

"How do the patients and their close relatives experience The Coordinated Investigation Model of Dementia in the North Denmark Region?"

Aase Marie Ottesen og praktiserende læge Hanne Hulgaard

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How do the patients and their close relatives experience The Coordinated Investigation Model of Dementia in the North Denmark Region? - And which dilemmas exist?

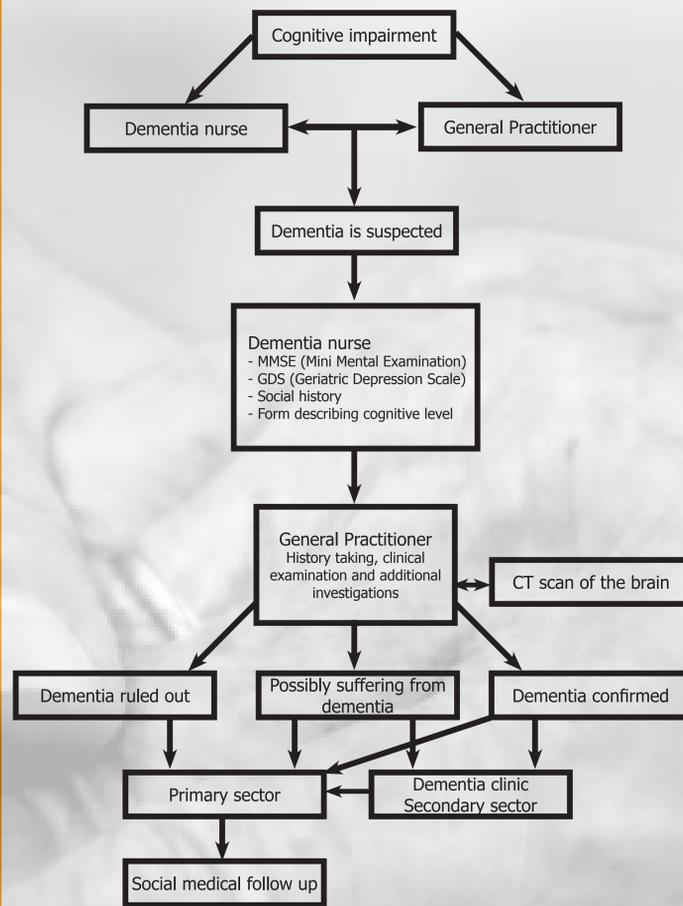
Citations

Dilemmas

It's not easy – A dilemma is a problem, offering two possibilities, neither of which is practically acceptable.

Main results

The Coordinated Investigation Model of Dementia in the North Denmark Region



The patients and their relatives don't relate to the model – but rather to episodes and aspects, which have been most important for them – in a positive or negative way.

Sense of coherence is found in close relations – e.g. in "the meeting" with the general practitioner and the dementia nurse, in their everyday life and when the investigation process works well.

The relatives generally asks for more information and guidance about dementia

The social medical help is optimized when relevant help is offered at the right time and the patients and their relatives experience that their needs are fulfilled

Meaningful occupation helps to make daily life work well

In The Coordinated Investigation Model, the general practitioner and dementia nurse in the primary sector is meant to play a central role having the main responsibility for the investigation and follow up process

But most important to the patients and their relatives was the investigation, the information and the decisions made by specialists in the secondary sector

The purpose of The Coordinated Investigation Model is to involve the patients and their relatives and to give satisfactory information about the disease, treatment and options for guidance and support

But some of the patients and their relatives don't want this information – even if they have given consent to investigation

The patients and their relatives asks for a special kind of help

But the help, that is wanted, can't always be offered or might not be considered relevant

A common understanding in families with a person suffering from dementia and clarity about plans for the future is necessary in order to make a satisfactory follow-up

But the patients and their relatives often don't talk with each other about the disease and their future life

"This makes me feel safe – I know who to ask when I have questions and problems (that means – the dementia nurse)"

Respecting the patients autonomy is based on the ethical principle that a patient have a fundamental right to know his diagnosis and to be involved in the decision-making dealing with investigation, treatment and social medical intervention

But patients with dementia often can't manage to get involved and participate on equal terms in the process

"He shouldn't have done that (the doctor shouldn't inform the patient in that way – i.e. the diagnosis was stated in a letter to the patient) but I think he (the patient with dementia) has to get involved, he must realize it"

Some of the relatives want and are ready to be informed about dementia

But patients with dementia can't always handle or relate to information about the disease

"We don't need any help, we want to take care of ourselves. She can still cook. She can bend down to the ground and remove weed in the garden – I can't" (spouse with grave physical handicaps)

The purpose of The Coordinated Investigation Model is to fulfill the social medicine needs of patients and their relatives

But the patients and their relatives doesn't always want help – even when it seems obvious that they need it!

Patients desire for autonomy, combined with lack of realization of their disease often put their relatives in a dilemma and cause transboundary situations

"In safe hands" – knowing that the dementia nurse is available and responsive makes the patients and their relatives feel safe

The role of the dementia nurse as main coordinator of the investigation process is generally appreciated by patients and their relatives, because she is proactive, easily available, helpful and takes her time

The relatives are not sufficiently involved in investigation process carried out by the general practitioner and dementia nurse

The patients and their relatives want to take care of themselves and ask for support to "self-help" – and relevant support at the right time

Trust and confidence in the doctor and the nurse is more important than information for some patients and their relatives

Patients desire for autonomy, combined with lack of realization of their disease often put their relatives in a dilemma and cause transboundary situations

Relatives respect the patients autonomy

Close relatives often suppress their own needs

But relatives need to intervene when the patients act inappropriately due to lack of realization of their disease

Because relatives fear accidents when the patients with dementia are not looked after

"To leave home, just a few hours, to take a short trip to town, that's all right. As long as he doesn't run away from home. He hasn't done it yet. And luckily, he sleeps during the nights"

"Surely, what we really want is some kind of treatment (for speech problems). That's the most important thing. Our daily life works well – no problem" (the patient with dementia has lost the ability to express herself sufficiently, and her spouse wanted help to regain her verbal skills)

"To remind my father to feed the horses I'm not sure that the municipal nurses are allowed to assist"

"I wish we had snow all year round, so my husband had something meaningful to do. It is so important for him, because when he has cleared the pavement for snow, he has done a proper piece of work"

"We got a leaflet about a meeting (about dementia); we were invited to a meeting in Aalborg with other people who would talk about their experiences. But I didn't go there... I have a sister in law, and the same thing happened to her... (She suffered from dementia) I don't want to learn more... it's no good looking ahead for trouble"