

Identity preserving care of persons with Alzheimer's disease and their families – a health promoting longitudinal controlled intervention study.

A longitudinal multicentre study is planned to be carried out with a participatory action research design in collaboration with care professionals in two centres in Norway (Oslo, Tromsø), two centres in Finland and five centres in Sweden. This application concerns the Norwegian part of the study. The study will be conducted in three phases: I. home care, II. Home care with day care, and III. Institutional care, from the time the persons are diagnosed with Alzheimer's disease (AD) until their death. The families will be followed up six months after the death of the person with AD. This application for money concerns phase I. We coordinate this study as much as possible with an ongoing dementia study in Nordland (Andersen F) such as use of assessment instruments to make comparisons possible.

Theoretical frame. The project is based on a system theoretical and social constructivist perspective (Bateson 1999, Cottone 2001). According to this perspective, how people with Alzheimer's disease (AD) experience themselves and others, and the way they behave is related to how they are met by others. Analogously, how family and personnel experience themselves as family and personnel is related to how they interact with the person who has AD. We presume that AD affects the whole family and we focus on patterns and relationships within the family. Thereby the family's wellbeing can be focused and health resources be used appropriately. Specific support adapted to each family's needs is provided. In the later phases of the project also professional caregivers will be the focus. Ideas about possible support is found in a systematic review of research about care of persons with dementia, their family carers and professional caregivers (SBU 2007, see below). Research about the care of persons with AD has tended to either emphasize medical, psychological or social aspects (rarely cultural or existential aspects). In this research we wish to combine aspects. We also wish to study the effects of a sense of identity- and integrity preserving care in combination with use of antidementia drugs. Research has also mainly been done with persons with AD as one group and with family members as another group. We want to study persons with AD within their family and also include young family members such as grandchildren and great grandchildren. Based on available knowledge about family support we wish to perform an intervention that persists over time, as earlier studies have been criticized for being too short in duration (SBU 2007).

Literature review. There are descriptive studies that document difficulties related to suffering from a dementia disease (Steeman et al 2006), being a close relative to such a person

(), being a family carer (Gottlieb & Wolfe 2002) and working as personnel in dementia care (Sung et al 2005). The experiences and behaviour of persons with AD will be affected by the brain damage as well as by social interaction. This also affects their families and professional caregivers. Depression especially among family carers (Schulz et al. 1995) and burning out symptoms among professional caregivers have been reported.

Intervention studies are fewer. We use the knowledge reported in (The Swedish Council on Technology Assessment in Health Care, 2007) systematic review of about 1000 research articles about interventions in the care of persons with dementia diseases, carers and personnel from 1975 to June 2004. Three of the participating researchers (AN, KE, KA) took part as experts, and this review shows that persons with AD have previously often been seen as having lost their identity (sense of self). More recent research, using qualitative methods, however indicates that persons with AD even in more advanced stages of the disease can have a preserved sense of self. Similar results are shown by case reports that have not been included in the SBU review but in the NICE Guidelines (2006). See also Ayalon et al (2006) and Robinson et al (2006). The SBU review of intervention studies also shows that effective interventions focused on persons with AD presupposes individualisation and that several care interventions are combined to care programmes. It is clear that the way family and personnel view the persons with AD, communicate, interact and relate to them is crucial.

Poorly described individualisation, few research participants, different interventions with different assessment instruments and outcome measures lead to the fact that no accumulated scientific evidence was found in the SBU review concerning interventions directed to persons with dementia diseases and personnel. Sparse scientific evidence was found for interventions focused on family carers concerning education and psychosocial support.

Identity preserving care. Sabat et al (1999), Sabat (2002) and Sabat et al (2004) have shown how persons with dementia diseases are dependent of how others communicate with them for their sense of self. Identity preserving care aims at helping persons with AD to maintain a sense of being oneself and a worthy person with meaningful relations to significant others, the memory of deceased significant others, nature, activities, things, God (transcendence) and self (Norberg 2001, Phinney 2006, Zingmark 2000). There are several research projects using this approach (using different labels) that have led to positive results (e.g. Kihlgren et al 1994, 1996, Tappen et al 1997). Perry and O'Connor (2002) described how spouses as carers work to help their spouses with AD to maintain their sense of self through various means. This approach is clearly evident in the planned intervention.

People newly diagnosed with AD and their families. The diagnosis of a dementia disease is preceded by a difficult period when the person feels that memory declines and loss of memory becomes a problem and eventually seeks help. Research shows that the persons often react positively when they receive the diagnosis because this explains their experiences (Robinson et al 1998). However, persons react differently. Some develop a “dream identity”, which can be interpreted as a defence against the disease. Others can integrate the insight that they suffer from a dementia disease in their identity and adapt to their changed situation. Family members can support in this process. How family members react to the diagnosis and their ability to integrate this insight is connected to their earlier relationship with the ill person (). Reasonably, support to persons with AD and their families at this early stage can prevent “loss of self” in later phases.

The family. When a family member has AD all family members are affected and the family’s life situation changes. Ways of coping with difficulties in families are described as different during different phases of the disease (Bickel et al. 2000; Davis et al. 2000). Disease related behaviour changes induce stress that affects family members’ health and life quality negatively (Liken 2001, Meuser & Marwit 2001). Family balance and relationships with partner and own children (Creasy et al., 1990; Lieberman & Fisher, 1999), and grand children (Beach 1997, Werner & Lowenstein 2001) are changed. Strong feelings within the family can directly or indirectly lead to decreased support for the person with dementia disease (McCarthy, 1996) and even to family conflicts (Peisah et al 2006) and abuse (Saveman 1994).

Few studies focus on health promotion and strengthening of families’ resources. It seems reasonable that especially during the first phases of the disease there are many health resources within the family that can be acknowledged. Especially the family’s cohesion (Brodaty et al 2006), the family members’ own competences and wish to support each other can be strengthened if the family gets an opportunity to take part in all decisions about care (Strang et al 2006), and by health promoting dialogues about own experiences (Davies et al. 2000; Lieberman & Fisher 1999). The organization today seem to lack continuity which often leave family “left alone” after being diagnosed, according to anecdotes from families and our clinical experience (jmf. Strang 2006). The period from being diagnosed to the time when support is needed from home service or home nursing is described as “A PERIOD OF EMPTINESS”. It seem urgent to cover that period and try to find new ways of organize and lead the care, which is what our intervention is trying /attempt to do.

Research questions. How do persons with AD and their families' experience getting the diagnosis and living with AD? How does living with AD affect the sense of identity and integrity and wellbeing among persons with AD and the experience of stress among families? How is the family affected as a system of relationships? How do interventions in the family affect the members including the person with AD. How do care interventions counteract or enhance effects of drugs? How do the interventions affect wellbeing, hope and coping ability of persons with AD and other family members? How can home aids and nurses support the family and how do they experience working in an identity preserving way. Are male and female burdened in the same extent and in the same way? Do males and females cope differently with the stress connected with AD? We will, if possible, also ask if the intervention is cost effective.

Design. This multiprofessional study is part of a Nordic multicentre controlled intervention study that has a longitudinal single subject design. Results from the centres can be added so that scientific evidence is reached. As the use of evidence based scientific knowledge must be combined with proven knowledge in order to be used in practice (Sackett et al 1996) a participatory action research design is used, which means that the project is performed in close collaboration with persons with AD, their families and personnel.

Participatory action research. Action research is a circular process that contains investigation of actual problems in the social situation researched, investigation of the participants' awareness of and willingness to take part in continuous improvement, shared formulation of goals and working out of methods to reach the goals, implementation of the intervention and evaluation of the effects of actions taken. In this project the Nordic researchers have developed a shared goal after dialogues with professionals in practical care work, who have declared willingness to participate in the project. Participatory action research means that even the families are regarded as active participants in the project and that the content of intervention leads to that new ideas and actions occur in the families and also those new possibilities of interventions and development of the project are identified.

Collaboration between Nordic centres. The researchers will meet and coordinate their studies. The participants that are responsible for the research at each centre will be trained in the same way. The coordination is facilitated by the fact that Norberg works part time at three centres in Sweden and in Tromsø.

Single subject design: Single subject design means an AB-design, i.e. assessments pre (A), and post intervention (B). In this study also in-between evaluations will be performed, as the interventions will be repeated with even intervals respectively be performed continuously.

Data will be collected at several (10) sessions for each case in order to make statistical calculations possible. This method is useful in this longitudinal patient-family centred study as the interaction between individual and intervention is unique. When a series of single case studies with similar evaluation instruments and methods is performed the possibility to get scientific evidence is enhanced as each case can be evaluated and cases can be added for horizontal evaluations. This project is planned to contain 25 families in the intervention group and 25 + 25 families in the control groups in Sweden and 10 respectively 10 + 10 groups in Norway and in Finland (in total 45 intervention families and 90 control families). Although the families are planned to be followed for many years it is possible to make conclusions after each phase of the project at any time with evidenced based results (and even end the project).

Study phases. Phase I: Family life at home with or without home aid(s) and/or home nurse(s). Phase II: Family life at home with or without home aid(s) and/or home nurse(s) and day care and/or respite care. Phase III: The person's with AD life at institution to death, family and personnel are included. The family is followed up 6 months after the death of the person with AD. This application focuses phase I.

Phase I. Life with the family at home with or without home aid(s) and/or home nurse(s). The intervention focuses the persons with AD and their families and includes possible home aid(s) and nurses. The social construction of the family is in focus.

Selection of persons with AD and their families. The selection of persons with AD and their families is performed at the geriatric clinics and psychogeriatric clinics in Oslo and Tromsø.

Inclusion criteria. Six persons diagnosed with probable AD, aged 65-80 years. No active psychoses, speaking Norwegian language and having at least two family members willing to participate in the intervention. The physician asks the person with AD if he/she is willing to meet a researcher who informs about the study (see ethics). Six persons with probable AD that take antidementia drugs and their families that are willing to participate in the study are randomly selected to intervention or control group 1, after 3 months (when it is clear if the patient can tolerate the drug). Six patients that cannot tolerate the drug are included in the control group 2. One drop out is tolerated and further drop outs are substituted with another family.

All families (intervention group as well as control groups) are assessed every sixths month concerning the situation for the family and the intervention group concerning effects of interventions.

Intervention One to three health promoting family dialogues are performed every year and when the family situation changes or the family calls for help. Personnel at the geriatric clinics take part in the data collections.

The intervention: Training of leaders of dialogues, collaborating nurses and home aids and/or nurses. In order to make it possible to perform comparable interventions and data collections all centres in the Nordic project use the same training programme for leaders of dialogues/researcher, aids and nurses. Content: Shared goals for and types of interventions to help people with AD and their families. Leaders of dialogues and participating nurses are trained together in the dialogue method, about research and proven experience about the care of persons with AD and family support. The training in dialoguing contains: attitudes towards dementia and persons with dementia, ways of communicating with and how to establish a non-hierarchical relationship to persons with AD and their families as well as the family's importance for the person with AD. Dialogue technique is emphasised. This training model contains elements of implementing change analogous with action research, concerning emotion, cognition and behaviour. The training philosophy is based on practiced based learning. In order for the participants in the project to understand the general principles that can be applied to specific situations, case studies and role play will be used in the educational model. Reflection is trained by observing and discussing dialogue sessions and specific situations. The participating aids, nurses and researchers apply their gained knowledge in their work with persons with AD and their families. The process of integrating reflection and evaluation is augmented by supervision of the leaders of dialogue groups throughout the intervention.

Case manager role: The nurses will take the role as case-managers, i.e. they support the person with AD and her or his family in using care available, as many families lack knowledge about available resources. They also give advices in practical matters based on their deep knowledge of care of persons with AD. The contact persons for the families' in the control groups will give advices on the families' requests.

Health promoting dialogues have previously been tried (Saveman et al. 2006). The preliminary results from a previous study using three health promoting dialogues for each o 10 families with a variety of diseases (especially dementia disease or cancer) indicate that the dialogues alleviated suffering and enhanced wellbeing, at least during the period the dialogues

were carried out. The families found the dialogues valuable and significant. To narrate one's story was felt as both enriching and difficult. The family members started to listen more carefully to each other's stories that seemed to give more understanding of the others' perspectives. The family members also stated that the dialogues meant that the family had become able to find new problem solutions.

Procedure: First three (3) health promoting dialogues are performed in a period of about 2 months. They are evaluated continuously through reflection in the groups (families and leaders) and personal interviews. After this the health promoting dialogues (series of 1-3) will be repeated after six months and at special occasions when the family asks for it. The leaders of the dialogues will have the opportunity to ask a medical, psychological or social consultant for advice or to request that a person to be seen by these if needed.

Then the health promoting dialogues (series of 1-3) will be held again after half a year and at special occasions in the family, initiated by the person with AD, family members, home aids or nurses. *The content* of the health promoting dialogues focuses on identifying patterns and relationships within the family, the actual life situation and available resources, suffering and vulnerability in the family, views on past-present-future and hope. The foci can vary between dialogues depending on what the family presents as important. The dialogue sessions are audio-taped and observed. The dialogues are characterised by continuous improvement, listening, and sharing. The dialogue sessions are tape recorded and observed.

During the first dialogue session the family members are invited to narrate their present situation, their concerns, positive and negative thoughts etc. Narratives create space for reflection and make room for new understanding of what is happening in the family and with the family members as individuals (Skott 2004). Questions that promote reflection focus on interactions in the family and create room for a new understanding of possible ways of relating and acting. The questions are adapted to family members' affective, cognitive and behavioural level of understanding and focus on *differences*; between persons, relations and between points in time. Other questions focus *effect of behaviour*; connections between specific behaviour and specific interactions. *Triadic questions* are addressed to one family member about the relationship between two other family members. *Hypothetical questions* focus future and investigate family members' expressions of possibilities and alternatives in their life situation (Wright & Leahy 2000).

Resources available within and outside the family are identified, emphasised and enhanced, and this can help the family to cope with stress, strengthen the bonds between the family members and help them confirm each others (Wright & Leahy 2000). The family will also get

support by information about and training in things they ask for directly or indirectly. *Family members' opinions* that are based on their understanding of and coping with the AD, are identified verbalised and challenged. These opinions can help or hinder the family to cope with their changed life situation. Strengthening and inhibiting opinions can lead to changes of family members' emotions, thoughts, and actions, which will lead to increased wellbeing in the family (Wright, Watson & Bell, 1996).

Data collection. Instruments for pre- and post assessments. Persons with AD: Instruments to assess cognitive, emotional, and functional ability, wellbeing, ill-being, quality of life and **use of antimentia drugs use of sedative and health care resources.** MMSE (Folstein, Folstein & McHugh 1975), Barthel's index (Mahoney & Barthel 1965), ADAS-cog (Schwarb, Koberle & Spiegel 1988), NPI (Cummings et al. 1994), SWE tool (Sandman et al. 2006). **Family** (including person with AD as long as possible): MADRS (Åberg et al 1978) Hearth Hope Index (Herth 1992) Swedish version (Benzein & Berg 2003), The Psychological Wellbeing Questionnaire (Kaasa et al. 1988a, b) Swedish version (Sahlberg Blom 2001). Family Hardiness Index (McCubbin, McCubbin & Thompson 1986) Swedish version is being tested.

Individual interviews are performed with all participants. The participants in the intervention- and control groups are assessed by instruments as pre-tests and post-tests, concerning wellbeing, hope, coping ability, functions, burden, view of people with AD. Strengths are focused. **The intervention group:** individual interviews after each session of health promoting dialogues: Content: The home situation, Experienced meaning with the dialogues, and the effect of the dialogues for the individual family members and for the family as a whole. Interviews are also performed if possible with family members that do not participate in the health promoting dialogues. Special questions to young family members (over 6 years) concerning the same areas as for the grown ups. Also home aids and/or home nurses are interviewed. *Persons in the control groups* are interviewed in the same manner but with no questions about the intervention.

Health promoting dialogues with families and supervision of aids, nurses and researcher are tape recorded.

Observation. During health promoting dialogues participant observations are performed. The leaders make notes that are completed immediately after each session, compared and discussed.

Analysis of pre-, in between, and post assessments:

Statistical analyses are performed for quantitative data.

Various types of qualitative analyses of individual interviews, tape recorded group dialogues and observation notes: interaction analysis (Bulow 2000), narrative analysis (Riessman 1998), and phenomenological hermeneutics (Lindseth & Norberg 2004).

Doctoral students. A doctoral student works at every centre. The doctoral students at the centres work with different research questions (they take part in the raising of questions) and can use data from all centres. In this way they can use data both from single subject studies and make horizontal comparisons between intervention groups and control groups.

Time planning: All three phases of the project will span over 10 years. Phase 1 will proceed as long as the family can manage care at home, only with home help. The lengths of phase I will thus differ for the families, so phase II will start with families at different points in time. Phase II starts when the person with AD needs day care. The intervention is then focused on the person with AD, the family and the day care personnel. As it is possible that both persons with AD from the intervention group and the control groups will attend the same day care, both groups will meet personnel that have education and support. Phase III starts when the person with AD moves into an institution. Then the intervention focuses the person with AD, the family and the personnel at the institution. The person with AD is investigated until they die and the family are followed six months after the person's death.

Ethics: Application for approval will be sent to relevant ethics committees. The study presupposes that person with AD as well as their families, home helpers and care personnel give their informed consent, are informed that they have a right to withdraw from the study at any time without explaining why, are promised confidentiality and anonymous presentation of results. Regardless of whether persons with AD gave their informed consent at the start of the study, they will be asked again at every data collection and when the person with AD perhaps has problems to express his or her opinions the researchers will carefully interpret the person's expression to understand if the study harms him or her.

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