

# Behavioral and Psychological Symptoms of Dementia (BPSD) Educational Pack



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## MODULE 4: Role of caregivers

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## ***Key messages***

- Support by caring relatives is a key factor in community care of people with dementia.
- The emotional relationship between the responsible relative and the older patient significantly determines whether family care can be maintained.
- An effective care system enables caregivers to continue caring for their demented relatives at home and, at the same time, minimizes the negative consequences to them.
- The demands of caregiving may not precipitate an illness event per se in the caregiver, but rather, may aggravate existing vulnerabilities to illness.
- Enhancing the skill of the caregiver in interacting with the patient may prolong the caregiver's ability to provide in-home care and improve the quality of life of both.
- Consideration of BPSD, without understanding the context for the behaviors, can cause staff to view the person with dementia as a collection of symptoms rather than as a whole person.
- Caregiver distress and poor interpersonal relations between the patient and the caregiver can exacerbate BPSD.
- Caregivers can provide useful information about antecedents of, and possible reasons for behavioral problems. This information usually requires more than a single, brief interview.
- Caregivers who have had a poor premorbid relationship with patients are more likely to misinterpret agitated behavior as purposefully provocative and worsen the situation with an angry retort.

## ***Introduction***

Support by caring relatives is the key to continuing community care of people with dementia. Community care is a valid recognition of the right of people with dementia to live as independently as possible in familiar surroundings, such as at home. But often, family care is not possible or sustainable for a number of reasons. Research studies have identified factors that affect the well being of caregivers. For example, the emotional relationship between the responsible relative and the person with dementia significantly determines whether family care can be maintained. Troublesome behavioral and psychological symptoms of dementia (BPSD), and the burden that they create for the family caregiver, are key factors in precipitating a move from family care to a nursing home or other residential care. Also, BPSD can impose a 'caregiver burden' on professionals involved in the care of dementia patients.

Fortunately, there are strategies that have been shown, both clinically and in research, to reduce the burden that caregivers experience in looking after a person with dementia. This module discusses the impact of BPSD on the psychological and physical health of the family and professional caregiver (i.e., their contribution to caregiver burden) and offers some suggestions for interventions shown to reduce that burden.

## ***What is caregiver burden?***

To define 'caregiver burden' more clearly, some researchers use the concepts of objective and subjective burden (Montgomery et al., 1985):

- objective burden refers to the practical problems associated with caregiving such as continuous nursing care
- subjective burden, also called strain, refers to the emotional reaction of the caregiver (e.g., reduced morale, anxiety and depression).

### ***Factors associated with caregiver burden***

BPSD rather than cognitive dysfunction per se or physical dependence/functional impairment impose the greatest burden on caregivers. These include:

- screaming
- physical aggression
- personality clashes (arguments between patients and caregivers)
- wandering
- depression
- resistance to help with activities of daily living (dressing, washing, toileting, eating)
- suspiciousness, accusations
- not sleeping at night.

The above symptoms are recognized as the most burdensome and the most common reasons for psychiatric referral and premature institutionalization.

Although BPSD themselves are clearly the major contributor to caregiver burden, the reaction of the caregiver to BPSD is also important. Caregivers differ in their responses to BPSD and vary in their skills to manage them – not all caregivers find the same symptoms to be troublesome. A number of research studies and clinical observations have identified caregiver characteristics that are either predictive of, or alleviate, burden (Gilleard et al., 1984; Zarit et al., 1986; Morris et al., 1988; Brodaty and Hadzi-Pavlovic, 1990; Vitaliano et al., 1991) (see boxes below and Figure 1).

### **Predictors of Burden**

#### **Very important in predicting caregiver burden**

- Delusions, hallucinations and depression
- Disruptive behaviors (e.g. physical aggression)

#### **Somewhat important in predicting caregiver burden**

- Male gender (though not independently of BPSD, which occur in a higher proportion of men than women)
- Younger age of patient

#### **Doubtful or not important in predicting caregiver burden**

- Type of dementia
- Severity of dementia (i.e., level of cognitive impairment, need for supervision and assistance)
- Cognitive status
- Functional status (ability to work and live independently, manage simple chores and care for self)
- Duration of dementia

### **Predictors of burden: caregiver characteristics**

- Care providers experience greater burden than care managers
- Spouses > relatives
- Women > men
- Proximity (caregivers in closest contact; cohabiting caregivers are under most stress)
- Immature coping mechanisms
- Less support from family and friends
- Less knowledge about dementia, its effects and management
- Poor premorbid relationship with dementia person
- High levels of negative expressed emotions, notably hostility and criticism

### **Protective factors: caregiver characteristics**

- Informal supports (e.g., caring family, friends, neighbors)
- Knowledge about dementia, its effects and management
- Mature coping skills (e.g., problem solving)
- Support groups (e.g., Alzheimer's Association)

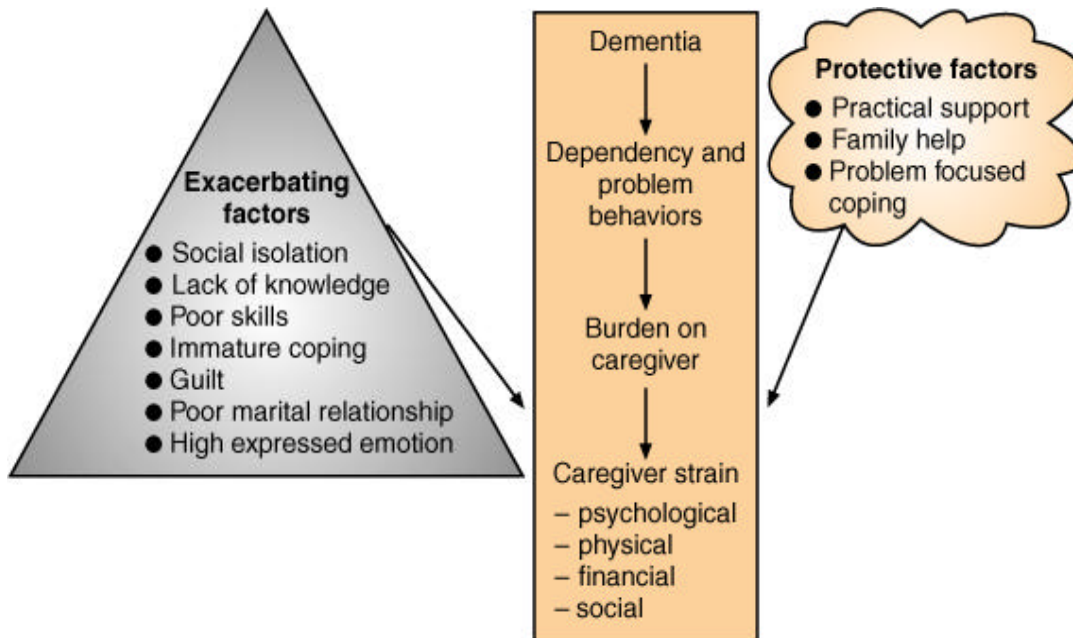


Figure 1. Model of effects of dementia on caregivers. Reprinted with permission from Brodaty, 1996.

## ***The impact of BPSD on family caregivers***

### **Psychological health**

Caregivers are at high risk for developing psychological distress (George and Gwyther, 1986; Whitlatch et al., 1991) and rates of depression and anxiety are increased compared with the general population. The prevalence of depression in adult caregivers of dementia patients has ranged from 14 - 47% in various studies. In addition, 10% of caregivers have been found to meet Diagnostic and Statistical Manual of Mental Disorders Revised Third Edition (DSM-III-R) criteria for anxiety (Dura et al., 1991). Furthermore, researchers report that 7 - 31% of dementia caregivers are taking psychotropic drugs; rates, which are slightly higher than, might be found in the general population (Schulz et al., 1995).

Anger and resentment are emotions commonly felt by caregivers, sometimes bringing the caregiver to the point of violence. In a study of 236 family caregivers of dementia patients, one-fifth experienced violent feelings and feared that they might act on their impulses. Of that one-fifth, one-third reported that they had actually engaged in violent behavior (Pillemer and Sutor, 1992).

Levels of interpersonal and family stress are high in families caring for a demented patient. Among the variables most strongly associated with a caregiver's perception of interpersonal and family stress are behavioral and emotional changes experienced by the patient, changes in the patient's sleep pattern (Schulz et al., 1995) and demanding behaviors (Gilleard et al., 1982; Brodaty and Hadzi-Pavlovic, 1990).

Aneshensel et al. (1995) examined what happens to caregivers as BPSD increase or decrease over time. BPSD were associated with greater caregiver depression when they resulted in:

- an increase in subjective burden

- a feeling of being trapped or confined in the caregiving role.

### **Physical health**

Caregiving has an effect on physical health. Studies have now reported:

- compromised immune function among caregivers (Kiecolt-Glaser, et al, 1987; );
- increased systolic blood pressure among men caring for persons with dementia (Schulz R, Vistainer P, Williamson GM. 1990. Psychiatric and physical morbidity effects of caregiving. J Gerontol; 45:P181-P191).

There is also some evidence linking caregiving to detrimental health-related behaviors such as inadequate sleep and rest, or not seeing a doctor when necessary.

An important emerging area of research evaluating health outcomes in caregivers focuses on changes in subclinical disease as indicators of health effects:

- hypertension
- pulmonary function
- blood chemistries
- cardiac arrhythmia
- Insulin glucose levels
- progression of cardiovascular disease.

- 
- Although demands of caregiving may not precipitate an illness event per se, they may aggravate existing vulnerabilities.
- 

It is likely that the prolonged distress, inherent in caring for a spouse with dementia, may combine with genetic vulnerabilities and current disease status leading to more serious pathophysiology, particularly when both the disease condition and the stressor have been present for several years.

### ***The impact of family caregivers on BPSD***

The behavior of the caregiver towards the person with BPSD has a direct and significant impact on the patient. While the negative effects of BPSD on the caregiver are well documented, there is little appreciation of the caregiver's ability to influence the occurrence and severity of BPSD (see box below). For example, many caregivers believe that the BPSD exhibited by the patient are under that person's control and so must represent antagonistic feelings to the caregiver. Such caregivers experience the patient's forgetfulness as irresponsibility, irascibility as a lack of appreciation, and repetitive questioning as a deliberate attempt to annoy, and are likely to express criticism or hostility towards the patient, which may well further distress the patient. Enhancing the skill of the caregiver in interacting with the patient may prolong the caregiver's ability to provide in-home care and enhance the quality of life of both parties.

#### Caregiver behaviors that can exacerbate BPSD

- Creating sudden and unexpected changes in a patient's routine or environment
- Instigating 'power struggles' with the patient: for example, insisting that a patient do something a certain way or wear a particular article of clothing
- Placing demands on the patient that exceed his or her capabilities

- Being excessively critical of the patient
- Ignoring the patient's needs
- Being excessively rigid or controlling
- Repeatedly prompting or questioning to 'make' the patient remember something
- Being angry or aggressive towards the patient
- Becoming exasperated

- 
- Adverse caregiver behaviors have the potential to incite a 'catastrophic reaction' when the patient exhibiting BPSD is unable to deal with the unexpected stress.
- 

**Caregiver characteristics that alleviate the occurrence and impact of BPSD**

- An empathic, patient, kind, caring, 'warm' attitude toward the patient
- Efforts to understand the causality and meaning behind the behavior
- Unhurried, patient attitude
- Flexible personality, enabling the caregiver not to insist rigidly on compliance
- Adaptability and ability to accept change
- Maintenance of realistic expectations of the patient's abilities
- Reasonable degree of tolerance for 'problem' behaviors such as repetitive activities
- Commitment to keep the patient involved in day-to-day activities
- Fostering of a sense of individualism in the patient
- Allowing the patient at least a perception of control over his or her life and environment
- Sense of genuine concern for the patient's well-being and best interests
- Respect for the patient as a person with emotions and feelings
- Absence of a feeling of shame over a loved one's illness
- Lack of desire to 'hide' the disease from others
- Maintenance of a sense of humor
- Absence of thoughts dwelling on the patient's limitations
- Development and maintenance of an emotional support structure

***Interventions for the caregiver to reduce caregiver burden***

The relief of caregiver burden may considerably decrease BPSD in persons with dementia and there is a range of caregiver interventions designed to do just that. Caregiver interventions can be targeted at three broad areas: psychological support, educational activity and development of a social support system for the caregiver. Specific elements within these broad categories are listed in Table 1.

**Table 1. Elements of caregiver interventions.** Reprinted with permission from Brodaty, 1992, (adapted from Toseland and Rossiter, 1989).

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**Psychological**

- Support
  - ventilation (talking about feelings; unburdening)
  - group process/sharing/universality (feeling part of a group and changing the perception from "I thought I was alone, the only one in the world going through this" to "I know that I am someone with a role. I am a caregiver")
  - learning (through didactic teaching by examples from others in similar positions)

- mutual support (emotional or practical support caregivers provide each other [e.g., mutual minding of dependents])
- Counseling/insight therapy/cognitive therapy/relaxation training/stress management (develop effective means of dealing with stress to relieve anxiety, depression and other negative effects)
- Emotional impact – stress, anger, grief, guilt
  - by talking about their feelings, caregivers realize that they are not the monsters they imagine themselves to be for harboring such thoughts and that their feelings can be a reaction to the primitive, infantile behaviors of the person with dementia
- Self-care (caregivers are better able to look after the demented patient and more capable of managing BPSD if they are well, both physically and psychologically)
- Interpersonal relations and communication
  - the means to managing dementia and BPSD are as important as the ends; how caregivers communicate in attempting to change a behavior can determine how successful they will be

### **Educational**

- Information (e.g., progression of the illness)
- Improving home care skills
- Developing therapeutic skills, problem-solving, behavioral techniques
- Planning – emergencies, legal, financial

### **Developing support system**

- Personal, family
- Community
- Professional e.g.,
  - a social worker able to listen to and counsel a caregiver
  - a nurse able to help with administering medication
  - an occupational therapist to help plan activities and organize the house
  - a care assistant able to help with dressing/washing the person with dementia
  - professional respite care

- 
- A detailed assessment of the caregiver is a necessary first step in reducing caregiver burden because a symptom or behavior that is stressful for one caregiver may not be stressful for another.
- 

It is important to help the caregiver control a situation that is stressful, but not to intervene when it is manageable. There are data to show that comprehensive counseling for caregivers and extended families (Mittelman et al, 1994,1995), and caregiver programs (Brodaty and Gresham, 1989, Brodaty et al, 1997) can both reduce caregiver distress and delay institutionalization.

The comprehensive caregiver training programs were multi-faceted:

- Psychological – relieving caregiver distress, allowing ventilation, dealing with guilt, encouraging more reliance on others, discouraging martyrdom
- Didactic – teaching the caregiver about dementia, BPSD, medications, management skills (i.e., how to cope with BPSD, how to communicate with a person with dementia)
- Physical relief - encouraging the caregivers to separate from the person with dementia by actually sending them on excursions while providing respite care
- Social welfare - informing them about social services and social benefit entitlements, organization in the home, exercise, diet and medico-legal matters.

For 12 months after the intensive 10-day training program (Brodaty and Gresham, 1989), caregivers received booster sessions by way of telephone conference calls. At the time of the exit interview, it was evident that different aspects of the program were most helpful for different caregivers and no one aspect was critical for all (Brodaty et al, 1997).

A meta-analysis of caregiver interventions concluded that they were of at least modest efficacy in reducing psychological morbidity in caregivers and moderate efficacy in enhancing caregiver knowledge. Success was more likely when the intervention included the patient as well as the caregiver. Short educational interventions were not successful and marital (dyadic) counseling appeared to be harmful to caregivers (Brodaty et al, in press). Early results from a combined drug treatment for AD and counseling for caregivers appear encouraging (Mittelman et al, 2001).

### **Provision of information**

Provision of information to family caregivers is a key intervention and one that can be executed relatively easily within a group setting or on an individual basis. Caregivers should be given:

- Information on the illness
- Techniques for dealing with specific BPSD (see Module 5)
- Techniques for ensuring the patient's physical safety and well-being
- Techniques for coping with difficult activities of daily living (such as bathing and dressing)
- Methods for obtaining additional personal assistance, entitlements and respite services (e.g., day care, home care).

### **Use of family meetings**

Family counseling has been shown to be effective in relieving caregiver burden (Whitlatch et al., 1991; Mittelman et al., 1994; 1995). The meetings with families are different from the typical case conference and were developed based on the premise that working directly with the whole family might be an effective way to increase the support available to the primary caregiver (Zarit et al., 1985). The primary goal is to facilitate the family's own skills at problem solving and bring these to bear on the situation. A detailed protocol for family meetings is found in Zarit et al. (1985).

### **Use of respite services**

Respite care aims to provide the caregiver with a break from the responsibility and confinement of caring for a dependent with dementia, enabling the caregiver to enjoy some time alone. There are different types of respite, including:

- In-home care - a professional comes into the family home to spend time with the patient with dementia
- Overnight or residential respite - the patient with dementia goes into residential care for a period ranging from one night to several weeks. There is some evidence for the efficacy of residential respite care, and some argue that using residential respite in dedicated facilities in a planned prophylactic manner can enhance this (Brodaty and Gresham, 1992).
- This should enable the caregiver to manage longer with less psychological distress. There is also some evidence that patients with dementia temporarily exhibit more BPSD after returning home after a period of residential respite. Caregivers require preparation for this occurrence.
- Adult day care - the person with dementia attends a day center, thus providing him or her with stimulation and the caregiver with some free time

- Short inpatient stay - admission of the patient with dementia to a hospital for a procedure, investigation or trial of new medication.

A major evaluation of adult day care for dementia found that adequate amounts of day care (twice a week for at least 3 months) reduced many different stress indicators compared with control subjects not receiving respite care (Zarit et al., 1996; Zarit, 2002). In addition, a meta-analysis of comparable studies of respite care (i.e., similar control groups) found a moderate effect of respite care in relieving caregiver burden and dysphoria (Knight et al., 1993).

Many families wait too long before using respite care. Respite care is best used in a prophylactic manner to prevent caregiver breakdown, rather than as an emergency measure once caregivers can no longer cope.

## **Examples of caregiver programs**

One caregiver program that combines many of the interventions outlined here is run by the Brooklyn Alzheimer's Disease Assistance Center (Magai et al., 1995). This program is designed to address educational and emotional aspects of 'caregiver distress' and takes a six-pronged approach, detailed below.

1. Information and case management  
Much of the initial effort is aimed at teaching caregivers about the stages of the disorder and the behaviors that commonly accompany each stage. It is emphasized that these behaviors are generally not intentional, but reflect underlying brain dysfunction.  
  
Caregivers are given oral, written and audio taped information about AD support services (e.g., respite care, home aides) and entitlements. They are also taught to identify and define carefully the troubling behaviors so that specific strategies can be employed. Once problems are viewed as specific and manageable, caregiver distress usually dissipates.
2. Support groups  
Caregivers are encouraged to attend a weekly support group in which members discuss techniques for handling behavioral problems and emotional concerns of the AD patient.
3. Activity groups  
Caregivers are encouraged to attend a weekly patient activity group to observe and learn techniques and activities for managing behavioral problems.
4. Accessibility to professional assistance  
Caregivers are encouraged to call or meet frequently with social work staff and psychiatrists who can assist with their concerns about the patient's behavior and illness as well as their own distress.
5. Respite services  
Caregivers are encouraged to utilize home support services and to send the patient to a day program. Case managers work closely with the caregiver to link them with these services.
6. Intensive individual, group or family therapy  
For caregivers who are experiencing more persistent and serious emotional difficulties referrals are made for individual or group psychotherapy or family therapy.

In another example from the USA, Mittelman et al. (1994; 1995) demonstrated how an eight-point program of counseling for families consistently reduced the number of emotional complaints (e.g., depression, anger, anxiety and insomnia) from caregivers. The program also effectively delayed the

decision to place a spouse or parent with dementia in a nursing home. By the end of the program, only one of the 41 families who had initially been considering nursing home placement for their demented relative actually needed to do so. The 6-month counseling program included:

- advice and assistance in getting auxiliary help
- support groups
- ensuring that families were aware of community resources
- direct counseling of individual caregivers and family members.

### ***Interventions targeted at the patient with BPSD (mediated by the caregiver)***

Management by the caregiver of BPSD has had promising results with a variety of problems, including:

- agitation
- aggressiveness
- depression.

The solid foundation for any clinical intervention directed at modifying the caregiver's contribution to BPSD is helping caregivers to think about and identify appropriate behavioral treatments, rather than responding in rigidly, predetermined ways to specific problems.

There are two main components of this approach:

1. Viewing behavior in the context of a disease which affects cognitive function.
  - Caregivers often misinterpret common problems. For example, they may erroneously believe that a patient asks the same question over and over again to annoy the caregiver or to get attention or because of laziness. The goal is to help caregivers understand that BPSD have an organic basis.
  - Caregivers are encouraged to think about why someone with a memory-impairing disease is behaving in this way (because the person with dementia actually cannot remember) and how that person must feel about this. While caregivers may not be able to respond effectively to the content of a question such as “When can I see my mother?” it is possible to respond to the underlying emotions (e.g., by providing comfort through reminiscence about the patient’s mother).
  - By re-labeling these symptoms, caregivers break the pattern of arguing with patients over factual issues.
  - Caregivers’ responses can contribute to BPSD.
2. Problem solving and BPSD.
  - Increasing the caregiver’s understanding of BPSD flows naturally into the second step: problem-solving
  - Drawn from contemporary behavior therapy, problem solving consists of a series of steps to identify causes and reinforcement of current problems, and generate and implement possible solutions (see Table 2). As an example, inactivity is frequently followed by agitation, which in turn is reinforced by attention. Once such a pattern is identified, the caregiver and clinician can work together to determine ways in which the sequence can be interrupted. Another answer is to introduce an activity that heads off periods of agitation. A further solution may be to reduce or adjust the level of environmental stimulation to eliminate agitation while providing verbal and/or non-verbal reassurance.

In a controlled study assessing different treatments for depression occurring in persons with Alzheimer's disease, Teri and colleagues (1997) found that family caregivers administering problem-solving techniques or pleasurable events schedules reduced the rates and levels of depression in persons with Alzheimer's disease. As a bonus, the caregivers' own levels of depression were significantly lower.

**Table 2. The problem-solving approach to management of BPSD.**

- 
- Assessment – describe and note frequency
  - Identify antecedents, describe behaviors and note consequences (A-B-C approach)
  - Generate solutions
  - Select a solution
  - Rehearse the solution
  - Implement and evaluate
- 

The assessment of patients with BPSD is complicated by the fact that patients are usually unable to express reasons for their behavior and feelings. It is very important that caregivers try to understand this and attempt to determine the underlying basis of the target symptom. Furthermore, establishing a baseline of the frequency and severity of the targeted BPSD is a significant step in problem solving. Then, when a pharmacological or non-pharmacological intervention is introduced, continued monitoring of the symptom by the caregiver can provide an accurate evaluation of the effectiveness of treatment. This information will help clinicians decide when an intervention has been helpful or when an alternative strategy should be initiated.

A study by Hinchliffe, et al (1992; 1995) illustrates the importance of a partnership approach between clinicians and family caregivers. In this study, individual care packages were developed for each patient in which the caregiver had a key role. The care package included:

- Twelve hours with a hospital physician specializing in psychiatry
- Medication for the patient
- Day care center respite (adult day care)
- Teaching behavioral techniques to the caregiver (see Module 5)
- Psychological support and, where necessary, medication for the caregiver.

The authors concluded that the intervention led to improvement in the mental health of the caregiver and decreased BPSD. When BPSD persisted, psychological problems, such as depression and anxiety, remained unresolved in caregivers, suggesting that BPSD are of central importance in determining caregiver mental health.

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- The use of behavioral treatment interventions requires training and experience to obtain optimal results. Clinicians without prior training in behavioral methods should seek consultation before using them.
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### ***Professional caregivers and BPSD***

It is not only family caregivers who can affect and be affected by BPSD – the reactions of professional staff to BPSD are also relevant in providing good care to patients with dementia. Once again, BPSD can cause staff stress and conversely staff management practices can influence BPSD.

Research into the stress levels experienced by professional caregivers has lagged behind similar inquiries into the experiences of family caregivers. Reports of high levels of stress symptoms in psychogeriatric nursing staff are inconsistent. One study found that work was cited as the main contributory factor to stress levels among nurses (Livingston and Livingston, 1984). Another study (Macpherson et al., 1994) found no relationship between psychological disturbance in staff and demographic or work-related factors. In some studies staff turnover has been higher in work places providing care for people with dementia compared to other geriatric facilities which may be because it is more stressful than general nursing (Åström 1990).

In addition to managing BPSD, health professionals caring for people suffering from dementia face several other major problems. These include:

- High dependence of the person with dementia (e.g., inability to dress or wash oneself and use cutlery, related to a patient's loss of functional abilities)
- Communication difficulties for the person with dementia (e.g., the patient may be unable to understand what is being said [receptive aphasia] or unable to express themselves [expressive aphasia])
- Lack of feedback from the person with dementia on actions which are meant to be in that person's interests (e.g., the caregiver does not know what the patient wants or how the patient is feeling about the caregiver intervention)
- Risk of abuse or of doing things that are experienced as abusive by the person with dementia (e.g., the person with dementia may misinterpret help with undressing as the caregiver trying to steal their clothes and react angrily).

These problems cause staff to feel uncertain about the care they provide. In an interview study by Berg et al (1998), it was found that nurses felt like the patients were completely in their hands and that they determined the life of the patient. The lack of validation of their actions evoked uncertainty.

Progression of dementia is accompanied by continuous loss of functional abilities. This makes the patient increasingly dependent on others to meet their physical needs and forces staff to encroach on the intimate zones or boundaries of the person. If this is perceived as offensive or intrusive, it will have direct relevance to BPSD.

## **Patient reactions to staff interventions**

The fact that people with dementia have impaired cognition does not mean that they are indifferent to what happens to them. They react to staff interventions in various ways:

- positively and with gratitude
- negatively by being hostile and aggressive
- in an uninterpretable way (inability to express feelings coherently).

Patients' reactions are often related to how they interpret the nurses' actions – a person with dementia may interpret an action differently from its purpose. For example, the person with dementia may view the caregiver helping him change into pajamas as someone trying to steal his clothes. Aggressive behaviors often occur during invasions of personal space or personal care.

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- Actions and reactions considered in isolation from the context and the person involved can result in staff withdrawing and viewing the patient from a diagnostic perspective rather than as a person.
- 

There is an active interaction between patients with dementia and the professionals who provide private, personal care from which the patient may recoil. Thus, professionals create the world

surrounding the person with dementia – it can be a world of hostility or anger, or the opposite. When it is hostile, the results for the care staff may be:

- low job satisfaction, guilt, low creativity, more burnout and a poorer quality of care
- task-oriented and impersonal care, poorly adapted to the needs of a person with a life history and likes and dislikes.

### **Absence of reliable communication**

Professional staff receives little, if any, verbal feedback from either the person with dementia or from the family, particularly in the later stages of dementia. Information gleaned from verbal communications may be inconsistent or incorrect. This increases the risk that:

- staff may misinterpret the patient's likes and dislikes
- interventions fail
- staff abandon further attempts to understand the wishes of the patient
- staff interprets a patient's behavior as disturbed or meaningless.

Thus there is a need for a supportive structure to support nurses in their caring.

### **The importance of perspective**

Most research has focused on the person with dementia from an 'outside' perspective (i.e., observing the person with dementia). From a caring perspective, more knowledge is needed from the 'inside', by understanding what it is like for the person. It is important to consider:

- what it means to the patient to be demented
- if there is any associated suffering
- how to interpret communication
- how to interact despite communication difficulties.

Some staff may be intuitive, have experience and know what to do; others often have to resort to trial and error, very much as mothers do with their infants. This kind of interpretative process is fraught with difficulty. A major issue is that, with the increasing loss of verbal and non-verbal communication abilities, the possibility to 'negotiate' between the patient and the professional caregiver on how best to provide care is severely curtailed.

There is always a risk of a vicious cycle developing in the professional care of the person with dementia that is harmful to both the professional and to the patient:

- the person with dementia acts in an uninterpretable or unacceptable manner
- the professional fails to understand why, feels distressed, communicates this non-verbally, but continues regardless with the task
- the patient becomes stressed and reacts with hostility or aggression.

In extreme cases, professionals may abuse patients by using physical force, neglecting them or demanding that they do things that are not in their best interest.

### **Supportive structures for professional caregivers**

Caring for patients manifesting BPSD can be very demanding for professional staff. Supportive structures can assist nurses and other staff to:

- understand the behaviors they encounter better
- help their patients more effectively

- debriefing
- help staff feel more fulfilled in their professional role.

Negative feedback loops (the 'vicious cycle' outlined above) can be turned into positive supportive ones by implementing structures that include a focus on the task-aspect of caring for patients. There are models and instruments for assessing the functional ability of the person with dementia that have been found to be successful in structuring provision of care based upon areas of the impaired person's life. (See Figure 2).

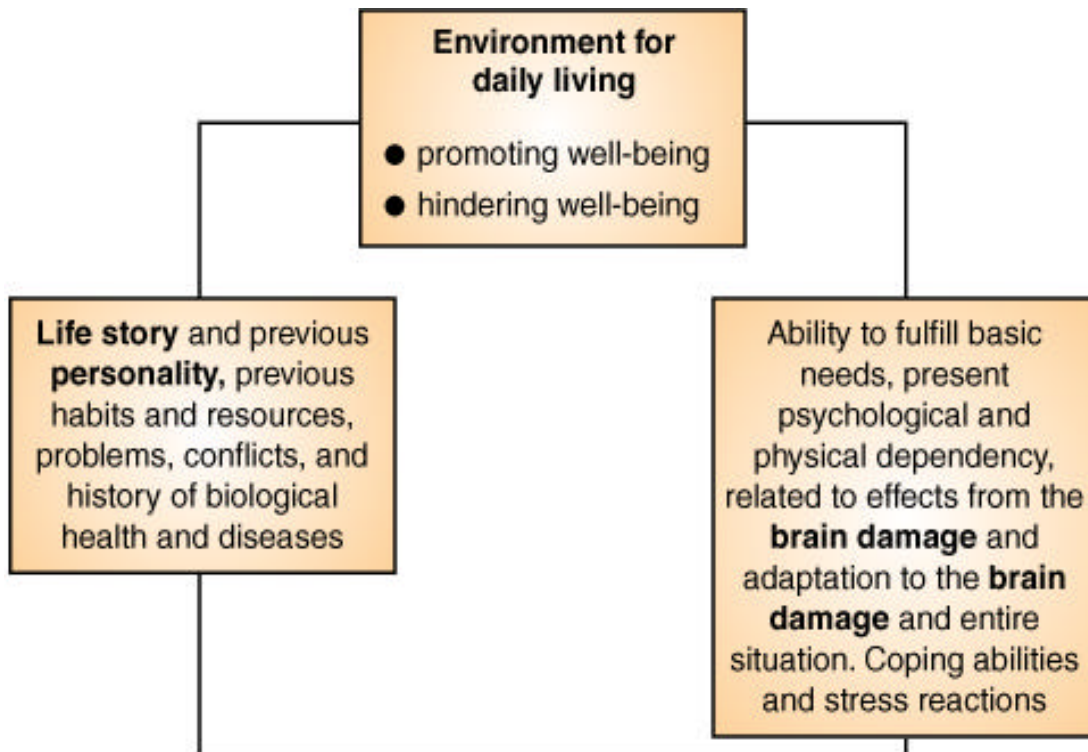


Figure 2. Various aspects of a cognitively impaired person's life that should be covered in the process of needs assessment. Reprinted with permission from Hallberg, 1997.

Proper analysis of BPSD requires knowledge of the affected person's biopsychosocial life history, current situation, the biopsychosocial consequences of brain damage and possible coping strategies.

Regular and repeated reviews are required. Documentation of the provision and outcomes of care procedures is critical in order to monitor how best to help the person with dementia. Examples of the content areas covered in a care plan are shown in the box below (for more details see Edberg 2000).

**Rest and activity**

- the patient's sleep pattern
- need for rest periods during the day
- ability to participate in proper activities
- taking past interests as well as present needs into consideration

**Nutrition**

- the patient's ability to eat, taking into consideration the ability to recognize, handle and understand the food on the plate
- the patient's habits: what times he or she wanted to eat, what were his or her dislikes and favorite dishes, did he or she want to eat in privacy or in a group

**Elimination**

- the patient's continence
- use of diapers
- toilet training
- special habits and whether the patient wishes to be alone or not on the toilet
- diseases and medical treatment that could affect the urinary quantity and the patient's ability to stay continent

**Mobility**

- the patient's ability to move in bed
- from bed to sitting
- from sitting to standing and walking
- mobility aids
- mobility training
- occupational therapy
- diseases and medical treatment that could affect mobility

**Clothing, dressing and hygiene**

- the patient's ability to wash him or herself and to get dressed, including gnosis and praxis
- favorite clothes and colors, hairstyle and use of jewelry
- contact and social needs
- abilities to communicate with others (i.e., ability to hear, see, and speak)
- the need for privacy and closeness/distance

**Personality**

- the patient's premorbid personality
- qualities and temperament (e.g., a bad morning mood)

**Special problems**

- Information on any special problems not described in the areas above

From a task perspective, another way to support the professional is to assign responsibility for the long-term care of each person to a primary professional caregiver. Having a single person as the primary caregiver enables that person to build up a strong relationship with the person with dementia and the patient's family.

This promotes:

- the interpretative process
  - being able to understand what the person is trying to say, being able to interpret the meanings behind some of the behaviors (e.g., agitation means needing to go to the bathroom)
- a deeper understanding of the patient
  - aberrant behaviors do not necessarily just mean pathology of AD, they reflect something about the patient and are therefore meaningful communications which staff should try to understand
- better cooperation with family members
  - family members learn to trust and work with the professional caregiver and devise ways to improve the quality of life of the person with dementia and strategies to manage BPSD.

Case management is also a useful model for supporting home care. A collaborative relationship developed early in the disease process between the professional, the patient and the family caregiver is vital in the collection of the information required to understand the dementia person properly.

A last method focuses on both the emotional reactions of professionals and the interpretation of the person with dementia from an existential perspective. During supervision and counseling, professionals share their feelings and reactions to specific patients and reflect on what they believe life looks like now for the person with dementia. The participants' reflections can be used to evaluate the current care provisions. Regular group supervision and counseling have been successful in:

- reducing staff burn-out
- increasing job satisfaction
- enhancing staff creativity
- improving the quality of care.

A controlled study combining individualized planned care and clinical group supervision (Edberg 2000; Berg 1994) showed staff improvement in job satisfaction, creativity, and reduced burnout and strain in nursing care. Objective indicators of better care include improved cooperation between the patient and staff, and greater patient activity in spite of disease progression (Edberg 2000).

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- Emotionally supporting staff functions as a regular debriefing as well as a means to create and preserve the image of the patient as a person with a life history and feelings, likes and dislikes.
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Palliative care may well be used as a model to care for dementia patients in the late stages. It is prudent to note that patients may sometimes also suffer from other conditions that contribute to suffering and morbidity, for example:

- cancer
- heart disease
- osteoarthritis
- urinary tract infection.

For instance, screaming can be related to pain secondary to osteoarthritis, untreated peptic ulcer, progressive malignancies or even being placed in a chair too long.

## **Conclusion**

Family and professional caregivers are critical to the well being of the person with dementia. Behavioral and psychological symptoms, which are ubiquitous in dementia and are a major source of distress to caregivers as well to the affected persons themselves, can be alleviated. Diagnosis of the cause of behavioral disturbance is always the first step after which there are many strategies to assist caregivers to handle distressing behaviors. These include behavior management, judicious use of medications and changes to the environment. Most importantly, the caregiver is uniquely placed to understand the context in which the behavior is occurring, its meaning, the person behind the behavior and the world of the person with dementia. Caregivers are crucial to the management of BPSD and the management of BPSD is crucial to caregivers.

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