

YOD Symposium Part 2

Objectives: LuBAIR™ Paradigm, a novel approach to ascribing meaning for behavioral expression in advanced neurocognitive disorder, was used to identify behavioral categories that are likely to respond to the use of atypical antipsychotics in their management.

Design: *A retrospective study.*

Setting: St. Peter's Hospital (SPH), Hamilton, Ontario, Canada.

Participants: *Forty patients qualified for the study.*

Intervention: LuBAIR™ Inventory populated on all recruited patients on two separate occasions. The first time was within two weeks of admission and the second time was after sixty days, if they *successfully de-prescribed* off the AAP, or sooner, if they *failed de-prescribing*.

Measurements: Chi-Square paired t-test and Cohen d Statistical tests were used to detect the difference in the behavioral categories between the two cohorts.

Results: Seventeen patients *were successfully de-prescribed*, and twenty-three *failed de-prescribing*. Results on the LuBAIR™ Inventory, filled on the second occasion, in the *successful de-prescribed* and the *failed de-prescribed* groups compared using the Chi-Square Statistical test to detect the difference in the behavioral categories the two cohorts. Patients who did not have *Mis-Identification Expressions (MiE)* and *Goal-Directed Expressions (GDE)*, amongst the cluster of behavioral categories in their clinical presentation, were more likely to *successfully de-prescribe of AAP*: $\chi^2(1, N = 40) = 29.119, p < .0001$ and $\chi^2(1, N = 40) = 32.374, p < .0001$, respectively. Alternatively, the same behavioral categories were more likely to be present in patients who *failed de-prescribing*: paired t-test and Cohen-d ($P < 0.0001$).

Conclusion: The MIE and GDE were statistically significant, suggesting that these behaviors were more present in patients who *failed de-prescribing*. Atypical antipsychotics, in their role as an antipsychotic and mood stabilizer, may be

Euthanasia on their mind: a qualitative analysis of spontaneous expressions of people with young-onset dementia and their family caregivers.

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Introduction: Previous research showed that people with young-onset dementia and their family caregivers spontaneously addressed the topic of euthanasia when talking about the broader topic of advance care planning. A better understanding of what people address and why may provide innovative insights to inform the evolving physician assisted dying legislation worldwide. This study aimed to identify what people with young-onset dementia and their family caregivers spontaneously expressed regarding (communication about) euthanasia when discussing the topic of advance care planning.

Methods: A secondary qualitative analysis was conducted, through the method of constant comparative analysis on semi-structured interviews. We included 10 people with young-onset dementia and 25 family caregivers in Flanders, Belgium.

Results: Respondents described similar contexts for discussions about euthanasia: the topic arose at several key moments, usually with informal caregivers, and was motivated by patients considering the impact of disease progression both for themselves, thereby mainly wanting to avoid decline and maintain dignity, and their loved ones. Family caregivers paid considerable attention to the legality of euthanasia in dementia, specifically with regard to cognitive capacity, and elaborated on the difficulties and emotional impact of discussing euthanasia.

Conclusions: Considerations of people with young-onset dementia towards euthanasia appeared rooted in personal unbearable suffering and in expected interpersonal and societal consequences of their condition. Negative social framing of young-onset dementia might contribute to the livelihood of euthanasia in respondents' thoughts. The incorporation of euthanasia as a legal end-of-life option was mirrored in its incorporation in patients' and family caregivers' thought framework.

Perspectives of people with young-onset dementia on future quality of life: a qualitative interview study with implications for advance care planning

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Introduction: Advance care planning (ACP), one of the key domains of palliative care, enables individuals to define and discuss goals and preferences for future treatment and care with family and healthcare professionals. By exploring the views of people with dementia on quality of life now and in the future, including the end of life, care provisions can be tailored to their values. The perspectives of people with young-onset dementia (YOD), with a symptom onset before the age of 65, may differ from those of older people with dementia given the different life phase and family context. Qualitative research methods can be used to elicit the attitudes and beliefs to generate insight into their perspectives.

Methods: Qualitative study, as part of the Care4Youngdem-study, using semi-structured interviews with a criterion-based purposive sample of community-dwelling people with YOD (n=10) and their (family) caregivers in the Netherlands. We adapted the interview guide based on discussion of the transcripts. Double coding of three interviews resulted in a codebook. The codes were subsequently analysed through thematic analysis.

Results: Interviews took place between December 2019 and February 2022. The most prevalent dementia subtype was Alzheimer's (n=7). Four overarching themes, based on 21 categories, were derived from the interviews: (1) connectedness with others, (2) sense of dignity, (3) acceptance versus no acceptance of the impact of dementia, (4) concerning oneself with the future versus not wishing to concern oneself with the future. Connectedness with others and a sense of dignity were deemed prerequisites for (future) quality of life but were affected by YOD. These themes overlapped in terms of axial codes. Ambiguities were seen in the attitude towards the impact of YOD and the preparation for the future. The degree of acceptance of YOD affected the orientation towards the future.

Discussion: Family and professional caregivers should discuss with people with YOD how to maintain connectedness with others and a sense of dignity. Opposite ways of coping with the present and future were found. Professional caregivers should take personal coping styles into account when starting ACP conversations.