were no quantitative differences as measured by the vigilance or health related quality of life scales, these factors were still found to be associated with the experience of both the carer and the person with dementia throughout TAP; i.e. carers who were more confident reported less vigilance time, and people with dementia who were more engaged had better quality of life. The potential for multi-component interventions to positively impact on the quality of life of people with dementia has been highlighted in a previous systematic review [71]. Reasons for not

finding specific changes to vigilance time or health related quality of life in the present study may be due to the small number of participants, or that the measures used were not sensitive to these specific variables.

Given the challenging issues facing families affected by FTD and also health professionals who provide clinical care, we will summarise here some key lessons learned from this carefully planned randomised controlled feasibility trial in FTD. Firstly, the finding that carers who had higher levels of readiness to change and confidence were more likely to have better communication and activity simplification skills, and less likely to feel “on duty” and be “doing things” for the person with dementia has important clinical implications. This is a crucial take-home message, as informal carers are the vital stakeholders when implementing an intervention in a community setting. Therefore, we recommend that ensuring adequate education and support to informal carers is requisite when developing any FTD interventions in a community setting. Secondly, the development of activity interventions should carefully consider the current functional abilities of the person with dementia. Specifically, we found that people who were more engaged in activities were less functionally impaired and had better health related quality of life. Clinically this is important to be taken into account for both the person and their carer. Providing activities that are achievable and allow for the typical behavioural disturbances that occur in FTD, such as agitation or motor behaviours, will reduce the chances of frustration or rejection of the activity from the person with dementia. Frustration of carers will also be reduced in that they will moderate their expectations and learn what reasonable engagement may be achieved from their family member. For a detailed case study description of TAP with participants with FTD, see O’Connor et al. [29].

A number of limitations exist in this study. Foremost is the small number of participants, which has obvious implications on lack of power to report a treatment effect. Secondly, it is known that considerable heterogeneity exists between the different subtypes of FTD [2, 3, 72], therefore the mixed FTD sample included in this study makes the results difficult to interpret. Thirdly, certain biases may exist in the data. For instance, relying on a carer-rated measure of quality of life for the person with dementia may introduce over/under-estimated ratings, and the therapist notes used for the thematic analysis may be subject to the therapist’s own personal biases.

Despite these limitations, completion of the post intervention/control period ratings by a research assistant blind to group allocation lends strength to the study.

This is the first activity-based intervention program to be systematically trialled with an FTD cohort. Despite the small number of participants, the results contribute important foundations to inform the future development of larger intervention studies for FTD. Another critical benefit appears to be in supporting carers in developing better management approaches. Future studies should take particular care in selecting sensitive measurement tools to capture specific program outcomes such as those relating to carer benefits, and include a much larger sample, which would allow for interpretation of the impact of TAP across FTD subtypes.

In summary, this study illustrates the feasibility of conducting non-pharmacological intervention research within an FTD cohort. TAP was an acceptable intervention for this cohort, with benefits reported across both the carer and the person with dementia. The design of a larger trial in TAP or a similar activity-based non-pharmacological intervention with an FTD cohort would contribute to improving the experience of families living with FTD who are often isolated from mainstream dementia services.

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Table 1: Demographic characteristics of FTD cohort TAP and Control subgroups at baseline

	TAP (n=9)	Control (n=11)
Person With Dementia		
Age, years	62.1 (56.7 – 67.3)	65.6 (62.0 – 76.0)
Sex (M/F)	7/2	6/5
Education, years	12.0 (11.0 – 13.9)	13.0 (10.0 – 15.0)
Baseline MoCA Score	12.0 (3.5 – 19.0)	9.0 (2.0 – 11.0)
Disease duration, yrs	4.9 (3.0 – 8.6)	5.0 (4.1 – 6.1)
FRS score	-.59 (-1.54 – 0.61)	-1.27 (-2.18 – -1.27)
FRS Dementia Stage		
	Severe	Severe
Carer		
Age, years	59.0 (13.4)	66.0 (7.3)
Sex (M/F)	2/7	6/5
Education, years	12.5 (3.1)	14.5 (2.7)
Baseline MoCA Score	27.0 (2.8)	27.0 (2.0)

Abbreviations: FRS = Frontotemporal dementia Rating Scale (Rasch score); MoCA = Montreal Cognitive Assessment (/30); NS = not significant. Disease duration refers to the time between symptom onset and baseline assessment date.

Table 2: TAP activities prescribed to FTD participants based on Allen’s Cognitive Levels scores

< 4.0 (Activities with less complexity)	4.0 - 4.4 (Activities with more complexity)
Photo scrapbook Painting Craft activity Chopping fruit Feeding the cat Playing cards e.g. snap	Vegetable garden Making a wooden model Jigsaw puzzle Word puzzles or finder-words Reading short stories Feeding the dog Playing Wii or watching music DVDs Making lunch, dinner, or baking Sorting items Paint-by-numbers Washing the car Photography Archery Household chores

Table 3: Prevalence of themes and subthemes identified in interventionist notes from TAP visits

Theme	Contributing subthemes	No. of participants (%)
1. Carer perceived benefits from meaningful engagement	TAP program is positive e.g. learning strategies	9 (100)
	Activity helped communication/made PWD “seem normal”	6 (66.7)
	Activity provides PWD with role/contribution/positive experience	5 (55.6)
2. Carer engagement in TAP	Showing interest/engagement with TAP process	9 (100)
	Keen to try new strategies; implements strategies/techniques	8 (88.9)
	Carer trials own ideas	8 (88.9)
	Generalising strategies to other care areas	5 (55.6)
3. Strategies used by carer to engage person with dementia	Set up of activity	9 (100)
	Skills in reading nuances of non-verbal cues e.g. when to prompt	8 (88.9)
	Carer managing own behaviour/interactions	8 (88.9)
	Prompting (e.g. visual cues; demonstration) before and/or during activity	8 (88.9)
	Tailoring activities to PWD skills/abilities e.g. fewer steps; simplify choices	7 (77.8)
	Relaxing the rules/changing own expectations e.g. allowing more/less time for an activity	7 (77.8)
	Education on FTD/dementia facilitated more effective interactions between carer and PWD	7 (77.8)
Involving children (or other family members) in care of PWD	6 (66.7)	
4. Barriers to TAP uptake/ implementation	Not much time for self/feeling stressed	5 (55.6)
	Difficulty finding time to introduce activities	3 (33.3)
	Difficulty thinking of future declines/wanting to take care day-by-day	3 (33.3)
	Concerns about infantilising PWD; carer felt they had over/under estimated PWD abilities in the past	3 (33.3)

	Carer seemed disengaged with TAP process; carer did not facilitate activities with PWD	2 (22.2)
5. Engagement of person with dementia in TAP	PWD keen to engage in activities	9 (100)
	Outward expression of positive engagement e.g. smile/happy when doing or completed activity	9 (100)
	Activity become habitual/part of PWD routine	5 (55.6)
	PWD included in decision of activities	5 (55.6)

Table 4. Longitudinal analysis of clinical variables between the FTD cohort TAP and Control subgroups

		TAP (n=9) Mean (95%CI)	Control (n=11) Mean (95%CI)	Main effect	
				Follow-up time	Group and follow-up time interaction
				F (<i>p</i>)	F (<i>p</i>)
NPI-C:					
# Behavioural domains endorsed (max 14)	Baseline 4 Months	7.6 (6.4 – 8.9) 5.9 (4.8 – 7.1)	6.8 (5.7 – 8.0) 6.6 (5.5 – 7.6)	8.073 (.011)*	4.728 (.043)*
Apathy (0 – 1452)	Baseline 4 Months	494.1 (143.2 – 845.1) 559.2 (224.7 – 893.8)	886.2 (568.4 – 1204.0) 851.7 (544.7 – 1158.8)	0.053 (.821)	0.557 (.465)
Agitation (0 – 2028)	Baseline 4 Months	128.6 (33.6 – 223.6) 142.2 (53.1 – 231.3)	169.3 (83.3 – 255.4) 93.6 (11.5 – 175.8)	2.277 (.148)	4.712 (.043)*
Disinhibition (0 – 3072)	Baseline 4 Months	112.0 (-17.6 – 241.5) 104.7 (-13.2 – 222.5)	141.6 (24.1 – 259.1) 87.1 (-22.7 – 196.9)	0.871 (.363)	0.509 (.485)
Motor disturbance (0 – 972)	Baseline 4 Months	50.7 (6.7 – 94.6) 45.4 (5.6 – 85.3)	32.0 (-7.9 – 71.8) 27.7 (-9.4 – 64.9)	0.175 (.680)	0.002 (.965)
DAD: Total	Baseline 4 Months	52.2 (36.7 – 67.7) 51.0 (35.7 – 66.2)	45.1 (31.1 – 59.1) 41.7 (27.8 – 55.6)	1.898 (.185)	0.428 (.521)
BADLs	Baseline 4 Months	74.3 (58.4 – 90.3) 67.9 (52.9 – 83.0)	64.4 (49.9 – 78.9) 65.0 (49.0 – 76.8)	1.436 (.246)	0.546 (.470)

IADLs	Baseline	35.0 (16.7 – 53.3)	29.2 (12.6 – 45.8)	0.375 (.548)	6.980 (.017)*
	4 Months	38.0 (19.8 – 56.2)	24.4 (7.9 – 40.9)		
EQ5D health scale	Baseline	69.9 (53.2 – 86.7)	58.9 (44.5 – 73.3)	2.234 (.152)	0.866 (.364)
	4 Months	66.9 (53.6 – 80.2)	46.0 (33.3 – 58.7)		
Vigilance: On duty	Baseline	10.8 (5.0 – 16.6)	11.0 (6.3 – 15.7)	0.951 (.342)	1.650 (.214)
	4 Months	10.3 (5.6 – 15.0)	14.3 (9.9 – 18.6)		
Doing things	Baseline	4.8 (2.2 – 7.5)	4.1 (2.0 – 6.3)	0.867 (.365)	0.017 (.898)
	4 Months	5.3 (3.0 – 7.6)	4.8 (2.7 – 6.8)		

FTD = Frontotemporal dementia; TAP = Tailored Activities Program; DAD = Disability Assessment for Dementia (%); EQ5D = Euroqol 5-D Health Scale (%); NPI-C = Neuropsychiatric Inventory Clinician rating scale (individual behavioural scores are composites = frequency x severity; score in bracket under behaviour name shows max possible score); Vigilance (hours).

F = Linear mixed models. Scores represent modelled means for all variables. * $p < .05$

Figure Legends

Figure 1: Randomisation flow chart of FTD participant dyads through the TAP trial

Figure 2: Frequency of behavioural symptoms present across all participants (n = 20) at baseline

For each participant, behavioural symptoms were rated as present if that behavioural domain was flagged on the NPI-C (Neuropsychiatric Inventory Clinician Rating Scale); # - behavioural domains analysed as individual outcomes of this study.

Figure 3: Carer acceptability of TAP

Figure A: Percentage of carers across stages of readiness to change at the beginning of TAP and again at the conclusion of the TAP intervention. Figure B: Percentage of carers at the beginning and conclusion of TAP who “extremely”/ “very much” or “moderately”/ “a little” found the TAP visits useful; had effective communication style with the person with dementia; and had effective approaches to activity simplification for the person.