**Whanau intervention in memory service for the prevention of dementia**

**Version 3**

As a memory service, we have recently compiled a brochure specifically for the children/ whanau of the people who have been diagnosed with memory impairment. The purpose of the brochure is to provide the whanau with information on the preventable risk factors for dementia so that they can alter them now when it counts and could decrease the risk of developing dementia. Many public health measures addressing these in the general public seem to fall on deaf ears, but my hope is that if our participants parent has just received a diagnosis of dementia, the response might be, “ I hope it won’t happen to me”. We therefore felt that this would be a perfect audience to target and potentially could have far reaching ramifications for the wider whanau.

This study will be working with the family members of people that have just been diagnosed with dementia or mild cognitive impairment in our memory service and investigating whether our intervention ( pamphlet) would be helpful in them reducing their risk factors for dementia. This is not a long-term longitudinal follow up study, it is more to investigate whether the information that we provide will alter their behaviours – ie smoking, exercise and diet in a 6-month period. If this proves to be beneficial, then we could consider a future longitudinal study.

**Researchers:**

Dr Bronwyn Copeland, Cheryl Collier, Dr Fiona Miller and Dr Gary Cheung

**Literature:**

Dementia is a growing health concern that is increasing in prevalence due to the ageing population. Along with the increase in prevalence, will come an increase in health cost as well as increased morbidity and mortality and carer stress. (1) There have been multiple study trials looking at disease modifying treatments specifically for Alzheimer’s Disease, but there has been limited success and to date there is no cure for dementia. (2) Therefore, many researchers are focussing in the realms of dementia prevention. (3)

Norton et al (2014) reported 7 reversible risk factors for dementia. These were midlife obesity, diabetes, sedentary lifestyle, depression, low education, uncontrolled midlife hypertension and smoking. It was estimated that about a third of dementia cases might be attributed to these modifiable risk factors. This has significant implications from a public health perspective. (4) In addition the multimodal intervention of the FINGER study targeting diet, cardiovascular risk factor reduction, exercise and cognitive stimulation was effective in improving or maintaining cognitive function in at risk elderly.(5)

There are many public health measures to improve the health of the population; and education is an essential component. It has been postulated that in order to produce behavioural change, education needs to be part of a comprehensive programme addressing some of the environmental and social factors underlying such behaviour. (6)

New Zealand has a growing obesity epidemic despite public health measures and health promotion aiming at healthy diet and exercise. (7) Along with the increase in obesity comes an increase in diabetes and hypertension. (8) Cardiovascular disease is a well-known risk factor for dementia. (4) Therefore, it is concerning to see the rise in obesity despite these existing public health measures.

As a Memory service we are seeing patients who are being diagnosed with dementia or mild cognitive impairment, which is an at risk state of developing dementia. It is not uncommon for clinicians in the Memory Service to involve the children of the patients during routine consultation. It is also not uncommon to be asked about their risk of developing dementia and what they could do to prevent them from developing it in the future. This led to our research question as to whether health education tailored specifically to the family members of a person with dementia would alter their health behaviour and decrease their reversible risk factors for dementia. This health education is tailored to the family member of a person with dementia, taking into account their current social and emotional status that may influence their ability to produce lasting change.

We completed a literature search using the following search terms: dementia, cognitive dysfunction, care givers, health behaviours and health promotion. We searched specifically for an educational intervention aimed at family members of people with dementia and the health behaviours of the family member. Unfortunately, despite an extensive search, no research in this area has been published. Most literature was about the health of caregivers in relation to the stress of caregiving, including their life style.

There has been research in other health areas such as smoking cessation in cancer and utilizing the diagnosis as a “teachable moment”. Gritz et al. (2006) commented on the under-utilization of this “teachable moment” to promote smoking cessation in the patients and family of the cancer sufferer. (9)

It is possible that providing psychoeducation to the target group of adult children of people with a new diagnosis of dementia - ie utilizing this “teachable moment” would perhaps be more effective at changing health behaviours than providing it to the general public.

We also needed to create an intervention that if proved to be feasible and effective, it could be easily transferred into primary care where the majority of dementia and mild cognitive impairment cases are diagnosed. We have developed a simple educational brochure on the reversible risk factors for dementia to see whether it would be more effective than treatment as usual, which comprises of a doctor’s appointment in which the treatment options for dementia are discussed. During this appointment there is a discussion on lifestyle factors that contribute to memory impairment, but it is more focussed on the individual with memory impairment rather than the family member.

We chose to conduct a pilot study, which will inform us about optimal design and numbers for a potentially larger study that could be rolled out in primary care. We chose 3 outcome measures related to health behaviours. These are diet, exercise and smoking status. We would also use weight as a more objective measure of behavioural change, as the other outcome measures are questionnaire based.

The first scale used is the Validated 14 Item Questionnaire of Mediterranean diet Adherence. This scale was developed as part of the PREDIMED trial. ([www.predimed.es](http://www.predimed.es); Schroder H et al; Martinez-Gonazalez MA et al) Permission has been granted by the authors to use this scale. (10,11,12)

For the exercise frequency and intensity measure we chose the New Zealand Physical Activity Questionnaire – Short form. This has been validate here in New Zealand is culturally acceptable and relevant. (13)

The 36-Item Short Form Survey (SF 36) is a commonly utilized measure of quality of life and captures both physical and mental health issues. (14)

The measure of smoking would be a simple yes and no answer and if yes we would ask the patient to quantify the amount they were smoking.

Whilst we are waiting for a cure for dementia, we need to focus on the preventing the disease and therefore focussing on the family members of people with dementia may be an important additional public health measure that could be used to supplement existing public health measures to decrease the risk factors for dementia and its’ prevalence.

**References**

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**Aims:**

The hypothesis is that an intervention targetted specifically at the family of the individual who has received a diagnosis of dementia or mild cognitive impairment is more effective in changing health related behaviours in the family than the treatment as usual ( which encompasses the same lifestyle factors) but is targetted at the person with the memory difficulties.

**Study participants:**

Our study participants would be the whanau of the individual who has attended our memory service.

Exclusion criteria: below the age of 18 years, unable to consent

Inclusion criteria: whanau of an individual assessed at the memory service

We would have two groups that are randomly assigned – control group and intervention. The control group will have the opportunity to receive the intervention after 6 months.

We would include family who have not been able to attend the appointment as it is not uncommon that if there is more than one child, only one will attend, as many of our patients children would still be working or living in a different part of New Zealand. We would have a standard video outlining the diagnosis and explanation of dementia or mild cognitive impairment and talk about management for the patient. It would be a generic reproduction of what is portrayed in the memory service appointment. We would analyse the data from this group separately.

**Estimated Sample size**

Since 2013 a Dementia pathway has been established in the Bay of Plenty which has meant that many straight forward cases of dementia are being diagnosed in primary care. Therefore the numbers coming through the memory service have reduced to below 50 per year. Assuming that not everyone will participate in the study potentially means that it would take a long time to recruit participants for a large study. Therefore in discussion with Prof Chris Frampton, biostatistician, the decision was made to have this as a pilot study to inform the methodology of a potentially larger study performed in primary care. We have therefore chosen to have 10 index cases per group, where the index case is the patient seen in the clinic.

**Time frame:**

The study would commence after ethics approval has been granted. I would hope that it could be running by mid 2018. We would run until we have gathered enough participants. The control group would be involved in the study for 12 months ( due to the 6 month delay in our study design) and the intervention group for 6 months.

**Design and method:**

This pilot study is a randomised control trial that will help inform the methodology and design of a larger study that could be performed in primary care. This pilot study will be based in the memory service of Mental Health Services for Older People building on the site of Tauranga hospital and is a secondary referral centre. The participants would be the family members of patients that have attended the memory service and have received a diagnosis of dementia or mild cognitive impairment. The study would have two groups. The control group whereby they attend the appointment as usual with their family members where they are present for the assessment and diagnosis as well as management plan which is aimed towards the patient. Intrinsic in the standard management one would be talking about lifestyle factors with the individual with the memory deficits – such as optimizing diet, exercise and smoking cessation.

The intervention group would get the treatment as usual plus an additional pamphlet outlining the above risk factors. This pamphlet is specifically designed for the family of people with memory impairment (see attachment). This pamphlet was designed by the clinicians in the service and was reviewed by 3 clinicians as well as the head of communications for the District Health board to review its health literacy.

Due to the fact that many family member of patients that attend the clinic are not able to attend due to work commitments or location, we would offer participation in the study to these individuals but would analyse the data separately. In this group there would be a slight variation in the method

 in that instead of them attending the consultation, we would show them a video of the standard advice that is given to the patient in the memory clinic concerning lifestyle and treatment for dementia or MCI. They would then follow the protocol as per the participants that could attend the appointment. The reason for this inclusion is to make the study as inclusive and as real world as possible. This group would also get randomised to either the control – ie the video of treatment as usual or treatment as usual plus the pamphlet.

We would provide an information booklet about the study to the family member and one of the researchers would explain the study and answer any questions. We would then get consent from the individual. We would do baseline measures of health related behaviours such as smoking status, exercise frequency and duration questionnaire and diet quality in particular adherence to a Mediterranean style diet. We would use weight as proxy objective measure of changes in behaviours as the other measures rely on self-reporting. We would also administer a quality of life measure. In the participants that are not able to attend the clinic to do these measures, we could administer it over the telephone and we could ask them to take a photo of their weight on their scale. Baseline demographics and information such as age, gender, ethnicity, marital status, highest education and years of education, occupation, medical problems, and medication would also be collected.

We would then repeat our outcome measures at 3 and 6 months in both groups. At the cessation of the study we would also aim to get qualitative feedback from the participants as to how helpful the intervention was. In order to help with ethics, after the 6 months, we would offer the control group the intervention ( ie the pamphlet)

Intervention group

Time 0 before interventions given as baseline:

 weight,

exercise questionnaire regarding frequency and duration-New Zealand Physical Activity questionnaire short form NZPAQ -SF,

smoking status,

adherence to Mediterranean diet (14 item Mediterranean diet scale – MEDAS- permission granted from the authors of the Predimed study

Quality of life scale (SF36)

Time 1 ( 3 months ):

weight,

exercise questionnaire regarding frequency and duration-NZPAQ,

smoking status,

adherence to Mediterranean diet (MEDAS)

quality of life scale (SF-36)

Time 2 (6 months):

weight,

exercise questionnaire regarding frequency and duration-NZPAQ,

smoking status,

adherence to Mediterranean diet (MEDAS)

quality of life (SF-36)

qualitative interview and feedback.

Control group:

Time 0: weight,

exercise questionnaire regarding frequency and duration-NZPAQ,

smoking status,

adherence to Mediterranean diet (MEDAS)

Quality of life scale (SF-36)

Time 1 (3 months): no contact

Time 2 (6 months- they would now be offered the intervention):

exercise questionnaire regarding frequency and duration-NZPAQ,

smoking status,

adherence to Mediterranean diet (MEDAS)

Quality of life scale (SF-36)

Time 3 (9 months):

 weight,

exercise questionnaire regarding frequency and duration - NZPAQ,

smoking status,

adherence to Mediterranean diet (MEDAS)

Quality of life scale (SF-36)

Time 4 (12 months):

weight,

exercise questionnaire regarding frequency and duration-NZPAQ,

smoking status,

adherence to Mediterranean diet (MEDAS)

Quality of life scale (SF36)

Qualitative interview and feedback

Summary of time line :

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| --- | --- | --- | --- | --- | --- |
|  | Time 0 | Time 1 (3months) | Time 2 (6 months) | Time 3 ( 9 months) | Time 4 ( 12 months) |
| Control group | Baseline measures | Nil contact | Baseline measures and then intervention given | Baseline measures | Repeat baseline measures + qualitative feedback. |
| Interventions group | Baseline measures | Repeat baseline measures | Repeat baseline measures + qualitative feedback. |  |  |

**Intervention:**

The intervention is simply providing the whanau with a brochure that our memory service has designed specifically looking at some of the reversible risk factors for dementia. See appendix

**Outcome measures:**

Weight

Exercise questionnaire ( New Zealand Physical Activity Questionnaire- short form –NZPAQ-Sf)

Smoking status – yes/ no/amount smoked

Adherence to Mediterranean diet (MEDAS scale

Quality of life scale (SF-36)

Qualitative interview and feedback