The Caregiver Analysis of Reported Experiences with Swallowing Disorders (CARES) v 2.1

PART A: ***Checklist of Behavioral and Functional Changes***

For each of the following statements, please think specifically about your loved one/care recipient's eating or swallowing difficulties **during the past month**. Has the situation described in the statement bothered **you**? If it has not occurred, please indicate "N/A".

	In the past month, has this situation bothered you?
1. Because of my loved one's swallowing difficulties, extra time is required for mealtimes (e.g., finding appropriate foods, cooking meals, preparing tube feedings, watching my loved one eat/drink).	YES NO N/A
2. Because of my loved one's swallowing difficulties, my mealtime- and nutrition-related responsibilities have increased (e.g., related to shopping, cooking, tube feeding).	YES NO N/A
3. Because of my loved one's swallowing difficulties, the costs associated with their nutrition-related needs have increased (e.g., supplies for tube feedings, thickening products or thickened liquids, supplements).	YES NO N/A
4. Other family members disagree with me about how to best manage my loved one's swallowing difficulties.	YES NO N/A
5. Managing my loved one's swallowing difficulties interferes with my daily routine. (e.g., job, school work, household chores).	YES NO N/A
6. Managing my loved one's swallowing difficulties takes away from other things I would prefer to be doing. (e.g., leisure activities).	YES NO N/A
7. Because of my loved one's swallowing difficulties, my loved one and I do not participate in meals together as often as we used to.	YES NO N/A
8. Because of my loved one's swallowing difficulties, I do not make plans with others as often as I would like.	YES NO N/A
9. Because of my loved one's swallowing difficulties, my loved one and I cannot go out to eat as much as I would like.	YES NO N/A
10. Because of my loved one's swallowing difficulties, I avoid eating or drinking items that they cannot have.	YES NO N/A

Of the 10 statements above, which would you rate as the most burdensome? Number _____

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PART B: *Checklist of Subjective Caregiver Stress*

For each of the following statements, please think specifically about your loved one/care recipient's eating or swallowing difficulties **during the past month**. Has the statement been true for you?

	In the past month, has the statement been true for you?
1. I do not feel prepared to help manage my loved one's swallowing difficulty (e.g. related to tube feeding, thickened liquids, Heimlich).	YES NO N/A
2. Because of my loved one's swallowing difficulties, I feel like it is hard to ensure they receive adequate nutrition.	YES NO N/A
3. I feel like my loved one does not do as much as they can to help with their swallowing difficulties.	YES NO N/A
4. Because of my loved one's swallowing difficulties, I am scared that they will choke.	YES NO N/A
5. Because of my loved one's swallowing difficulties, I feel guilty eating or drinking items that they cannot have.	YES NO N/A
6. Because of my loved one's swallowing difficulties, I feel like I don't have enough time to take care of my own physical health.	YES NO N/A
7. Because of my loved one's swallowing difficulties, I feel like I don't have enough time for activities that make me feel good.	YES NO N/A
8. Because of my loved one's swallowing difficulties, I feel depressed.	YES NO N/A
9. Because of my loved one's swallowing difficulties, I feel stressed.	YES NO N/A
10. Because of my loved one's swallowing difficulties, I feel anxious.	YES NO N/A
11. I feel embarrassed by my loved one's swallowing difficulties when other people are around.	YES NO N/A
12. I worry about how my loved one feels about their swallowing difficulties.	YES NO N/A

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	In the past month, has the statement been true for you?
13. Because of my loved one's swallowing difficulties, I feel like the social and togetherness aspects of mealtimes are reduced.	YES NO N/A
14. Because of my loved one's swallowing difficulties, I feel isolated from family and friends.	YES NO N/A
15. I feel trapped as a result of managing my loved one's swallowing difficulties.	YES NO N/A
16. I worry that my loved one's swallowing difficulties will not improve.	YES NO N/A

Of the 16 statements above, which would you rate as the most burdensome? Number _____