

## Memo

To: UnderstAID  
From: Danish Alzheimer Association  
Date: October 2013

# Danish Dementia Help Line 2009 – 2013 – An analysis

## 1. Background

The Danish Dementia Help Line is an open non-government telephone help line operated by the Danish Alzheimer Association. The staffs – telephone advisers – are all paid professionals (one full-time and 3-5 part-time) with an education as nurse or other relevant skills and all with an extensive training and working experience with in the field of dementia.

The Dementia Help Line receives between 1.500 and 2.000 calls a year. Each call is registered in a database based upon observations done by the advisers during the conversation and small written notes – 5-10 lines – from the advisers, written after the conversation. No personal data is registered and the persons contacting the Dementia Help Line are not asked to participate in any inquiry or to answer any question to the database. But during the conversation it is possible to extract certain information and register this information in the database. The fields in the database are a combination of open ended text fields and closed fields with fixed option. The database has been in use since 2009 and contains more than 7.000 registered calls.

## 2. Methodology

The analysis is based upon the registered data from the Danish Dementia Help Line. In order to answer the research question – “What are they talking about during the conversation” – the open ended text fields with the written notes from the advisers were analyzed semantically in order to identify different discourses in the conversations. More than 2.000 individual calls have been analyzed separately identifying words – indicators – relevant for each discourse.<sup>1</sup>

Via the database search engine the total number of calls containing one of the identified indicators are found and “filtered” for irrelevant words. The total numbers of the different discourses are then analyzed and various themes from the conversation is extracted and compared according to different variables such as relation to dementia patient and age of patient etc.<sup>2</sup>

In principles the semantic analysis allows for an unlimited number of research questions, but only the most relevant for the UnderstAID project is included in this analysis.

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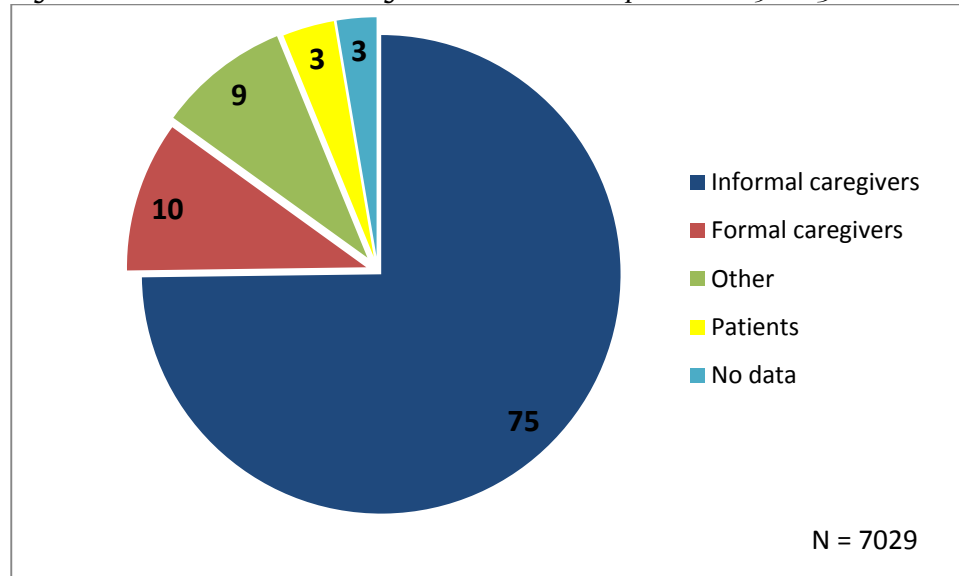
<sup>1</sup> Certain words contain meaning relevant for different discourses. The words *economy, expenditure, costs, value, money, finance* ex. illustrates that there is an economical discourse present in the text. The words *disease, doctor, nurse, hospital, medicine, diagnose* ex. illustrates that there is a disease and treatment discourse present in the text. These words are labeled indicators together they illustrates the presence of a specific discourse. Each conversation can subscribe to many different discourses.

<sup>2</sup> A Z-test with a critical value of +/- 1,96 (5% two tailed) has been applied were relevant in order to test the significant of the found results.

### 3. Demography

Three out of four persons contacting the Dementia Help Line are informal caregivers – spouses, children, brother/sister, other family or friends – and one out of ten is a professional caregiver asking for advice. Three percentages are patients suffering from dementia. (Figure 1)

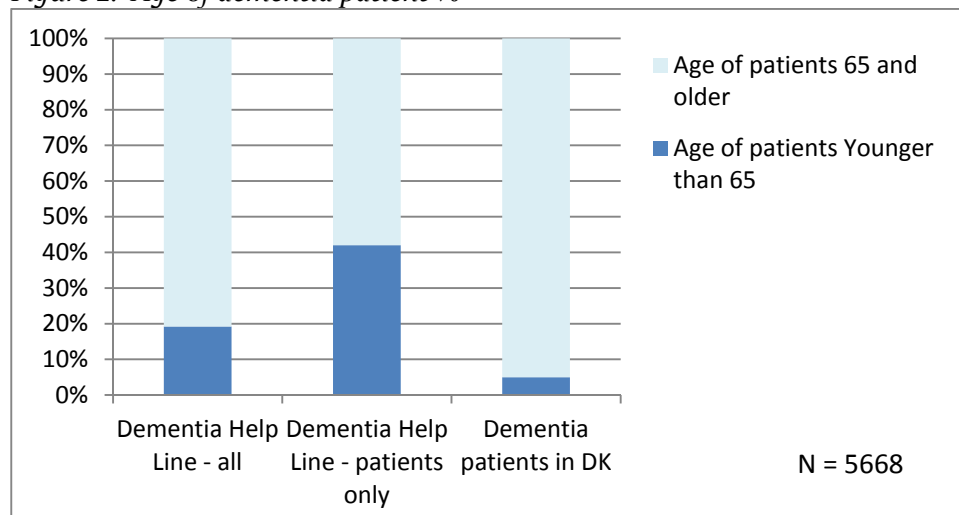
Figure 1: Individuals contacting the Dementia Help Line 2009-2013 %



It is mainly women (75%) who contact the Dementia Help Line. But looking at patients only 43% are men and 56% are women. Looking at the relation of the informal caregiver who contacts the Dementia Help Line to the dementia patient we found that in more than half (52%) of the conversations it was a child of a person with dementia who contacted the helpline, 32% were spouses, 10% brothers, sisters or other family and 5% a friend, neighbor or colleague.

If it during the conversation is relevant to ask about the age of the patient who is the object of the conversation, the age is registered in the database. From this it can be seen that in the majority (81%) of the conversations the patients (objects) are 65 years or older while 19% are younger than 65 years. Compared to the general prevalence figures in Denmark there is an overrepresentation of dementia patients younger than 65 years. If we look at the patients only this overrepresentation is even bigger. More than 40% of all dementia patients contacting the Dementia Help Line are younger than 65 years of age. (Figure 2)

Figure 2: Age of dementia patient %



In two thirds of all conversations it has been possible to register the diagnoses of the dementia patients. In 54% of the conversations the patient suffered from Alzheimer Disease, 4% had a Frontotemporal Dementia, 3% a Vascular Dementia and 2% a Lewy Body Dementia, while it was impossible in 37% of the conversations to register the specific dementia diagnosis of the patient.

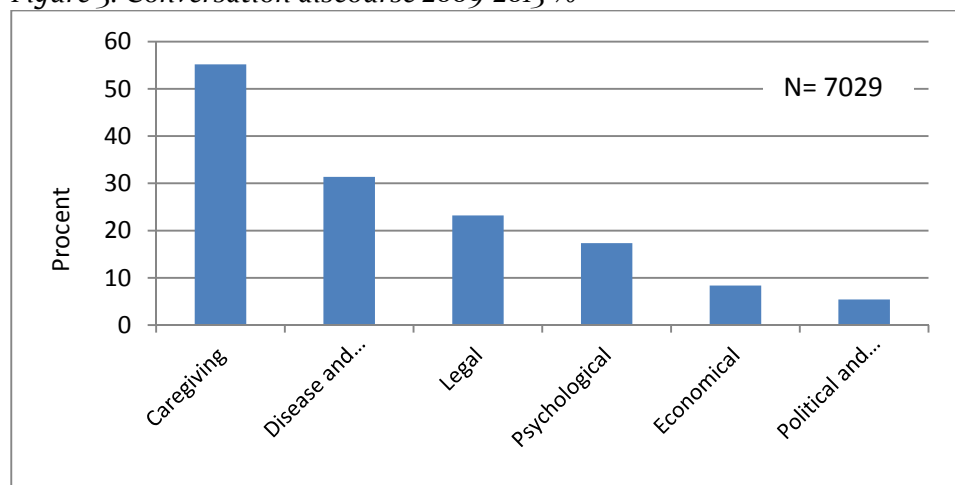
#### 4. Dementia Help Line discourses

The semantic analysis has identified six major discourses relevant to the project:<sup>3</sup>

- Caregiving
- Disease and treatment
- Legal
- Psychological
- Economical
- Political and administrative

The discourses are sometimes overlapping. In a conversation about administration of antipsychotic medicine at a nursing home making the dementia patient hypersensitive to physical contact and therefore difficult to help with her bath without the use of physical force covers a caregiving, a disease, a psychological and a legal discourse. The semantic analysis cannot see which of the different discourses is the most relevant in the specific conversation. But by analysing all conversations it is possible to see which discourses are most present in the conversations all together.

Figure 3: Conversation discourse 2009-2013 %



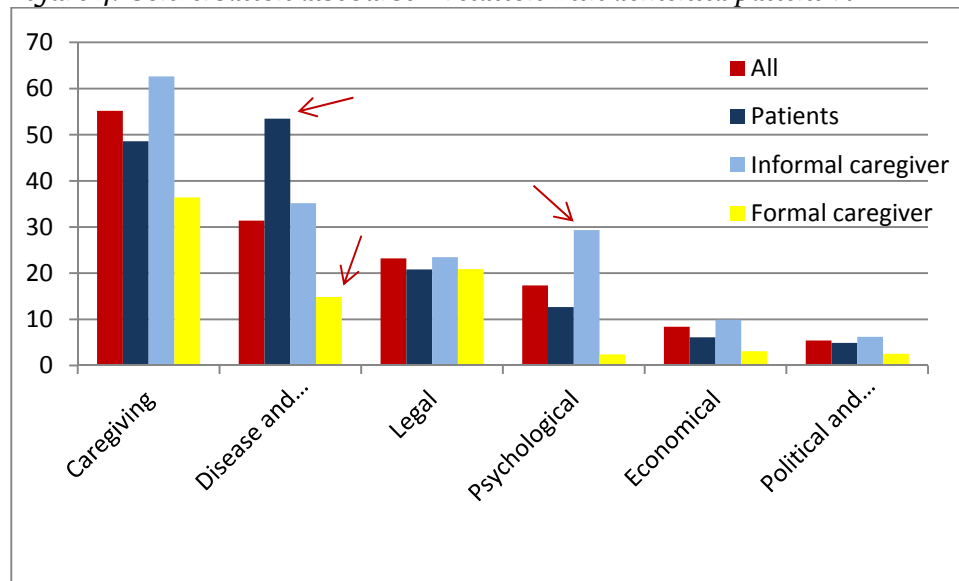
The caregiving discourse was present in more than half (55%) of all conversations. Almost a third of all conversations subscribed to the disease and treatment discourse and in every fourth conversation the legal discourse was present. (Figure 3).

If we look at the different demographical variables we can see, that there are some relevant differences. Firstly there seem to be no significant gender specific differences regarding which discourse was most present. For both men and women, the caregiver discourse (56%) was equally present in most conversations, followed by the disease and treatment discourse (32%). But there seem to be a small tendency that the legal discourse was a little more present in conversations with men (26%) compared to women (23%), and that the psychological discourse was a little more present in the conversations with women (19%) compared to men (16%) although these differences were not significant.

<sup>3</sup> For more details about the discourses see page 4 ff

Depending off the relationship between the dementia patient and the person contacting the Dementia Help Line different discourses were present.

*Figure 4: Conversation discourse – relation with dementia patient %*

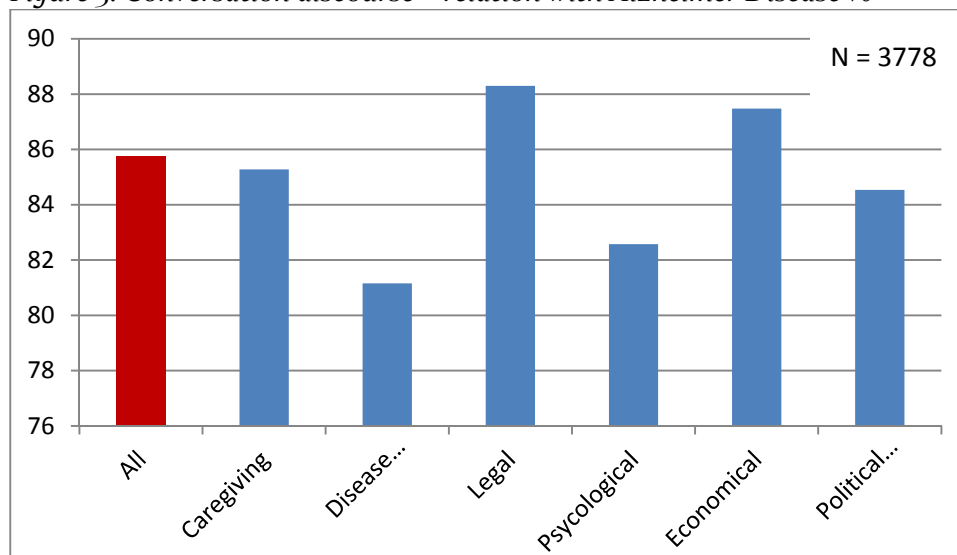


In conversations with patients with dementia themselves contacting the Dementia Help Line the disease and treatment discourse (53%) was present in little more than half the conversations, followed by the caregiver discourse (49%) and the legal discourse (21%). In conversations with informal caregivers the caregiver discourse was present in all most two thirds (63%) of all conversations, followed by the disease and treatment discourse (35%) and the psychological discourse (26%). In conversations with formal caregivers the caregiver discourse is present in one third (36%) of the conversations, followed by the legal discourse (21%) and the disease and treatment discourse (15%). (Figure 4)

Looking at how the different discourses are represented in conversations with different subjects – patients, informal and formal caregivers – compared to all conversations it is interesting to see that for patients the disease and treatment discourse was present almost twice as frequent compared to all conversations. Likewise the psychological discourse was present in almost 30 % of conversations with informal caregivers compared to “only” 17% in all conversations. In conversations with formal caregivers the disease and treatment discourse was present only half as often (15%) as in all conversations (31%) and the psychological discourse almost not present. (Figure 4)

Apart from Alzheimer Disease there seem not to be a significant difference in the conversation discourses in relation to other sub diagnosis - FTD, VD and LBD. When looking at conversations where the patients had a Alzheimer Disease diagnose only we found, that questions about the disease and treatment were less frequent compared to all conversations. Questions about legal matters were on other other hand a little more frequent in conversations where the patients had a Alzheimer Disease diagnose. (Figure 5)

Figure 5: Conversation discourse – relation with Alzheimer Disease %

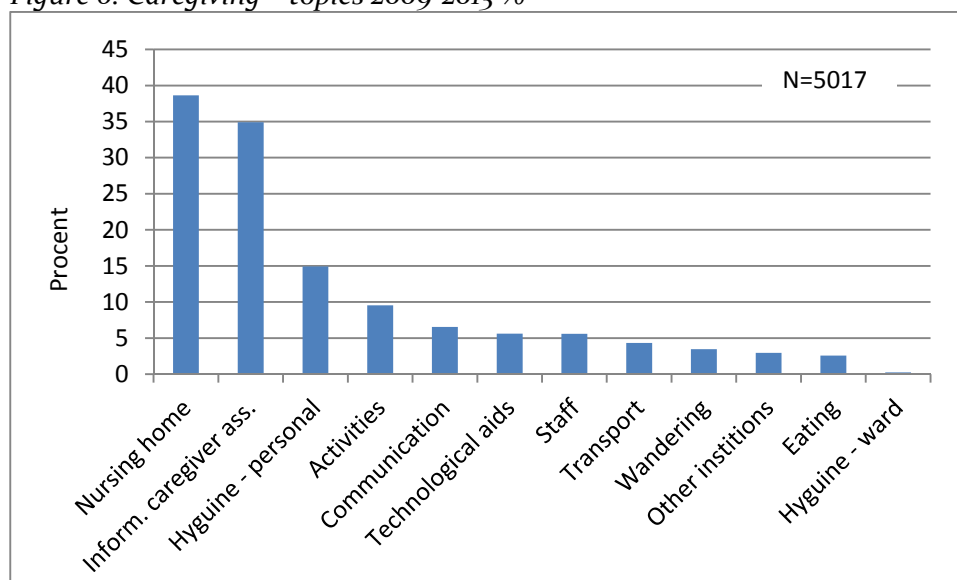


#### 4.1. Caregiving discourse

The analysis identified more than 25 indicators of a caregiving discourse. These were words like *care, bath, meal, nursing home, hygiene, communication, wash, technological aids, wandering, transport, dippers, activity and hairdressing* etc.

Questions about nursing homes (39%) and assistance to informal caregivers (35%) were the most common questions in the caregiving discourse, followed by questions about personal hygiene of the dementia patient (15%) and activity based training (10%) (Figure 6)

Figure 6: Caregiving – topics 2009-2013 %

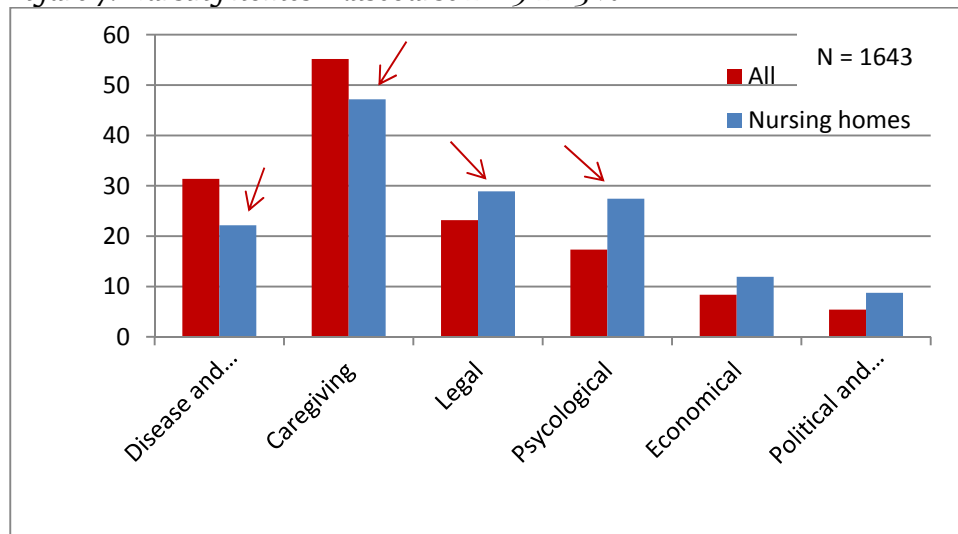


Questions about nursing homes covers both the situation where a person with dementia are about to move to a nursing home and the situation where the dementia patient is staying/living at the nursing home.

The caregiving discourse was present in almost half the questions (47%) about nursing homes compared to 55% in all conversations. Looking at the discourses in the conversations where questions about nursing homes appear, we found that the psychological and legal discourses were more frequent compared to the discourses in

all conversations in general, and the disease and treatment discourse and the care-giving discourse were less frequent in conversations about nursing homes compared to all conversations (se figure 7)

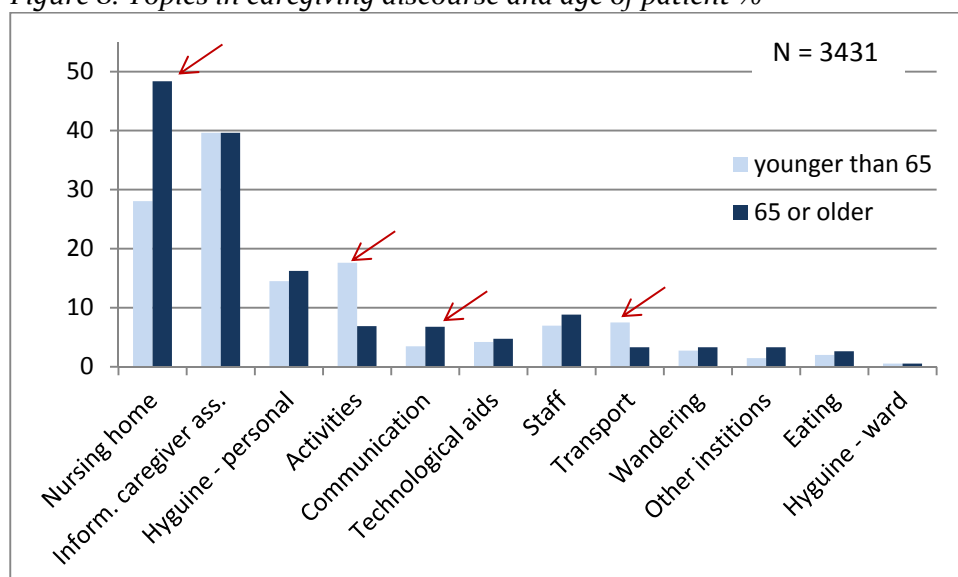
Figure 7: Nursing homes – discourse 2009-2013 %



Age of the patient do influence which topics were present in the conversations subscribing to the caregiving discourse. When the dementia patients were 65 or older questions about nursing homes were present in almost half (48%) of the conversations within the caregiving discourse, while these questions were “only” present in little more than every fourth (28%) questions when the patient were younger than 65 years. (Figure 8).

Questions about activity and physical training of dementia patients were almost three times as frequent (18%) in conversations about patients younger than 65 years compared to in conversations about dementia patients 65 years or older (7%). Transport was another topic, which was much more frequent in conversations about patients younger than 65 years compared to conversations about patient 65 or older. On the other hand questions on how to communicate with dementia patients were twice as frequent in conversations when the patients were 65 years or older compared to in conversations with patients younger than 65. (Figure 8)

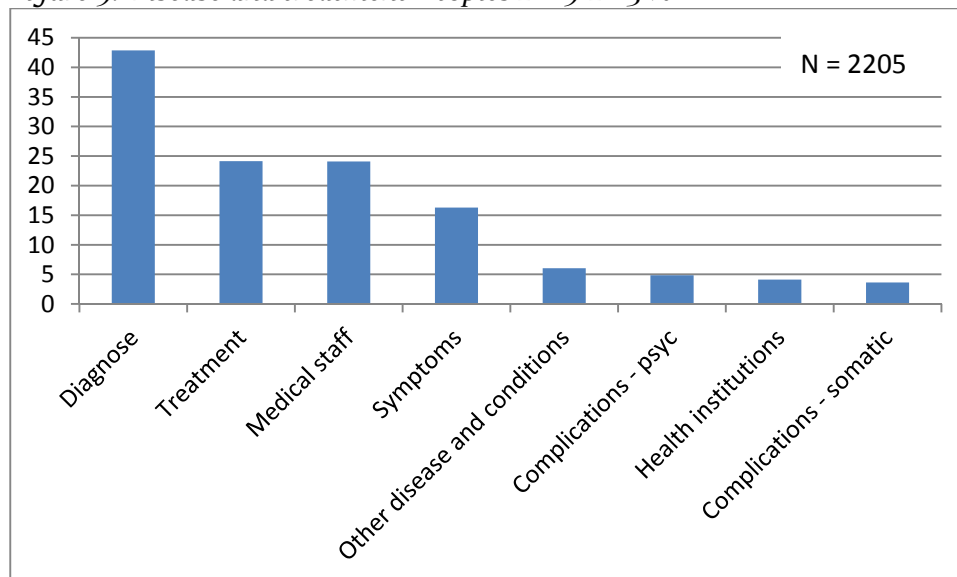
Figure 8: Topics in caregiving discourse and age of patient %



#### 4.2 Disease and treatment discourse

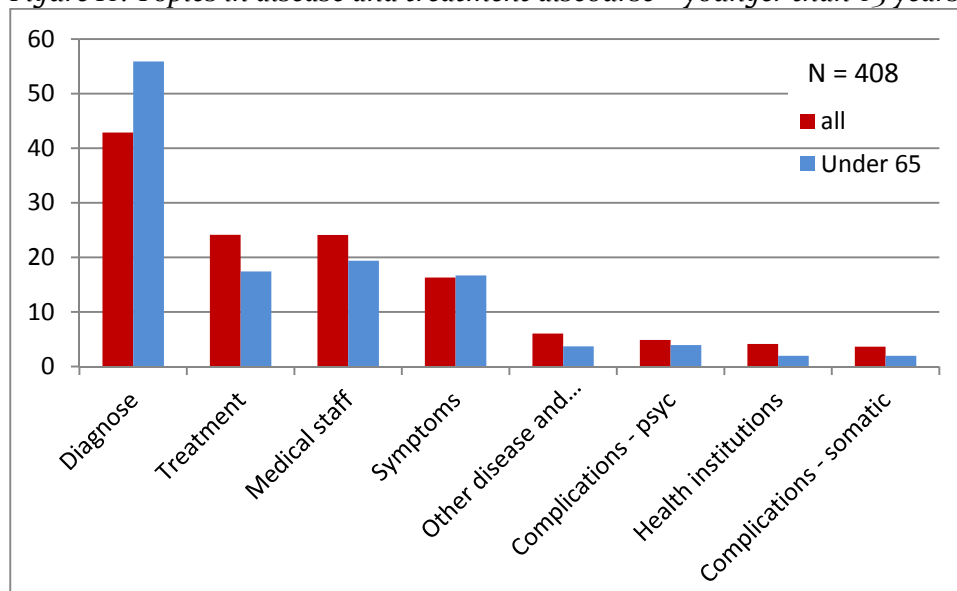
The analysis identified more than 25 indicators of a disease and treatment discourse. These were words like *disease*, *treatment*, *diagnose*, *medicine*, *doctor/GP*, *nurse*, *hospital*, *symptom*, *dehydration*, *cancer*, *pain* and *infection* etc.

Figure 9: Disease and treatment – topics 2009-2013 %



Questions where the diagnostic evaluation was mentioned were the most frequent question (43%) in the disease and treatment discourse. It was questions about the elements of the evaluation ex. scanning or about genetic predisposition (6%). Next from questions about the diagnoses the most common questions in the disease and treatment discourse were questions about the treatment (24%) and questions where medical staff was mentioned (24%). (Figure 9).

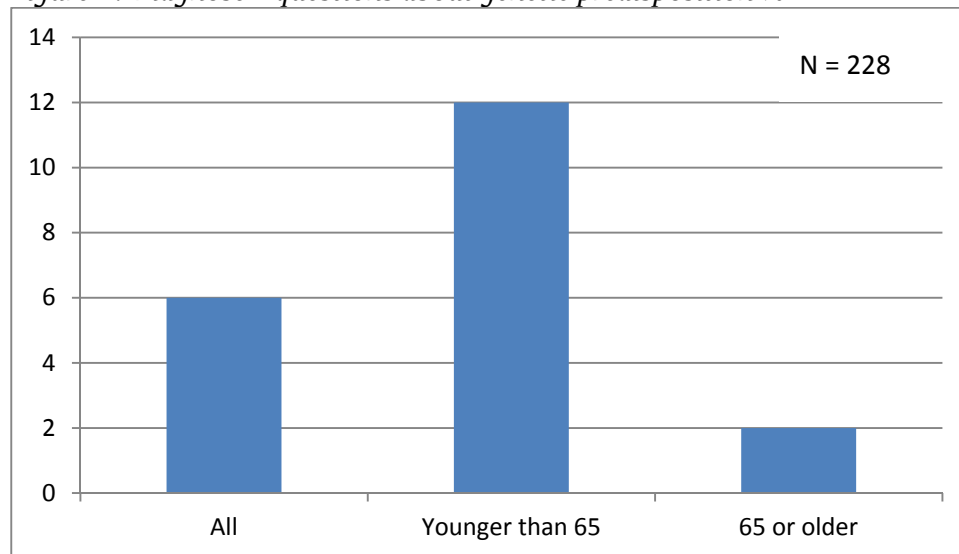
Figure 10: Topics in disease and treatment discourse – younger than 65 years %



When the patients are younger than 65 years questions about the diagnostic evaluation were present in more than half of all conversations. (Figure 10) It was mainly question about the elements of the evaluation (46%). But there were also many questions about genetic predisposition, which accounts for almost 12%. This was double compared to all conversations about diagnose and almost six times higher

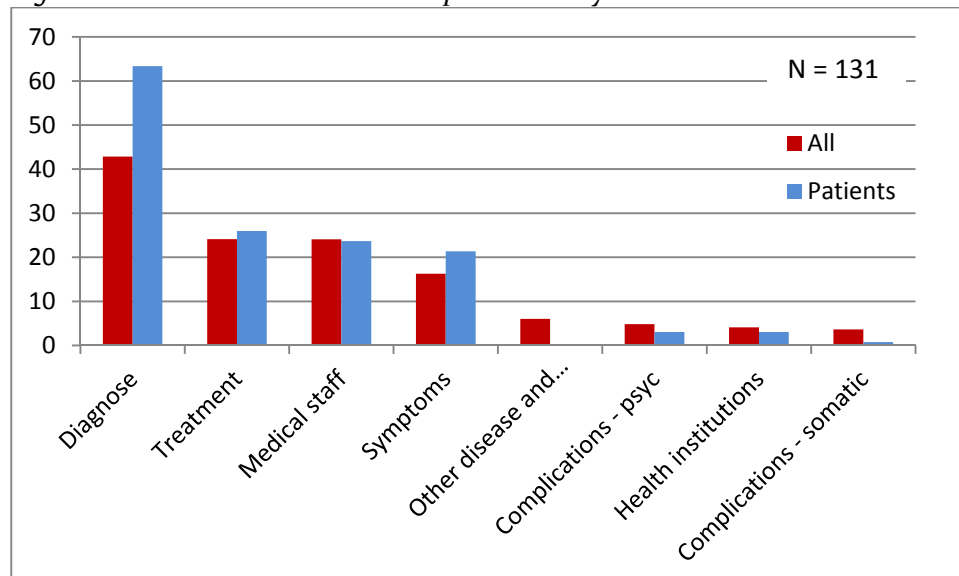
than the share of questions about genetic predisposition in conversations where the dementia patient was 65 years or older. (Figure 11)

Figure 11: Diagnose – questions about genetic predisposition %



Looking at patients only questions about the diagnose were present in almost to third of all questions (63%) which is significant more compared to all conversations within the disease and treatment discourse. It was mainly questions about the diagnostic evaluation (60%) while questions about genetic precondition was only present in less than two percentage of all questions from patients about the diagnoses. (Figure 12).

Figure 12: Disease and treatment – patients only



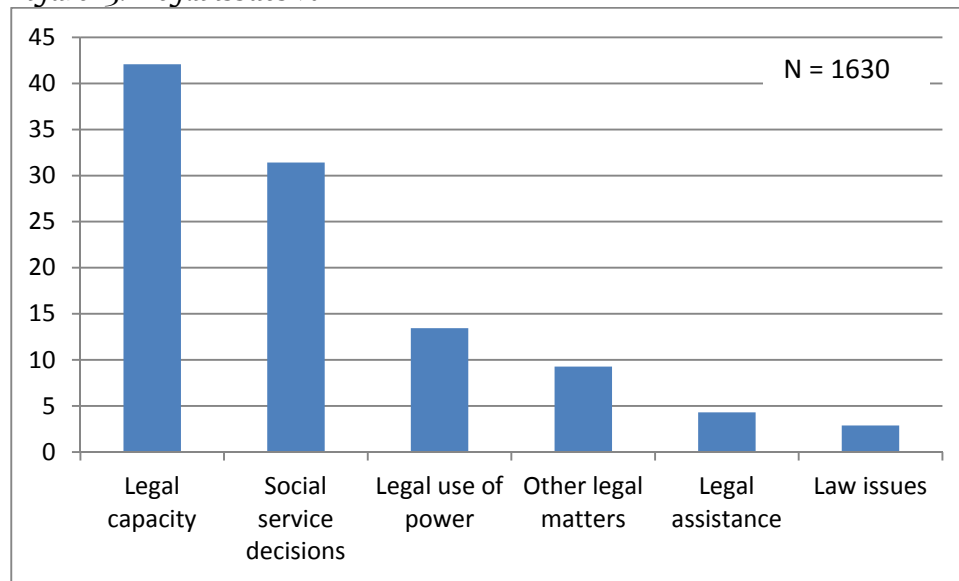
#### 4.3 Legal discourse

The legal discourse covers words like *legal*, *lawyer*, *§*, *law*, (*legal*) *complain*, *attorney*, (*legal*) *assistance* and (*legal*) *documents*.

Four out of ten conversations within the legal discourse were about a legal capacity matter (42%) covering questions about power of attorney and guardianship etc. One of three conversations were about a social service decision (31%) often questioning the decision made by the municipality. Questions about the actual law – either

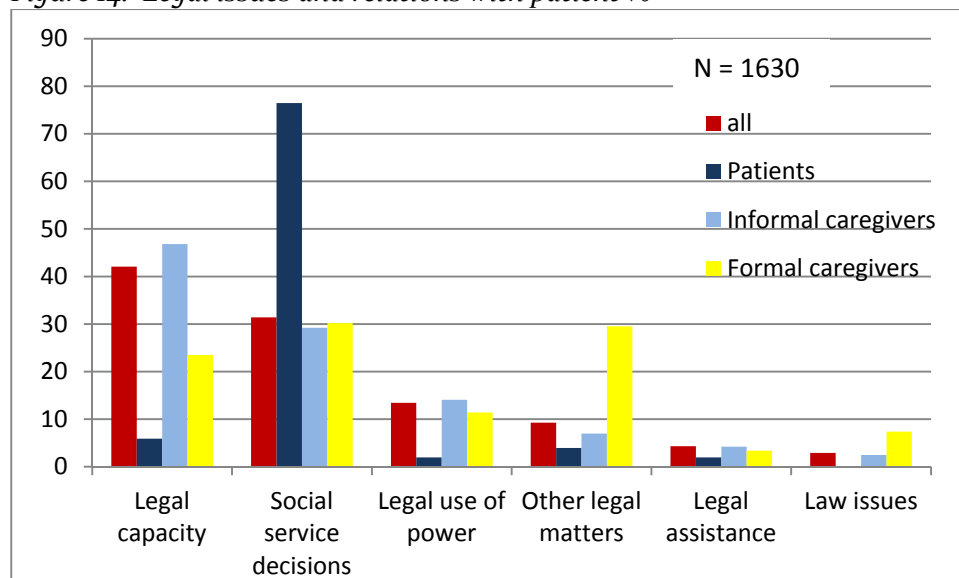
healthcare or social service – were only present in less than 5% of all conversations within the legal discourse. (Figure 13)

Figure 13: Legal issues %



Looking at how the different topics relate to the relation between the dementia patients and the person calling it is interesting to see, that questions about legal capacity is present in almost half the conversations with informal caregivers and only in 6% of conversations with patients. The most common topic in conversation with patients themselves were questions about social service decisions while there were very few questions about legal capacity and legal use if power and no questions about law matters. (Figure 14)

Figure 14: Legal issues and relations with patient %

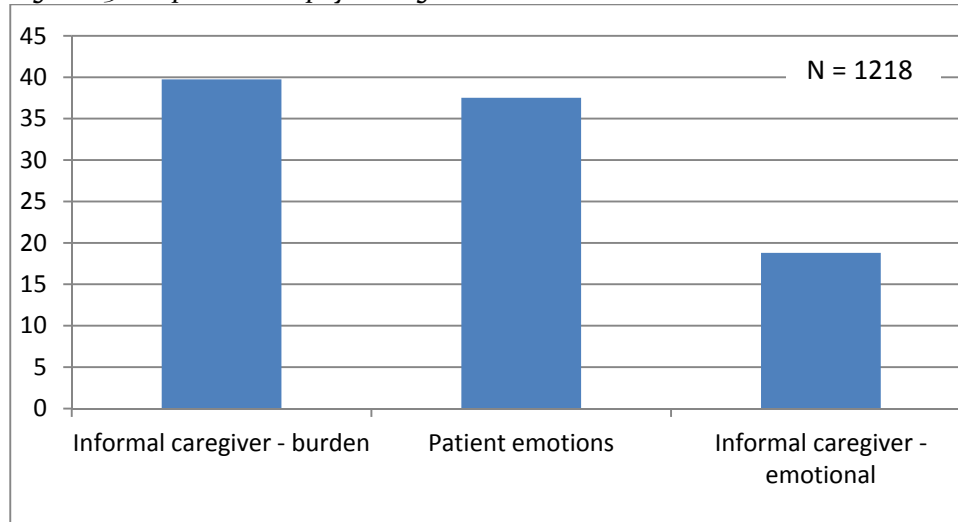


When it was a formal caregiver, the most common question were about other legal mattes which were present almost three times more frequent in conversations with informal caregivers than they were in all conversations in general. Also questions about law issues had an overrepresentation compared to all conversations. Figure 14)

#### 4.4. Psychological discourse

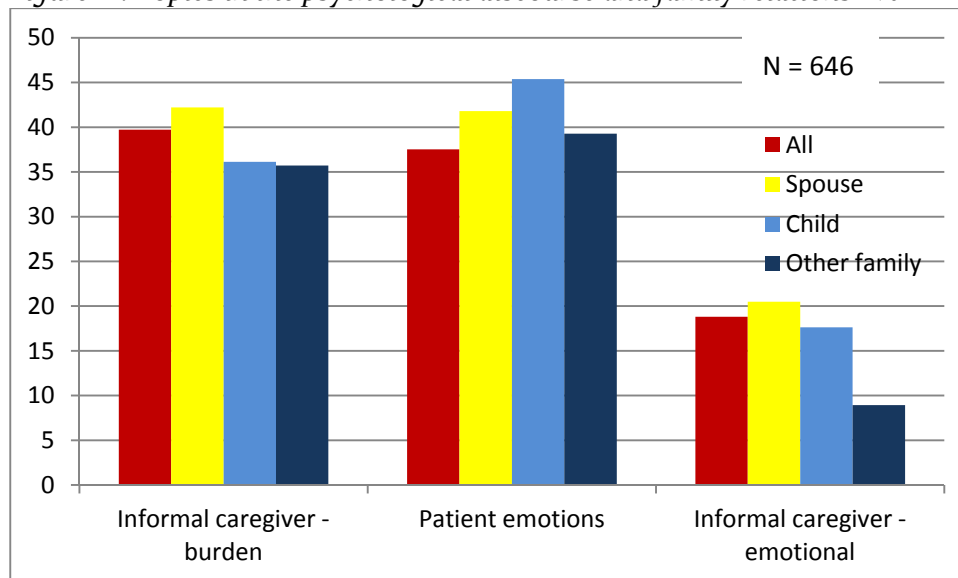
The psychological discourse covers words like *anxiety, anger, grief, feelings, aggression, sadness, depression, isolated, happy, unhappy, guilt* and *psychologist*. The indicating words of the psychological discourse were grouped in three topics – informal caregiver burden, patient emotions and informal caregiver emotions.

Figure 15: Topics in the psychological discourse %



Conversations subscribing to the psychological discourse covers both emotional aspects among patients as well as informal caregiver burden. Informal caregiver burden were identified via indicators as *guilt, pressure, isolation* and *conscience* and they were present in four out of ten conversations within the psychological discourse. Patients emotions were identified via indicators as *anger, depression, anxiety, uneasy* and *sadness* and were also present in almost four out of ten conversations while informal caregiver emotions covering indicators as *feeling, sorrow, distraught* and *loneliness* were present in less than to out of ten conversations within the psychological discourse. (Figure 15)

Figure 16: Topics in the psychological discourse and family relations - %



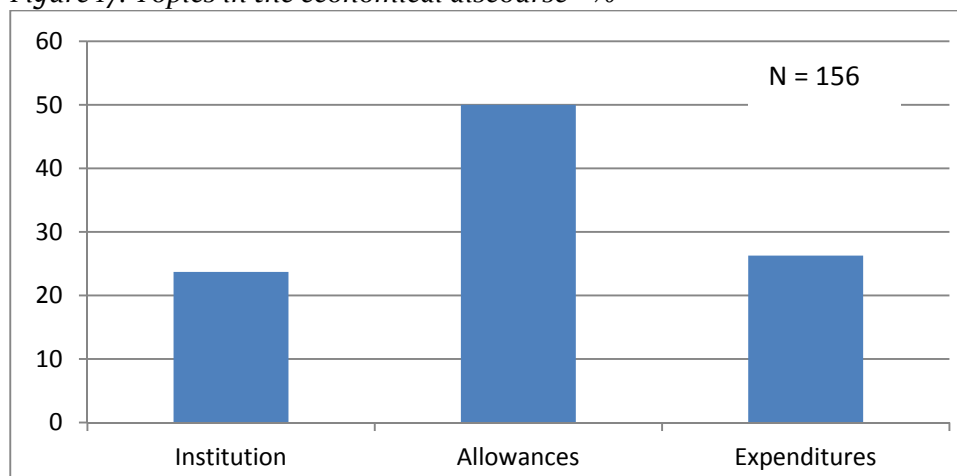
Looking at the family relations of the informal caregiver there was no significant difference regarding the topics of the conversations whether the informal caregiver was the spouse or the child of the dementia patient. (Figure 16)

#### 4.5. Economical discourse

The economical discourse covers words like *economy*, *money*, *bank*, *insurance*, *social allowances*, *pension* and *housing rent*. The indicating words of the economical discourse were grouped in three topics – institutions (*bank*, *insurance company* etc.), allowances and expenditures <sup>4</sup>

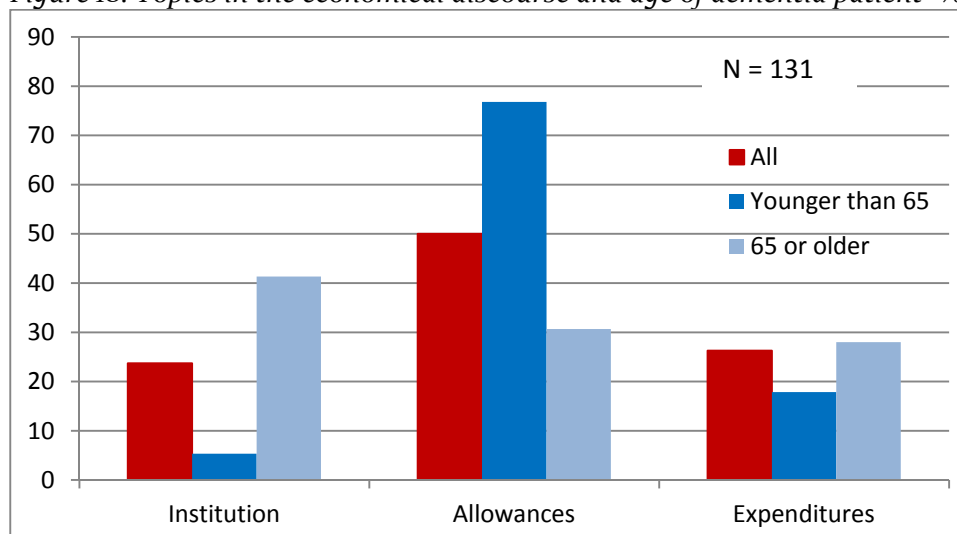
In half the conversations subscribing to the economical discourse the conversations covered topics about allowances of either pensions or social allowances etc. One out of four conversations covered topics about a bank or another financial institution or about different kind of expenditures. (Figure 17)

Figure 17: Topics in the economical discourse - %



Looking at the age of the dementia patients (the object of the conversation) it is interesting to see, that in more than 75% of conversations where the dementia patients were younger than 65 years the topic was about some kind of allowances. It is also interesting to see, that questions about a financial institution was more frequent when the object of the conversation was 65 years or older than in conversations where the dementia patient was younger than 65 years. Questions about a financial institution were often about general power of attorney. (Figure 18)

Figure 18: Topics in the economical discourse and age of dementia patient- %

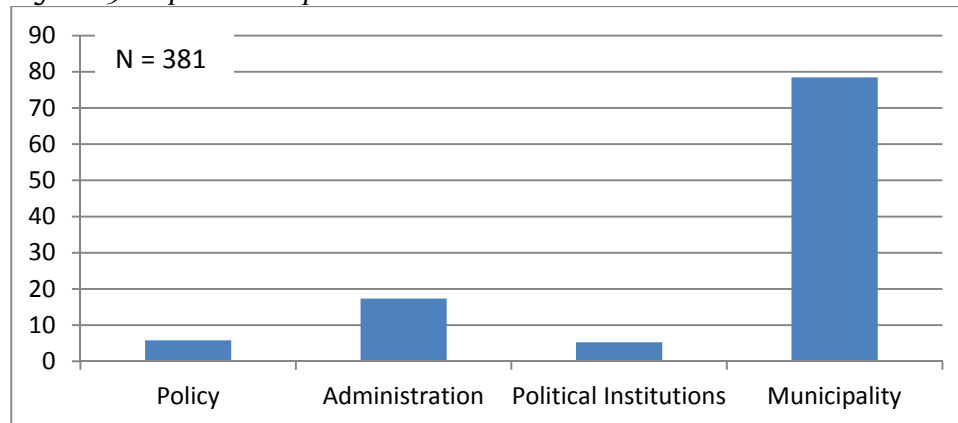


<sup>4</sup> Nonspecific indicators like *economy* or *money* were not included in the analysis of the topics within the economical discourse because it could not be determined to which topics these indicators should be included.

#### 4.5. Political and administrative discourse

The political and administrative discourse covers words like *politicians*, *political*, *municipality*, *government*, *local municipality board*, *cut downs*, *administration*, *assessment officer* and *political party*. The indicating words of the political and administrative discourse were grouped in four topics – policy, administration, political institutions and municipality<sup>5</sup>.

Figure 19: Topics in the political and administrative discourse - %



Apart from the unspecified “municipality” questions about administrative matters are most common (17%), while questions concerning dementia policy – ex. cut downs on dementia treatment or services – and political institutions – ex. local municipality boards or national government – are present in less than one in ten questions with in the political and administrative discourse. (Figure 19).

#### 5. Conclusion

The analysis of the conversations of the the Dementia Help Line operated by the Danish Alzheimer Association gives some answers to the question of “What are they talking about during the conversation.” Giving the fact, that it is mainly informal caregivers who contacts the Dementia Help Line it is not surprisingly questions about everyday aspects of their life with dementia – caregiving, the disease, legal matters and the psychological aspects of the caregiver role - that are most common. Questions concerning the political and administrative aspects of dementia were on the other hand not a question of big importance in the conversations of the Dementia Help Line.

The analysis also disclosed that there were some relevant differences according to who was contacting the help line and the relation he or she had with the dementia patient. Informal caregivers are more likely to have questions about the psychological and legal aspects of the caregiver role, and patients themselves seem to have more interests in the disease and treatment questions.

The differences according to the relation to the dementia patient were also present when the analysis went even deeper into the specific discourses and topics of the conversations. In questions about legal matters it is interesting to note, that among patients themselves questions about social service decisions were fare the most frequent topic, while their informal caregiver seem to have a bigger interest in questions about legal capacity.

<sup>5</sup> The Danish word “kommune” covers both the administrative bodies of the local municipalities as well as the local municipality boards. It is therefore not possible to distinguish between questions about administrative matters and political matters

The age of the dementia patient was another factor of difference. Not surprisingly questions about nursing homes were the most frequent question in the caregiver discourse when the patients were 65 years or older. But when the patient was younger than 65 years it is interesting to note that in almost every third conversations questions about nursing homes arose too. Questions about help to transport and activities and physical training were on the other hand twice as frequent in conversations were the patient was younger than 65 years compared to when the patient was 65 or older.

Most significant the difference according to the age of the patient is seen in the questions about the genetic predisposition of dementia diseases. All though these questions were only present in very few conversations the questions were six times more frequent when the patient was younger than 65 years compared to when the patient was 65 years or older. The difference is also seen when we look at questions about economic matters, where questions about social service allowances were present in more than 75 % of conversations when the patient was younger than 65 years compared to 30% when he or she were 65 years or older.

As a concluding remark it is therefore relevant to argue that people living with dementia – whether they are patients or informal caregivers – have relevant questions about everyday aspects of dementia, and they need – according to the age of and relation with the patient – targeted answers suited to fit to their special needs and specific circumstances. Counseling and advice-giving therefore have to be professional, based upon general knowledge about the everyday life of dementia and at the same time both specific and personalized as well.

To sum it up – no size fits all when it comes to counseling patients and informal caregivers living with dementia.