




A thematic analysis of psychotic symptoms in young-onset dementia

Liam F. Borelli-Millott,^{1,2}  Samantha M. Loi,^{1,3}  Dennis Velakoulis,^{1,3}
and Anita M.Y. Goh^{1,2,3} 

¹Department of Psychiatry, The University of Melbourne, Parkville, Victoria, Australia

²National Ageing Research Institute, Parkville, Victoria, Australia

³Royal Melbourne Hospital, Parkville, Victoria, Australia

ABSTRACT

Objectives: Exploration of the themes and content of psychotic symptoms in young-onset dementia (YOD) is limited to case analysis. The primary objective of this study was to determine the themes of psychotic symptoms in individuals diagnosed with YOD.

Design: Comprehensive retrospective file review of discharge summaries.

Setting: *Neuropsychiatry*, a specialist mental health service located at the Royal Melbourne Hospital, Australia.

Participants: Inpatients at *Neuropsychiatry* admitted between 2018 and 2020 (inclusive).

Measurements: Data extracted included descriptions and prevalence of psychotic symptoms as well as general demographic and clinical data. Data analysis was conducted using a thematic approach.

Results: Twenty-three inpatients had a diagnosis of YOD with psychotic symptoms. Themes were identified in the domains of delusions (six themes), auditory hallucinations (five themes), and visual hallucinations (two themes). Strong recurring themes across the modalities of hallucinations and delusions were beliefs and experiences relating to paranoia, suspicion, harm, and abuse. Themes did not clearly intersect across the modalities of hallucinations and delusions. A degree of thematic heterogeneity existed within individuals, and individuals experienced delusions or hallucinations of multiple themes. The themes of the psychotic symptoms did not clearly relate to diagnostic category, nor to time from diagnosis.

Conclusion: This study is the first thematic analysis of psychotic symptoms in YOD and provides further understanding of patient phenomenology and experiences of psychosis in YOD.

Key words: early-onset dementia, neurodegenerative disorders, neuropsychiatric symptoms, behavioral and psychological symptoms of dementia, psychosis, dementia symptomatology, qualitative research

Introduction

Young-onset dementia (YOD) is characterized by an onset of symptoms before the age of 65 (Rossor *et al.*, 2010). YOD is far less common than later-onset dementia (LOD) and often more challenging to diagnose due to its heterogeneous presentation (Koedam *et al.*, 2010; Loi *et al.*, 2021b). However, rising prevalence of dementia includes an increase of people living with YOD, estimated at 5–10% (Hendriks *et al.*, 2021)

which has significant psychosocial, medical, and policy implications (Cations *et al.*, 2021; Sansoni *et al.*, 2016).

Psychotic symptoms are one of the many neuropsychiatric symptoms that may be present in individuals with YOD and have been reported in both early- and late-disease stages (Waldö *et al.*, 2015). A study of nursing home residents with YOD found that 7.1% presented with delusions and 5.8% presented with hallucinations (Mulders *et al.*, 2016). In a longitudinal assessment of neuropsychiatric symptoms in nursing home residents with YOD, 9.1% presented with delusions and 1.1% presented with hallucinations at initial assessment (Bauhuis *et al.*, 2020). In a retrospective study of individuals with

Correspondence should be addressed to: Mr. Liam Franco Borelli-Millott, 34-54 Poplar Road, Gate 4, Building 8 (PO Box 2127), Royal Melbourne Hospital, Victoria, 3050, Australia. Email: lborellimill@student.unimelb.edu.au. Received 30 Aug 2022; revision requested 15 Nov 2022; revised version received 04 Jan 2023; accepted 02 Feb 2023. First published online 09 March 2023.

young-onset frontotemporal dementia (FTD), approximately 29% initially presented with psychotic illness (Velakoulis *et al.*, 2009). Loi *et al.* found that 21.6% of people with YOD had a new diagnosis of psychosis, within 10 years of YOD diagnosis (2021b). Gossink *et al.* (2017) used the Positive and Negative Symptoms Scale (PANSS, designed to assess the symptoms of schizophrenia) in a cohort of FTD patients and compared their results with a cohort with only primary psychiatric diagnoses (no dementia). Age of onset of symptoms included up to 70 years. Clinician PANSS assessment found all those with FTD except one had at least one negative symptom, and 23% of their sample with FTD experienced symptoms of suspiciousness alongside delusions and hallucinations, and 88% had a syndrome consistent with formal thought disorder.

While the phenomenology and themes of psychotic symptoms have been well characterized in individuals with psychotic disorders, including schizophrenia (McCarthy-Jones *et al.*, 2012; Paolini *et al.*, 2016; Rajapaske *et al.*, 2011; Wong and Van Tol, 2003), there is extremely limited literature on the content or phenomenology of psychotic symptoms in YOD, with the published literature limited to case studies. These case study reports include delusional themes of persecution, grandiosity (Omar *et al.*, 2009), religiosity (Tartaglia *et al.*, 2008), romantic and sexual (Loy *et al.*, 2010; Olojugba *et al.*, 2007), somatic (Larner, 2008; Musso *et al.*, 2013; Tartaglia *et al.*, 2008), and jealousy (Mendez *et al.*, 2011). Although the published case studies support associations between a diagnosis of YOD and symptoms of psychosis and provide detailed clinical pictures of the type of symptoms seen amongst people with YOD, they lack a specific focus or analysis of the symptom narratives in the YOD cohort.

Investigations in LOD may provide a broader insight into the themes and approach to thematic analysis amongst people with dementia who experience psychotic symptoms. One study qualitatively investigated the content of delusions held by residents with LOD in nursing homes via thematic analysis (Cohen-Mansfield *et al.*, 2011). Themes of delusions included reality, disorientation, reexperience of past events, loneliness and insecurity, boredom, and trigger (as in a triggered delusion). The authors proposed that delusions may be reflective of reality or an understandable perception of reality that the person with dementia has (Cohen-Mansfield *et al.*, 2011) and posited that delusions may not be true delusions in the traditional sense, but rather re-manifestations of past and current experiences, and that delusions may be partly caused by misinterpretations of one's lived experience and past.

Psychotic symptoms may fall into discrete thematic classes characterized by their phenomenology and content. The primary objective of this study was to use qualitative methods to determine if there were themes in the psychotic symptoms in a sample of individuals with YOD. Given the nature of qualitative research, there are no *a priori* hypotheses to limit the inquiry as themes are generated from the data by researchers.

Methods

This study used quantitative and qualitative analysis of data extracted from a file review of discharge summaries for all inpatients at a specialist health service in Australia, *Neuropsychiatry*, Royal Melbourne Hospital, between 2018 and 2020 (inclusive). Discharge summaries include detailed summaries of a range of multidisciplinary inputs, carer input, and investigations, including thorough accounts of patients' symptoms. Discharge summaries are written by a senior registrar at *Neuropsychiatry*, and there is a set format and style that each Registrar is trained to follow, thus leading to increased consistency in the source material. The Clinical Director (author DV) was the lead consultant for the inpatient unit over our sampling period and cosigned most discharge summaries. As this study collected retrospective data from 2018 to 2020, information from a participant's most recent inpatient admission was selected for analysis. For example, for a repeat inpatient from both 2019 and 2020, only information contained in the 2020 discharge summary was considered. A data extraction tool (available on request) was designed and refined by discussion between authors, and all variables were discussed and refined until consensus was reached. A sample of discharge summaries was double-coded between two authors (LBM and AG) ensuring further refinement of the data extraction tool and to check quality of data collection. Qualitative data extracted were descriptions of psychotic symptoms described in the discharge summaries. Descriptions were either as described by patient, clinician, and/or significant others. Psychotic symptoms were attributed as described in the discharge summary, and no additional interpretation of symptoms was made during the extraction process. We included psychotic symptoms of delusions and hallucinations across all sensory modes and perceptual disturbances. The following variables were collected: symptom descriptions, symptom age of onset, insight, family history, and any prescribed antipsychotic medications. Data regarding demographics and clinical

characteristics were also extracted. This also included psychiatric history (e.g. diagnoses, substance use, and trauma history).

Ethical approval was obtained from the Melbourne Health Human Research Ethics Committee (HREC/48030/MH-2018) as part of the BeYOND study. BeYOND is a clinically oriented longitudinal study that follows younger people presenting with an onset of neuropsychiatric symptoms ≤ 65 years of age (Loi *et al.*, 2021a). All participants are deemed by the research team to have capacity to consent to research and provide written informed consent. In this project, data were de-identified and pseudonyms allocated.

Guidelines for thematic analysis categorize sample size suggestions by data collection type and size of the project (small, medium, or large), for example, 10–50 for participant-generated text and 10–100 for secondary sources (Clarke and Braun, 2013). Our study consisted of a mixture of participant-generated text and secondary sources; hence, we aimed for a goal of a minimum of 10 inpatient discharge summaries of YOD inpatients with psychotic symptoms to sample for our thematic analysis. Inclusion criteria for participants to be categorized as YOD with psychotic symptoms were dementia onset prior to age 65 who are referred for assessment for a possible YOD, who have an existing diagnosis of YOD, or who have a diagnosis of YOD made at time of assessment of psychotic symptoms detailed in their discharge summary. Inpatients below age 18 and/or with significant intellectual disability were excluded, as were those with previous or concurrent primary psychiatric diagnoses.

A qualitative software program was used for analysis (QSR International NVivo 1.0 Qualitative Data Analysis software (QSR International Pty Ltd)) (Jackson & Bazeley, 2019). Each patient was converted into a case within NVivo; labeled with diagnosis, age at dementia onset, age at dementia diagnosis, and timing of psychotic symptom onset. An onset of psychotic symptoms around dementia diagnosis was defined as within 3.4 years prior to age at diagnosis, based on mean time to YOD diagnosis from onset (Loi *et al.*, 2020). Any age of onset prior to this was considered prior to diagnosis, and any age of onset after age at diagnosis was considered post-diagnosis. Descriptions of all symptom types were transposed and stored under the patient's case. This allowed researchers to view codes as they related to patients and their relevant attributes.

Data analysis was conducted using a thematic approach (Braun and Clarke, 2006; 2021), chosen for its flexible qualitative analytical method. The analyzing authors' (LBM and AG) approach to coding and theme determination was both data-driven and driven by pre-existing concepts.

Pre-existing categorizations of psychotic symptoms (as described in the background) were used as a conceptual reference point for coding and theme determination. However, the authors did not use any rigid definitions stemming from these categorizations, and the content of the data was used to essentially redefine these categories as themes within the context of this study. It is also important to note that not all content contained in the data collected in this study fit into any of these pre-existing categories, and therefore, analysis was also mostly data-driven. The two analyzing authors (LBM and AG) performed the exact same roles and steps in the analysis process. Authors (LBM and AG) familiarized themselves with the data through repeated independent reading to develop an intimate understanding of the symptom narrative as described. After discussion to reach consensus hierarchy of coding structure, they then coded all data independently, including creating more detailed 'child nodes' under 'parent nodes'. The authors then discussed their coding again, to merge codes, synthesize or revise nodes, and then independently check the revised coding for consistency and accuracy. They then determined the themes by examining similarities between these codes. There were minimal differences of opinion, which were discussed among authors until agreement was reached. All researchers agreed on the final interpretation of the data.

Results

Sample characteristics

Demographics, clinical history, and psychosocial factors: From 245 inpatients who were seen at *Neuropsychiatry* from 2018 to 2020, there were twenty-three inpatients with YOD and psychosis (9.3% of all inpatients). Mean age of diagnosis was 57.0 years ± 10.6 and 52% ($n = 12$) self-identified as male. Twelve patients (52%) had an established psychiatric history including 10 patients (43.5%) with a history of mood disorders. Forty-eight percent ($n = 11$) were prescribed antipsychotic medication at the time of admission with 61% being prescribed these by the time of discharge. Most patients lived with at least one other person ($n = 18.78\%$). Most patients ($n = 18$) had at least an upper secondary level of education ($n = 12$, 66.7%); however, 5 (22%) had no educational attainment specified in their discharge summary. Most had no history of smoking ($n = 18.78\%$), only two (9%) were obese, five were diabetic (21%), and six (26%) had hypertension. Ten patients (43%) had a history of abnormal blood lipids including dyslipidemia and hypercholesterolemia. Ten (43%) patients had a

Table 1. Diagnoses and psychotic symptoms

DIAGNOSIS	NUMBER (%)
Frontotemporal Dementia	10 (43.5)
- <i>Behavioural Variant</i>	6
- <i>with Motor Neuron Disease</i>	1
- <i>Undifferentiated</i>	3
Alzheimer's Disease	3 (13.0)
- <i>Posterior Cortical Atrophy</i>	2
- <i>Mixed-Vascular Dementia</i>	1
Huntington's Disease	2 (8.7)
Dementia in Parkinson's Disease	2 (8.7)
Dementia with Lewy Body's	1 (4.3)
Progressive Supranuclear Palsy	1 (4.3)
Niemann-Pick Type C	1 (4.3)
Dementia – Other/Undifferentiated ¹	3 (13.0)
Psychotic Symptoms²	
Delusions	12
Auditory Hallucinations	11
Visual Hallucinations	5
Olfactory/Gustatory Hallucinations	1
Somatosensory Hallucinations	0
Other Perceptual Disturbance	3
Other symptoms associated with Psychosis	19
Reported psychotic symptom onset³	
Pre-diagnosis	5 (22)
Around diagnosis	17 (74)
Post-diagnosis	1 (4)

¹ $n = 1$ "Dominant, unknown, unstable, expanded trinucleotide repeat," $n = 2$ Dementia with specific diagnosis undifferentiated.

² Individuals could have more than one symptom type reported; therefore, percentage proportion is not given.

self-reported history of psychosocial or significant trauma, with some having more than one type of reported traumatic experience. These experiences were recorded as traumatic if the patient identified it as such in their clinical interview. The type of experiences reported included loss of a loved one that the patient perceived was traumatic, child abuse (physical, sexual, and emotional), domestic abuse, traumatic accident, and other developmental trauma.

Diagnostic category (Table 1): Of the 23 inpatients with a YOD diagnosis with psychotic symptoms, the largest proportion of diagnoses was FTD ($n = 10$). Of these, 6 were diagnosed with behavioral variant FTD (bvFTD), 3 were diagnosed with FTD of an undifferentiated or unspecified subtype, and 1 patient was diagnosed with FTD with motor neuron disease. The next most frequent diagnosis was Alzheimer's disease ($n = 2$) with posterior cortical atrophy (PCA) and $n = 1$ with mixed diagnosis with vascular dementia. Other diagnoses were Huntington's disease (HD, $n = 2$), dementia in Parkinson's disease ($n = 2$), dementia with Lewy bodies (DLB, $n = 1$), progressive supranuclear palsy (PSP, $n = 1$) and Niemann-Pick type C disease (NPC, $n = 1$). Three patients were diagnosed with dementia with an "other" or undifferentiated diagnosis.

Psychotic symptoms (Table 1): Seventy-four percent of patients ($n = 17$) had an onset of psychotic symptoms around their diagnosis of YOD. Twelve patients experienced delusions, 11 experienced auditory hallucinations, five experienced visual hallucinations, and one experienced olfactory/ gustatory hallucination. Multiple psychotic symptoms were often experienced concurrently. Three patients experienced what was classed as other perceptual disturbances which consisted of visual distortions and misidentification of individuals. Nineteen patients reported what was classed as 'other symptoms of psychosis', which included speech, affect and behavioral disturbances, paranoia (not delusional), agitation, and confusion. No somatosensory hallucinations were reported.

Themes

Themes are split into two domains of symptoms for reporting 1) delusions and 2) hallucinations. Although we initially sought to analyze the data for the psychotic symptoms classified as "other" (e.g. sub-delusional paranoia, agitation, behavioral changes) and other perceptual disturbances (e.g. mirror sign), the descriptions of these symptoms had a high degree of heterogeneity and/or were rarely reported in detail. As such, we could not determine any consistent themes and these symptoms were excluded from final analysis. We could not analyze olfactory hallucinations due to only one patient reporting experiencing these.

Themes of delusional symptoms

Six themes were identified. Exemplar quotes are provided with pseudonyms, with other identifying information removed.

Paranoid/Suspicious: Patients experienced false beliefs regarding others spying or conspiring against them, describing beliefs about individuals close to them spying on them and larger scale conspiracies from state apparatus. Beliefs often involved elaborate schemes involving surveillance and unsolicited video and audio recording, with many patients reporting prominent beliefs that they were being watched, listened to, or recorded with hidden cameras or microphones. "Surveillers" varied from individuals or groups in authority to individuals that the patient personally knew. Another common element of this theme is related to those in authority (e.g. politicians, police, military, courts, health care professionals). This manifested as suspicion surrounding being targeted (and surveilled) by these institutions/individuals. A lack of trust for individuals involved in the care and treatment of their condition was a prominent aspect of this theme and, when related to medical and

healthcare professionals, often involved a sense of deception or maleficence.

[Bobby had an] obsession with car number plates and paranoia about others being out to get him or hunt him down. (Bobby, Male, bvFTD, diagnosed age 60)

[Ian] was suspicious towards the [Crisis Assessment Treatment Team] saying they were government officers spying to bomb the house. (Ian, Male, bvFTD, diagnosed age 55)

Harm/Abuse: Several patients reported delusions relating to being the victim of violence or psychological abuse. This was distinct from the paranoid/suspicious theme, in that it involved the patient believing that they had actually been subject to harm (over and above suspicions about this). The victims of harm were either the patient themselves or someone close to them.

Whispering about being a "victim of torture" . . . "The physical assaults started three months ago. But mental assaults more recently" . . . She "knew" that she had been a victim of "attempted drowning, sleep deprivation, strangling" . . . she knew this because she once saw two marks on her wrist. (Felicity, Female, Alzheimer's Disease – PCA, diagnosed age 59)

Loss: This theme was characterized as a false belief that the patient had suffered, or was on the verge of, suffering a catastrophic loss. Ideas of loss were primarily focused on losing material assets such as money, property, and clothing. It also involved beliefs surrounding the breakdown of interpersonal relationships and overvalued fears and beliefs that the individual was going to be abandoned by others.

Richard had persistent delusions surrounding poverty, saying they do not have enough food, clothes, and shoes despite seeing full wardrobe and fridge. Repeatedly stating that he has no food. Believes his house is derelict. Bulk buying items because he says supermarkets are running out of food . . . Tells wife they're derelict, have no clothes, no food and it will be a matter of time until they live under a bridge . . . "I'm concerned about my children, my daughter is living on the smell of an oily rag, and my son can't pay for all his clothing." (Richard, Male, bvFTD, diagnosed age 62)

Romantic/Sexual: Delusions with a romantic or sexual nature were commonly reported, with many characterized by extreme and (most likely) unreasonable suspicions that the patient's significant other was having sexual or romantic relationships with others. Romantic/sexual delusions were not limited to jealousy and were not just limited to beliefs about romantic partners but also revolved around the patient themselves, where patients falsely believed that they were the object of romantic interest by others. False beliefs surrounding sexual perversion of others and risqué behavior were also apparent.

Over 5 years Nick has developed symptoms in keeping with delusional jealousy – accusing wife of sleeping with

other men constantly . . . Delusions of jealousy with associated agitation constantly focused on wife . . . refusing to allow his wife to leave the ward without him . . . observed searching the ward to find the man his wife was having an affair with . . . One episode of waking at night, punching hole in the wall, and verbally abusing wife, swearing, claiming she had slept with many men including her nephews. (Nick, Male, Dementia – Undifferentiated, diagnosed age 69)

Grandiose: This theme was characterized by patients who believed that they had an unrealistic position of power or ability. It presented as a false belief that the patient possessed a particular level of status, importance, or wealth (that they did not have, in reality). This theme also included beliefs that the patient could do things that were supernatural or impossible.

Grandiose and paranoid delusional system, including a belief that he has been offered a secret government defense contract . . . On night of admission to a psychiatric ward, was waiting for a car he believed had been sent for him by the government at 2am on [a highway] . . . Stated he was interviewed and had to sign a confidentiality agreement for secret defense contract. (Christopher, Male, FTD with Motor Neuron Disease, diagnosed age 56)

Somatic: This theme of delusions was characterized by a preoccupation or false belief surrounding the patient's body or bodily functioning. There was a focus on illness and death, with a general sense of worry, anxiety, or low mood.

Preoccupation with bowels, reported feeling that he needed to pass a stool without being able to do so . . . Would become very anxious about this . . . Spent significant time sitting on the toilet without passing a stool. (Adam, Male, DLB, diagnosed age 67)

Themes of auditory hallucinations

Five overarching themes were identified.

Danger: These hallucinations were characterized by danger to the patient or others close to them. These manifested in two ways: as sounds or voices indicating that the patient (or someone else) was in danger and as voices or noises encouraging the patient to get out of a dangerous situation. This could be experienced as a voice giving a direct imperative to escape.

Tracy heard ringing sounds which she believed indicated something was going to happen with her mother. (Tracy, Female, Dementia – Other/Undifferentiated, diagnosed age 23)

Paranoid/Suspicious: This theme had correlates with the theme identified in the delusional symptoms. Hallucinations were often characterized by voices or sounds that the patient was paranoid about and increased their paranoia or suspicion about someone or something. For example, sounds

of ladders propping against a house were reported in keeping with delusional beliefs surrounding people breaking in:

Felicity was hearing noises of ladders being propped against her house, doors slamming, people around the side. (Felicity, Female, Alzheimer's Disease – PCA, diagnosed age 59)

Non-specific/Unintelligible: Many hallucinations were characterized by mundane or unintelligible content, such as non-specific mumbled conversations. Patients experiencing this kind of hallucination were able to identify that people were speaking but were either unable to understand it or claimed that the conversation was not of any significance to them. These types of hallucinations were reported as being both positive and negative in nature. Other forms of unintelligible hallucinations included hearing music or noises.

[Partner] described that Bobby seems to hear noises/voices at times although he is very guarded about this. Sometimes at night he will ask where the noise is coming from, for example, voices or music next door when there is no noise, or seem distracted by something. (Bobby, Male, bvFTD, diagnosed age 60)

Harm/Abuse: Many hallucinations were characterized by hallucinations, particularly hearing voices, discussing physical or psychological harm or abuse of the patient or their family. Suicide and self-harm were prominent elements of this theme and manifested as verbal imperatives to self-harm or end one's own life, or to harm others (such as a family member or significant other). Verbal abuse was also a prominent feature of this theme, towards the patient themselves or others.

Bobby was hearing voices that were abusive about his partner. (Bobby, Male, bvFTD, diagnosed age 60)

Religious/Mystical: Hallucinations of individuals of a religious or mystical significance were common in our cohort. The voices were attributed to unspecified individuals but discussed things of a religious or spiritual nature. These did not necessarily have to be of a positive or negative quality.

Daria described ongoing auditory hallucinations of voices talking to her about God, religious themes. (Daria, Female, NPC, diagnosed age 37)

Themes of visual hallucinations

Two overarching themes were identified

People/Faces: This theme was characterized by visual hallucinations of people and faces. This ranged from complex and detailed hallucinations of real people to apparitions of unspecified individuals in objects and windows.

Seeing things in periphery, seeing faces in a bowl of yoghurt. (Paul, Male, Alzheimer's Disease with vascular dementia, diagnosed age 64)

Audio-visual hallucinations of Steve Jobs and Robin Williams telling him to commit suicide. (Ricardo, Male, FTD – Undifferentiated, diagnosed age 55)

Objects/Shapes: These hallucinations were commonly apparitions of shapes and objects. These shapes or objects could be abstract or of commonplace items.

Seeing shapes in front of him, then went onto deny this – drew shapes from the NUCOG test. (Jacques, Male, bvFTD, diagnosed age 53)

Discussion

This study identified that individuals with YOD present with a range of psychiatric symptoms, including psychotic symptoms, consistent with the existing literature (Bauhuis *et al.*, 2020; Gossink *et al.*, 2017; Loi *et al.*, 2021b; Mulders *et al.*, 2016; Velakoulis *et al.*, 2009). Twenty-three inpatients with YOD presented with psychotic symptoms which included delusions and hallucinations, which were the primary focus of our thematic analysis.

Thematic analysis resulted in six themes that were predominant in delusions (themes of paranoia/suspiciousness, harm/abuse, loss, romantic/sexual delusions, grandiosity, and somatic delusions), five themes that characterized auditory hallucinations (themes of danger, paranoia/suspiciousness, non-specific/unintelligible voices, and hallucinations about harm/abuse and religious/mystical themes), and two themes that related to visual hallucinations (seeing people/faces, and objects/shapes). Synthesizing these, the most common themes across modalities were beliefs and experiences relating to 1) paranoid/suspicious thoughts and hallucinations and 2) relating to harm/abuse. The strong theme of paranoia and suspiciousness (in both delusions and hallucinations) manifested in people living with YOD in our sample experiencing paranoia and distrust about people they knew and about people in authority, including the medical profession and government actors, and often felt that they were being watched or monitored. The other strong theme of harm and abuse (also occurring in both delusions and hallucinations) was characterized by people with YOD reporting themes of harming others, self-harming, and some with religious overtones. Auditory hallucinations tended to be experienced as adversarial and negative.

Somatic delusions were not commonly reported in our sample and presented more as an overvalued anxiety of illness and death. In our sample, psychotic symptoms with non-specific/unintelligible voices and religious content were the only two symptom types that did not necessarily have a negative or distressing quality to them.

Another key finding was the degree of thematic heterogeneity that existed within individual cases. That is, patients could experience delusions or hallucinations with multiple thematic content, and a particular individual could have symptoms that contributed to multiple themes in the qualitative analysis. Themes did not clearly intersect across the modalities of hallucinations and delusions in this patient cohort, and intersection of themes occurred mainly within each patient's own narrative and experience. For example, patients with a particular delusional system may (or may not) experience hallucinations that directly relate to or reinforce their delusional belief system.

The cross-modal intersection of themes at the individual level could be interpreted as evidence for a possible intersection of themes at the modal level. However, themes were not the same between modes across the entire data set. Cross-modal intersection between themes across the whole dataset were only observed between paranoid/suspicious delusions and auditory hallucinations, and between some elements of the harm/abuse delusions and auditory hallucinations. Even within the intersecting themes, the qualities that characterized themes varied somewhat. For example, delusions of the harm/abuse theme tended to be related to false memories or delusional beliefs about being the victim of harm, whereas in the case of the auditory hallucinations, the theme centered on abusive speech about the patient or others and encouragement to commit harm. Furthermore, cross-modal similarities between themes as a whole were not apparent in the same way that cross-modal similarities were apparent at an individual narrative level. In only three cases, psychotic symptoms of both modes (hallucinations and delusions) were congruent with the general narrative quality of their psychotic symptoms. For example, an inpatient with hallucinations of gates opening and ladders being popped up against their house, also believed that her home had been broken into and was being monitored.

No clear relationships were apparent between themes of psychotic symptoms and diagnostic groups. The themes generated from our qualitative analysis were found across all diagnoses. There were also no clear relationships between psychotic symptoms and time of onset of these symptoms (prior to dementia diagnosis, around dementia diagnosis, or post-dementia diagnosis).

While similarities across modes and diagnosis were not observed, there were similarities between themes *within* a particular mode. That is, some delusional themes shared similar properties. This was particularly true in the case of the suspicious/paranoid, harm/abuse themes and the jealous

subthemes, which all shared a sense of mistrust, victimization, and hostility towards others.

There is no published literature on the themes of psychotic symptoms in YOD. As a result, it is difficult to discuss the findings in relation to previous research. In most of the published case study reports, people with YOD experienced hallucinations which directly reinforced or were related to the delusional belief system that the patient possessed (Loy *et al.*, 2010; Omar *et al.*, 2009; Tartaglia *et al.*, 2008). There were similarities across narratives seen in the case literature and the narratives we analyzed and themes arising from them. For example, one of our patients with intersecting hallucinations and delusions surrounding being broken into was akin to a similar narrative seen in the literature (Omar *et al.*, 2009). Another similarity between our findings and the case literature was thematic heterogeneity on an individual symptom narrative basis. For example, some of the patients reported in the case literature were described as having psychotic symptom narratives (specifically of the same mode) that were relatively heterogeneous in terms of thematic properties (Mendez *et al.*, 2011; Omar *et al.*, 2009). Similarly, our study found that some patients presented with symptom narratives that were characterized by the presence of multiple themes.

The study is novel and provides the first qualitative analysis of the themes of psychotic symptoms in YOD where the research has previously been limited to $n = 1$ case studies. The heterogeneity of the source data was a strength, as discharge summaries had multiple inputs, including self-report by the patient, and historical summaries of previous admissions at other medical services, and collateral information from clinicians, family, and friends. There were limitations relating to data sources, in that data were taken from discharge summaries and thus limited to what was contained within them. Specifically relating to psychotic symptoms, patients may not be presenting at *Neuropsychiatry* with active psychosis; thus, information regarding onset, frequency, and distress relating to historical accounts may not be reported. Due to the retrospective nature of the study, another limitation was the method by which we established psychotic symptom onset. Many patients had an onset prior to their diagnosis, and it is not possible to know whether psychotic symptoms were a part of the onset of the neurodegenerative disease or due to the concurrent emergence or part of an established diagnosis of a primary psychiatric condition. To counter this limitation, we excluded patients with a pre- or comorbid history of psychotic illness in our analysis. It is still possible, however, that some patients may not have had this detailed in their history.

Future research opportunities include investigations comparing age at onset and psychosocial contributors to psychotic symptoms. Additionally, prospective and longitudinal approaches would further our understanding of psychotic symptom development in the scope of YOD trajectory. Further research could also directly investigate thematic relationships of psychotic symptoms in YOD and in primary psychiatric disorders, as the themes of psychotic symptoms identified in this study are also commonly documented in the psychotic symptoms that occur in primary psychiatric disorders (McCarthy-Jones *et al.*, 2012; Paolini *et al.*, 2016; Rajapakse *et al.*, 2011).

This study is the first thematic analysis of psychotic symptoms in YOD and provides further understanding of patient phenomenology and experiences of psychosis in YOD. It is a valuable contribution to the scant literature in this area and informs future research directions. Findings can also be useful in the clinical setting. Indeed, for primary psychiatric conditions like schizophrenia, clinical tools, and the parameters on which psychotic symptoms are defined are based on detailed patient experience and report (Wong and Van Tol, 2003). However, in the case of dementia, where neuroimaging and biomarker investigations are increasingly commonplace in providing a provisional diagnosis, a more in-depth understanding of symptom phenomenology adds additional depth to identifying and understanding YOD diagnoses and symptoms. Increased knowledge about signs and symptoms of psychotic symptoms in YOD may also assist with reducing diagnostic delay in this cohort, which has been estimated to be 3.4 years (Loi *et al.*, 2020).

Conflict of interest

None.

Description of authors' roles

Borelli-Millott: Designed the study, collected the data, conducted analysis and interpretation of data, drafted, and wrote manuscript. **Goh:** Formulated the research questions, assisted, and supervised the design of the study, supervised the collection of data, assisted and supervised analysis and interpretation of data, drafted, and wrote the manuscript. **Loi and Velakoulis:** Supervised design of the study, supervised data collection, supervised analysis, and interpretation. Revised the paper critically for important intellectual content.

Acknowledgements

None.

References

- Bauhuis, R., Mulders, A. J. and Koopmans, R. T.** (2020). The course of neuropsychiatric symptoms in institutionalized patients with young onset dementia. *Aging & Mental Health*, 24, 439–444. <https://doi.org/10.1080/13607863.2018.1531379>.
- Braun, V. and Clarke, V.** (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77–101.
- Braun, V. and Clarke, V.** (2021). One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative Research in Psychology*, 18, 328–352. <https://doi.org/10.1080/14780887.2020.1769238>.
- Cations, M., Loi, S. M., Draper, B., Swaffer, K., Velakoulis, D. and Goh, A. M.** (2021). A call to action for the improved identification, diagnosis, treatment and care of people with young onset dementia. *Australian & New Zealand Journal of Psychiatry*, 55, 837–840. <https://doi.org/10.1177/00048674211037542>.
- Clarke, V. and Braun, V.** (2013). Successful qualitative research: a practical guide for beginners. *Successful Qualitative Research*, 1–400.
- Cohen-Mansfield, J., Golander, H., Ben-Israel, J. and Garfinkel, D.** (2011). The meanings of delusions in dementia: a preliminary study. *Psychiatry Research*, 189, 97–104. <https://doi.org/10.1016/j.psychres.2011.05.022>.
- Dementia Australia** (2021). Dementia Statistics [Online]. Available: <https://www.dementia.org.au/statistics> [Accessed 15th of March 2021].
- Gossink, F. T. et al.** (2017). Psychosis in behavioral variant frontotemporal dementia. *Neuropsychiatric Disease and Treatment*, 13, 1099–1106. <https://doi.org/10.2147/NDT.S127863>.
- Hendriks, S. et al.** (2021). Global prevalence of young-onset dementia: a systematic review and meta-analysis. *JAMA Neurology*, 78, 1080–1090. <https://doi.org/10.1001/jamaneurol.2021.2161>.
- Jackson, K. and Bazeley, P.** (2019). *Qualitative Data Analysis with NVivo*. Sage.
- Koedam, E. L., Lauffer, V., Van Der Vlies, A. E., Van Der Flier, W. M., Scheltens, P. and Pijnenburg, Y. A.** (2010). Early-versus late-onset Alzheimer's disease: more than age alone. *Journal of Alzheimer's Disease*, 19, 1401–1408. <https://doi.org/10.3233/JAD-2010-1337>.
- Larner, A.** (2008). Delusion of pregnancy in frontotemporal lobar degeneration with motor neurone disease (FTLD/MND). *Behavioural Neurology*, 19, 199–200.
- Loi, S. M. et al.** (2021a). Investigating the clinical utility of biomarkers and other novel tests in younger onset neurocognitive disorders: the BeYOND study, protocol for a longitudinal clinical study in a real-world setting. <https://doi.org/10.1101/2021.07.03.21259825>.
- Loi, S. M. et al.** (2021b). A 10 year retrospective cohort study of inpatients with younger-onset dementia. *International*

- Journal of Geriatric Psychiatry*, 36, 294–301. <https://doi.org/10.1002/gps.5424>.
- Loi, S. M. et al.** (2020). Time to diagnosis in younger-onset dementia and the impact of a specialist diagnostic service. *International Psychogeriatrics*, 34, 1–9. <https://doi.org/10.1017/S1041610220001489>.
- Loy, C. T. et al.** (2010). The case of a 48 year-old woman with bizarre and complex delusions. *Nature Reviews Neurology*, 6, 175–179.
- McCarthy-Jones, S., Trauer, T., MacKinnon, A., Sims, E., Thomas, N. and Copolov, D. L.** (2012). A new phenomenological survey of auditory hallucinations: evidence for subtypes and implications for theory and practice. *Schizophrenia Bulletin*, 40, 231–235. <https://doi.org/10.1093/schbul/sbs156>.
- Mendez, M. F., Fras, I. A., Kremen, S. A. and Tsai, P. H.** (2011). False reports from patients with frontotemporal dementia: delusions or confabulations? *Behavioural Neurology*, 24, 237–244. <https://doi.org/10.3233/BEN-2011-0335>.
- Mulders, A. J. M. J., Fick, I. W. F., Bor, H., Verhey, F. R. J., Zuidema, S. U. and Koopmans, R. T. C. M.** (2016). Prevalence and correlates of neuropsychiatric symptoms in nursing home patients with young-onset dementia: the BEYOnD study. *Journal of the American Medical Directors Association*, 17, 495–500. <https://doi.org/10.1016/j.jamda.2016.01.002>.
- Musso, M. W., Jones, G. N., Heck, M. C. and Gouvier, D.** (2013). Delusional parasitosis as a presenting feature of HIV dementia: a case study. *Applied Neuropsychology: Adult*, 20, 66–72. <https://doi.org/10.1080/09084282.2012.704602>.
- Olojugba, C., de Silva, R., Kartsounis, L. D., Royan, L. and Carter, J.** (2007). De clerambault's syndrome (erotomania) as a presenting feature of fronto-temporal dementia and motor neurone disease (FTD-MND). *Behavioural Neurology*, 18, 193–195. <https://doi.org/10.1155/2007/274156>.
- Omar, R. et al.** (2009). Delusions in frontotemporal lobar degeneration. *Journal of Neurology*, 256, 600–607. <https://doi.org/10.1007/s00415-009-0128-7>.
- Paolini, E., Moretti, P. and Compton, M. T.** (2016). Delusions in first-episode psychosis: principal component analysis of twelve types of delusions and demographic and clinical correlates of resulting domains. *Psychiatry Research*, 243, 5–13. <https://doi.org/10.1016/j.psychres.2016.06.002>.
- Rajapakse, T., Garcia-Rosales, A., Weerawardene, S., Cotton, S. and Fraser, R.** (2011). Themes of delusions and hallucinations in first-episode psychosis. *Early Intervention in Psychiatry*, 5, 254–258. <https://doi.org/10.1111/j.1751-7893.2011.00281.x>.
- Rossor, M. N., Fox, N. C., Mummery, C. J., Schott, J. M. and Warren, J. D.** (2010). The diagnosis of young-onset dementia. *The Lancet Neurology*, 9, 793–806. [https://doi.org/10.1016/S1474-4422\(10\)70159-9](https://doi.org/10.1016/S1474-4422(10)70159-9).
- Sansoni, J., Duncan, C., Grootemaat, P., Capell, J., Samsa, P. and Westera, A.** (2016). Younger onset dementia: a review of the literature to inform service development. *American Journal of Alzheimer's Disease & Other Dementias*, 31, 693–705. <https://doi.org/10.1177/1533317515619481>.
- Tartaglia, M. C., Kertesz, A. and Ang, L. C.** (2008). Delusions and hallucinations in frontotemporal dementia: a clinicopathologic case report. *Cognitive and Behavioral Neurology*, 21, 107–110. <https://doi.org/10.1097/WNN.0b013e3181799e19>.
- Velakoulis, D., Walterfang, M., Mocellin, R., Pantelis, C. and McLean, C.** (2009). Frontotemporal dementia presenting as schizophrenia-like psychosis in young people: clinicopathological series and review of cases. *The British Journal of Psychiatry*, 194, 298–305. <https://doi.org/10.1192/bjp.bp.108.057034>.
- Waldö, M. L., Gustafson, L., Passant, U. and Englund, E.** (2015). Psychotic symptoms in frontotemporal dementia: a diagnostic dilemma? *International Psychogeriatrics*, 27, 531–539. <https://doi.org/10.1017/S1041610214002580>.
- Wong, A. H. C. and Van Tol, H. H.** (2003). Schizophrenia: from phenomenology to neurobiology. *Neuroscience & Biobehavioral Reviews*, 27, 269–306. [https://doi.org/10.1016/S0149-7634\(03\)00035-6](https://doi.org/10.1016/S0149-7634(03)00035-6).