

Saturday

Psychosocial Effects on FTD Families

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State of the art

There is a profound psychosocial impact on individuals with a family member diagnosed with Frontotemporal Degeneration (FTD).

Methodology

“Remember Me” Podcast conducted 43 one-hour interviews with family members of persons diagnosed with FTD. Interviews detailed the diagnosis process, caregiving, disease progression, and the dramatic personality and behavioral changes in the person diagnosed.

Interviewed family members geographically represent The United States (20 states), Brazil, Canada and Spain.

Remember Me developed a survey to associate data with key interview findings. 54 podcasts listeners participated and reported the diagnosed individual as their: Parent (35), Spouse (10), Aunt/Uncle (3), Father-in-law/Mother-in-law (2), Sibling (2) or Multiple Family Members (2).

Results

91% of individuals reported going through periods of depression and isolation post diagnosis. 72% reported difficulty performing the duties of their job. 91% reported finding it difficult to relate to others.

48% disagreed with the statement “I left the [diagnosis] visit with an understanding of what the diagnosis meant.” 68% disagreed with the statement “I was given resources for myself and my family”. 89% agreed “I often lived in fear of what was coming next.”

38 of 54 individuals reported seeking support from a “counselor, therapist or psychiatrist”.

50 reported developing medical conditions during their family member’s disease. Most commonly reported: Anxiety (38), Insomnia or other Sleep Issues (30), Depression (27), Excessive Weight Gain or Loss (25).

Conclusion

As evidenced, FTD is a “disease of the family” with a profound psychosocial impact. Support from the medical community is critical.

Conflicts of interest

None.