
**CENTRE FOR HEALTH
PROGRAM EVALUATION**

WORKING PAPER 21

**EVALUATION OF INNOVATIVE DEMENTIA
PROGRAMMES: A SHORT REVIEW**

Colleen Doyle, PhD
Senior Research Fellow

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The Co-ordinator
Centre for Health Program Evaluation
PO Box 477
West Heidelberg Vic 3081, Australia
Telephone + 61 3 9496 4433/4434 **Facsimile** + 61 3 9496 4424
E-mail CHPE@BusEco.monash.edu.au

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ABSTRACT

Dementia patients are now surviving longer than they did 30 years ago. The result is that in the absence of a cure, carers have to come up with increasingly innovative solutions to the management and treatment of dementia and its behavioural manifestations. This working paper focuses on the social and behavioural techniques used to manage dementia, and discusses alternative ways to evaluate these techniques. Five main attributes of dementia programmes are reviewed: the use of physical design to ameliorate symptoms; communication and the significance of interpersonal relationships; activity programmes; segregated care; and behaviour modification techniques. Finally, alternative models of evaluation programmes are discussed.

Evaluation of Innovative Dementia Programmes: A Short Review

1 Introduction

Professor J. Grimley Evans, a prominent British geriatrician, said at a research symposium in 1987,

"Translating 'senile dementia' into Alzheimer's Disease has undoubtedly produced support for research... If dementia had not been for so many years categorized as normal ageing, the relevant research might have started decades ago." (p. 47)

One interesting report in the *British Journal of Psychiatry* (Christie, 1982) has shown that demented patients are now surviving much longer than they did 30 years ago (see also Gruenberg, 1977). The consequence of this greater physical robustness is that carers have to come up with increasingly innovative solutions to the management and treatment of dementia and its behavioural manifestations.

This paper does not consider the medical or pharmacological treatment of dementia. Instead, it focuses on the social and behavioural techniques currently used to manage dementia, and poses the question of how to evaluate these approaches. The aim is to examine the scientific basis of some aspects of innovative dementia programs, and to discuss possible models to further evaluate the effectiveness of such programs. All clinical interventions rely initially on anecdotal evidence, trial and error and peer review, but it is only by moving beyond these that any solid foundations for treatment can be laid.

In the absence of a treatment for the cause of dementia, management concentrates on alleviating symptoms. Symptom presentation in Alzheimer's Disease (AD) can be affected by a variety of factors. These include areas of the brain affected; size of the lesions; premorbid personality including coping skills, intelligence and motivation, cultural, and ethnic affiliations; and external resources such as the environment, demands of others and economic resources (Buckwater, 1989). Conceptual models for care planning are largely based on symptom presentation. This paper explores the evaluation of programs of management of the symptoms of dementia.

There is widespread support for the behavioural management of cognitive impairment, at the same time minimizing the role of pharmacological treatment. Zarit et al (1990) concluded that in special units for dementia, there is a trade-off between medications and behavioural management. They reported that in their experience, behavioural approaches are more successful in the long run.

"Where medications are emphasized, staff will end up dealing with the side effects, or drugs will generate a new set of problems which then get treated with another medication. For instance, the patient who is over-tranquilized then may need a sleeping medication at night and a medication to counter the tardive dyskinesia symptoms of the tranquilizer." (p.62)

The effectiveness of drug treatment in alleviating behavioural disorders is rarely documented in prevalence surveys (Findlay et al, 1989). Coccaro et al (1990) examined the relative effectiveness of three drug treatments for agitation in demented residents, but found only "modest" efficacy in treating behavioural disturbance. Similarly, Salzman (1987) summarised the therapeutic efficacy of neuroleptics in treating agitation in the elderly as "modest rather than striking" (p.1172).

The following discussion considers the effectiveness of five main attributes of care that are sometimes incorporated into special dementia programmes: the use of physical design to ameliorate symptoms; communication and the significance of interpersonal relationships; activity programmes; segregated care; and behaviour modification techniques.

ROLE OF THE ENVIRONMENT

Sommer & Ross (1958) were the first to report the beneficial effect of changing the physical environment in old people's homes. Theirs was the first study to demonstrate that day rooms with the periphery lined with chairs discouraged social interaction. Lindsley (1964) introduced the idea of 'prosthetic environments'. Just as prostheses are available for a range of physical impairments to restore competent performance, so prosthetic environments may alleviate a behavioural disability. The prosthetic environment is not a re-training environment - it compensates for disabilities rather than seeking to modify them. Zarit et al (1990) suggested that the role of the environment is important in creating a situation in which minimal restraint is needed to assure patient safety. They also suggested that the homelike atmosphere of the unit may have stimulated more appropriate social behaviour. Designers of special care units have paid attention to the size of the unit (smaller is better), physical designs which help in spatial orientation, walking circuits which cater to wanderer behaviour and so on.

However, little evaluation has been carried out of aspects of prosthetic environments in an experimental way. In 1941, Cameron experimented with blindfolds and artificial light to demonstrate a link between light, delirium and agitation. He found that:

"In every instance delirium appeared within an hour after the patient had been put back into the dark room, and in some cases a degree of agitation also had become apparent. This subsided again in about an hour after the patient was brought back into the light. The 'dark room' delirium appeared earlier and was more marked in those patients in whom it was most severe during the night hours."

The implication of Cameron's behavioural analysis was that, since nocturnal wandering was brought about by the interaction between darkness and the memory deficit, then preventing the darkness by leaving on a light might be sufficient to prevent it. He could also have varied the social isolation of his subjects in a similarly simple experiment, but such systematic experimentation is unfortunately rare. Similarly, the objective evidence

of other management based on changes to the physical environment needs to be collected.

STAFF:RESIDENT RELATIONSHIPS

It is commonly agreed that flexibility of staff is crucial to the success of managing residential aged care in general, including dementia patients. While some routines are necessary to the operation of a treatment program, there needs to be as much flexibility as possible. Staff must learn to develop and use personal relationships to play a facilitating and calming role. These relationships provide a humanizing element and permit patients to live in a dignified way. Communication skills of the staff are also emphasised in nursing management. Bartol (1979) recommended altering style of speech, speaking slowly, clearly, increasing volume, decreasing tone. Nonverbal communication strategies recommended were overemphasis and exaggeration of facial expressions, standing directly in front of the patient, always maintaining eye contact, moving slowly, and not abruptly confronting the demented client from behind.

A non-confrontational approach to communication is recommended. Buckwater (1989) referred to the provision of unconditional positive regard, a therapeutic skill emphasised by Carl Rogers in the 1950's, not specifically for demented people. Ways in which carers provide unconditional positive regard include using reminiscence and validation approaches rather than forcing reality orientation, eliminating the number of negative responses from the environment, and using distraction rather than confrontation as a nursing approach.

A systematic version of these altered communication styles is called Validation Therapy. This therapy was first marketed by Naomi Feil (1982). The main goal of validation therapy is to "give disoriented individuals a sense of identity, dignity, and self-worth by validating their feelings without analyzing and interpreting their behaviour" (Babins, 1988, p. 161). An assumption of validation therapy is that disorientation and confusion stems not from neuropathological changes but from 'despair' in the Eriksonian sense (Erikson, 1963) and unresolved life conflicts. While the approach is acknowledged to be unsuitable for the management of primary dementia or disorientation due to an identifiable medical illness (Babins, 1988), it is not clear what type of disorientation the therapy is most effective in treating, as there have been few scientific evaluations of the effectiveness of the technique. In one study, Babins, Dillion & Merovitz (1988) found no change in cognitive impairment among five confused elderly after 21 sessions of validation therapy, but gains were made on some social measures as rated by nursing staff, such as smiling and talking in groups. It may be that the clearest outcome of using this 'therapy' is improved morale of the staff, although this idea has not been tested formally.

ACTIVITY

There is substantial disagreement in the literature between proponents of stimulus reduction and those who recommend stimulus enhancement as an intervention mode for the behavioural management of dementia. Anecdotally, there are reports of catastrophic reactions observed from excesses of sensory, cognitive or social stimulation. But the extent to which sensory stimulation needs to be reduced for maximum effect is not clear. The sensory deprivation theory that supported bare traditional institutional environments for the intellectually disabled was evaluated and found to be without support, but there is no similar evidence for a deleterious effect of

stimulus reduction on dementing elderly. Berg et al (1991) suggested:

"Clearly, research is needed to understand the conditions under which decreases or increases in stimulation are more therapeutic."

Zarit et al (1990) recommended two major components to a behavioural management strategy: an activities program and use of applied behavioural analysis for control of problem behaviours. Their patients were kept as busy as possible, and their clinical observations suggested that agitation and not sleeping at night were more frequent when patients spent long periods of time inactive.

Buckwater (1989) on the other hand suggested that AD patients suffer from a 'progressively lowered stress threshold'. She postulated that when AD patients' stress thresholds were exceeded, that led to symptoms such as increased anxiety, night wakening, catastrophic behaviours, 'sundown syndrome', purposeful wandering, confusion and agitation, combative behaviour, and diminished reserve. Factors that heightened stress according to this theory include fatigue, change of environment, caregiver routine, multiple competing stimuli, demands to achieve beyond ability, and physical stressors such as illness, medications and comfort.

Low or controlled stimulus care units were proposed as one approach to management of behavioural problems commonly associated with AD. Hall et al (1986) postulated that nursing units are characterised by unending spaces and stimuli that can be overwhelming to the AD client with cognitive, affective and conative losses, and a diminished stress threshold. Low stimulus care units included such features as chairs that invited the demented patient to rest for short periods, eating groups limited to three or four residents in their own room rather than a congregate setting, decreased disturbing stimuli such as mirrors and artwork, and decreased aural stimuli such as public address systems, telephones and television sets. These authors recommended implementation of 'time-out' periods twice daily, usually mid-morning and mid-afternoon, and alternating high stimulus activities with more restful ones when negative reactions occur.

There is the possibility that the optimal level of stimulation is dependent on the stage reached in the course of the dementing disease. There is of course wide variation in cognitive ability according to the stage of progression of dementia. Sensitivity to environmental stimulation may gradually reduce over the course of the disease so that by the stage of severe cognitive impairment, passive reception of some stimuli may be comforting, whereas in earlier stages, the extra stimulation of activities may be disorienting.

Studies of severely demented individuals yield some support for this suggestion. Correlational studies of disruptive behaviours associated with severe cognitive impairment, such as screaming, suggest that social isolation may exacerbate the condition. For example, Cohen-Mansfield et al (1990) reported two studies of screaming in nursing home residents. They found that the only influence of the physical environment on screaming was an improvement when exposed to music, suggesting that music therapy may be an effective management technique for some dementing elderly who cry out indiscriminantly. However, screaming was considered by the authors to be a response to social isolation.

Differing levels of activity are probably appropriate according to the stage of dementia of the client. Whether activity can actually alter the course of the disease is still controversial. Animal models provide some support for the hypothesis that activity can prevent deterioration of mental ability. Experimental studies have demonstrated that increased stimulation is accompanied by increased number of neural connections. Rats raised in dull environments gained neuronal connections when they were given greater stimulation, while rats raised in enriched environments suffered loss of connections when the stimulation was taken away. The logical extension of these results is to maintain mental activity as one ages in order to stimulate and maintain neural connections.

However, it is a long inferential path from these animal studies to plasticity of function in the deteriorating brain of a dementing elderly person. The 'use it or lose it' idea has intuitive appeal, but scientific evidence for the beneficial effects of mental activity in humans is in short supply.

In the 1970's, Albert Kushlick explored the relationship between engagement and quality of life (Blunden & Kushlick, 1975). His measure of engagement was used by the Wessex Health Care Evaluation Research Team in studies of methods of increasing engagement in old people's homes, but less work has been done on engagement and its relation to dementia. In exploring the suggestion that inactivity was a symptom of dementia, McFadyen et al (1982) reported a study of two populations, 30 patients in a geriatric psychiatry ward and 24 residents in an old people's home. Staff ratings of cognitive impairment showed low and non-significant correlations with non-engagement, suggesting that lack of activity was not simply another aspect of dementia. The study did not go further, though, to examine whether increased activity could alleviate any cognitive impairment.

In summary, increased activity seems to be more prevalent than stimulus reduction programmes. There is no concrete evidence that increased stimulation would do any harm, but both the theory of reduced stimulation and the benefits of increased activity require further evaluation.

INTEGRATION/SEGREGATION

Related to the idea that it is possible to maintain mental alertness by stimulation, Meacher (1972) raised the possibility that a normal social environment will tend to re-orient impaired patients. To date there is little objective evidence that living with cognitively alert residents improves the alertness of the intellectually impaired, or that contact with other impaired residents increases the rate of deterioration of dementing elderly. Given the current trend towards segregated facilities and special dementia units, Meacher's original suggestion warrants closer investigation. More generally, Moos (1980) suggested that behaviour may conform to that of the majority in some settings, implying an association between behaviour and environment.

It is not clear whether such a global effect would apply to both cognitively alert and impaired residents of long term care. Some evidence for the idea that alertness can be encouraged by social interaction with more cognitively alert residents was presented by Fernie and Fernie (1990). Their paper described a controlled trial which examined the comparative effectiveness of segregated and integrated groups for early and late stage

AD patients in three nursing homes. They found that integration of late stage AD subjects with mentally alert subjects within the same group was ineffective. However, segregated groups comprised of 4 early and 4 late stage AD members and integrated groups comprised of 4 early stage AD and 4 mentally alert members were found to be effective and appropriate sized groups. Outcomes measured were members' participation and sharing of personal experiences. Movement, reminiscence and motivational therapy were found to be complements of groups sessions which prompted members' participation.

COMMON ACTIVITIES PROGRAMS

Rosewarne et al (1991) identified the following activities provided by a sample of 64 hostels in Victoria for demented residents:

- a) Large group activities involving either active participation such as bingo, singing or passive participation such as watching films or visiting entertainers.
- b) Occupational therapy such as craft, gardening.
- c) Mental activity such as reality orientation, sensory stimulation;
- d) Physical activity such as physiotherapy, walks outside.

Few of these occupational, physical or activity therapy programs have been evaluated to determine whether they are beneficial for the residents, staff and families involved. Even relatively well-established and well-known "therapies" have yet to be evaluated systematically.

REMINISCENCE THERAPY

The applicability of reminiscence therapy for the management of more confused elderly has not been properly evaluated (Burnside, 1987). Goldwasser et al (1987) found improvement in a group of confused elderly while acknowledging that the therapy was not suitable for the more severely demented. However, their improvement was limited to significant decreases in depression in the group. They found no change in cognitive or behavioral functioning. The improvements were not maintained at follow-up, when the group had deteriorated to pre-test levels again.

REALITY ORIENTATION THERAPY

Reality orientation therapy (RO) originated in 1958 when James Folsom set up an 'aide-centred activity program for elderly patients' at the Veterans Administration Hospital in Kansas (see Woods and Britton, 1985 for further discussion of the origins of Reality orientation therapy). The first published descriptions appeared in the 1960's. Three major components of the therapy were originally intended:

- (i) informal, or 24-hour, RO involves staff presenting current information to the patient in every interaction, a commentary on what is happening and reminding the patient of the time, place and identities around them. Confused, rambling speech is systematically not reinforced.
- (ii) RO classes were originally intended to supplement the 24 hour approach. One of the innovative aspects of RO was its involvement of all grades of staff in group work.
- (iii) The third aspect involved staff maintaining a particular attitude to each patient, according to the patient's personality and needs. This involved the staff in identifying the person's mechanism of coping with their memory loss (e.g. blaming others, self-blame, denial or withdrawal) and responding appropriately. While individualisation of care has continued to be emphasised, this 'attitude therapy' aspect seems not to have been developed or investigated further.

RO has certainly been the most written and talked about social intervention for cognitive impairment. Woods and Holden have published a book on it ("Reality orientation: psychological approaches to the 'confused' elderly").

Evaluative research overall concludes that verbal orientation is most frequently found to be improved by RO, with much less evidence for more generalized behavioural change. Relatively few studies have identified positive changes in the patients' general functioning, despite many anecdotal accounts. For example, Zepelin et al (1981) carried out a very detailed and thorough study of RO over a twelve month period. Yet such behavioural changes as were found in their study actually favoured the untreated control group, who were residents of a similar nursing home to where the RO program was implemented. It may be that behavioural change is more difficult to assess objectively and consistently. Scales used may be insensitive to small changes. Another problem may be that as Hanley (1984) points out, there is no evidence that staff actually do put the 24 hour RO into practice consistently. Therefore lack of attention to evaluating and changing staff behaviour may account for some of the disappointing results so far reported with regard to general behavioural change.

BEHAVIOUR MODIFICATION TECHNIQUES

Ullman and Krasner (1975) have described the essential nature of the behavioural approach as using 'systematic environmental contingencies to alter directly the subject's reactions to situations' (p.233). General principles of operant conditioning are applied after behaviour analysis identifies the situational context of the behaviour (antecedents), the behaviour itself, and the consequences of the behaviour for the individual. Problem behaviour is modified by manipulating either the situational context or the consequences.

The underlying assumption is that there is sufficient neurological plasticity of function remaining in some demented patients to ameliorate the specific neuropsychological deficits underlying some of their problem behaviour.

This approach has not been used very much to treat dementia, although its use in the treatment of chronic schizophrenia, autism, mental retardation and brain-damaged individuals is well documented. Holden & Woods (1982) pointed out that "there is disappointingly little research in the use of behaviour modification per se with patients clearly diagnosed as having dementia". (p.33).

One of few studies to be published using these techniques is that of Nilsson et al (1988), who found that social reinforcement was successful in treating aggressive behaviour in dementing psychogeriatric patients. However, they were unable to attribute the success of their therapy to a specific component of the programme, since it appeared that there was a Hawthorne effect, systematic observation of the patients by the staff resulting in a reduction in patient aggression. They suggested that nursing staff may have learned patients' individual aggression patterns and avoided provocative elements in their care.

Early studies indicated that dementia patients are limited in their operant learning, suggesting that operant reinforcement as a technique to manage behaviour disorders would also be limited. Hodge (1984) described in detail an unpublished study by

Mackay, who found that compared to elderly controls, demented subjects were seriously impaired in learning with lower, more variable response rates, together with little response to changes in schedules of reinforcement. However, later studies have indicated that brain damage per se in the elderly is not a bar to learning. Two clinical studies, by Hanley (1981) and Gilleard et al (1981) have shown that disoriented dementing patients can be oriented to their ward environment, using an instructional training format within the context of a reality orientation program, providing some evidence that a behavioural or learning-based treatment approach could be successful. However, at present there is little evidence to either support or reject the idea that any behavioural changes achieved through behaviour modification would be lost quickly.

SCIENTIFIC EVALUATIONS ARE RARE

Several publications have already called for rigorous scientific investigation of the issues raised here (Rabins, 1986; Ohta & Ohta, 1988; Holmes, Teresi, Weiner et al, 1990).

The trouble with many so called "evaluations" is that it is not possible to draw any conclusions about relation of treatment plans to residents function or outcome.

"Despite the plausible thesis that special care is beneficial, the available studies have failed to establish dramatic effects of special care units on resident outcome compared to those seen in demented residents receiving routine management." (Berg et al, 1991).

Sixty-nine percent of hostels in the Rosewarne et al (1991) study reported that there was no real evaluation of program benefits.

Surprisingly, real evaluation is rare in this area. The aim is to link treatment to outcome clearly. However, many evaluations stop at description or monitoring of programs rather than really attempting to examine the causal link between the program and its outcome for the recipients. Would a similar outcome have been obtained in the absence of the program, (for example as a result of changes over time in the recipients' status), or with another program?

Evaluations need to take into account staff attitudes and behaviours that may affect the program outcomes.

MODELS OF EVALUATION

Berg et al (1991) pointed out that non-randomized studies, where program recipients are simply described at one point in time while they are in the program, are subject to selection bias. For example, recipients may be discharged systematically from the program if their behaviour disturbs the other participants. Recipients may not all receive the same version of the treatment being evaluated (non-standardization of treatment), and data collectors may unwittingly bias their own results by knowing that the recipients are in the program (non-blinding of data collectors).

On the other hand, randomized controlled trials will be quite expensive and may suffer from similar problems of subjects in the program group not all receiving the same treatment (non-standardisation of treatment), subjects may move between special dementia units and traditional care, non-blinding of on-site data collectors. The small sample sizes of randomized controlled trials may limit acceptability of the results.

Truncated followup periods may not demonstrate the true effect of the program.

A simpler way of evaluating these programs, as suggested by Berg et al (1991), may be through studies using a classic Pre-post intervention design. This would focus the evaluation on the effect of the intervention, to address whether or not a particular intervention works without attempting to understand the underlying processes.

Whatever the design chosen, the program cannot be evaluated in the true sense of the word without demonstrating changes over time. However, because the underlying disease of dementia due to Alzheimer's Disease is degenerative, evaluation programmes have to address the interaction of possible benefits of the programme and costs of deterioration over time. The outcome for the participant may be lack of deterioration rather than improvement.

The unit of analysis in evaluating dementia programmes could either be the individual or the setting. If the unit of analysis is the setting, then global measures of change in individuals participating in the programme could be used. However, it would be difficult with this model to attribute any change in the individuals to particular aspects of the programme. With eclectic approaches to dementia therapies being common in special care units, a more appropriate model of evaluation may be to undertake case studies first, using pre-post intervention designs as used in behaviour modification programmes.

An accumulation of case studies in which the participants and exact nature of their programmes were carefully documented could then be used as a basis for studies of homogeneous groups of subjects. Such an approach might circumvent the problems of studying the general effect of an amorphous programme on heterogeneous subjects, which seems to happen when special care units are studied as a whole.

OUTCOME MEASURES

STAFF MORALE AS AN OUTCOME OF STRUCTURED PROGRAMS

Given the limited comprehension and deteriorating abilities of the dementing elderly, and in the absence of proper evaluation of their effect, one could argue that these therapies may be of greatest benefit to the morale of staff and relatives, rather than acting on the cognitive capabilities of the residents, although this suggestion has not been tested formally. There may be a non-specific effect of changed social interaction with the staff, whereby a structured program of activities and extra training for the staff engenders more respect for the residents and a feeling of purposefulness in caring. Either way, few proper evaluations have been carried out on the effect of these therapies on the mental health of recipients rather than on the morale or well being of caregivers providing the programs.

However, the value of programs in improving staff and families' well-being should not be overemphasised, since it is the welfare of the resident that is paramount. In seeking medical care, you would not want the treatment that above all made your doctor feel as though he was doing a good job; you would surely prefer the one that was best for you the patient.

Another way of involving staff and relatives in evaluation of the dementia program is by using their opinions as substitutes for asking for the opinion of the recipients of the program. As Berg et al (1991) pointed out, there needs to be improved reliability and validity of proxy-derived data by dealing with proxy agreement/disagreement, precision

of response and bias of response.

The best studies appear to be those that combine outcome measures of the patients and the effect of the program on caregivers. For example, Holmes et al (1990) studied residents of special care units and matched controls in traditional units over a six month period. Their study showed no deleterious or beneficial impacts of the special dementia unit on patient behaviours, activities of daily living, or mood. In their study, residents placed in icu tended to be more severely impaired in cognition and behaviour than control residents, but more often ambulatory. Staff in special dementia units appeared less disturbed by difficult behaviours than did staff in traditional units.

Outcome measures based on health indices are also important to include in evaluation. Coleman et al (1990) found higher rates of hospitalisation of residents in a special dementia unit than in traditional units. Increased admissions were due to pneumonia, urinary tract infections and hip fractures. Possible outcome measures that could be used in future evaluations are: efficacy of resident care, level of family satisfaction, staff satisfaction or burnout, medication use, malnutrition among residents with increased energy utilisation (wanderers). There obviously needs to be different outcome measures depending on the stage of dementia reached by the residents of the unit.

Evaluations also need to include some assessment of the cost-effectiveness and cost-benefits of programs. There is no point in demonstrating that a special program is beneficial to the recipients compared with other programs unless some evaluation can also be made of the alternative costs.

CONCLUSION

To what extent are evaluations needed? Evaluations have an intrinsic cost which could arguably be channelled in to direct care instead. Direct care staff cannot be expected to evaluate their own programs because of possible contamination of the program by the evaluation process itself. Independent evaluations are the only way that properly designed, scientifically valid studies can take place. The social and behavioural interventions outlined in this paper cannot gain respectability until more evidence accumulates about their scientific basis. And in many ways, the programs themselves cannot be further refined and improved without continuing evaluation of their benefits. However, given that evaluations themselves can be costly, priorities need to be assigned to the multitude of programs that are now available, not all of which can or need to be evaluated with the same precision or expense.

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