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

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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?

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

Citations

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

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

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.

Some of the relatives want and need help to make decisions about the disease.

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

Relatives respect the patients autonomy.

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

Close relatives often suppress their own needs.

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

Further information about the project
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“Surely, what we really wanted was some kind of treatment (for speech problems). That's the most important thing. Our daily life works well – no problem” (the patient with dementia who lost the ability to express himself sufficiently and her spouse had to stop having social contacts regaining her verbal skills).

“I wish we had snow all year round. My husband had something funny 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.”

“Of course, we need more help, but it is quite similar to before the disease” (the patient, 80 years old, had severe cognitive impairment and his wife had a good overview of their everyday life, so they were satisfied with what was offered).

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 information, the decisions made by the specialists in the secondary sector.

We need more help. I really want to learn English. I don’t want to live like this anymore... It’s no good leading a second life ahead for trouble.”

“Surely, what we really wanted was some kind of treatment (for speech problems). That's the most important thing. Our daily life works well – no problem.” (the patient with dementia who lost the ability to express himself sufficiently and her spouse had to stop having social contacts regaining her verbal skills).

“To remind my father to feed the horses … I’m not sure that the municipal nurses are allowed to do that.”

“The help that is offered, can’t always 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 decisions that affect their future life.

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

In the follow-up process, the patients and their relatives ask for more information and guidance about dementia.

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

The relatives feel safe because the dementia nurse is available and responsive.

“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 is main coordinator of the investigation process and 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 the investigation process carried out by the general practitioner and dementia nurse.

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

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