Advance Care Planning in Young-onset Dementia

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Advance care planning (ACP)

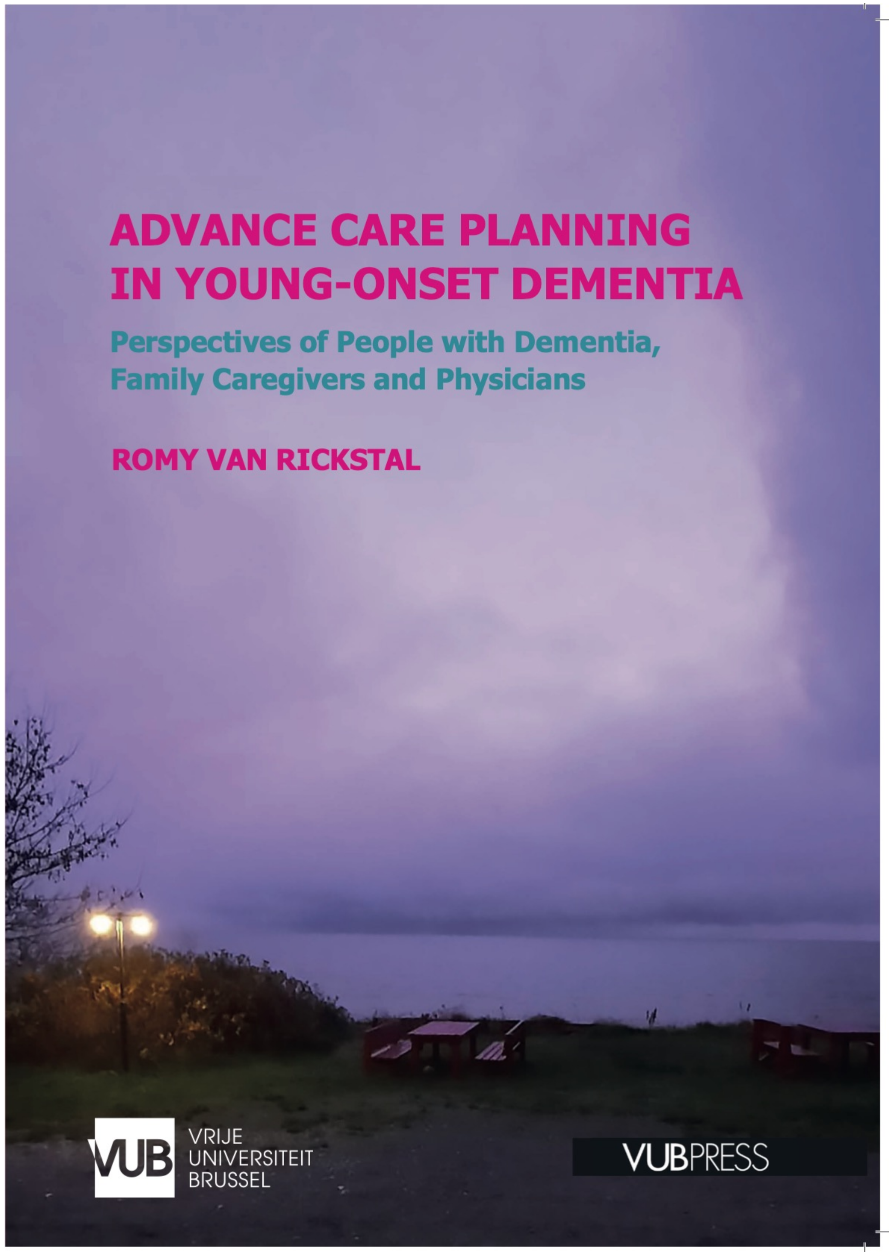
Process of communication

Lesser focus on documentation

Aim is to increase the chance that care received = care desired

Young-onset dementia

What are the experiences with, the preferences for and the perspectives on advance care planning of people with young-onset dementia, their family caregivers and physicians?



ADVANCE CARE PLANNING IN YOUNG-ONSET DEMENTIA

Perspectives of People with Dementia, Family Caregivers and Physicians

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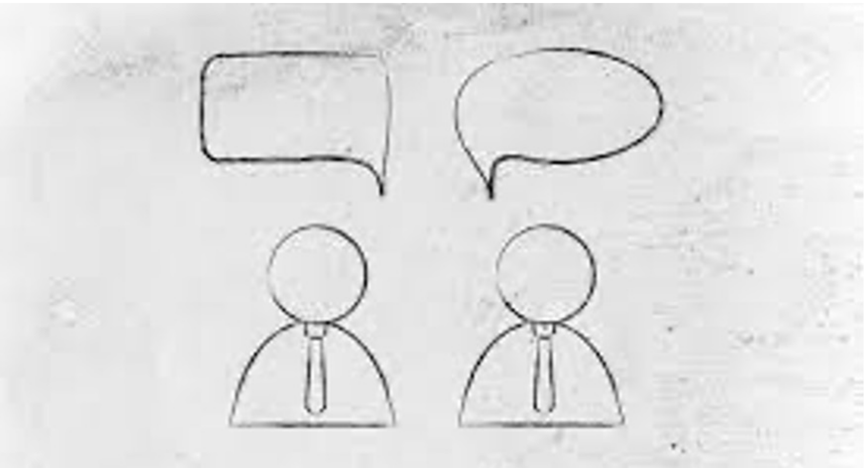
Qualitative studies



People living with young-onset dementia & their caregivers

Physicians

Original Article

PALLIATIVE MEDICINE

Palliative Medicine
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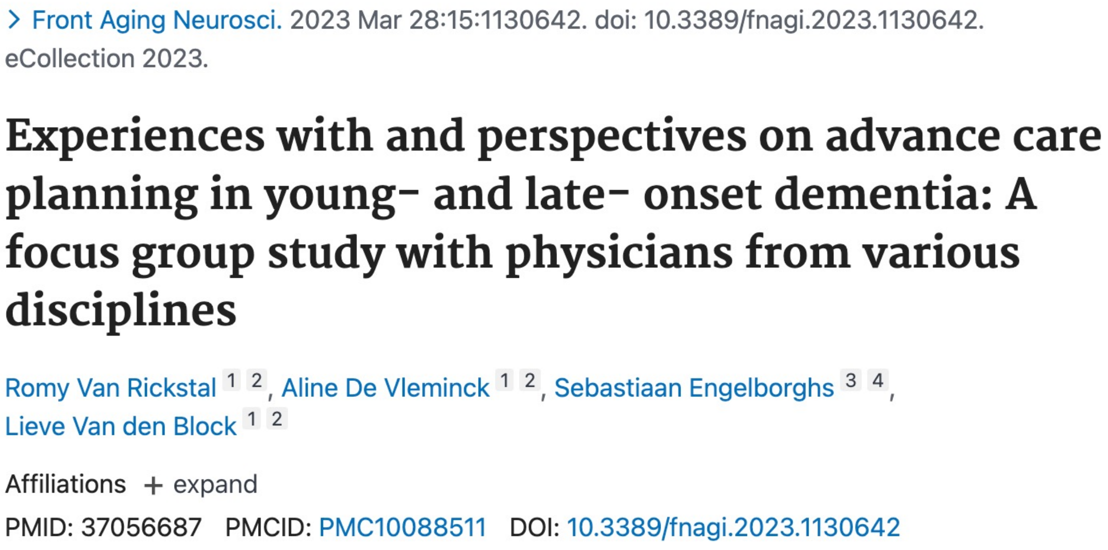
A qualitative study with people with young-onset dementia and their family caregivers on advance care planning: A holistic, flexible, and relational approach is recommended

Romy Van Rickstal[1,2], Aline De Vleminck[1,2], Sebastiaan Engelborghs[3,4,5], Jan Versijpt[6,7] and Lieve Van den Block[1,2,8]



> Front Aging Neurosci. 2023 Mar 28:15:1130642. doi: 10.3389/fnagi.2023.1130642. eCollection 2023.

Experiences with and perspectives on advance care planning in young- and late- onset dementia: A focus group study with physicians from various disciplines

Romy Van Rickstal [1] [2], Aline De Vleminck [1] [2], Sebastiaan Engelborghs [3] [4], Lieve Van den Block [1] [2]

Affiliations + expand

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Key message

Engagement in ACP; possibly hindered when

- Overly medicalized
- Exclusively patient-centered

=> holistic, flexible and relational communication process

Holistic

Lacking awareness about ACP as communication process

Respondents do not compartmentalize medical, mental and social health

‘What matters most?’

Responsibility of policy makers and physicians

“It’s only by knowing what exists, that you know how you can be helped. . . The more you know, the better the trajectory will be. I am convinced of that.” (person with young-onset dementia, man)

“There is information, but you always have to go look for it yourself. . .. Information is the most important step -within advance care planning.” (caregiver, woman)

Flexible

Field of tension: needing to know VS not needing to know more

Sensitive and step-by-step information provision

Synchronize process to individual

Uncertainty for all stakeholders: inevitable

Process > product

“Yes, it can change. . . I always have difficulty with ACP -advance care planning- on paper because it changes. Right , not wanting a few things any longer, yeah, until the time is there. . . To me it has to remain vivid. I am under the impression that if I write it down, then it’s somewhere outside of me -my control-.” (caregiver, woman)

“It progresses differently for everyone, so you can’t focus on that, right. So yes, we know something is coming, but we don’t know what.” (caregiver, woman)

“You can discuss certain scenarios like ‘I think of it like this’, but at the moment it happens, you can never say like ‘this is exactly identical to what we have discussed’.” (caregiver, woman)

Flexible

Field of tension: needing to know VS not needing to know more

Sensitive and step-by-step information provision

Synchronize process to individual

Uncertainty for all stakeholders: inevitable

Process > product

“The way in which you get more concrete in terms of prognosis, that’s also an advancing insight. After the diagnosis, the progression, the first two years. . . that always gives an indication of how quickly it could evolve.” *(neurologist)*

“If they say “I don’t ever want to be in a wheelchair”, or “I always want to be able to feed myself”, or something like that, then eventually, when push comes to shove, they don’t mind being driven around or they don’t mind that they’re being cooked for. So, it changes so much that it’s not fully predictable.” *(neurologist)*

Flexible

Field of tension: needing to know VS not needing to know more

Sensitive and step-by-step information provision

Synchronize process to individual

Uncertainty for all stakeholders: inevitable

<u>Process > product</u>

Relational

The benefits of ACP and the need for ACP are relational

ACP as an act of care

Relational autonomy

ACP as means to counter stigma

“Actually, if you do that -advance care planning, document a will-, at this point I think that you do it more so for your relatives than for yourself. Because I am not yet convinced that those people -people living with more advanced stages of dementia- actually suffer pain or that those people experience an unbearable feeling.” (person with young-onset dementia, man)

“I have to do that for myself as well, not just for him.” (caregiver, woman)

Relational

The benefits of ACP and the need for ACP are relational

ACP as an act of care

<u>Relational autonomy</u>

ACP as means to counter stigma

“That they -people in general- do not have to immediately think or say to others ‘oh, but he doesn’t know it anyway’. Okay, that will be the impression these people have, you can’t blame them, that a group of people still have that taboo and that they don’t know. . .” *(person with young-onset dementia, man)*

“I was once allowed to join -in support group for patients and caregivers- and then the first time I could be with the group, uum. . . it was a meeting. And then the second time I wasn’t allowed to participate anymore, only those who were not sick were allowed in that room. And I had to make drawings, do another thing. And then I was a bit angry. . . I was very angry actually.” *(person with young-onset dementia, man)*

Relational

The benefits of ACP and the need for ACP are relational

ACP as an act of care

<u>Relational autonomy</u>

ACP as means to counter stigma

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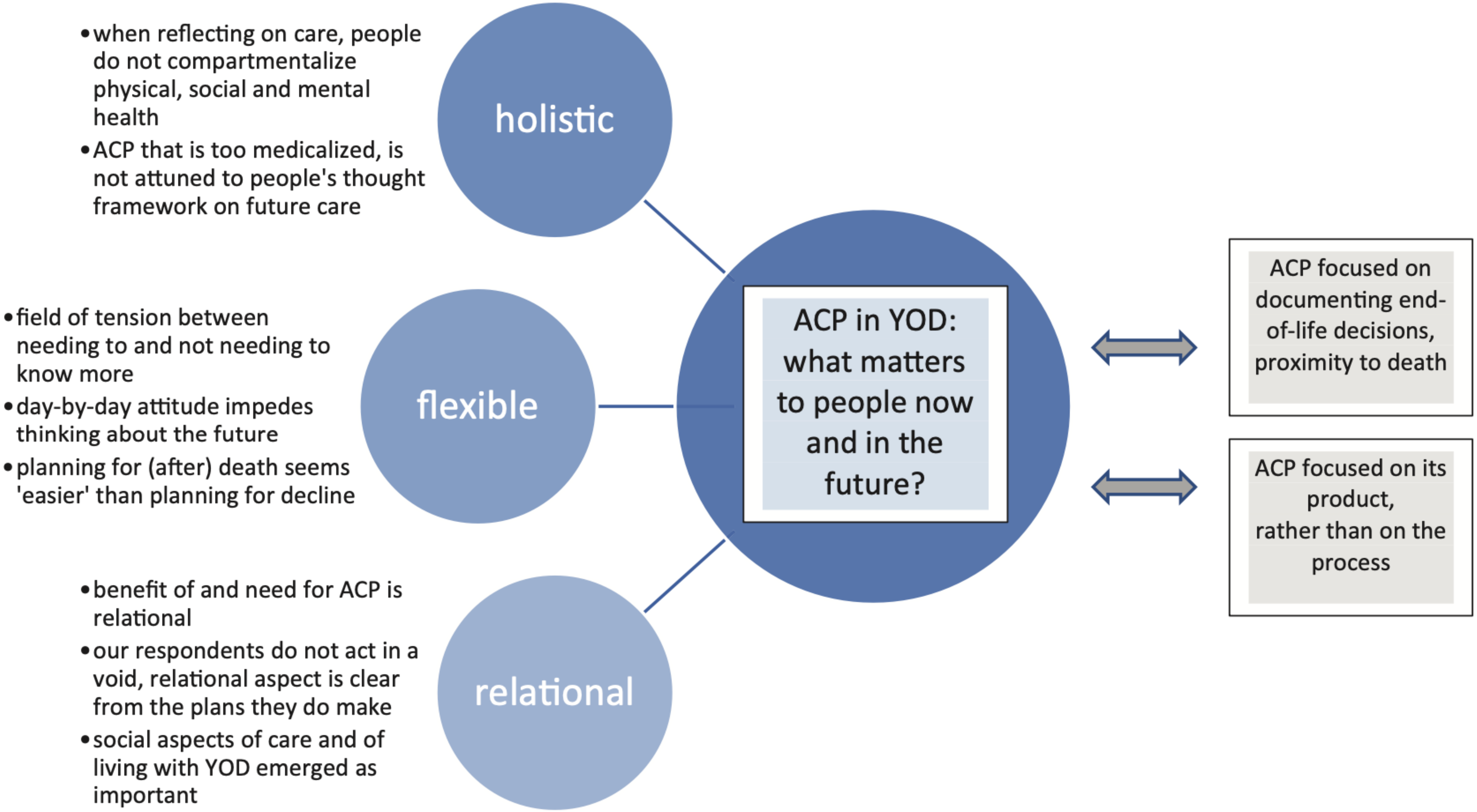

- when reflecting on care, people do not compartmentalize physical, social and mental health
- ACP that is too medicalized, is not attuned to people's thought framework on future care

holistic

- field of tension between needing to and not needing to know more
- day-by-day attitude impedes thinking about the future
- planning for (after) death seems 'easier' than planning for decline

flexible

- benefit of and need for ACP is relational
- our respondents do not act in a void, relational aspect is clear from the plans they do make
- social aspects of care and of living with YOD emerged as important

relational

ACP in YOD: what matters to people now and in the future?

ACP focused on documenting end-of-life decisions, proximity to death

ACP focused on its product, rather than on the process

Thank you!

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