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Care Pathway of People with Frontotemporal Dementia (FTD) Living in States that have Expanded Medicaid under ACA Vesus Those Living in States that have not.

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ABSTRACT

CARE PATHWAY OF PEOPLE WITH FRONTOTEMPORAL DEMENTIA (FTD) LIVING IN STATES THAT HAVE EXPANDED MEDICAID UNDER ACA VERSUS THOSE LIVING IN STATES THAT HAVE NOT

BY

CATHERINE ESTHER ALEXANDRA SCIPION

APRIL 30, 2024

INTRODUCTION: The care pathway of people with Frontotemporal Dementia (FTD) is strongly influenced by differences in health insurance coverage. Medicaid expansion under the Patient Protection and Affordable Care Act (ACA) has been demonstrated to impact the care pathway of adults with chronic conditions such as cancer, mental health disorders, and cardiovascular diseases. Yet, no study has focused on its impact on the care pathway of people with FTD. This study hypothesized that people living in states that have expanded Medicaid under ACA have better care pathway outcomes than their counterparts.

METHODS: I analyzed self-reported data of caregivers for people with FTD from the Association for Frontotemporal Dementia (AFTD) Insights Survey. Variables related to the care pathway included diagnosis journey (defined by misdiagnosis and number of doctors consulted before FTD diagnosis was made), treatment of FTD symptoms (i.e., use of prescription and over-the-corner medications, cost-related drawbacks to prescription medications, and non-pharmacological management), and level of functional impairment as a proxy for quality of life. Individuals diagnosed with FTD were grouped based on the “Medicaid expansion status” of the state they lived in. I used Pearson chi-squared tests to compare the care pathway of individuals with FTD living in states based on their Medicaid expansion status at the time of their diagnosis. Statistical significance was defined as p-value < 0.05.

FINDINGS: People diagnosed with FTD in states with Medicaid expansion status had a better diagnosis journey. Specifically, in states with Medicaid expansion status, we observed the lowest proportion of people with FTD who experienced misdiagnosis (44.4%, p=0.04) and highest proportion who consulted only 1 or 2 doctors before FTD diagnosis was made (46.7%, p=0.04). However, other aspects of the care pathway, such as the experience of individuals related to the use of prescription medications (p=0.05), non-pharmacological management (p=0.7) to treat FTD, cost-related drawbacks to prescription medications (p=0.06), and the patient’s level of functional impairment (p=0.3) did not significantly differ across states based on their Medicaid expansion status.

CONCLUSION: This study demonstrated that, within their care pathway, the diagnosis journey of people with FTD was more favorable in states that expanded Medicaid under ACA. This study provides insights into the potential inequalities in the diagnosis journey of people with FTD associated with inconsistent health insurance coverage. Therefore, this study set the stage for future studies aimed at informing health policies to improve the diagnosis experiences of patients with FTD.

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Author’s Statement Page

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1. INTRODUCTION

1.1. Background

Frontotemporal dementia (FTD) refers to a group of clinical symptoms that arises from a neurodegenerative disease, the frontotemporal lobal degeneration (FTLD). FTLD is a progressive damage in the frontal and temporal lobes of the brain due to the pathological deposition of misfolded proteins (i.e., FTLD-tau and FTLD-TDP) in neurons or glial cells (Irwin et al., 2016, NIA, 2021, Grossman et al., 2023). FTD represents the most common clinical forms of early-onset dementia (Barker et al., 2023, Grossman et al., 2023). The estimated prevalence of FTD is approximatively 15-22 cases per 100,000 individuals (Knopman & Roberts, 2011). 60% of FTD cases occurs between the ages of 45 and 64 (NIA, 2024).

There are two common frontotemporal dementia (FTD) clinical syndromes: Behavioral variant FTD (bvFTD) and Primary progressive aphasia (PPA). BvFTD is characterized by symptoms related to personality changes (e.g., apathy, lack of motivation), and inappropriate social behavior (e.g., touching strangers, public urination, or temper tantrums). PPA is a primary language disorder that is further subdivided into three disorders. Non-fluent/agrammatic variant (nfvPPA) is characterized by poor grammar and spoken language. Semantic variant (svPPA) is characterized by difficulties with finding and the meaning of words, and naming people or objects. Logopenic variant (lvPPA) is characterized by repetition of sentences. PPA and bvFTD may be associated with motor impairments. When associated with balance difficulties and poor coordination, we refer to corticobasal degeneration (CBD). When associated with difficulty with or excessive blanking or rapid eyes movements, we refer to progressive supranuclear palsy (PSP) or Richardson's syndrome. When associated with muscles weakness and atrophy leading to progressive paralysis, we refer to FTD with amyotrophic lateral sclerosis (FTD-ALS) (Barker et al., 2023, Grossman et al., 2023, Lee, 2022). It is important to note that there are no treatments for any of the FTD clinical syndromes. There are strategies that can only help manage some of the symptoms. Hence, it is primordial to make the right diagnosis of FTD syndromes to inform the appropriate management of symptoms.

The care pathway for people affected by (FTD) is a structured approach that outlines the essential steps of a multidisciplinary and integrated healthcare from the diagnosis of clinical syndromes to end-of-life (Rother et al., 2019, Chan and al., 2016, Morhardt et al., 2015). The diagnosis consists of a cognitive-behavioral, and psychosocial assessment which informs the development of specific recommendations and strategies. Clinicians used clinical examination, laboratory (e.g., genetic testing), and imagery (e.g., MRI, PET Scan) to make the diagnosis of FTD clinical syndromes. Management strategies includes both non-pharmacological (e.g., Speech therapy for PPA or cognitive rehabilitation for BvFTD) and pharmacological managements (e.g., antipsychotics, anticonvulsants, or antidepressants) (Grossman et al., 2023, Leroy et al., 2021, Dodge et al., 2021). Given the unavailability of treatment, the primary goal of an effective care pathway for people affected with FTD is to improve their quality of life (Morhardt et al., 2015).

However, demographic and social determinants of patients may hamper the effectiveness of the care pathway for FTD. The annual healthcare cost per patient affected with FTD is 53% higher than the cost burden of dementia and amounts to nearly $120,000 (Hurd et al., 2013, Galvin et al., 2017). Differences in socioeconomic status of patients, specifically lack of or inconsistency in health insurance to cover these healthcare costs, seriously impede the access to care of patients affected with FTD leading to delayed and inaccurate diagnosis (Chao et al. 2013, Onyike et al., 2021, Franzen et al., 2023, AFTD, 2024). As a result, many people with FTD have experienced an inefficient care pathway characterized by repeated misdiagnosis associated with lack of timely care. This results in poor quality of life (Baker et al., 2023, Dodge et al., 2021, AFTD, 2024). Compared to Alzheimer’s disease (AD), FTD has a longer time to diagnosis, leads to higher clinical dementia rating (i.e. severe FTD) and a longer time to referral to a specialist (Leroy et al., 2023). In addition, the prevalence of FTD is vastly underestimated (Baker et al, 2023). Hence, given the significant impact of health insurance coverage on the care pathway for FTD, policy strategies that increase the health insurance coverage among the group of people affected with FTD might impact their care pathway.

In January 2014, a new health policy reform, the Patient Protection and Affordable Care Act (ACA), became effective in the U.S. One of its provisions is the full Medicaid expansion which is optional for states due to the 2012 Supreme Court Ruling. In states that have expanded Medicaid under ACA, health insurance coverage for low-income people aged 50 to 64 has increased (Bin Abdul Baten & Wehby, 2023). Consequently, this policy change has increased access to healthcare among 50 to 64 (Houtven et al., 2020). Therefore, the research question of this study was: given that Medicaid expansion has increased health insurance coverage and access to care among low-income people aged 50 to 64, consistent with age of people affected with FTD, does it impact the care pathway for FTD? There is a large literature about the impact of Medicaid expansion under ACA on the care pathway of chronic diseases, such as cancer, mental health disorders, cardiovascular diseases (McInerney et al., 2020, Lind et al., 2021, Nathan et al., 2021, Nathan et al., 2021, Hotca et al., 2023). To date, however, there are no studies on its impact on the care pathway for FTD. Hence, this study aimed to compare the care pathway of people with FTD in states that have expanded Medicaid under ACA with that of people affected by FTD in states that have not. The findings of this current study will advance evidence on the impact of Medicaid expansion under ACA on the experience of people affected by FTD throughout their care pathway, and therefore set the stage for future studies aimed at informing health policies to improve the care pathway for people with FTD.

1.2. Research hypothesis

This study hypothesizes that people living in states that have expanded Medicaid under ACA have better care pathway outcomes than their counterparts.

2. LITERATURE REVIEW

2.1. Effects of Medicaid expansion under ACA relevant to the FTD care pathway

Medicaid expansion under ACA increases rates of Medicaid coverage for low-income people aged 50 to 64 years (Bin Abdul Baten & Wehby, 2023), consistent with age of individuals affected by FTD. The expansion of the eligibility of Medicaid under ACA may explain this observed trend. Unlike traditional Medicaid (i.e., 100 % of FPL), Medicaid Expansion eligibility extends to an income threshold up to 138% of federal poverty level (FPL) for U.S. citizens, legal immigrants who have resided in the U.S. for at least 5 years, and people under age 65. There is no need to be part of a pre-approved category (i.e., pregnant women, children, individuals with disabilities, and older adults) or no conditions to maintain coverage (Wilensky & Teitelbaum, 2023, Kaiser Family Foundation, 2024). Individuals affected by FTD experience repeated loss of day work in seeking diagnosis (Besser & Galvin, 2020) and premature resignments due to progressive worsening of symptoms (Galvin et al., 2017, Dodge et al., 2021). Given this context of inconsistency in employment, the overall household income declines by 50% (Galvin et al., 2017). Assuming that the income level of FTD patients can thus fall to 138% of the FPL, a large number of them might become eligible for Medicaid expansion under the ACA in their state.

As a result to the increase in health insurance coverage, low-income people aged 50 to 64 in states that have expanded Medicaid under ACA have experienced an increase in access to and utilization of care and decrease in delayed and discontinued care due to cost (Bin Abdul Baten & Wehby, 2023, Van Houtven et al., 2020). The expanded benefit of Medicaid may further explain this observed trend. Medicaid expansion includes benefits similar to a “standard employer plan”, the Essential Health Benefits (EHB) plus non-emergency transportation to rural and federally qualified medical care and health services. The EHB relevant to the care pathway for FTD include prescription drugs; hospitalization; emergency services; outpatient services; rehabilitation and habilitation services and devices; laboratory services. Galvin et al. (2017)

accounted for these healthcare services in the estimation of the annual healthcare cost burden for FTD. With all of these services covered, medicaid expansion might impact the annual healthcare cost per patients affected with FTD. Another relevant healthcare service from EHB of Medicaid expansion under ACA is the preventive and wellness services and chronic disease management services. Patients can benefit, free of cost-sharing, early detection and subsequent management of chronic health conditions including dementia. As part of wellness services from the EHB, the ACA added a new program to Medicare Part B aimed at providing patient-centered preventive care to improve individual health, called the Medicare Annual Wellness Visit (AWV) starting in 2011 (Cordell et al., 2013). The ACA required the AWV to screen for cognitive impairment at every visit free of cost-sharing (Wilensky & Teitelbaum, 2023, Kaiser Family Foundation, 2024). The 40% of individuals with Late-onset FTD (>65) might benefit early diagnosis and subsequent management from the AWV.

As seen above, Medicaid expansion has increased health insurance coverage and access to care for low-income people aged 50 to 64, consistent with age of people affected by FTD. The expanded eligibility and benefits of Medicaid under ACA described above might play a great role in supporting low-income people aged 50 to 64 in seeking diagnosis and management of their health conditions. Given differences in health insurance coverage and access to care among people affected by FTD significantly impact their care pathway, I wanted to analyze the impact of Medicaid expansion under ACA on the care pathway for FTD.

2.2. Impacts of ACA on care pathways- Prior studies

Prior research demonstrated that Medicaid expansion under ACA led to positive care pathway outcomes for multiple chronic diseases. Specifically, studies evaluated the impacts of Medicaid expansion under ACA on early screening and diagnosis, timely treatment, and quality of life. Several studies demonstrated a beneficial impact of Medicaid expansion on cardiovascular diseases. Specifically, diagnosis, treatment, and control of hypertension and diabetes considerably improved in states that have expanded medicaid under ACA (Angier et al., 2020, Huguet et al., 2023). Medicaid expansion also led to long-term control of hypertension and diabetes (Cole et al., 2021). Similarly, studies focused on cancers. Overall, Medicaid expansion is associated with early diagnosis of cancer, decreases treatment delay (Nathan et al., 2021, Hotca et al., 2023), and allows the provision of cancer-appropriate treatment (Hotca et al., 2023). The impact of Medicaid expansion under ACA on mental health disorders was similar to cardiovascular diseases and cancers. Ortega (2022) demonstrated an increase in treatment access for people with mental health disorders. Two study evaluated the impacts of the Annual Wellness Visit (AWV) in the Medicare part B free of cost-sharing on dementia diagnosis. The AWV was associated with an increase of dementia diagnosis rates in primary care (Lind et al., 2021, Thunell et al., 2022) with a higher diagnosis rate among Blacks (Thunell et al., 2022). However, these studies focused on Medicare enrollees (>65). There was also evidence of improved quality of life of people living in states that had expanded Medicaid under ACA. Mclnerney et al. (2020) demonstrated an improvement in the realization of activities of daily living (ADL), particularly bathing, eating, or dressing among adults aged 50 to 64 years old. No studies have examined the impact of Medicaid expansion on the care pathway of people with FTD in the literature. This study is, therefore, the first of its kind to investigate differences in the care pathway of people with FTD based on their state's Medicaid expansion status, using a dataset specific to the lived experiences of people affected by FTD.

3. MATERIALS AND METHODS

3.1. Data Source

The study analyzed data from the Association of Frontotemporal Degeneration (AFTD) Insights Survey (Barker et al., 2023). The AFTD Insights Survey is the largest data source to date specifically focused on community experiences of FTD in the United States, Canada and the United Kingdom. AFTD conducted this anonymous online survey between October 1st, 2020, and March 31st, 2021. The survey collected data about the experiences of 219 people with any FTD clinical syndromes, 338 biological relatives and 1238 care partners (current or past) of people with FTD. A total of 1,796 people took part in the survey. It was a self-reported survey comprising of 191 questions in total, but not all participants answered all the questions. Based on the responses to questions about the status of respondents, the questionnaire used a branch-and-skip logic to progress through the survey. The questions about the status of respondents included five respondent cohorts: a person diagnosed with FTD, a biological relative of a person who was not a caregiver, a person considered to be at biological risk of developing FTD, a current caregiver of a person with FTD, or a former caregiver of a person who had died at the time of the survey. Survey measures included demographic information, family history of FTD, diagnostic history, experience of symptoms, symptom-related distress, independence and quality of life, past experiences with treatments, hopes for future treatments, and perspectives on research participants and clinical trials.

3.2. Study Sample

For this study, I analyzed data from respondents in the United States who identified as care partners (current or past) of people with FTD. Current care partners included respondents who cared for people affected by FTD who were still alive at the time of the survey. Past care partners were those who cared for individuals with FTD who were deceased at the time of the survey. Using data provided by care partners allowed me to include data regardless of the level of functional impairment of people with FTD, or whether people with FTD were alive or deceased. It also enabled me to include questions focused on the care pathway (see the section on variables below), as care partners answered all survey questions. In total, I included 1133 participants in my analysis (see statistical analysis below).

3.3. Variables

I analyzed measures related to *care pathway*, including diagnosis journey, management of FTD symptoms, and quality of life. To group individuals diagnosed with FTD based on their state’s Medicaid expansion under ACA, I defined a new variable "Medicaid expansion status".

3.3.1. Care Pathway

Table 1 summarizes the variables related to care pathway for people diagnosed with FTD. The diagnostic journey included questions relating to “misdiagnosis” and “number of doctors consulted before the diagnosis of FTD was made”. Management of FTD symptoms included questions related to "use of prescription medication to treat FTD symptoms", "drawbacks of prescription medication", "use of over-the-counter medication", and "use of non-pharmacological management". The variables, “Use of over-the-counter medications” and “Use of non-pharmacological management”, were recoded as dichotomous variables, with response options: “Yes”, “No”. The variable “drawbacks of prescription medication” was also recoded to define a dichotomous variable with cost considered alone. The variable was labelled “cost-related drawbacks to prescription medication”, with response options: “Yes”, “No”. I used the survey question related to “current level of functional impairment” as a proxy for quality of life of people with FTD. All response options of “I’m not sure” were recoded as missing values. Survey questions with differing stems for care partners of people with FTD who were still alive and care partners of people with FTD who were deceased at the time of the survey were merged to be single variables based on the question content.

Table1. Summary of variables related to the care pathway of people diagnosed with FTD.

Variables name	**Type of variable**	**Question survey`**	**Answer options**
Diagnosis journey			
Misdiagnosis	Dichotomous	Before obtaining a diagnosis of FTD, were one or more different diagnoses made?	"Yes" or "No"
Number of doctors consulted before the FTD diagnosis	Categorical	How many different doctors were consulted before the diagnosis of FTD was made?	“1-2”, “3-4”, “4-5”, “more than 5”, or "I'm not sure"
Management of FTD symptoms			
Use of prescription medications to treat FTD symptoms	Dichotomous	Has the person diagnosed with FTD ever taken a prescription medication to treat FTD symptoms?	"Yes" or "No"
Cost-related drawbacks related to prescription medications	Categorical, Cost considered alone as dichotomous	What were the main disadvantages, if any, of the prescribed medication used? Choose up to three	"Cost", "Number of pills/medications per day", "Side effects", "Trip to hospital, clinic or doctor to keep prescriptions", "Ineffective", "Other", "None", "Not sure"
Use of non-pharmacological management	Endorsement of any treated as dichotomous	Has the person diagnosed with FTD done any of the following to help manage symptoms? Select all that apply	“Diet modification”, “Exercise”, “Meditation”, “Support Group”, “Speech-language therapy”, Physical therapy”, “Occupational therapy”, “Physical therapy”, “Research involving an experimental medical”, “Research involving an experimental medication”, “Research involving brain stimulation (electrodes or magnets placed on head)”, “Other (Specify up to three)”, “None of the above”, “I’m not sure”
Use of over-the-counter medication	Endorsement of any treated as dichotomous	Has the person diagnosed with FTD ever taken over-the-counter medications to treat FTD? Select all that apply.	“No”, “Vitamins or Minerals”, “Herbals”, “Other (Write in)”, “I’m not sure”
Quality of life			
Level of functional impairment	Categorical	How would you describe the person’s current level of functional impairment?	“Mild (Needs little supervision to perform daily activities)”, “Moderate (Needs supervision to perform most daily activities)”, “Severe (Needs full supervision to perform nearly all daily activities)”, “Profound (Can no longer perform daily activities and has limited mobility and ability to communicate)”.

3.3.2. Medicaid Expansion status of state

I classified individuals in terms of whether they lived in a state with Medicaid expansion status at the time of FTD diagnosis using a categorical variable: “Medicaid expansion (Yes)”, “Medicaid expansion (No)”, and “Inconclusive status”. Thus, I used the date of FTD diagnosis of patients as cut-off to mark states as Medicaid expansion status or not. This way, I made sure that the experience of each patient within his/her care pathway happened after Medicaid expansion of the state she/she lived in. However, the date of FTD diagnosis of patient was not available in the AFTD survey dataset, so I had to estimate this variable. To estimate the date of FTD diagnosis of patients, I used the following formula:

1- If the individual was still alive at the time of the survey:

   FTD diagnosis date = survey date – time since diagnosis → *survey date - (age when taking the survey - age at FTD diagnosis).*

2- If the individual was deceased at the time of the survey:

   FTD diagnosis date = *survey date - time since diagnosis* → *survey date - (how long they lived with FTD diagnosis* + *how long since death)* → *survey date - ([age at death - age at FTD diagnosis]* + *time since death).*

However, AFTD survey was administrated during a time range (October 1st, 2020 - March 31st , 2021) and collected the variables used to compute *time since diagnosis* in the above formulas as categorical variables. As a result, I estimated *earliest and latest FTD diagnosis dates* for each patient using the following formulas:

1- If the individual was still alive at the time of the survey:

   - *Earliest FTD diagnosis date = earliest survey date (October 1st,2020) - longest possible time since FTD diagnosis → earliest survey date - (oldest possible age when taking the survey - youngest possible age at FTD diagnosis)*

- *Latest FTD diagnosis date = latest survey date (March 31st , 2021) - shortest time since FTD diagnosis → latest survey date - [(youngest possible age when taking the survey - oldest possible age at FTD diagnosis), or 0 if negative]*

2- If the individual was deceased at the time of the survey*:*

- *Earliest FTD diagnosis date = earliest survey date (October 1st,2020) - (longest time since FTD diagnosis) → earliest survey date - (longest time the patient lived with FTD diagnosis + longest time since death) → earliest survey date - ([oldest possible age at death - youngest possible age at FTD diagnosis] + longest time since death)*
- *Latest FTD diagnosis date: latest survey date (March 31st , 2021) - (shortest time the patient lived since FTD diagnosis) → latest survey date - (shortest time the patient lived with FTD diagnosis + shortest time since death) → latest survey date - (max[youngest age at death - oldest age at FTD diagnosis, 0] + shortest time since death)*

Based on the date of Medicaid expansion of each state [Fig. 1], I marked each individual as follows:

- "No Medicaid expansion", if the state the individual was living in expanded Medicaid after its earliest FTD diagnosis. If the individual was living in a state that have not expanded medicaid, I marked as "No Medicaid expansion status" as well.
- "Medicaid expansion status", if the state the individual was living in expanded Medicaid before the estimated earliest date of FTD diagnosis.
- "Inconclusive status", if the state the individual was living in expanded Medicaid after the earliest date of FTD diagnosis but before the latest date of FTD diagnosis.

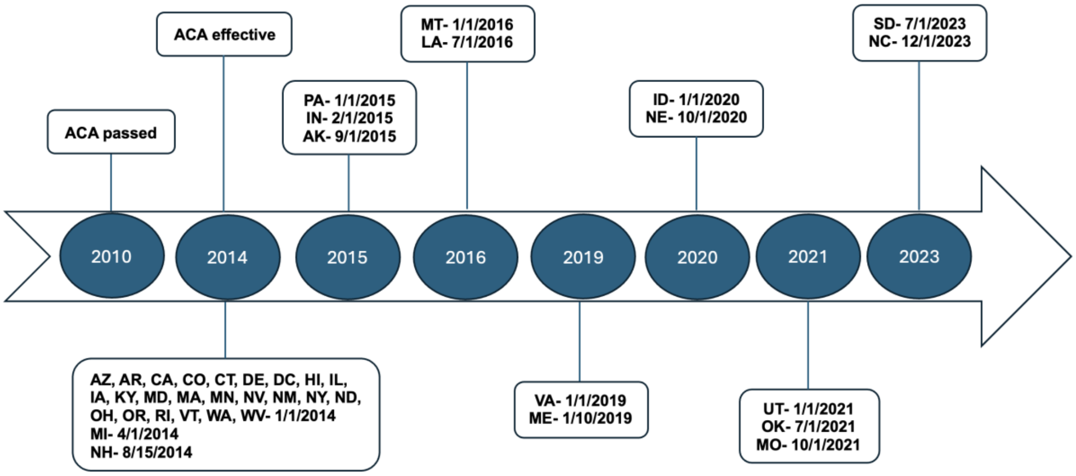

Fig. 1. Effective date of coverage under Medicaid expansion by state. (KFF, 2024)

3.4. Statistical Analysis

I performed all estimations and data analyses through the statistical software R. I described categorical variables as frequencies and proportions, and continuous variables as median and range. I compared data related to care pathway experienced by individuals with FTD living in states with “Medicaid expansion status”, individuals with FTD in states with “No Medicaid expansion status”, and those in states with “Inconclusive status”. To carry out this comparison, I used Pearson chi-squared tests as all variables related to care pathway were categorical. I defined statistical significance as p-value < 0.05. I made no corrections for multiple testing.

4. RESULTS

4.1. Descriptive of Caregivers

Table 2 provides descriptive summaries of caregivers for people diagnosed with FTD. Overall, the median age of caregivers for people with FTD was 65 [range: 23-89] years old. 76.4% of caregivers were female and 22.4% were male. The caregivers were mostly

White/Caucasian (91.9%) followed by Black/African American/African British (1.6%) and Hispanic/Latino (1.4%). The most reported levels of education of caregivers were College / Bachelor's Degree (37.1%) and Master's degree (29.6%). The majority of caregivers were not employed (62.2%) at the time of the survey. Almost all caregivers were not enrolled in school (98%) at the time of the survey. Finally, most of the caregivers had one or more children (83.1%).

4.2. Descriptive of patients diagnosed with FTD

Table 3 summarizes descriptive of patients diagnosed with FTD. Overall, the majority of patients diagnosed with FTD were male (67.1%). The median age of patients with FTD who were still alive at the time of the survey was 68 [range: 24-89] years old. 92% of the patients diagnosed with FTD were White / Caucasian. The most reported level of education for patients diagnosed with FTD was College / Bachelor's degree (34.2%) followed by High School Diploma (21.3%) and Master's Degree (20.9%). The majority of patients diagnosed with FTD who were still alive were not employed at the time of the survey (96.4%). Finally, 85.8% of patients with FTD were married. Overall, 57.4% of patients were diagnosed with behavioral FTD, 21.4% with Primary Progressive Aphasia (PPA).

Table 2: Descriptive of caregivers for people diagnosed with FTD.

	n (%) (N=1133)
Age (years)	
Median [Min, Max]	65.0 [23.0, 89.0]
Missing	56 (4.9%)
Gender	
Male	254 (22.4%)
Female	866 (76.4%)
Missing	13 (1.1%)

	n (%) (N=1133)
Race or Ethnicity	
White / Caucasian	1041 (91.9%)
Black / African American / African British	18 (1.6%)
Hispanic / Latino	16 (1.4%)
Middle Eastern / East Asian	13 (1.1%)
Other	13 (1.1%)
More than one race	12 (1.1%)
Missing	20 (1.8%)
Level of Education	
College / Bachelor's Degree	420 (37.1%)
Master's Degree	335 (29.6%)
Associate's Degree	149 (13.2%)
High School Diploma	133 (11.7%)
Doctoral Degree	85 (7.5%)
Missing	11 (1.0%)
Currently employed	
Yes (part-time / full-time)	424 (37.4%)
No	705 (62.2%)
Missing	4 (0.4%)
Currently in school	
Yes	13 (1.1%)
No	1110 (98.0%)
Missing	10 (0.9%)
Marital status	
Married	735 (64.9%)
Widowed	276 (24.4%)
Single / Separated / Divorced	70 (6.2%)
Domestic partner	30 (2.6%)
Never Married	16 (1.4%)
Missing	6 (0.5%)
Having children	
Yes	941 (83.1%)
No	188 (16.6%)
Missing	4 (0.4%)

Table 3. Descriptive of Patients diagnosed with FTD

	n (%) (N=1133)
Gender	
Female	379 (33.5%)
Male	745 (65.8%)
Missing	9 (0.8%)
Age (Years)[ψ]	
Median [Min, Max]	68.0 [24.0, 89.0]
Missing	4 (0.006%)
Race or Ethnicity	
White / Caucasian	1042 (92.0%)
Black / African American / African British	21 (1.9%)
Other	21 (1.9%)
Hispanic / Latino	14 (1.2%)
Middle Eastern / East Asian	11 (1.0%)
More than one race	6 (0.5%)
Missing	9 (0.8%)
Level of Education	
College / Bachelor's Degree	388 (34.2%)
High School Diploma	241 (21.3%)
Master's Degree	237 (20.9%)
Associate's Degree	142 (12.5%)
Doctoral Degree	102 (9.0%)
Elementary or Middle School	10 (0.9%)
Missing	13 (1.1%)
Currently employed[ψ]	
Yes (part-time / full-time)	21 (3%)
No	667 (96.4%)
Missing	4 (0.006%)
Marital Status	
Married	972 (85.8%)
Single / Separated / Divorced	85 (7.5%)
Widowed	41 (3.6%)
Domestic partner	15 (1.3%)
Never Married	7 (0.6%)

	n (%) (N=1133)
Missing	13 (1.1%)
FTD diagnosis	
bvFTD* — behavioral variant FTD	650 (57.4%)
PPA —primary progressive aphasia	242 (21.4%)
Corticobasal syndrome (CBS)	37 (3.3%)
Progressive supranuclear palsy	64 (5.6%)
FTD with ALS	58 (5.1%)
Missing	50 (4.4%)

Ψ These variables were reported only for individuals with FTD who were alive at the time of the survey. Percentages are based on N=692.

* nfvPPA: nonfluent agrammatic variant aphasia; FTD with ALS: Frontotemporal dementia with amyotrophic lateral sclerosis.

4.3. Care pathway of patients diagnosed with FTD

Table 4 summarizes the care pathway outcomes of patients diagnosed with FTD according to the Medicaid expansion status of their state of residency at the time of their diagnosis. Within their care pathway, specifically diagnosis journey, this sample of patients experienced nearly same proportion of correct FTD diagnosis and misdiagnosis, respectively 48.2% and 48.6%. However, when comparing individuals based on the Medicaid expansion status of their state of residency at the time of their diagnosis, I observed the lowest proportion of individuals with FTD who were misdiagnosed in states with Medicaid expansion status (44.4%). This difference was significant (p=0.04). 42.3% of patients represented consulted 1 or 2 doctors during their care pathway followed by 36.6% who consulted 3 or 4 doctors. I observed the highest proportion of patients who consulted 1 or 2 doctors in states with Medicaid expansion status (46.7%). These differences of proportion of individuals in terms of number of doctors consulted based on the Medicaid expansion status of their state at the time of their diagnosis were significant (p=0.02).

Regarding the management of FTD symptoms throughout their care pathway, the majority of patients took prescription medications to treat the FTD symptoms (76.8%). When comparing individuals based on the Medicaid expansion status of their state of residency at the time of their diagnosis, the highest proportion of patients who took prescription medications to treat their FTD symptoms were in states without Medicaid expansion (80.7%). However, this difference was not significant (p=0.05). 68% of people used non-pharmacological management of FTD symptoms on the whole. When comparing individuals based on the Medicaid expansion status of their state of residency at the time of their diagnosis, I observed the highest proportion of individuals who used non-pharmacological management of FTD symptoms in states with no Medicaid expansion status (68.3%), followed by those with inconclusive status (67.8%), and those with Medicaid expansion status (65.6%). These differences were not significant (p=0.7). Overall, the majority of patients with FTD did not take over-the-counter (OTC) medication to treat FTD symptoms (60.9%).The highest proportion of people who did not take OTC medication was in states with inconclusive status (62.5%). Proportions were lower in states with no Medicaid expansion status (60.2%) and those with Medicaid expansion status (57.8%). The proportion of individuals taking OTC medication to treat FTD symptoms based on the Medicaid expansion status of their state were not significantly different (p=0.2). Overall, only 7.6% of caregivers reported that cost was a major drawback of prescription medications. When comparing individuals in terms of the Medicaid expansion status of their state, the lowest proportion of individuals who experienced cost-related drawbacks to prescription medications were observed in states with Medicaid expansion status (5.6%). However, this difference in proportions of individuals who experiences cost-related drawbacks to prescriptions medications in states based on their Medicaid expansion status was not significant (p=0.1).

Finally, 34.8% of individuals with FTD who were still alive at the time of the survey had a moderate level of functional impairment. This was followed by those with severe (23.4%), mild (22.4%), and profound (18.9%) level of functional impairment. When comparing individuals with FTD based on the Medicaid expansion status of their state of residence at the time of the survey, we observed the highest proportion of individuals with mild level of functional impairment in states with Medicaid expansion status (25.6%). However, the observed pattern of functional impairment did not differ significantly between Medicaid expansion status (p=0.3).

Table 4. Care pathway of patients diagnosed with FTD

	Overall (N=1133)	Medicaid Expansion (YES) (N=90)	Medicaid Expansion (NO) (N=410)	Inconclusive (N=584)	chi-squared test, df p-value
Misdiagnosis					**6.31, 2 0.04**
Yes	547 (48.3%)	40 (44.4%)	220 (53.7%)	267 (45.7%)	
No	548 (48.4%)	48 (53.3%)	179 (43.7%)	295 (50.5%)	
Missing	3 (3.4%)	2 (2.2%)	11 (2.7%)	22 (3.8%)	
Number of doctors consulted before FTD diagnosis					**15.03, 6 0.02**
1 or 2	479 (42.3%)	42 (46.7%)	159 (38.8%)	256 (43.8%)	
3 or 4	415 (36.6%)	22 (24.4%)	149 (36.3%)	223 (38.2%)	
4 or 5	128 (11.3%)	13 (14.4%)	59 (14.4%)	53 (9.1%)	
More than 5	89 (7.9%)	10 (11.1%)	36 (8.8%)	40 (6.8%)	
Missing	22 (2.0%)	3 (3.3%)	7 (1.7%)	12 (2.1%)	
Use of prescription medication to treat FTD symptoms					5.93, 2 0.05
Yes	870 (76.8%)	67 (74.4%)	331 (80.7%)	440 (75.3%)	
No	242 (21.4%)	23 (25.6%)	70 (17.1%)	134 (22.9%)	
Missing	21 (1.9%)	0 (0%)	9 (2.2%)	10 (1.7%)	
Use of non-pharmacological management of FTD					0.52, 2 0.7
Yes	771 (68.0%)	59 (65.6%)	280 (68.3%)	396 (67.8%)	
No	347 (30.6%)	31 (34.4%)	123 (30.0%)	181 (31.0%)	
Missing	15 (1.3%)	0 (0%)	7 (1.7%)	7 (1.2%)	
Use of OTC medication to treat FTD symptoms					2.74, 2 0.2
Yes	370 (32.7%)	35 (38.9%)	139 (33.9%)	177 (30.3%)	
No	727 (64.2%)	54 (60%)	260 (63.4%)	386 (66.1%)	

	Overall (N=1133)	Medicaid Expansion (YES) (N=90)	Medicaid Expansion (NO) (N=410)	Inconclusive (N=584)	chi-squared test, df p-value
Missing	36 (3.2%)	1 (1.1%)	11 (2.7%)	21 (3.6%)	
Cost-related drawbacks to prescription medications					5.35, 2 0.06
Yes	86 (7.6%)	5 (5.6%)	42 (10.2%)	38 (6.5%)	
No	1047 (92.4%)	85 (95.4%)	368 (89.8%)	546 (93.5%)	
Level of functional impairment[ψ]					7.03, 6 0.3
Mild	155 (22.4%)	23 (25.6%)	53 (12.9%)	74 (12.7%)	
Moderate	241 (34.8%)	34 (37.8%)	89 (21.7%)	107 (18.3%)	
Severe	162 (23.4%)	24 (26.7%)	52 (12.7%%)	80 (13.7%)	
Profound	131 (18.9%)	9 (10.0%)	48 (11.7%)	70 (12.0%)	
Missing	3 (0.004%)	0 (0%)	168 (41.0%)	253 (43.3%)	

[ψ] This variable was reported only for individuals with FTD who were alive at the time of the survey. Percentages are based on N=692.

5. DISCUSSION

5.1. Context of study findings in the literature

As stated in the literature review, this study is the first that looked at the impact of Medicaid expansion under ACA on the care pathway for FTD. So, I was not able to make comparisons of this study's findings based on Medicaid expansion status of states with the literature. Direct comparisons with the literature were possible only for the overall descriptive of the care pathway of people affected with FTD. Even there, within the care pathway, the studies I found looked only at the diagnostic journey of people living with FTD, that is misdiagnosis and number of doctors consulted before the FTD diagnosis was made.

Within the care pathway, this study demonstrated that people with FTD had a better diagnostic journey in states that have expanded Medicaid under ACA. Specifically, in states that have expanded Medicaid, individuals with FTD had the lowest proportion of misdiagnosis and highest proportion of consultation with only one or two doctors before the FTD diagnostic was made. Other aspects of care pathway, such as the experience of individuals related to the use of prescription medications and non-pharmacological management to treat FTD symptoms, cost-related drawbacks to prescription medicaments, and quality of life did not significantly differ across states based on their Medicaid expansion status.

The efficiency of the diagnostic process in states that expanded Medicaid ACA might explain the favorable diagnostic journey of people with FTD. Given the increased Medicaid coverage rates among low-income people aged 50-64 (Bin Abdul Baten & Wehby, 2023), clinicians might be incentivized to use more useful and costly diagnostic tools (e.g. genetic tests, PET scans, protein marker tests) (Grossman et al., 2023) because they are reassured Medicaid will reimburse them for the services. In addition, these exams would be affordable to a greater proportion of patients living in states that expanded Medicaid under ACA given the increase in insured low-income resident rates (Van Houtven et al., 2020, Bin Abdul Baten & Wehby, 2023). Consequently, clinicians made the appropriate diagnostic of FTD at the first or second patient visit. However, in contrast to this study's finding of nearly similar FTD misdiagnosis and correct diagnosis proportion among the overall patient sample, prior studies found high proportion of misdiagnosis among patients affected by FTD (Beber & Chaves, 2013, Giamarelou et al., 2017, Zapata-Restrepo et al., 2021). Regarding the number of doctors consulted before the diagnostic of FTD was made, the literature was in contrast with the findings of this study. Besser et al. (2020) showed that patients consulted three or more physicians before the diagnosis of FTD was made.

Looking at the comparison of the diagnosis journey within their care pathway across states based on their Medicaid expansion status, people with FTD had the lowest proportion of misdiagnosis in states that expanded medicaid in this study. Two previous studies looked at the differences in diagnosis rates between two groups of people with dementia based on whether or not they had an annual wellness visit, one key essential health benefit of Medicaid expansion free of cost-sharing. However, those studies looked only at Medicare enrollees (>65). Direct comparison was not possible as the sample of this study aged between 24 to 89 years old. Similarly, when comparing across states, a significantly higher proportion of people consulted 1 or 2 doctors in states with Medicaid expansion. Direct comparisons were not possible with the literature as any studies in the literature focused on the impact of Medicaid expansion on the number of doctors consulted before FTD diagnosis was made.

Other aspects of care pathway such as the use of prescription, over-the-corner medications, and non-pharmacological management to treat FTD symptoms, and cost-related drawbacks to prescription medications did not significantly differ across states based on their expansion status of Medicaid under ACA. Fowler et al. (2018) looked at the differences in the use of medications between two groups of people with dementia based on whether or not they had an annual wellness visit. They found no significant differences between AWV and the initiation of medication for cognitive impairment. However, this study looked only at Medicare enrollees (>65), and did not account for younger onset of dementia (< 65). Direct comparison was not possible with the findings of this study as the sample of this study aged between 24 to 89 years old.

In addition to the findings concerning the use of medications to treat FTD symptoms, this analysis did not uncover significant differences in the impact of FTD on the level of functional impairment of individuals who were still alive at the time of the survey between states based on their Medicaid expansion status. Nevertheless, I observed that people were more likely to experience a mild level of functional impairment in states with Medicaid expansion status, which means better ability to perform activities of daily living (an important domain of quality of life of people living with dementia in general) (Grossman et al., 2023). Further studies might shed light to the impact of Medicaid expansion on the quality of life of people with FTD.

5.2. Strengths and limitations

To our knowledge, this is the first study to focus on the care pathway of FTD patients and the differences between states that have adopted the ACA and those that have not. The main strength of this study is the analysis of the FTD Insights Survey, the largest survey devoted to FTD patients and their experience from symptom onset to treatment. However, this study has its limitations. I did not capture potential systematic differences between groups in the analysis. As the FTD Insights Survey did not collect data related to the income of patients, I assumed that all patients living with FTD were eligible for medicaid expansion in their states. Indeed, given the context of inconsistency in employment (loss of day work and premature resignments), the overall household income declines by 50% (Galvin et al., 2017), a large number of them might become eligible for Medicaid expansion under the ACA in their state. This study was observational in which I realized descriptive analysis, comparing groups of individuals based on the Medicaid expansion status. The analysis did not account for differences in demographics such as age, gender, race, or level of education. These factors might influence the care pathway outcomes of people living with FTD. Furthermore, the available data was limited. Given that AFTD survey collected data in categorical nature, the estimation of the FTD diagnosis date of patients (cut-off to determine the states' Medicaid expansion status) displayed as a range. This led to a large third group of inconclusive status of the state's Medicaid expansion. In addition, I was unable to estimate the time elapsed between the age of symptom onset and the age of FTD diagnosis (these variables were categorical in the dataset). Because of these broader categories, the estimates would display even broader categories without much predictive value. Consequently, I was unable to analyze the difference in delay of FTD diagnosis within the care pathway between states based on their Medicaid expansion status ACA. Neither I could not consider other dimensions of the quality of life such as cognition function, psychological well-being, and social integration. I used one dimension of

QOL, the level of functional impairment, as proxy for QOL. Another limitation of this study is the unequal group sizes with smaller size of the Medicaid expansion status group. This might have decreased the power of the chi-squared test with difficulty to detect a true difference between Medicaid expansion status groups. However, the choice to use chi-squared test was appropriate as my simple size was large (N=1133) and I had 3 non-overlapping groups. Given these limitations, future studies are needed such as quasi-experimental studies using longitudinal survey. These studies could consider the incomes level of patients living with FTD based on the federal poverty level and look at the impact of Medicaid expansion under ACA on delay in FTD diagnosis and all dimensions of quality of life.

6. IMPLICATIONS TO HEALTH POLICY AND CONCLUSION

This current study added to the evidence in the literature about the positive impact of the full Medicaid expansion under ACA on the care pathway of chronic diseases. Specifically, within the care pathway, this study demonstrated that diagnosis journey of people with FTD was more favorable in states that expanded Medicaid under ACA. The above limitations, specifically those related to the limitation of the AFTD dataset, could mean impact of Medicaid expansion on the care pathway of people living with FTD is under reported in this study. Being the first of its kind, this study set the stage for future studies aimed at informing health policies aimed to improve the diagnosis experience of patients with FTD. Specifically, the current study gives a first glance at the potential inequalities in diagnosis journey of people with FTD associated with inconsistent health insurance coverage and access to healthcare services. As we saw in the literature review, the Medicaid expansion under ACA is associated with higher Medicaid coverage and access to care among low-income adults aged 50-64, consistent with group age of people affected by FTD. Therefore, expanding Medicaid under ACA in all 50 states of the U.S. would promote health equity in the diagnosis journey for people with FTD.

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