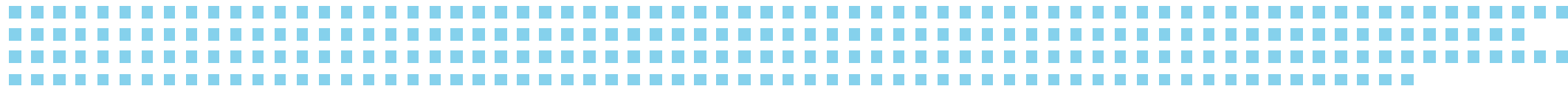


BRIDGING THE GAP FROM DIAGNOSIS TO POST-DIAGNOSTIC CARE

Supporting people with young-onset dementia and their families
during the diagnostic trajectory

Jackie Poos, PhD

Alzheimercenter Erasmus MC, the Netherlands



OVERVIEW

1. Current gaps – lessons learned from YOD research
 - Availability of support following diagnosis – *what is out there?*
 - Lived experiences – *what is needed?*
2. Post-diagnostic care **immediately** following diagnosis at the memory clinic
 - Preliminary results – *what have we done?*
 - Developing a framework for YOD – *what are we currently doing?*

LESSONS LEARNED

Availability of support following the diagnosis

Alzheimer Europe (2020): 'post-diagnostic support provision varied considerably and in some cases it was not a distinct service'

- Germany & Finland: public providers for information on dementia, counseling, and peer support
- Ireland & Wales: key workers for coordination
- Greece: Regional person or service for supporting person with dementia
- Israel: draft care plan immediately following diagnosis

LESSONS LEARNED

Availability of support following the diagnosis

World Alzheimer Report 2022:

- 37-45% of people no support after diagnosis
 - 66% of people no personalized care plan
 - 54% of carers stressed often or all the time
-
- Governments must urgently built robust models of post-diagnosis support that are tested, funded, monitored, and fine-tuned
 - Person-centered care must become the norm
 - Support for carers must be prioritized

LESSONS LEARNED

UK

Availability of support following the diagnosis

ANGELA project - national survey on services for people with YOD (n=233)

- Approximately 42% no follow-up first 6 weeks after diagnosis
- 39% reported seeing no healthcare professional within previous 3 months
- 1/3 reported having no routine follow-up appointments
- Only 38% had support from a casemanager / keyworker
- Differed between specialist YOD centres (1/5) and general neurology or GP (1/5)

LESSONS LEARNED

Lived experiences – Boots 2015



Figure 2. Schematic representation of the early-stage needs paradox and the acceptance process.

LESSONS LEARNED

Lived experiences – Chirico 2022

Methode: 38 interviews with 26 spouses and 12 adult children

Results (3 themes):

1. Problems around diagnosis

- a. Difficulty in the pre-diagnostic phase
- b. Delayed diagnosis
- c. Inappropriate communication
- d. Need of counseling

Many participants reported that the YOD condition was not named clearly to their relatives, but rather euphemisms and vague words such as memory problems were used.

2. Lack of post-diagnostic support

- a. Financial barriers
- b. Lack of case management
- c. Geographic barriers
- d. Care needs

“When the diagnosis was told, we didn’t know anything about dementia. We didn’t know what it would have implied, how the condition would have developed and how much time it would have lasted. It was shocking. I had to learn all by myself, and it wasn’t easy at all. There’s the need for someone teaching you how to cope with this condition” (husband, 70 yrs).

“There is a lack of coordination among services. There is the need of a person helping you with every aspect of the condition” (daughter, 42 yrs).

3. Living with YOD as a family

- a) Couple relationships
- b) Parent-child relationships
- c) Social isolation

“I was really lucky because a neurologist gave me all the information about the available services and resources for the condition” (wife, 62 yrs).

LESSONS LEARNED

Lived experiences – Grunberg 2022

USA

Negative experiences with providers

“...the doctor there’s words were: “You have FTD. You have 4, 5 years to live. Come back in six months” (person living with dementia)

“A regular interaction over 6-weeks would be helpful’ (spouse)

‘I was noticing things that were different, and he said well maybe you should just stop watching him...I was horrified’ (spouse)

“See you in 6 months”. And I’m like, “What about this?” And they’re like, “Well, we really don’t know.” And as we move through it, it’s like what else is out there? And it’s really hard to figure that out’ (spouse)

“everywhere we went, was oh its terminal, so let’s try this. It can’t do any harm because she is dying anyway’ (’ (spouse)

“We were kind of like dropped a bombshell into our lives, and then it was like OK, drive home. It’s pretty much hey, guess what – this is what you got. Bye’ (spouse)

Positive experiences with providers:

‘we’ve found it later he’d be pretty responsive, if we had a question, he had an answer’ (spouse)

‘she told me about the support groups, she told me about AFTD, the alzheimers.org has been very helpful as far as getting some information. We both have the medical alert bracelets. Which I thought, just the fact they thought of to give the caregiver the bracelet as well is huge’ (spouse)

‘I think the medical community has come a long way in a short period of time... let’s treat them with more dignity and let’s try to figure out how to make their life better’ (spouse)

“the team... they were a cohesive unit. They were completely on the same page, very supportive of one another’ (spouse)

“it was a whole team approach. It was really well done and we felt well cared for’ (SP,’ (spouse)

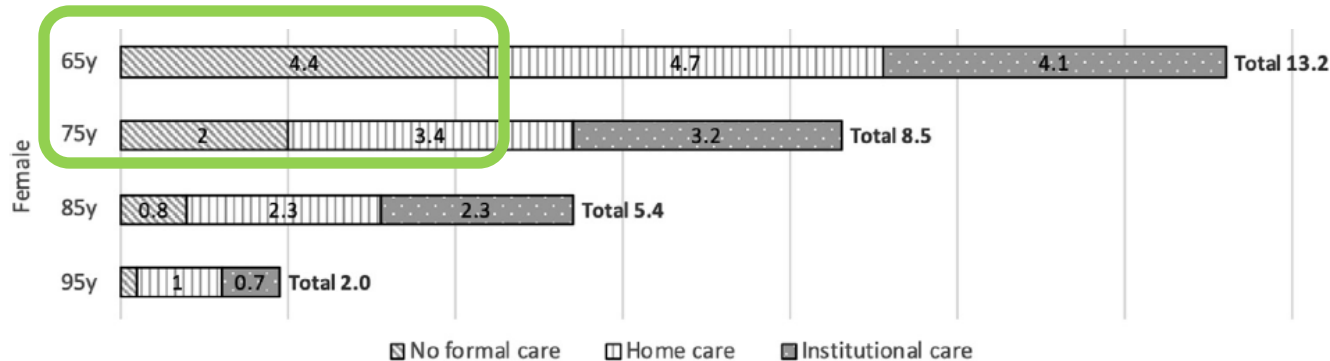
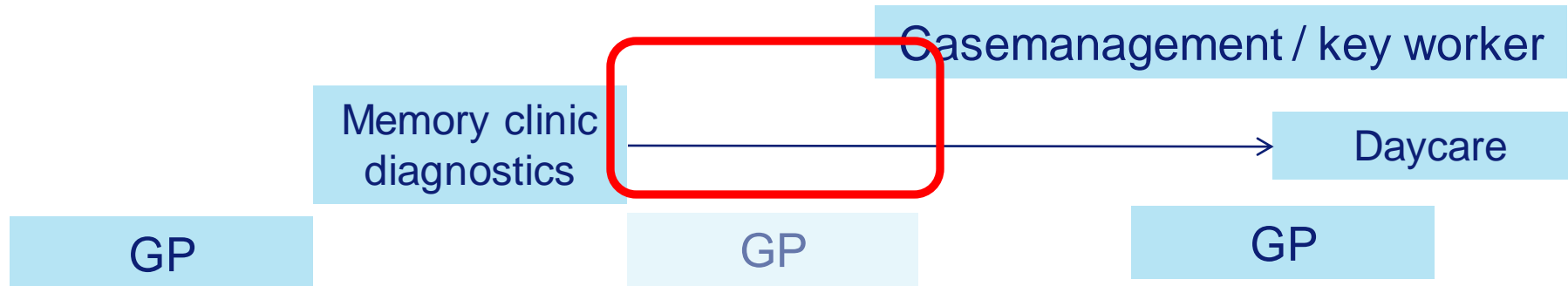
LESSONS LEARNED

Lived experiences – O’Malley 2021

Diagnostic phase	Statement	Diagnostic phase	Statement	Diagnostic phase	Statement
Referral process	For the GP to identify dementia in younger people	Clinicians should be compassionate, empathic and respectful during the assessment and particularly sensitive when providing information about a diagnosis To be seen at home for assessments and post-diagnostic support where appropriate Giving the person with dementia and their family enough opportunities to ask questions Clinicians should be calm, approachable and easy to talk to Clinicians should offer opportunities for the person with dementia and their supporters to speak separately about any issues they wish to discuss To have a multidisciplinary team involved in diagnosis to provide appropriate support More awareness and training on rarer dementia types as well as the issues faced by younger people with dementia in mental health trusts Being understanding during the assessments, especially visual tests for people with PCA Assessments should be conducted in a quiet and private room	Having more information on what the SPECT scanning was all about Better access to sleep and anger clinics The MRI experience should provide blankets, ear protectors to reduce noise and allow supporters to be in the room if the person wishes Results to be given in clinic more quickly The time taken to achieve a formal diagnosis needs to be shortened if possible Providing the people with dementia and their families with information about their diagnosis and prognosis if they wish it	Diagnosis process	Clinicians should explain medical terms, and what they mean in a simplified manner Remembering that receiving the diagnosis is a lot to take in for the person with dementia and supporter Providing the person with dementia and their supporters with a letter which details the diagnosis
	Ensure there is enough notice between appointment letters being issued and the appointment				
	Making appointments convenient for working adults				
	Being kept in the loop and feeling involved in the assessment				
	Healthcare professionals should make contact with family supporters if unable to get through to the person with dementia directly regarding appointments				
	The clinicians should listen to the person with dementia and their family as a whole				
	Having an identified key person as a single point of contact throughout the whole diagnostic process				
	Communication with clinicians should ideally be in person				
	Avoid the same questions being asked by the separate clinicians where possible				
	Assessment process				
Referrals should ideally be made to specialist YOD clinicians and services					

POST-DIAGNOSTIC CARE

Situation in the Netherlands



- Long waiting lists for casemanagers / keyworkers (specifically those specialized in YOD)

POST-DIAGNOSTIC CARE

The memory clinic of the Alzheimercenter Erasmus MC



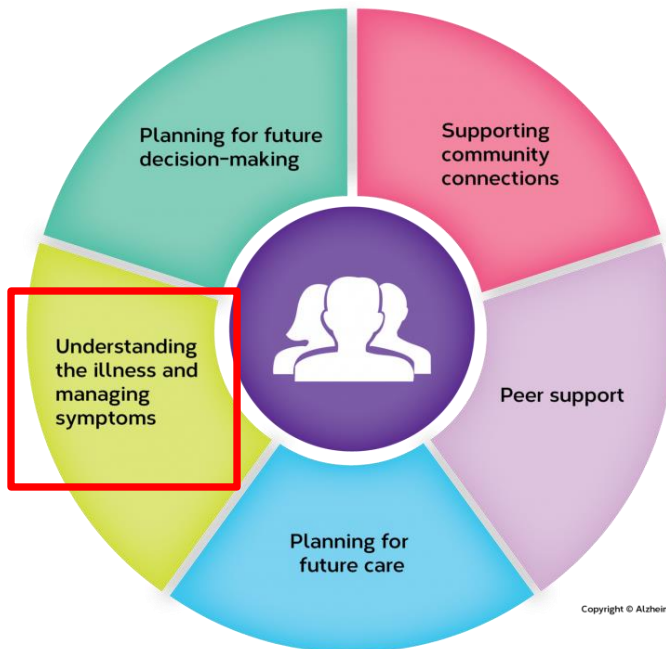
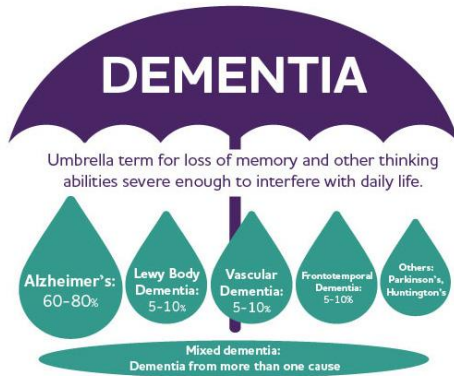
Key principle: proactive and structured, for everyone newly diagnosed with dementia

- Six weeks after receiving diagnosis
- 60 minutes
- Care consultant

Research into the effectiveness (knowledge about dementia and dementia care & coping)

POSTDIAGNOSTIC CARE

Psychoeducation about the disease, symptoms and management



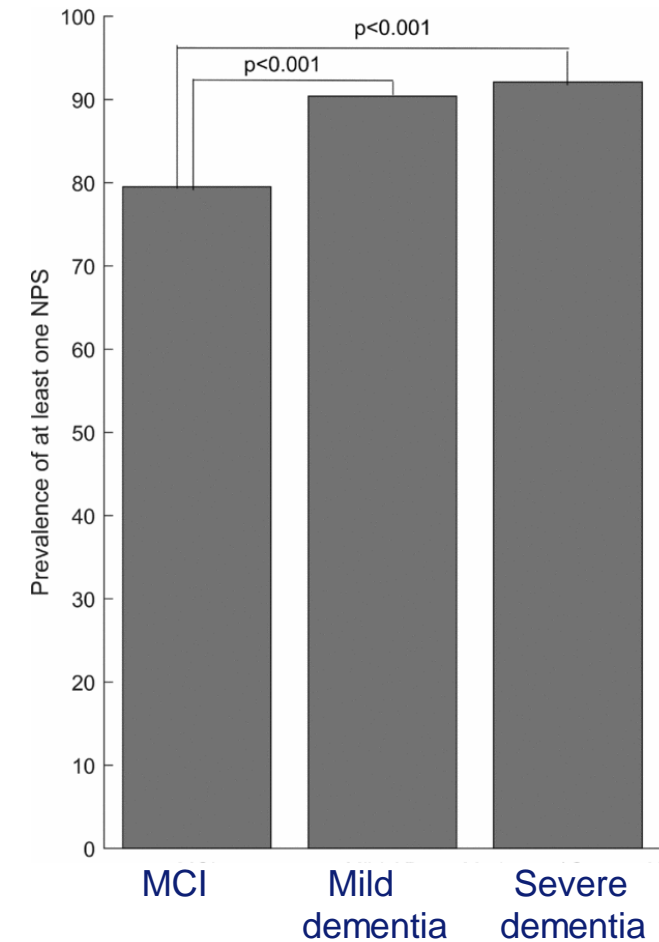
- Dementia as a syndrome
- Personalized explanation on nosological diagnosis (symptoms and prognosis)
- Personalized explanation of identified cognitive and behavioural symptoms during diagnostic trajectory
- Personalized coaching in how to deal with these symptoms in daily life

POST-DIAGNOSTIC CARE

Neuropsychiatric symptoms

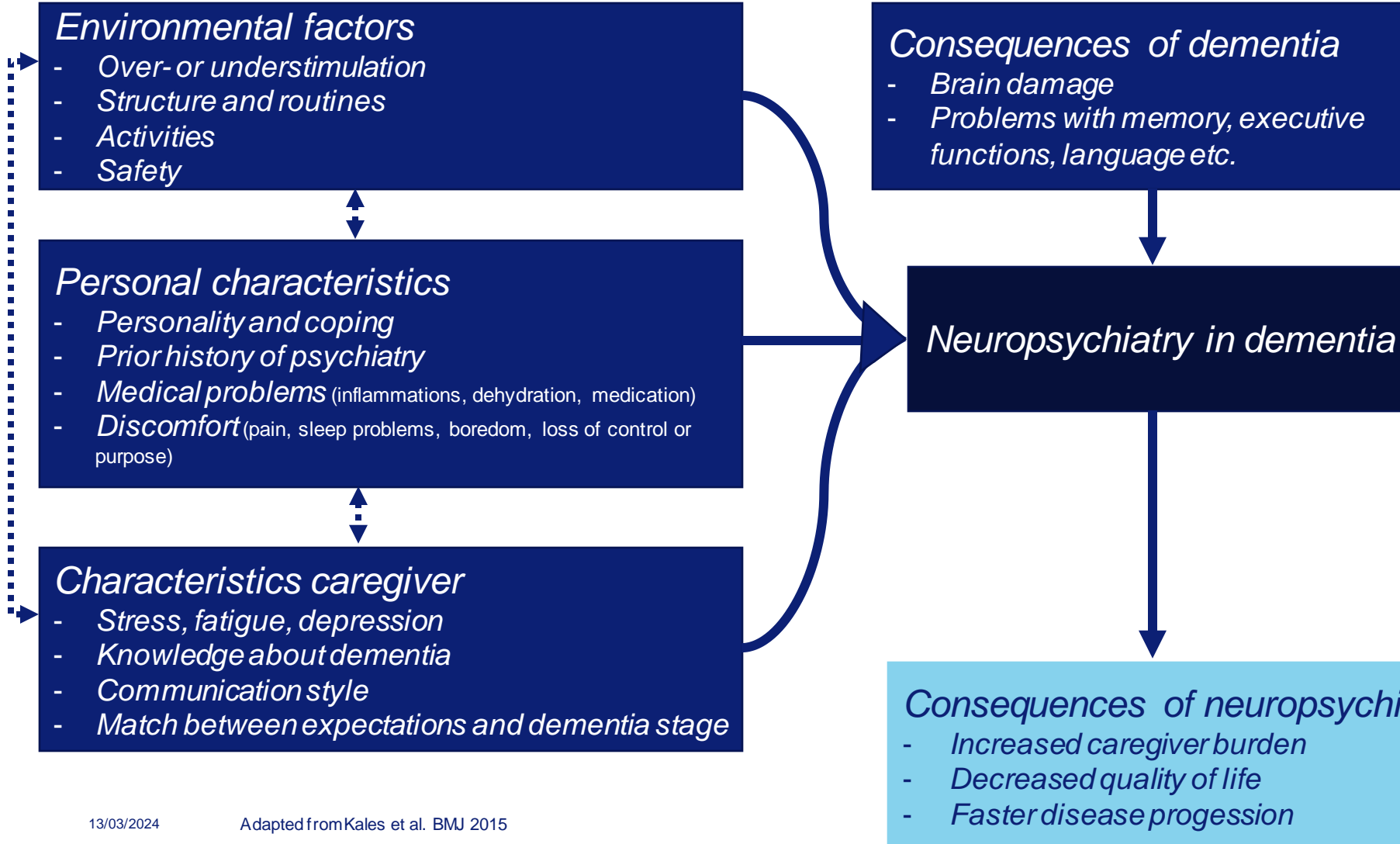
- Increasing evidence for the presence of neuropsychiatric symptoms in the early stage of dementia
- Lot of differences in presentation and trajectory between people
- Impacts nearly every patient with dementia during care trajectory

Alzheimer	FTD	Vascular	Lewy Body
Apathy	Disinhibition	Apathy	Hallucinations
Depression/anxiety	Changes in eating behaviour	Sleep problems	Delusions
Agitation/suspicion	Compulsive behaviour	Agitation	Depression
Sleep problems	Apathy	Depression	Apathy



POST-DIAGNOSTIC CARE

Neuropsychiatric symptoms



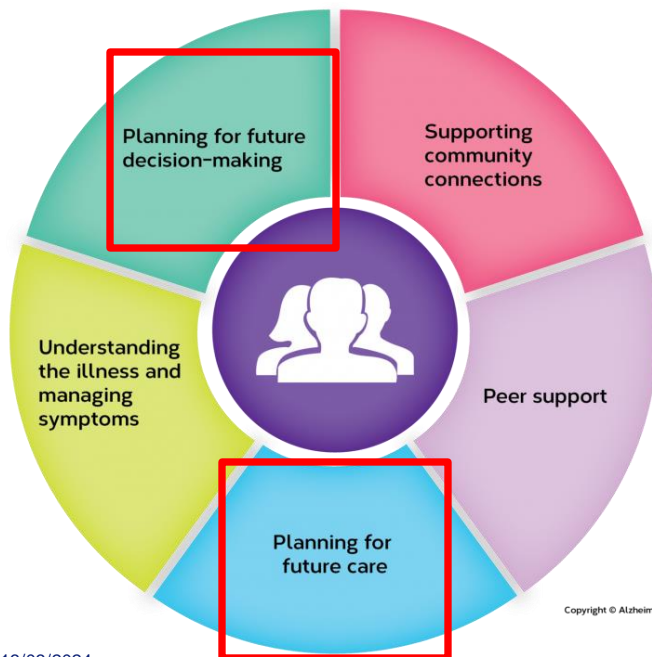
- Often unknown that NPS can be (a first) symptom of dementia
- Often medication-targeted
 - Little evidence for effectiveness and serious side effects
 - (Inter)national guidelines recommend non-pharmalogical treatment
 - But are not specific, and targeted at severe dementia/nursing home

POST-DIAGNOSTIC CARE

Future care and advanced care planning



- Education on available dementia care and services
 - Casemanagement / keyworker, daycare, day treatment, intramural care
- Education on local institutions and settlements (promote proactive approach)
- Encourage to think about suitable approach and advanced care planning (with GP and (future) keyworker)



POST-DIAGNOSTIC SUPPORT

Caregiver support

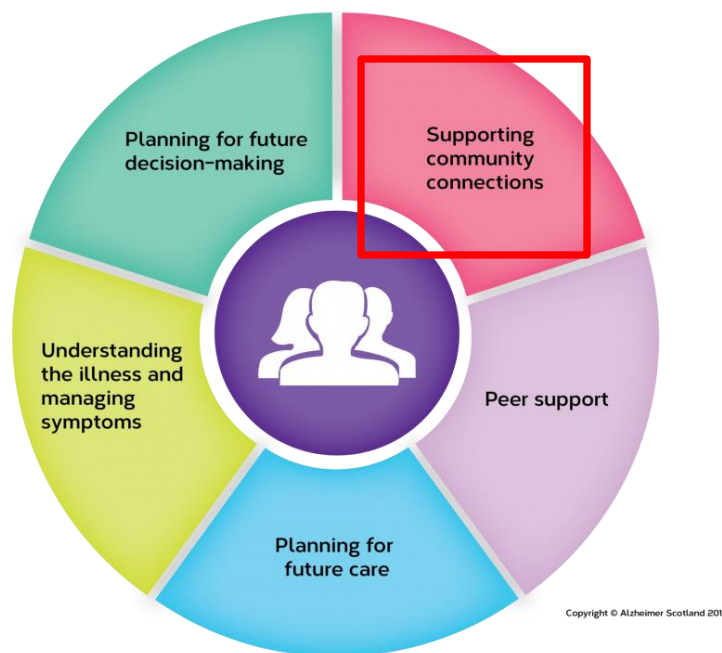
Disentangling factors that influence the spousal relationship of people with young-onset dementia: starting points for person-centered care and support?

Hanna E Bodde¹, Janne M Papma^{1, 2}, Jackie M Poos¹

Affiliations + expand

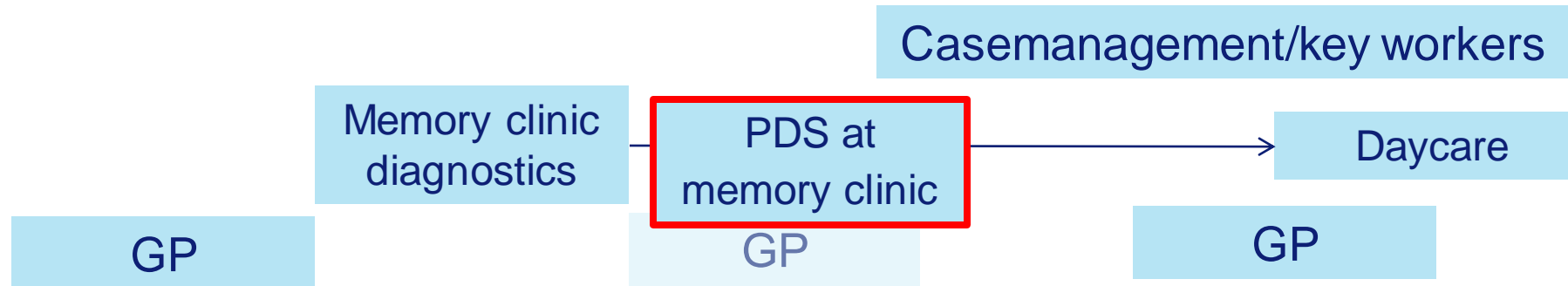
PMID: 38351545 DOI: 10.1017/S1041610224000395

- Address quality of/changes in spousal relationship
- Practical: driving test



POST-DIAGNOSTIC CARE

Pilot results



- 7 couples from department of Neurology and Geriatrics
- Pre- and post measurement
- Four questionnaires targeting: knowledge of dementia, knowledge of care/services, use of healthcare, and caregiver support and confidence
- All scores increased

POST-DIAGNOSTIC CARE

Developing a framework for YOD



- YOD very different from late-onset dementia
 - Time to diagnosis (~1 to 2 years longer)
 - Living situation
 - Etiology (atypical forms), disease progression, and clinical presentation (more NPS)
 - Caregiver needs
- YOD-INCLUDED subproject:
 1. Identify red flag in prodromal FTD
 2. Develop holistic and personalized patient profiles
 3. Investigate lived experiences/needs during diagnostic trajectory
 4. Gain national overview of available services post-diagnostic care immediately following diagnosis
 5. **To develop a framework for person-centered (post-)diagnostic care and support for YOD in the period *immediately* following the diagnosis**



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