

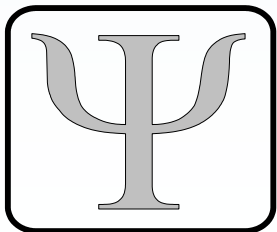
Training and supervision in delivering the START intervention

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*Thanks to Gill Livingston, Claudia Cooper, Dolores Gallagher
Thompson, all the START Team*



Introductions

- Self and research project
- Hopes for the session?
- Current service contexts?
 - Working with carers
 - Supervision experience
 - Training experience

Aims for today's session

- To provide brief overview of evidence base for psychological interventions with family carers
- To outline the START intervention and the RCT
- To summarise the training & supervision processes
- To consider the challenges / dilemmas in training and supervising others to deliver START
- To consider how the START can be developed in our particular service settings

Dementia in the UK

- 70-80% of people with dementia are cared for at home by a relative or friend, saving a considerable amount of public money
- 40% of family carers of people with dementia have depression or anxiety
- Others have significant psychological symptoms
- Psychological symptoms in family carer predicts breakdown of care, institutionalisation and abuse



Policy context

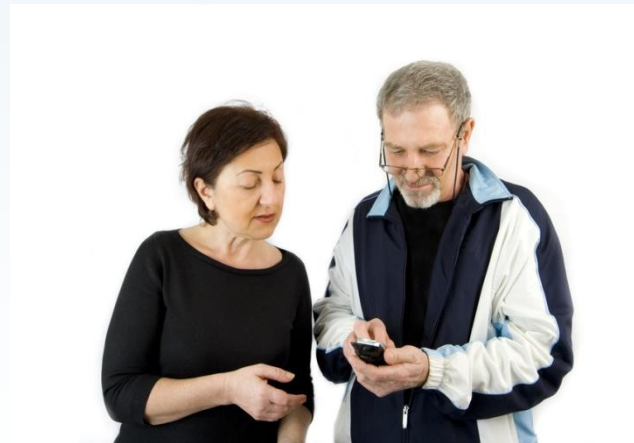
NICE - psychological therapy for family dementia carers is key component of high quality dementia care (Dementia Guidelines)

MSNAP - quality standards recommend psychosocial interventions for family carers as a key dementia care component

However – Limited resources available in practice

Range of interventions currently offered:

- Dementia specific education
- Coping strategies based therapies
- Behavioural management techniques
- Supportive therapy
- Both group and individual formats



Research context

- Consistent excellent evidence that individual BMT for 6+ sessions are effective.
- Good evidence that individual and group coping strategy based interventions are effective.
- Group BMT interventions are not effective (Teaches techniques rather than focuses on specific behaviours)
- Education and supportive therapy alone were not effective. (Systematic review - Selwood et al, 2007)

START Project

Strategies for Relatives (NIHR HTA Funded)

- First Randomised Controlled Trial (RCT) in the UK to test a manual based therapy for dementia carers
- first study worldwide to test the effectiveness of graduates without clinical qualifications in delivering therapy to this group.
- Delivered to individuals



Research questions

Primary objective: What is (1) the clinical and (2) the cost-effectiveness of eight sessions of manual based coping strategy therapy, delivered by supervised graduate mental health workers to family carers, compared to usual service provision, over 8 months (short term) and 2 years (long term)?

Secondary objective: What is the effect of the intervention on carer abusive behaviour and case level anxiety and depression?

Key aspects of Intervention: 8 sessions carer fills in and keeps manual

- Education - about dementia, carer stress and understanding behaviour
- Managing challenging behaviour
- Communication skills
- Skills for self care, including relaxation
- Challenging negative thoughts
- Getting emotional and practical support
- Planning for the future
- Increasing pleasant activities
- Developing an individualised maintenance plan

FIDELITY RATED BY OTHER RESEARCHERS

Acceptability and practicality of intervention

- 260 carers recruited; 173 randomised to intervention and 87 to TAU
- 5 + of the 8 therapy sessions were attended by 130 (75%) carers in the intervention group offered.
- 8(4.6%) withdrew before taking part in any therapy sessions.
- Most liked it and said it helped

Clinical effectiveness

- Carers in the intervention group did better than TAU at 8 months and at 2 years
- At two years the odds of being depressed in the TAU group was 7 x that of the intervention group (OR) =0.14 (95% CI: 0.04 to 0.53)
- Quality of life (HSQ mental health) was higher for carers in the intervention than the TAU group (difference in means = 4.09; 95% CI: 0.34-7.83)

Cost effectiveness

- The costs were slightly higher for the intervention group because of the cost of the intervention
- The intervention cost £232 per carer
- Overall carer costs over 2 years were £170 higher in the intervention group (so less than the cost per carer)
- Overall patient's costs were lower in the intervention groups: £1368

Carer Quotes (Sommerlad et al., 2014)

- “NHS services gave a lot of information at diagnosis; too much negative info at once. I felt START was more supportive and gave smaller bits at a time”
- “I now feel I have all the tools before she gets worse”
- “Sometimes I sit and go through my orange folder [therapy manual] and there is a peace and understanding that someone is there with me”
- “I felt it OK to be angry, upset, made to feel less guilty”
- “What was an added bonus was that it centered on me rather than my husband. Previously all attention and energy had been focused on them”

Feedback also offered improvements to the program

Implications

- First study of family carers evaluating a structured psychological intervention delivered by psychology graduates.
- Rates of clinical depression increased in the control group and decreased in the intervention group suggesting that our intervention may be preventative and treat.
- Cost effective when added to usual care by reference to reductions in carer affective symptoms and improvements in carer health-related quality of life.
- Fits with move towards specialist staff supervising 'low intensity' interventions in stepped care model.

Exercise: Considering the START intervention

Large group discussion, based on reading the sessions:

- What struck you about the intervention?
- How does this fit with your work as psychologists?

Break

Training others to deliver START to family carers

To date training has:

- Combined clinical knowledge and therapeutic skills training
- Been tailored to reflect the specific team context
- Included a combination of formal teaching, small group exercises and role play
- Been delivered as 2 day training with additional self directed time to learn the manual

Training programme – clinical setting 1

Session 1 - Understanding dementia – Including:

- What is dementia – causes, stages, types, symptoms
- What interventions are available – psychosocial, medical
- Organisation of services for people with dementia and their families

Training programme – clinical setting 2

Session 2 - Psychosocial interventions for family carers:

- Overview of current evidence base – including START research
- Theoretical basis of the intervention
- Clinical dilemmas and challenges in delivering the intervention. E.g. ethical considerations, managing risk, lack of fit for carers.

Training programme – clinical setting 3

Sessions 3 & 4 - Training in delivering the manual including:

- Guiding therapists through each session and dilemmas & challenges, including role play / self directed learning.
- Outlining the processes involved in delivering the intervention e.g. receiving referrals, documenting, liaising with other services.

General tips in training therapists to deliver START

- Reflect upon how recently pwd has been diagnosed and the nature of their presentation
- Adjust pace, style, language to fit with the carer
- There are a range of bio-psycho-social factors that will impact upon behaviour
- Homework tasks are a way to identify patterns / reinforce new strategies
- Guide the carers to develop their own solutions for difficulties
- Do not feel you have to be an 'expert' on everything
- Value the carers experience / expertise
- Use supervision to reflect on safeguarding / risk
- Be pragmatic / flexible about completing all 8 sessions

Considerations on training and supervision

- What do you feel it would be important to focus upon in training graduate therapists?
- What challenges and dilemmas could you foresee in training & supervising others?

Supervision structure

- Group supervision with individual support available
- Case management
- Clinical skills development
- Ensuring safe practice with clients
- Staff support

Exercise considerations in supervision:

- **In groups of 5-6 take a vignette and consider the following questions:**
- What challenges may this raise in supervision?
- How might you address this with your supervisee?
- What possible actions might you encourage them to take?
- **Feedback / reflections**

Vignette 1

- Mr Jenkins is a 74 year old man who is caring for his wife who has a diagnosis of Alzheimer's disease. He has attended session 1 and is unsure whether the intervention is for him. During the second session, Mr Jenkins explains that during the day he goes out and in order to make sure that his wife does not wander outside and get lost he locks the front door so that she cannot get out when he is not there. Mrs Jenkins smokes and has increasingly been telephoning Mr Jenkins when he is out crying and frightened about being on her own.

Vignette 2

- Mrs Porter is caring for her mother who has a diagnosis of fronto-temporal dementia. She has had a telephone screening for the intervention. She does not live with her mother but lives locally and visits her everyday. During the screening assessment Mrs Porter reports that she has always had a difficult relationship with her mother however lately her mother has become verbally and at times physically aggressive towards her daughter. Mrs Porter explains to you that she will often get into arguments with her mother and she has recently got hold of her mother when trying to stop her mother from hitting her, gripping her arms. Mrs Porter said that at this time she was frightened that she may hit her mother back.

Vignette 3

- Mr Brown has a diagnosis of Vascular dementia and he lives near his daughter Jeannette who is his main carer. They have always been a close family and since his wife died last year he has become increasingly anxious about being on his own at night. Jeanette has completed 4 sessions of the intervention and during session 4 she explains that she and her brothers have arranged a rota so that one of the family sleep in the spare room at Mr Brown's house at night. He tends not to get up but occasionally will wander into their room and need to be guided back to bed. Jeanette mentions to the therapist that her 14 year old daughter will also stay with her grandfather once a week.

Considerations for implementing in local services

- Resources available
- Referral pathways, How? Who? When?
- Assessment process
- Training processes
- Supervision arrangements
- Risk management
- Practical issues When? Where?
- Evaluation / measures

Looking forward....

In groups with people from your trust / area consider:

- How could this intervention be delivered in your services in the future?
- What are some of the potential barriers / solutions?
- What would be the first steps in your services?

Final learning / action points

- One learning point and one action point from each group
- Any last questions...

References

Knapp M, King D, Romeo R, Schehl B, Barber J, Griffin M et al. Cost effectiveness of a manual based coping strategy programme in promoting the mental health of family carers of people with dementia (the START (STrAtegies for RelaTives) study): a pragmatic randomised controlled trial. *BMJ* 2013; 347:f6342.

Livingston G, Barber J, Rapaport P, Knapp M, Griffin M, King D et al. Clinical effectiveness of a manual based coping strategy programme (START, STrAtegies for RelaTives) in promoting the mental health of carers of family members with dementia: pragmatic randomised controlled trial. *BMJ* 2013; 347:f6276.

Li R, Cooper C, Bradley J, Shulman A, Livingston G. 2012. Coping strategies and psychological morbidity in family carers of people with dementia: A systematic Review and meta-analysis. *Journal of Affective Disorders* 139: 1-11.

Selwood A, Johnston K, Katona C. et al. 2007. Systematic review of the effect of psychological interventions on family caregivers of people with dementia. *Journal of Affective Disorders* 101: 75-89

Sommerlad, A, Manela, M, Cooper, C, Rapaport, P. & Livingston, G. 2014. START (STrAtegies for RelaTives) coping strategy for family carers of adults with dementia: qualitative study of participants' views about the intervention. *BMJ Open* 2014;4:6 e005273 doi:10.1136/bmjopen-2014-005273

<http://www.journalslibrary.nihr.ac.uk/hta/volume-18/issue-61> (Full START HTA report)

Coping based interventions

- The coping strategies family carers use are important predictors of their mental health
- Use of **more emotion focused and acceptance based** and **less dysfunctional coping strategies** is associated with decreased symptoms of anxiety and depression (Cooper et al, 2008, Li et al, 2012)
- **Problem and solution focussed coping strategies** do not protect carers from developing symptoms of anxiety and depression one year later (Cooper et al, 2008)