

The early diagnosis of dementia: triggers, early signs and luxating events

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Background. In order to make it possible and feasible that GPs diagnose dementia at an earlier phase than usual, it is important to know what elements in the available information on the patient and the family may trigger the diagnostic hypothesis of dementia.

Method. By qualitative research, the stories of family members of dementia patients, according to DSM-III-R criteria, were analysed.

Results and conclusions. This work produced the following hypotheses: disturbances in functioning at work and ADL-IADL disturbances, the seeking of the carer's support and emotional problems—in addition to the more classical memory problems—are early signs and may be essential triggers for the GP to consider the possibility of an emerging dementia. Change of medication, narcosis, loss of the carer and hospital admission are luxating moments for the sudden appearance of symptoms and disturbances caused by dementia. Further research should be carried out to develop instruments for the early detection of dementia that step across neuropsychological tests and are feasible for daily use in a primary care setting.

Keywords. Dementia, early diagnosis, family practice, general practice, luxating events.

Introduction

Dementia is an important social problem.^{1,2} The number of elderly people in the population and especially of the very elderly, the major risk group for dementia, is rising rapidly.³ Dementia needs attention because it is a major factor of burden for both patient and carers. Many authors have stressed that general practice is the appropriate setting for early detection and treatment.^{4–8}

Despite the development of diagnostic aids,⁹ early diagnosis remains difficult for several reasons:⁷ in the early stage symptoms are vague, people with dementia do not present themselves with memory problems, there is no final gold standard and discussion remains about the potential of the assessment tools. One of the problems is the lack of knowledge about the early signs and symptoms that trigger a hypothesis of dementia.⁴ This is essential, since the diagnostic process in general

practice is mainly hypothetico-deductive.^{10,11} Something in the patient's clinical appearance, story or clinical picture rings a bell: a hypothesis is generated.¹² This first step in the hypothetico-deductive process is called 'triggering'.¹³ In dementing patients this often occurs late, resulting in a long time interval between the first signs—as stated retrospectively—and the final diagnosis.¹⁴ Moreover, the diagnosis is often made only in relation to some crisis.¹⁵

The GP tends to have regular contacts with those elderly persons at risk of dementia.^{9,16} He should, therefore, be in a perfect situation to detect early signs.¹⁷ Furthermore, the GP can be contacted with somatic, psychosomatic and psychological problems. Maybe GPs can be triggered by signs other than the classical cognitive deterioration, such as behavioural problems.⁴ Family members, carers and health care professionals can provide valuable information contributing to the diagnosis.¹⁸ Early in the dementing process they often mention that something is going wrong. Although valid for diagnostic triggering, these messages are ignored by GPs.^{19,20} On the other hand, progressively taking over the role and duties of the dementing person,²¹ family members are often unlikely to bring their difficulties to the GP's attention.¹⁴

TABLE 1 *Basic characteristics of the patients*

Patient	Duration of dementia (years)	Gender	Age	Living at home (H) or institution (I)	Group members involved in the daily care for one of the patients ^a
A	10	female	77	I	3 daughters and a volunteer
B	2.5	male	75	I	daughter
C	0.5	female	76	H	help for the elderly, GP, nurse, 2 daughters
D	5	female	64	H	husband

^a Three out of the 14 group members were not involved in the daily care of these patients: two GPs and one social worker.

Like the patients themselves, they often mask the problems.²² Therefore, it is worthwhile to explore the doctor's, the patient's and the family members' sides of the problem in a detailed way.

Looking for elements that can generate the hypothesis dementia in a GP setting, the following question was formulated: "Which symptoms, signs or triggers, mentioned by the patient, his family, carers or health care professionals can generate the hypothesis of dementia in the GP's diagnostic reasoning? What events are luxating (understood as causing a contact with a physician or any other action resulting in labelling the patient with a diagnosis of possible dementia) in the course of the disease?"

Method

Selection of the research method

Inductive research methods can be valuable to the exploration of undeveloped areas.^{23,24} Therefore, qualitative exploratory research is progressively more frequently used as a group of methods which are complementary to quantitative research.^{25,26} For this study an exploration circle—a variant of a focus group—was used. This is a structured group interview with interaction between the group members.²⁷

The major difference with the better-known focus groups is that the same group meets several times and that the composition is not homogeneous.²⁸⁻³⁰ All people involved in the care of a dementing person participate in the analysis of the process and the interaction between the participants is explicitly used.²⁹ The group is moderated by a professional trained in handling group processes.³¹ Participation is based on equivalence. The size of the group is small and it meets a limited number of times. Preparation includes decisions about the theme, selection of the group members and logistic elements. The group decides on the

subthemes that are explored in depth. The final conclusions are made in consensus.

Procedure

The group focused on the stories of four patients all meeting the DSM III R criteria for dementia (Table 1).³² Basic data were identified by reviewing specialist reports as well as the records of the GPs.

The group was composed of seven health care professionals (one nurse, one social worker, three GPs, one elderly help and one volunteer) and seven family members of a dementing elderly person. There was no patient included in the group because it was expected that, due to cognitive deterioration, a demented patient could not significantly contribute to the discussions. All group members consented to the use of all the research methods.

During a period of 5 months, the group met eight times for 90–120 minutes. All sessions were audiotaped and transcribed. The chronological course of events is noted in Table 2. During the first and second meeting, data were gathered essentially by listening to the stories and experiences of the group members. At the end of the second meeting, after all stories had been told, an inventory of possible subthemes to be examined afterwards was put forward by the group (Table 3). The three main items were the early signs and diagnosis, the family members' own genetic risk of dementia and the question of whether or not biographical elements of the patient played an important role in the course and aetiology of the disease. At the end of the third meeting, the group decided to concentrate on early signs and diagnosis of dementia.

Analysis

The researcher listened several times to the tapes of all sessions and read the transcriptions. For each session, an inventory was made of all elements that could be

TABLE 2 *Chronological course of the meetings*

Meeting	Course
1 and 2	each participant tells his/her experience and involvement in the dementia case
3	thematizing
4 and 5	the family members tell their story again in detail, elaborating on the course of the disease
6	focusing on the relationship between GP and family members in these cases of dementia
7	discussion about dementia with a psychiatrist
8	discussion on triggers, evaluation and closing remarks

TABLE 3 *Elements of the initial discussion and problems resulting from meetings one and two*

- (1) Do live events play a role in the course of dementia?
- (2) Is memory training useful?
- (3) What about genetics in dementia?
- (4) How can dementia be diagnosed at an early phase?
- (5) What care is possible in the home? What are the limits?
- (6) There is a taboo on dementia. Is it difficult to talk with other people?
- (7) Does medication exist?
- (8) Is an emotional person more at risk of getting dementia?
- (9) Is narcosis a risk factor?
- (10) What are the causes of dementia?
- (11) The carers' stress is exhausting.
- (12) There are problems when a dementing person is hospitalized.
- (13) Why is money such a worry for dementing people?
- (14) How should disturbing behaviour be managed?
- (15) How did you progress when you identified the first signs of dementia?

an early sign, symptom or trigger for the hypothesis 'dementia syndrome'. Also possible luxating events were inventoried.

The list of triggers and early signs was posted to the group members to be rated in order of importance (1 = not important as an early sign or trigger, 10 = very important as an early sign or trigger). Health care professionals received one rating list (subgroup 1). Family members received two copies: one to be rated with the stories of all four cases in mind (subgroup 2),

TABLE 4 *Exhaustive list of possible early signs and triggers as mentioned by the group without any ranking order*

Restlessness at night
Disturbance of the day-night rhythm
Fixation on emotional events (e.g. death of family member or friend)
Motoric agitation
Disturbance of daily functioning (doing dishes, personal hygiene, shopping) = ADL
Disturbed function at work
Incapable of following a conversation
Wrong reaction to stimuli in the environment (e.g. telephone ringing)
Making lists as a memory support
Disturbed behaviour (e.g. paranoia)
Looking for partner's support
Anxious look
Formulating own complaints (e.g. I am going mad)
Disturbed recent memory
Disturbed old memory
Outsider notices that something is wrong

the other to be rated according to their own experience with their own family member only (subgroup 3). Several classifications were made by sumscores. Therefore, in each subgroup the sum was made of all ratings as mentioned above. The items were ranked for each subgroup, the item with the highest sum scoring the highest.

Results

Triggers

Table 4 provides an exhaustive list of all elements extracted from the stories told by the family members. After scoring and summing the scores for each of the three subgroups (professionals, family members evaluating all four cases and family members rating according to their own experience), a series of the top five elements was identified (Table 5). The most important was at the top and the least important at the bottom. Disturbed function at work, ADL problems and behavioural problems were important items for the professionals. For our purposes it was important to have insight into the elements that can sound the alarm bell 'possible dementia' for people other than family members, who are often deeply emotionally involved.

TABLE 5 *Early signs and possible main triggers according to the three subgroups*

	Professionals	Family members, all cases	Family members, own case
1	disturbed function at work + ADL disturbance	disturbed function at work	fixation on emotional event
2	abnormal reaction to stimuli in the environment	disturbed recent memory	disturbed recent memory
3	fixation on emotional event	disturbed old memory	incapable of following a conversation
4	formulating own complaint	incapable of following a conversation	formulating own complaint
5	looking for partner's support	looking for partner's support + disturbed ADL function	looking for partner's support

Therefore a separate ranking was constructed by adding the scores of the professionals and the scores of the family members that were based on all cases (subgroups 1 and 2). Disturbed function at work, ADL disturbances, problems with recent memory, not being able to have a conversation and disturbed behaviour were the most important triggers and early signs.

Luxating events

The main luxating events were a change of medication, the loss of a partner or carer, a narcosis and hospital admission.

Discussion

This study focused on the identification of early signs of dementia that could be used as triggers for the GP with respect to a working hypothesis of (possible) dementia. They should include both information gained by the GP when examining the patient and information given by family members and carers.

Disturbed function at work was identified most frequently as an early sign of dementia in two of the subgroups. It was not included by the family members keeping in mind the story of their own relative. Disturbances in ADL-IADL functioning are closely related to disturbances at work. Also with respect to this item, professionals were more triggered than carers, despite the fact that only half of all demented people living at home are able to perform minimal self-care.³³ An explanation could be that carers and families protect their relative against institutionalization, gradually taking over tasks and responsibilities.²¹ People who are less personally involved seem to pick up the disturbances of ADL-IADL more easily than do relatives. When formally asked for it, however, carers also rated the ADL-IADL problems as being very important.³⁴ In a

previous study which examined how GPs diagnose dementia, we also concluded that ADL-IADL disturbances are important triggers.³⁵ Both the DSM-IV criteria³⁶ and the NINCDS ADRDA criteria for dementia³⁷ include ADL-IADL disturbances as essential, and the relation between these disturbances and cognitive impairment was acknowledged in a number of studies.³⁸⁻⁴¹

Problems of recent memory have been mentioned by most carers. They were only ranked in eleventh place however by the professionals. This is in agreement with the findings of Kurz who describes the reports of caregivers of 143 dementing patients.³⁴ It could result from the fact that patients are very tricky and try, at least in the early phase, to hide and mask their problems.²² Patients often do not express memory complaints.⁴² Moreover, during a routine visit by the GP memory tasks are seldom performed. If the physician does not take an active step, he may not recognize any recent memory impairment. Carers do not easily bring memory complaints of their relative to the doctor's attention because they interpret it as an age-associated symptom and because they respect their relative and do not want a diagnosis with negative connotations. In some cases they are not aware of the problems.¹⁴ For these reasons GPs are generally not confronted with complaints triggering for cognitive impairment and therefore do not diagnose dementia: the available instruments focus mainly on memory problems, while patients or carers do not mention these types of problems and physicians do not observe them spontaneously.

In most of our cases, an event in the past brought about emotional distress, resulting in perseveration and/or fixation: bad luck in professional life, relational problems or a deceased partner or friend. This was interpreted by the carers as the cause of the dementia. It should be noted, however, that the fixation or

perseveration on an emotional event can also be part of a depression, which is difficult to distinguish from early dementia.⁴³

Being incapable of following a conversation was less important for professionals than it was for the family members. On the contrary, the professionals focused on inadequate reactions to stimuli in the environment. Both items may have the same aetiology: recent memory impairment causes an incapability to understand what is happening and to react to it in a proper way.

Looking for the partner's support is mentioned in all three subgroups. This is not surprising when one considers that growing functional loss is an inevitable mark of dementia. For professionals this is an important hint: in the caring process one has to keep one's attention on the loss of autonomy that is causing a growing need for support. When the most important carer disappears, often a crisis follows.

A formulation of their own complaint by the dementing patient was an important sign. The idea that one who worries about a cognitive problem is not demented or can be reassured has to be corrected. It is becoming apparent that memory complaints and problems like 'benign forgetfulness' may not be totally benign.⁴⁴⁻⁴⁶

In this study, some items seem to be less important in the early phase: restlessness at night and psychiatric symptoms. Nearly all items were also detected by Kurz.³⁴ He concludes that "the impairment in daily functioning and abnormal social and emotional behavior were the most important disturbances for the carers".

Our results give some idea of how health care professionals may evaluate patients in the early phase of dementia and what items in the patients' story may trigger the hypothesis of 'probable dementia'. These results also reveal that carers of early dementing patients very gradually adapt to the situation, often without being aware of the present pathology. This is a reason for not consulting, which delays diagnosis.

This attitude also partially explains the luxating events. The gradual taking over of tasks and the protection of the demented person by his or her partner and relatives creates a very frail balance often not apparent to the children, relatives or neighbours of the older couple. When the partner or most important carer, for whatever unexpected reason, such as illness, hospital admission or death, is not able to support, the frail balance is broken. A crisis occurs and it becomes clear how dependent the dementing person has become. A crisis often occurs. The change of medication, a narcosis or a hospital admission are other disequilibrating elements. Longer existing but masked problems then come forward.

The testing for ADL-IADL impairment and a growing loss of autonomy are less challenging for patients and their families compared with neuropsychological testing.²⁵ This result makes a good case for the consideration of the development of a dementia-detecting

instrument focusing on ADL-IADL impairment, growing loss of autonomy and emotional or behavioural problems rather than on memory impairment, as most current instruments do.

Qualitative research cannot result in proven statements. It does provide, however, a sound basis for hypothesis generation. Out of the results of this study, the following final hypotheses were formulated: disturbances in functioning at work and ADL-IADL disturbances, and seeking the carer's support and emotional problems—in addition to more classical memory problems—are early signs and may be essential triggers for the GP to consider the possibility of an ongoing dementia syndrome. Change of medication, narcosis, loss of the carer and hospital admission are luxating moments for the appearance of symptoms and disturbances caused by dementia.

Further research has to be carried out to develop broad instruments for the early detection of dementia. The results of this qualitative study may be a first step towards the development of such instrument.

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