Telling “the truth” in dementia—Do attitude and approach of general practitioners and specialists differ?

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Abstract

Objective: The prevailing opinion in the literature that disclosing the diagnosis of dementia to patients is important is not always put into practice. The purpose of this study was to investigate differences between GPs and specialists (neurologists and psychiatrists) in the German ambulatory care system concerning the disclosure of the diagnosis of dementia.

Methods: Thirty in depth interviews with randomly selected GPs were conducted. On this basis a standardised questionnaire was developed and sent to 389 GPs and 239 neurologists and psychiatrists.

Results: The postal survey revealed only minor differences between GPs and specialists, both groups being equally in favour of a timely disclosure. For example, 70% of the GPs and 77% of the specialists strongly agreed that “patients with dementia should be informed early because of the possibility to plan their lives”. This positive attitude is pronounced among younger physicians, but is somewhat contradicted by difficulties in the communication with patients expressed in the interviews. In the interviews, what may be described as a “double taboo” emerges, in that GPs describe taboo topic areas related to dementia for them and for their patients.

Conclusion: The postal survey shows the two professional groups to be very much in favour of a timely disclosure—an attitude that is pronounced among younger physicians. These findings can be interpreted as a recent change of attitudes regarding the disclosure of the diagnosis of dementia in the medical profession.

Practice implications: Training opportunities are needed in order to overcome communication obstacles in the doctor–patient-communication about dementia.

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1. Introduction

General practitioners (GPs) are sometimes criticized for a presumed nihilistic attitude towards dementia, as demonstrated by underdiagnosis [1–5], delayed diagnosis [6–8], and/or insufficient communication with patients and their caregivers, especially with regard to the disclosure of the diagnosis [9–11]. This criticism often implicitly assumes a more dedicated and effective approach from the side of the specialists. However, the evidence for this assumption is low. Up to now, studies on diagnosis disclosure by professionals have focussed on a single professional group, be it GPs [4,12–17], geriatricians [18,19], psychiatrists [19–22] or nurses [23]. The studies on GPs’ attitudes or reported practice show percentages between 39% and 53% in favour of disclosure. Two recent reviews concluded that some one-half of the physicians is in favour of diagnosis disclosure and the other-half is not [24,25]. Comparative studies investigating the question as to whether GPs truly differ from specialists in this respect are few, as only two small-scale studies on this topic were found. In a survey on 35 Scottish consultants in the field of geriatric psychiatry and 35 GPs, a small majority of the psychiatrists indicated that they were in favour of informing the patients whereas most GPs felt that patients should be kept in the dark. This difference was not statistically significant [26]. Conclusions from this result are limited on account of the small sample size. The second study, a postal survey of GPs, psychiatrists, neurologists and geriatricians in Italy suffered from very low response rates (15%, 16%, 23% and 28%). The limited sample size and the unevenness of representation of GPs and specialists did not permit inferences to be made regarding differences between the two professions [27].
The purpose of the present study was to systematically investigate the differences between GPs and specialists—neurologists and psychiatrists—in the German health care system with regard to their attitude and approach to the disclosure of the diagnosis “dementia”. A comparison of GPs and specialists is of interest, as in the German health care system GPs and specialists compete with each other. The German health service is of a social insurance type (“Bismarkian”) on the side of the clients combined with a controlled market system on the side of the providers [29]. Physicians in ambulatory care work as entrepreneurs in a market characterized by unlimited direct access of patients to all disciplines without any gatekeeping. Task descriptions and competence delineations do not exist for the single medical disciplines. The results of this study provide empirical data to be used as the basis for improved communication between GPs and specialists concerning the disclosure of dementia as a diagnosis.

2. Methods

This study combines a qualitative and a quantitative approach. In order to elicit the attitudes of GPs, thirty semi-structured individual interviews were conducted by GP research fellows with randomly selected GPs in the towns of Hamburg and Düsseldorf. Questions focused on the process of care, i.e. how the suspicion of dementia arises, what next steps the GP undertakes and how he communicates suspicion, diagnostic and therapeutic steps with patients and relatives. Interviews were audiotaped, transcribed and analyzed according to the procedure described by Mayring [28]. In brief, this procedure consists of inductive development of categories and deductive application of prior formulated, theoretically derived aspects of analysis. The procedure was performed independently by two raters who, in a second-step, discussed all results and reached a consensus in case of inconsistencies. In the results section the number of interviewees who reflected the specific issues are presented in brackets. This was done in order to gain some sense of frequency—although, the data are drawn from semi-structured interviews and not from a standardized survey.

Based on the results of the interviews a 49 item standardized questionnaire on the following aspects of ambulatory care of people with dementia was developed: general attitude towards dementia care, diagnostic process, therapy, disclosure to patients, interaction with caregivers, quality of usual care, cooperation between professionals. The questionnaire consisted of statements to be rated on a six point Likert-type scale (1, does not apply at all; 6, applies very well). In the analysis presented here, scores were grouped as follows to rank the degree of assent/dissent (1 + 2, “does not apply”; 3 + 4, “partially applies”; 5 + 6, “applies very well”). Time need to complete the questionnaire was assumed to be 15 min. Nine items were related to diagnosis disclosure (see Table 2). Results on other topics will be published later.

Ten of the interviewed GPs and research staff with GP qualification piloted the questionnaire and commented on its content. The questionnaire was sent to all 129 GPs who are members of the German Competence Network Dementia (CND; return rate 84%), 260 randomly selected GPs (return rate, 40%)—all GPs not having been interviewed earlier—and 239 randomly selected neurologists and psychiatrists working in ambulatory care (return rate, 40%). The study was conducted in six towns (Hamburg, Düsseldorf, Bonn, Leipzig, Mannheim and Munich) and their surrounding areas, thus covering the metropolitan areas of the country relatively well. The return rates were achieved after one reminder by telephone. Fifty-three percent of the responding specialists were psychiatrists and neurologists, 32% were psychiatrists, 10% neurologists and 4% had other equivalent specialisations. Due to the fact, that a specialist in psychiatry or neurology usually spends a prolonged period of postgraduate training in the sister discipline, boundaries between the two disciplines are blurred. Therefore subgroup analyses were not appropriate and the term “specialists” is used for the whole group in the present study. Since no differences were found between the GPs belonging to the German Competence Network Dementia and those not belonging to it, results are presented as a comparison between GPs and specialists, using the Mann–Whitney U-test for the calculation of differences between the two professional groups.

3. Results

Table 1 shows the demographics of the participating doctors in the interviews and in the postal survey. Approximately, one third of the participants in each group were women, a percentage corresponding to their representation in ambulatory care. The GPs reported caring for a number of 15 dementia patients on their premises and 10 in nursing homes (median values). Specialists saw 40 patients on their premises, only (median value).

3.1. Results of the interviews

In the interviews the GPs emphasized the difficulties in communicating the diagnosis to the patients. GPs described taboo topic areas related to dementia for them and for their patients.

Patient reaction patterns range from total refusal in admitting cognitive deficits to aggressiveness. The following explanations for such resistances on the side of the patient were offered by the GPs:

• Fear of becoming dependent (6 interviewees):

“People get older and they are aware of the problems accompanying old age. (...) A lot of people say ‘If I am not in a position to think any more, then I will become dependent on my daughter’ or, given that no family is present, then a nursing service will come and swaddle me.” (A-15-A-60)

• Fear of being stigmatized as “crazy” (5 interviewees):

Interviewer: “How do the patients react to the disclosure of the diagnosis?”
GP: “They partially block off. They contradict and claim: ‘No, that’s not true; I’m not soft in the head. I’m not insane.’ and they feel as if I had accused them”. (A8-A-84)

- Feelings of shame (4 interviewees):
  “These patients try to appear very fit in the consultation; men especially try to convey that everything is fine. And they are not willing to answer questions (on their cognitive performance)”. (A28-A-16)

While they do not directly employ the term taboo, physicians describe many situations and reasons for not (fully) informing the patient themselves:

- Fear of inflicting damage on the patient (12 interviewees):
  “This [patient] suffered greatly. She said that she feared becoming more and more idiotic; that’s the reason why I think to myself ‘what is the use of telling her?’” (A5-A-166)
  “I would never say that the existing personality will at some point be eradicated. That is over the limit, something that I just wouldn’t say. Not even to the relatives. This knowledge is important for me as a doctor, but it must remain in the head and heart of the doctor. It would destroy the patient. How can someone ever recover from such knowledge?” (A26-A-68)

- Opinion that disclosure carries no benefit for the patient (6 interviewees):
  “When it comes to diseases where there are no sound therapeutic options the question must be asked: what is the benefit of (…) the diagnosis to me and what do I gain when the patient knows everything?” (A2-A-210)
  “I also think that non-disclosure is all right as long as the patient doesn’t suffer and is in some way happy and nothing bad happens.” (A20-A-182)

- Fear of ruining the doctor–patient-relationship (6 interviewees):
  “I avoid conflict with the patient. I don’t want him to get angry and I don’t want to lose him as my patient. It’s not for financial reasons; every patient I lose will be replaced by another, but for me mutual trust is very important. And I think that such a disclosure can be very offending for the patient”. (A20-A-182)

- Feeling that the patient would not understand the diagnosis anyway (6 interviewees):
  “Dementia diagnosed in early stages is seldom. When it is diagnosed the patient doesn’t understand the diagnosis and its implications, anyway. And then I simply explain it with forgetfulness and concentration problems”. (A27-A-44)

- Uncertainty about the course of the disease (5 interviewees):
  “I remember one patient where I thought that it would be better if he no longer drove his car. Funny enough, after a while he recovered without any medical intervention. That means that I was wrong”. (A11-A-18)

The GPs also described several strategies to circumnavigate their problem when talking about dementia (21 interviewees). Instead of ‘dementia’ or ‘Alzheimer’, they use attenuating circumscriptions like ‘normal aging process’ or ‘circulatory disturbances of the brain’. A further strategy is to attribute the symptoms to another disease, a strategy also used to motivate patients to seek further diagnosis:

  “In that case I forward the hypothesis that the patient has circulatory problems. And when I say, the heart and the blood pressure should be checked, these usual shabby arguments, they are sufficient to motivate people, mostly”. (A30-A-26)

In the interviews, only a minority of GPs (5 interviewees) favoured full disclosure. Those in favour showed a strong general attitude towards disclosing diagnoses:

  “A diagnosis is an offer, not a verdict. The offer shows to what extent the patient can accept and is able to cooperate. (…) The patients only have the possibility to decide for themselves when we talk about the issue with them (about AD). When we hide (the problem), then they have no chance. That’s why we are always in favour of an early diagnosis”. (A1-A-58)

3.2. Results of the postal survey

The results for all disclosure items are presented in Table 2 for the two professional groups.
In contrast to the interviews, a majority of GPs favoured a full disclosure in the postal survey. The survey shows both professional groups to be largely and equally in favour of timely diagnosis disclosure (items 1, 6, 7). For example, 70% of the GPs and 77% of the specialists strongly agree that “patients with dementia should be informed early because of their possibility to plan their lives” (p = 0.686).

However, the answers to the questions addressing the process of diagnosis disclosure point at a more complicated view which corresponds to the findings in the interviews. For example, both groups strongly confirm that they inform the relatives in more detail than the patient on the course of the disease (item 8; p = 0.836). Also, relatives are not left with the term ‘dementia’ and ‘Alzheimer’ less (p = 0.011) compared to male doctors.

The differences between GPs and specialists were small. As specified above the only statistically significant difference concerning disclosure found was that specialists reported to use the terms ‘dementia’ and ‘Alzheimer’ more often in the communication with the patient. Another difference relates to training interest: GPs express an interest in further training concerning communication with dementia patients and their relatives more often than specialists (50% of the GPs versus 30% of the specialists; p < 0.001; see Fig. 1).

A logistic regression analysis with the nine items on diagnosis disclosure as target variables and controlled for gender, specialisation, years in practice, and number of dementia patients seen, shows a greater reservation of older doctors towards diagnosis disclosure: they tend to regard disclosure of dementia as more harmful (p < 0.001), to disclose only when the patient demands it (p = 0.001), to use the terms ‘dementia’ and ‘Alzheimer’ less (p < 0.05) than their younger colleagues and to inform the relatives in more detail than the patients (p < 0.05). Gender differences were weaker but showed in the same direction, e.g. female doctors felt more strongly that the patients react with shame when confronted with cognitive decline (p < 0.01) or tended to regard disclosure as more harmful (p < 0.05) compared to male doctors. Specialisation and number of dementia patients seen did not contribute statistically significantly to the model.

### 4. Discussion and conclusion

#### 4.1. Discussion

This study is the first one of adequate size that systematically compares attitudes and approaches of GPs and specialists concerning disclosure of dementia. In summary, the postal survey shows that the self-reported differences between GPs

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### Table 2
Diagnosis disclosure items by profession

<table>
<thead>
<tr>
<th>Item</th>
<th>GPs</th>
<th>Specialists</th>
<th>p-Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Disclosing diagnosis and prognosis does more harm than good to the patient</td>
<td>2</td>
<td>2.43</td>
<td>1.33</td>
</tr>
<tr>
<td>2. Most patients are grateful when I address their cognitive decline</td>
<td>4</td>
<td>3.93</td>
<td>1.36</td>
</tr>
<tr>
<td>3. Patients react with shame when their cognitive deficits are addressed</td>
<td>4</td>
<td>3.73</td>
<td>1.37</td>
</tr>
<tr>
<td>4. When communicating the diagnosis to the patient I never use the term dementia</td>
<td>4</td>
<td>3.93</td>
<td>1.76</td>
</tr>
<tr>
<td>5. When communicating the diagnosis to the patient I never use the term Alzheimer</td>
<td>4</td>
<td>3.91</td>
<td>1.68</td>
</tr>
<tr>
<td>6. I only disclose when the patient demands it</td>
<td>2</td>
<td>2.51</td>
<td>1.57</td>
</tr>
<tr>
<td>7. Patients with dementia should be informed early because of their possibility to plan their lives</td>
<td>5</td>
<td>4.88</td>
<td>1.31</td>
</tr>
<tr>
<td>8. I inform the relatives more in detail than the patient on the course of the disease</td>
<td>5</td>
<td>4.91</td>
<td>1.21</td>
</tr>
<tr>
<td>9. Addressing the relatives I avoid the true diagnosis and I prefer to use terms like “senility” or “perfusion problems”</td>
<td>2</td>
<td>2.02</td>
<td>1.31</td>
</tr>
</tbody>
</table>

*p: Statistical significance of difference between GPs and specialists (Mann-Whitney U-test, **, p < 0.01; *, p < 0.05).

*a Range 1–6, 1: statement does not apply at all, and 6: statement applies very well.
and neurologists and psychiatrists in ambulatory care concerning disclosure of dementia are minor. Minor, i.e. not statistically significant differences related to disclosure between GPs and specialists were also found by Wolff et al. for Scotland [26]. In fact, the only statistically significant differences concerning diagnosis disclosure found in the present study indicate that specialists are somewhat less reluctant to use the terms ‘dementia’ or ‘Alzheimer’. This result is in line with a study on carers reporting more explanation of the terminology by psychiatrists than by GPs [30] and the survey of Wolff et al. [26].

The postal survey shows the two professional groups to be equally very much in favour of a timely disclosure and reporting similar problems in practice. This result differs from the majority of studies, which showed greater reluctance both for GPs [4,12–17] and for specialists [18–22,26]. This difference may partly be due to a recent change of attitudes regarding dementia in the medical profession. Also, a recruitment bias in the sense that more dedicated and interested physicians took part in the postal survey may be responsible.

This basic positive attitude towards disclosure in the postal survey is somewhat questioned by the communication difficulties described, e.g. the tendency to inform the patient less than the relatives, a phenomenon also shown in other studies [4,13,14,31] or to avoid the terms ‘dementia’ or ‘Alzheimer’ [20,3,18,32]. The results of the interviews underline the impression of existing communication difficulties. The specific reasons for not informing the patient derived from the interviews also confirm the results of other authors and reviewers [15,33,24,25]. Thus, in this study the mix of methods (triangulation) was helpful in explaining the divergence of a positive attitude towards disclosure on the one side and e.g. informing the relatives more than the patient on the other side. The interviews allowed more insight into the complexity of the disclosure of dementia.

In fact, the large majority of the interviewed GPs described a communication process, which can be characterized as a “double taboo” setting comparable to the “conspiracy of silence” described for schizophrenia [7,34], a setting in which both patients and GPs show a mutual behaviour aiming at not perceiving the disease and its consequences fully. The concept of the “double taboo” derived from the interviews appears to be a handy model to describe not only the problems of the patients concerning disclosure of dementia but also the problems of the GPs, which seem to interact with each other.

In line with other studies, the present study indicates greater disclosure difficulties in female physicians [35,36]. The data analysis also revealed significant differences between younger and older physicians, indicating a greater reservation of older doctors towards diagnosis disclosure. This also confirms the findings of other studies [4,14].

In contrast to GPs, neurologists and psychiatrists seem less interested in training programs related to communication with patients and relatives. This difference can be attributed to differences in postgraduate training but also to task differences between the GP and the specialist within the diagnostic chain in Germany. A referral to a specialist usually takes place at the end of a longer period of uncertainty and awaiting, both on the side of patient and relatives and the GP himself. The explicit reason for referral is then to obtain an unequivocal conclusion about the diagnosis, a situation in which communication has a clear subject. This role may be perceived as less incriminatory by the specialists, resulting in a reduced interest in training programs on communication.

Our study has several limitations. Although relatively large, the samples are probably not representative for the total professional groups. Participants stem from metropolitan areas, thus excluding the perspectives of physicians in rural and remote areas. As stated earlier, the samples might consist of more dedicated and interested members of the professional groups. Postal survey and interview techniques have limits when the aim is to document real behaviour. This is especially the case in a problem loaded topic like diagnosis disclosure in the case of dementia. The higher rate of positive attitudes towards disclosure among GPs in the postal survey in comparison to the results of the interviews may be due to the phenomenon of social desirability in answering questionnaires. Thus, over-reporting of positive attitudes may be inherent to a standardized questionnaire. Semi-structured interviews on the other hand—especially when performed by fellow GPs as in this study—may produce a situation of informal consent (“we all know”), allowing for more reflective and self-critical opinions on the part of the interviewed GPs. These possible pitfalls stress the importance of addressing research questions by means of a combination of various methodological approaches in the sense of triangulation [37].

4.2. Conclusion

The postal survey shows the two professional groups to be very much in favour of a timely disclosure—an attitude that is pronounced among younger physicians. These findings can be interpreted as a recent change of attitudes regarding the disclosure of the diagnosis of dementia in the medical profession. However, this study also shows various communication difficulties regarding an open disclosure of the diagnosis dementia to patients: the interviews revealed problems on both the patient’s and the GP’s side (“double taboo”), the postal survey provided more indirect references to problems, e.g. the tendency to inform the patient less than the relatives or to avoid the terms ‘dementia’ and ‘Alzheimer’. These difficulties demonstrate the need for suitable strategies for disclosure and for corresponding training schemes. Without disclosure of the diagnosis, a systematic information process concerning the course of the disease and the forthcoming problems and burdens related to it appears impossible. Bearing this in mind, it is understandable, yet nonetheless disturbing, that caregivers report that the information provided by health professionals on the course and prognosis of the disease is even scarcer than information concerning the diagnosis [31,38–40].
4.3. Practice implications

Training opportunities considering the specific tasks of the GP and the specialist within the diagnostic chain are needed in order to overcome communication obstacles in the doctor–patient-communication about dementia. These training opportunities also need to address the taboo on the doctors’ as well as the patients’ side.

5. Confirmation

We confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

Conflicts of interest

None.

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References

[31] Mayring P. Qualitative Content Analysis . Forum Qualitative Sozialforschung/Forum Qualitative Social Research [On-line Journal], 1(2). Available at: http://www.qualitative-research.net/fqs-texte/2-00/2-00mayring-e.htm [Date of Access: March 30, 2006].


