

# The development of the Grip on Challenging Behaviour dementia care programme

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Challenging behaviour is very common in people with dementia. Over 80% of nursing home residents with dementia have been found to show signs of challenging behaviour at any given time (Zuidema et al, 2007). Moreover, recent research shows that almost every resident with dementia will display challenging behaviour at some point during their stay in the nursing home (Wetzels et al, 2010).

The term 'challenging behaviour' (Stokes, 1996; Woods, 2001) is relatively new, succeeding names like disturbed behaviour, neuropsychiatric symptoms, and behavioural and psychological symptoms of dementia. The different ways of naming the behaviour show the gradual evolution from explaining it as a result of organic deterioration to a psychological model of behaviour and finally to a model in which the behaviour is seen as a combination of characteristics of the person with dementia, the social environment, and the interaction between the two (Kitwood, 1997; Cohen-Mansfield, 2001).

The concept of challenging behaviour, however, is quite ambiguous. For example, it is unclear how severe the behaviour must be to be classified as challenging and to whom the behaviour must present a challenge. Behaviour can be challenging to nursing staff or other residents, but behaviour that mainly affects the quality of life of the resident themselves (e.g. through apathy or depression) should not be overlooked either. Nonetheless, problems of definition also exist when using other terms. What is more, where other terms simply state that the behaviour is present, 'challenging behaviour' implies that coping with the behaviour requires attention and a proactive attitude; the behaviour challenges both the person with dementia and the environment to find ways to better understand the reasons why it occurs.

Understanding and then choosing the right treatment for challenging behaviour is not straightforward either. Perhaps one resident should be urged to be more active, while another

### Abstract

**Background:** Current guidelines and theories on the origin of challenging behaviour in dementia indicate that a structured multidisciplinary approach to its management is necessary. In the Grip on Challenging Behaviour study, a care programme was developed to improve the management of challenging behaviour. **Method:** In developing the care programme, the overlapping parts of dementia care guidelines were supplemented with discipline-specific parts. Three meetings with experts were arranged to further develop the structure of the care programme and to ensure a good fit with practice. **Results:** The care programme consists of four steps: detection, analysis, treatment, and evaluation. For each step, forms were developed to guide and structure the process and assign responsibilities for each discipline. As well as a description of the development and the content of the care programme, this paper presents two case studies in which the programme was used. **Conclusion:** The Grip on Challenging Behaviour care programme provides a way for dementia special care units to manage challenging behaviour in a structured way and with a multidisciplinary approach making use of their own resources. **Key words:** Dementia ● Long-term care ● Behaviour ● Intervention development ● Multidisciplinary treatment

resident should get less stimulation. Some residents would benefit from getting help to express their feelings; others should be offered help to turn their thoughts to more positive matters. In some instances medication might be indicated, whereas in most cases psychosocial interventions are preferred. Obviously, before choosing a treatment, a thorough analysis should be made of what constitutes the challenging behaviour and what causes the behaviour to occur and persist.

These considerations about how to manage challenging behaviour in dementia are far from new. Indeed, they have been considered in several evidence-based guidelines (International Psychogeriatric Association (IPA), 2002; Centraal Begeleidings Orgaan, 2005; National Institute for Health and Care Excellence (NICE), 2006). However, in practice the management of

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challenging behaviour is often unstructured and poorly organised (Dorland et al, 2007). Wetzels et al (2010) showed that almost all residents of dementia special care units (DSCUs) develop behavioural symptoms in a 2-year follow up period, and many symptoms are persistent over time, implying that treatment is either insufficient or ineffective. Also, although guidelines state that prescription of psychoactive drugs should be a last resort, this type of medication is prescribed to almost two thirds of the residents of Dutch DSCUs (Wetzels et al, 2011).

It is clear that publishing guidelines is not enough to improve the management of challenging behaviour. A tool is needed that converts the abstract ideas of the guidelines into a method that can be used in practice and that connects the guidelines of different disciplines, so that a structured, evidence-based multidisciplinary approach to challenging behaviour arises.

For the Grip on Challenging Behaviour project, a care programme was developed that structures the steps of detection, analysis, treatment, and evaluation of treatment of challenging behaviour. The programme is directed at care staff, psychologists, and physicians and emphasises multidisciplinary collaboration. The care programme was based on the available guidelines, which were transformed into four practical, ready-to-use steps. In this paper, the development and content of the Grip on Challenging Behaviour care programme are described.

### Methods

#### *Step 1: Merging the guidelines*

The first step of the development of the care programme was to examine the national guidelines on the management of challenging

behaviour. Two of the researchers (MS and SAZ) closely examined the guidelines for elderly care physicians (Verenso, 2008; Koopmans et al, 2010), psychologists (Nederlands Instituut van Psychologen, 2013), and care staff (Verpleegkundigen and Verzorgenden Nederland, 2005) for common ground and differences (Box 2). Because the care programme was initially developed for the Dutch situation, the Dutch guidelines were used as a foundation. However, these guidelines are adaptations from the international evidenced-based guidelines of the IPA (2002) and NICE (2006).

All of the different guidelines follow a stepwise approach to assessing challenging behaviour, which was adopted in the care programme. The process starts with an exploration of the behaviour and the situation; the actual approach differs depending on the discipline. Next, analysis of the possible causes is necessary. Again, in the guidelines the main focus of the analysis differs for each discipline: the physician guidelines have more focus on physical causes and medication whereas the psychologist guidelines emphasise analysis of the environment and psychological causes. The next step is the treatment plan, for which a clear treatment goal should be stated according to the guidelines. The guidelines for physicians and psychologists describe an array of possible treatments and stress that the treatment should primarily be focused on the cause of the behaviour. The guidelines for nursing staff on the other hand list the psychosocial treatment options that are indicated for each behavioural symptom. Next, according to the nursing guidelines, it should be clear who is responsible for executing and evaluating the treatment. The guidelines for psychologists and physicians end with a separate, more elaborate, chapter on how to evaluate treatment.

In short, according to the guidelines it is important that a thorough analysis of the behaviour take place before treatment is started. Also, a clear treatment goal should be described. The guidelines differ in the extent to which they advise on how to actually perform a good analysis. Also, the starting point of the process is different: the guidelines for physicians begin with advice on how and when detection of challenging behaviour should take place; the other guidelines start when challenging behaviour has somehow already become apparent. In developing the outline of the care programme, the overlapping parts of the guidelines were used, such as the stepwise approach and the clear stating of the treatment goal, and were supplemented with the several discipline-specific parts of the guidelines.

**Box 2. Summary of the Dutch guidelines on challenging behaviour in dementia**

Physicians:	Psychologists:	Nursing staff:
<ul style="list-style-type: none"> <li>● By who and when should behaviour be detected</li> <li>● Describe the behaviour</li> <li>● Analyse possible causes (multidisciplinary)</li> <li>● State a clear treatment goal</li> <li>● Kinds of treatment</li> <li>● Evaluation</li> </ul>	<ul style="list-style-type: none"> <li>● Exploration of the (urgency of the) behaviour</li> <li>● Analyse the situation</li> <li>● Make a diagnostic and functional analysis</li> <li>● State a clear treatment goal</li> <li>● Kinds of treatment</li> <li>● Evaluation</li> </ul>	<ul style="list-style-type: none"> <li>● Define who suffers from the behaviour</li> <li>● Describe the behaviour</li> <li>● Determine the cause of the behaviour</li> <li>● Determine treatment, treatment goal, and treatment supervisor; treatments for specific behavioural symptoms are suggested</li> </ul>

**Step 2: Meetings with the experts**

The next step in developing the care programme was to arrange three meetings with a group of care professionals. This group consisted of three psychologist researchers (authors SAZ, DLG, and AMP) with expertise in dementia and the quality of life of nursing home residents, an elderly care physician researcher (author MS) involved in the development of the guideline on challenging behaviour for physicians, a psychologist representative of the Dutch association of psychologists who was involved in the development of the guideline on managing challenging behaviour in nursing homes, a representative of the Dutch association of elderly care physicians, a representative of the Dutch association for care staff, and a nurse and a nurse assistant both working in the nursing home setting. The purpose of involving this group of people was to ensure a good fit between the care programme and actual practice, to make the care programme easy to use in daily care.

The first meeting was used to outline the background and aim of the project. The first two steps of the care programme—detection and analysis of challenging behaviour—were discussed. This meeting focused on which discipline should be involved at different points. With input from this first session, the forms and structure for the first two steps in the care programme were further developed. In the second session, the forms were presented to the expert group. The remarks that were made in this session were used to fine-tune the forms. In the second session the next two steps in the care programme—treatment and evaluation—were discussed. Particularly, the way in which behaviour should be measured for evaluation and by whom were discussed and ideas for the training sessions to introduce the care programme were assembled. In the third and last session the structure of the care programme was discussed. For instance, agreements were made about who should fill in which form, how multidisciplinary consultation

could be prearranged, and who would be responsible for which part of the care programme. After the last session, the final care programme was put together by the project team, which consists of three elderly care physicians and three elderly care psychologists.

**Results****The care programme**

The Grip on Challenging Behaviour care programme consists of four steps.

**Step 1: Detection**

The goal of this step is to detect signs of challenging behaviour early on, to prevent it from escalating or being overlooked—as is often the case with, for example, apathy and depression (Prado-Jean et al, 2010; Leone et al, 2013). Care staff initiate this step, and other disciplines can support it by emphasising the importance of early detection.

To better detect all possible symptoms of challenging behaviour, the care programme introduces the use of a screening tool. The tool used is the NPI-Q, a shortened version of the Neuropsychiatric Inventory (Kaufert et al, 2000). The NPI-Q examines 12 possible symptoms of challenging behaviour, enabling scoring of its severity (range: 1–3) and the emotional distress it causes (range: 0–5). The screening tool should be filled in every 6 months by two or more members of the care staff. In the development of the care programme, the experts expressed concerns about the possibility of care staff getting demoralised in using the care programme if every form of slightly aberrant behaviour were classified as behaviour for which the care programme should be used. Therefore, after thorough deliberation it was determined that a cut-off score of 2 for severity or 3 for emotional distress could be seen as an indicator of the presence of clinically relevant challenging behaviour and could be used to detect signs of challenging behaviour. When a resident scores above the cut-off score, the next

### Box 3. Questions from the care staff analysis form of Mr K

- Could you describe the behaviour? (What do you see, what is problematic about the behaviour?)

*Mr K often hits another resident, mostly Mrs G, and she ends up with a black eye.*

- How often is this behaviour apparent?

*Almost every day.*

- Does something in the direct surroundings happen before this behaviour occurs? (For example music, other sounds, someone entering, interaction with care staff.)

*Yes, often there are other residents in the hallway or in the living room.*

- Where does the behaviour take place?

*Living room, hallway.*

- At which time points does the behaviour occur?

*Several different time points.*

- Did something happen to the resident before the behaviour took place?

*No, if he enters the living room he instantly goes to a resident and hits them.*

- What did you already try to do about the challenging behaviour?

*Remove other residents from the living room.*

step in the care programme is commenced. By introducing the screening tool, the care programme provides a new way to pick up on signs of challenging behaviour at an early stage, which can prevent the behaviour from developing into an acute and unmanageable situation. It also forces care staff to discuss signs of challenging behaviour in a structured way, which should lead to increased awareness and also to earlier detection of symptoms.

### Step 2: Analysis

When symptoms of challenging behaviour are detected (either in normal daily care or via the screening tool in step 1), the analysis of the behaviour begins. The goal of this step is to get a clearer picture of the behaviour and its possible causes. The analysis is started by the care staff and followed up by the physician, the psychologist, or both disciplines.

The care staff starts the analysis using a form. This analysis form was designed for structured gathering of information on the situation, the environment, and the feelings surrounding the challenging behaviour. The 13 questions on the form were derived from the recommendations in the guidelines about clarifying and analysing behaviour (for examples of the questions on the form, see *Boxes 3 and 4*). The form is not a measurement tool of any kind, but filling in the form supports care staff to reflect on the situation and generate possible solutions. It also helps the psychologist and physician to start their own analyses. The form contains questions regarding

the behaviour, the time and place of occurrence of the behaviour, its possible causes, and the actions already being undertaken by the care staff. After filling in the analysis form, care staff can call in either the physician (if they suspect somatic causes or in case of 'acute' behaviour, which points to possible delirium) or the psychologist (when psychosocial causes are suspected). If a psychologist was not part of the care team then an external geropsychologist would be consulted or, if this was also not an option, another discipline with expertise in analysing challenging behaviour would be involved.

Both the physician and the psychologist have their own analysis form, which they fill in when they decide the behaviour should be further examined and treated. The analysis form for the physician consists of a checklist to rule out physical causes, a check of the prescribed medication, and a checklist to rule out psychiatric diagnoses, i.e. delirium, psychotic disorders, depression, anxiety disorder, sleep disorder, or personality disorder. The analysis form for the psychologist consists of several diagnostic options and ends with a functional analysis of the behaviour (Iwata et al, 1982; Lydon et al, 2012). An extra form was developed to help the psychologist with questions to guide an extensive exploration of the behaviour. Both the physician and the psychologist may refer to each other and end their analysis with a conclusion about the possible causes of the behaviour as a start for step 3, treatment.

### Step 3: Treatment

When the care staff, psychologist, and/or physician have finished their analysis, a meeting is arranged between the involved disciplines to discuss the results of the analysis. The goal of the next step is to make a treatment plan containing a clear treatment goal. The psychologist or physician is responsible for this step, depending on their involvement during the analysis. The treatment goal should be stated as specifically as possible, e.g. 'the resident is not pacing more than once a day for a maximum of 5 minutes', instead of 'the resident is less restless'. The current situation should then be rated on a 10-point scale (e.g. resident does not pace at all = 0; resident is constantly pacing = 10). On the treatment form, an evaluation date should also be planned.

The actual treatment is based on the functional analyses of the psychologist and physician. Exact indications for psychosocial interventions such as music therapy and reminiscence are not specified in the literature, therefore the choice for these interventions relies on hypotheses of the causes

of the behaviour, the individual preferences of the resident, and the availability of treatment options in the nursing home. The use of psychoactive drugs or restraint should be prevented as much as possible, which should be a logical consequence of following the steps of the care programme in aiming the treatment at the underlying causes rather than the behaviour itself.

#### Step 4: Evaluation

The goal of this last step is structured evaluation of the results of the intervention. The psychologist or physician is responsible for this step, depending on who drew up the treatment plan. At the time point that was agreed on the treatment form, the involved disciplines sit down together to evaluate the treatment. First, the current situation is again rated on a 10-point scale to determine whether improvements have taken place. Next, either the psychologist or the physician runs through the evaluation form with the care staff. For this, a flowchart is used in which one has to fill in, first, whether the treatment goal has been achieved, next, whether all actions that were agreed on have taken place and, finally, whether these actions should be continued. By following the flowchart, a decision can be made about which steps should be taken next: stopping or continuing treatment (if the treatment goal was achieved after intervening), using another treatment, or revising the analysis (if the treatment goal was not achieved when all planned actions were undertaken).

The forms that are filled in are kept together in one place at the DSCU, preferably as part of the patient's record. The forms are filed under an agenda form, on which every step that is taken is noted with a date and the name of the person responsible for that step. This not only helps to clarify who does what at which time point, it also forces disciplines to actually meet on the DSCU when forms should be discussed.

To clarify the way the care programme can be used, two case studies of its use are presented below. For each case, some of the questions from the analysis using the care staff form are presented.

#### Case 1: Mr K

After filling in the detection form, care staff detected that Mr K showed symptoms of agitation and disinhibition. Symptoms of aberrant motor behaviour and night-time disturbances were also apparent, but they did not exceed the cut-off for detecting clinically relevant challenging behaviour. Because symptoms were detected, the care staff filled in the analysis form, describing Mr K's behaviour

#### Box 4. Questions from the care staff analysis form of Mrs V

- Could you describe the behaviour? (What do you see, what is problematic about the behaviour?)  
*In the morning, Mrs V complains she is feeling nauseated. She refuses care at such moments.*
- How often is this behaviour apparent?  
*Every day.*
- For whom is this behaviour challenging? (For example, resident, family carer, care staff, other residents.)  
*Both for Mrs V herself and for care staff.*
- At which time points does the behaviour occur?  
*In the morning and during the day.*
- Are there situations in which the behaviour does not occur?  
*Sometimes it helps if you provide clear information and direction.*
- What could be the cause of the behaviour?  
*Psychological?*
- What did you already try to do about the challenging behaviour?  
*We consulted the physician and have talked about it with her. There was no effect, we cannot find out why she is feeling this way.*

(Box 3). They sent the form to the unit's psychologist, who decided to have a meeting with the whole care team in response. During this meeting, the behaviour of Mr K was discussed using questions from one of the behaviour exploration forms for the psychologist.

It became clear that certain residents triggered Mr K's memories of his past working experiences and experiences with homecare, which made him violent to those residents. It also seemed that Mr K enjoyed helping out with simple tasks or being offered another activity like drinking coffee. The psychologist pointed out that the challenging behaviour did not start as abruptly as one might think and suggested that if the care staff observed Mr K carefully they would be able to distract him with pleasant activities before his behaviour escalated into hitting another resident.

The results of this analysis from the psychologist were written down on the analysis form. The psychologist gave the care staff practical advice and together with the care team they made a treatment plan and a clear treatment goal ('Mr K is less often irritated by specific other residents and irritation should not last as long as it does now'), which was written down on the treatment form. The team agreed on evaluation in 1 month's time. After 1 month, the care staff confirmed on the evaluation form that they had followed the treatment plan and the behaviour was rated as happening less often and being far less serious.

*‘The Grip on Challenging Behaviour care programme provides a way for dementia special care units to manage challenging behaviour in a structured way and with a multi-disciplinary approach by making better use of their own resources ...’*

### Case 2: Mrs V

The detection form for Mrs V showed symptoms of agitation, depression, apathy, and night-time disturbance. Care staff filled out their analysis form, through which it became clear that Mrs V often complained of feeling nauseated and refused the care that was being offered (Box 4). The physician had already ruled out physical causes so the care staff sent their form to the psychologist. After looking through the file on Mrs V, the psychologist decided to further analyse the behaviour in a meeting with the member of the care staff responsible for Mrs V and in a one-to-one meeting with Mrs V herself.

It became clear that Mrs V was an insecure woman who needed lots of confirmation and structure. Her memory and executive functioning were severely impaired, making it hard to take stock of situations. Her feelings of insecurity and fear of failure expressed themselves in feeling sick. Mrs V did not seem to be clinically depressed. The psychologist advised the care staff to offer structure by, for example, explaining each small step of the process of getting dressed in the morning. It was also important that Mrs V be persuaded to undertake pleasurable activities (and if the problems persisted, a thorough examination of her personality might be appropriate).

The advice was written down in a treatment plan and on the treatment form a clear goal was described (‘Mrs V complains of feeling sick no more than three times a week’). The evaluation date was set for 1 month later, after which it seemed Mrs V was feeling better and the situation had become more acceptable for both the care staff and Mrs V herself.

### Discussion

The national and international guidelines that were used to develop the care programme clearly follow the currently prevailing view that challenging behaviour should be seen as a symptom of an underlying problem rather than a direct result of cognitive and organic deterioration. Algase et al (1996), Cohen-Mansfield (2000), Kovach et al (2005), and others have proposed that challenging behaviour is an expression of distress that arises from physical or psychological unmet needs, and that finding and resolving the unmet needs should be the focus of treatment. In yet another model—the model of lowered threshold—it is assumed people with dementia are more vulnerable to environmental stimuli, which makes them experience more stress than other elderly people (Hall and Buckwalter, 1987). When the threshold of stress is exceeded, symptoms of challenging behaviour may appear. The

adaptation-coping model of Droës (1991) focuses on the coping process of people with dementia and explains challenging behaviour as a (possibly improper) way of adapting to the situations that arise from being cognitively impaired. These models do not exclude one another but rather are supplementary to each other. In accordance, the care programme contains aspects of the different models and emphasises thorough and complete analysis of the behaviour, situation, and environment.

Two earlier attempts to introduce a more structured multidisciplinary approach to challenging behaviour showed positive effects (Opie et al, 2002; Kovach et al, 2006). However, both of these studies involved consulting external professionals. The Grip on Challenging Behaviour care programme provides a way for DSCUs to manage challenging behaviour in a structured way and with a multidisciplinary approach by making better use of their own resources, as a result of which the care programme is more likely to be embedded in usual care.

### Limitations

There are some limitations to the care programme. It was based on Dutch guidelines on challenging behaviour in dementia in long-term care, which presume that both a psychologist and a physician are available for analysing and treating the behaviour. Although it is preferable that a psychologist be involved in the process of managing behaviour, not every long-term care facility has this option. In these cases, an external geropsychologist should be consulted. If another discipline with expertise on challenging behaviour was involved, it would be prudent for this discipline to use the extra form for extensive exploration of the behaviour. Also, in the training sessions prior to implementation of the care programme, extra attention should be given to the analysis being performed by a different discipline to psychology.

In addition, the development process was supported by consulting a group of experts on challenging behaviour. Although this consultation and the background of the authors gives the care programme external validity, the validity is based on the Dutch situation. Translating the care programme for international use might require some culture-specific adaptations.

### Conclusion

Because the published guidelines were not being sufficiently used in daily care, the Grip on Challenging Behaviour care programme was developed as a way to structure the management

of challenging behaviour on DSCUs. The programme consists of four steps: detection, analysis, treatment, and evaluation. Initial implementation indicates that the use of the care programme can indeed support DSCUs in structuring the management of challenging behaviour and can relieve some of the burden on care staff. 

#### Declaration of interest

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