



Curtin University

RECEIVING THE NEWS OF A DIAGNOSIS OF MOTOR NEURONE DISEASE

What does it take to make it better?

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Background

- Breaking the news of the diagnosis of MND is challenging for both neurologists and patients
- The manner the patient is imparted the diagnosis is acknowledged to be the first and one of the most sensitive steps in palliative care
- To date there are no large studies that have been conducted to ascertain the nature and extent of these challenging experiences.

Objectives

- To identify the experiences of people with MND in receiving the diagnosis
- To determine overall satisfaction with the way the diagnosis was given
- To determine which aspects of the process of breaking this news were associated with greater satisfaction



Method

- Anonymous postal survey, facilitated by all MND Associations in Australia
- Demographic information
- Disease specific information:
 - Date symptoms first started
 - Type of symptoms
 - Date diagnosis first made
 - Other specialists seen
 - Diagnosing physician
 - Time spent by the neurologists giving the diagnosis



Method (cont.)

- Questions centred on the SPIKES protocol for communicating bad news

Setting – establishing the appropriate setting

Perception – determining needs & perception of patient

Invitation – requesting an invitation to give the news

Knowledge – providing knowledge and information

Emotion/Empathy – exploring the patient's feelings

Strategy – forming a strategy with the patient to go forward

Results-Demographics

- 864 surveys mailed, 248 responded, 29% response rate (range 26% to 35%)
- Mean age, 66.4 years (SD=11.0, range 30-91)
- Male, 59%
- Married, 78%
- Retiree, 75%

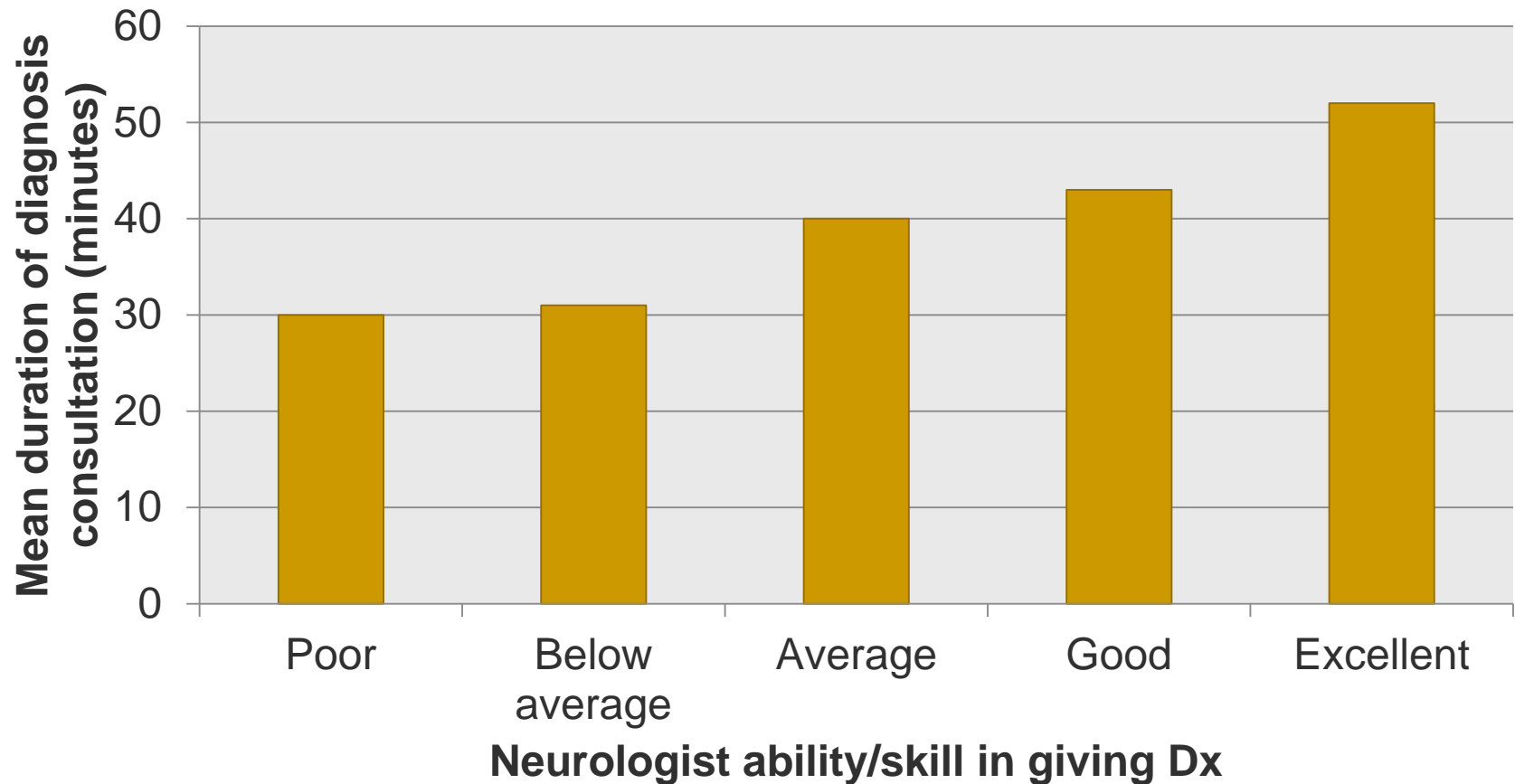
Results - Diagnosis

- Median period from diagnosis, 15 months (1-87)
- Median period from first symptoms to diagnosis, 10 months (1-119)
- Symptoms at onset:
 - Cervical/lumbar 69%; Bulbar symptoms 19%
- Consultation with other specialists prior to diagnosis;
 - Other neurologist, 31%
 - ENT surgeon, 15%
 - Orthopaedic surgeon, 11%
 - Speech pathologist, 9%

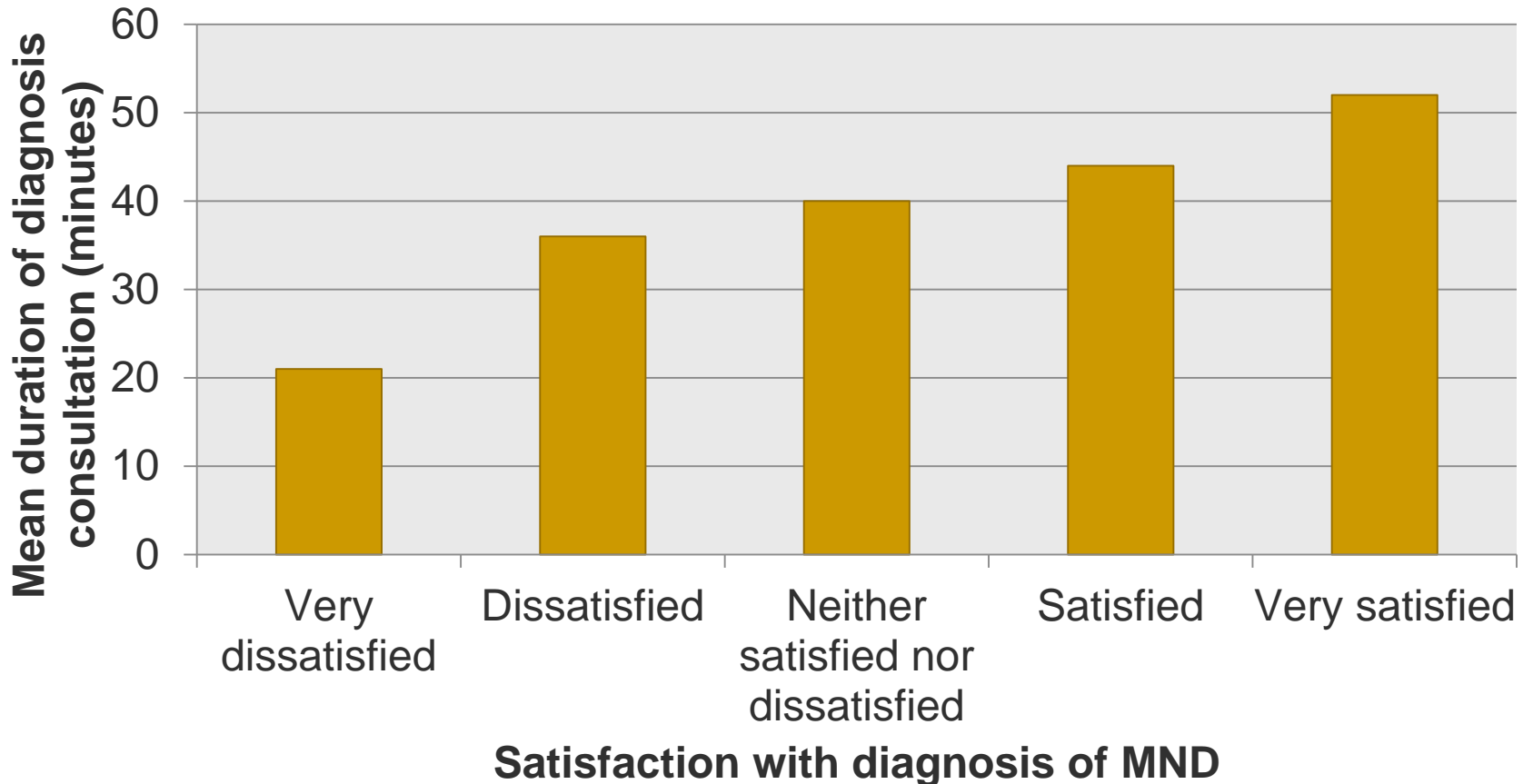
Results - Diagnosis

- Diagnosis by a neurologist, 95%
Other e.g. neurogeneticist, 3% or GP, 2%
- Number of visits to convey diagnosis:
 - 2 visits, 33%
 - 3 visits, 17%
 - >3 visits, 19%
- Median length of consultation, 30 minutes

Ratings of neurologists' ability/skills and consultation duration



Ratings of satisfaction with delivery of diagnosis and consultation duration



Ratings of neurologists' skills and satisfaction

- Ratings of ability/skill of neurologist in giving the diagnosis:
 - Above average, 64%
 - Average and below average, 36%
- Satisfaction with the delivery of diagnosis:
 - Very satisfied/satisfied, 65%
 - Very dissatisfied/dissatisfied/ neither, 35%

Results – SPIKES domain - Setting

- **Private space (98% vs 91%, p=0.019)**

High: *“The relaxed atmosphere and a clear belief that I was being looked after by a very competent specialist.”(P326)*

Low: *“Info given to me only referred to negatives which upset me - at time of info given no private area to remain in and went out to public area that was full and I was upset in front of them.” (P190)*

Results – SPIKES domain - Setting

- **No interruptions (95% vs 86%, p=0.027)**

High: *“The neurologist was good and not pushy to get me out the door.” (P109)*

Low: *“I was not impressed by the number of interruptions during my neurologist consultations ie. Phone calls, missing reports, and copies of reports being brought in ...”(P340)*

Results – SPIKES domain- Invitation

- **Asked by neurologist how much they knew about MND (54% vs 24%, $p < 0.001$)**

High: *“I had been told by my first neurologist that MND was on the table so I had done some research in the months between him and seeing neurologist... It was all pretty grim so I did not delve too deeply”. (P09)*

Low: *“I think they should start with “What do you know about MND?” As an icebreaker.” (P229)*

Results – SPIKES domain- Invitation

- **Asked by neurologist how much detail they wanted to know (40% vs 13%, $p < 0.001$)**

High: *“The Dr was very kind, sympathetic. He asked how much I wanted to know.” (P73)*

Low: *“At the first interview I should have been given the opportunity to be asked if I would like more information or not. The internet is a daunting place and that is where I had to source information.” (P205)*

Results – SPIKES domain- Knowledge

- **Satisfied with detail provided (82%-45%,
p<0.001)**

High: *“I was not bombarded with the whole story in one hit and allowed time to deal with it.” (P296)*

Low: *“I was told very bluntly about my situation and how it would basically progress. He said if I had any plans do them now.” (P176)*

Results – SPIKES domain- Knowledge

- **Satisfied with type of information received (76% vs 31%, $p < 0.001$)**

High: *“Information given also by way of DVD - excellent!” (P94)*

High: *“The neurologist spoke clearly, calmly and answered my questions in 'layman's' language.” (P162)*

Low: *“Would gladly have driven into a pole on the way home because I was given no hope.” (P64)*

Low: *“Not enough information given, certainly at the first two appointments. His presentation could best be described as robotic.” (P205)*

Results – SPIKES domain- Knowledge

- **How the diagnosis was reached (71% vs 56%, p=0.024)**

High: *“... I asked whether it could be MND and she replied that that was what she was thinking. She then explained the reasons for her diagnosis to my wife and I, and explained the associated implications very clearly and with empathy.” (P152)*

Low: *“1st visit to neurologist said he would like to do nerve conduction tests. He didn't say why. I asked could I have an ageing disease like MS. He was surprised that I asked and said No, I suspect Motor Neurone Disease.” (P234)*

Results – SPIKES domain- Knowledge

- **Current state of knowledge (42% vs 22%, p=0.002)**

High: *“The support and professional advice I am receiving are as good as it gets. Because the disease develops in different parts of the body and at different rates of progression, getting accurate answers on the future are virtually impossible.” (P158)*

Low: *“Diagnosis and explanation were quite perfunctory with no explanation to follow up care. Terminology used was outdated and wrong as to specifics. Expected lifespan estimate was optimistic (7 years).”(P341)*

Results – SPIKES domain - Emotion

- **Diagnosis given with warmth, care & empathy (88% vs 29%, $p < 0.001$)**

High: *“He detected it very quickly and was so gentle and caring in the way he told me, I was not upset. I was glad to find a name for all my medical problems.” (P264)*

Low: *“No positive aspects at all (no help or care). Had the bedside manner of a brick.” (P335)*

Low: *“Neurologist was clinically thorough but uncaring when providing diagnosis of MND. Gave brochure for information. Told me I had 3 years left to live. Was left alone in city 2hrs from home after diagnosis”. (P85)*

Results – SPIKES domain - Emotion

- **Allowed time to express their emotions (84% vs 28%, $p < 0.001$)**

High: *“The neurologist was lovely... the appointment was in the afternoon and she spent quite a long time with us we did not feel rushed.” (P09)*

High: *“I received diagnosis by neurologist and then [she] left room so I could maintain my composure in private. Then [she] came back and gave me time to question her before seeing me again next day.” (P54)*

Results – SPIKES domain - Emotion

Low: *“I felt the neurologist was very insensitive. Especially saying it is "terminal" I didn't have enough time to comprehend what I had just been told.” (P234)*

Low: *“Despite knowing a lot, expecting the bad mutation, it was a shock. We didn't have time (or empathy?) to discuss feelings and consequences..” (P430)*

Results – SPIKES domain - Emotion

- **Allowed time to have these emotions responded to (83% vs 26%, $p < 0.001$)**

High: *“The diagnosis was given very professionally with appropriate empathy and a good understanding of my reactions to it - which were calm.”(P152)*

Low: *“More information and more time would have allowed opportunity for me to be questioned about my feelings and for me to respond accordingly.”
(P205)*

Results – SPIKES domain - Strategy

- **Referral to a multidisciplinary MND clinic (44% vs 22%, p<0.001)**

High: *“After making contact with specialist neurologist, support and care have been all one could hope for. Local allied health, as well as staff at MND clinic have provided all the information I have needed. Also kept one step ahead with any equipment required. Local rep of MND Association has also been very supportive.” (P284)*

Low: *“Was not offered follow up from initial neurologist. By internet research we made contact with Professor [Name] and had initial consultation...where diagnosis of ALS was given and support through medication and clinic.” (P341)*

Results – SPIKES domain - Strategy

- **Referral to MND Association (51% vs 23%, $p < 0.001$)**

Low: “Yes - in hindsight while original neurologist diagnosed and was compassionate - no f/up plan or support was given - we had to source this ourselves - no idea there was an MND association etc. poorly supported until I contacted MND Association - have been well supported since then.” (P30)

Results – SPIKES domain - Strategy

- **Follow-up plan for immediate and long term support (37% vs 8%, $p < 0.001$)**

High: *“Needed more [support] at beginning - monthly for first 4-6 months, then longer intervals. Need time to ask all Q's, go through anger/grief, then settle into monitoring and adapting to progress of disease.” (P52)*

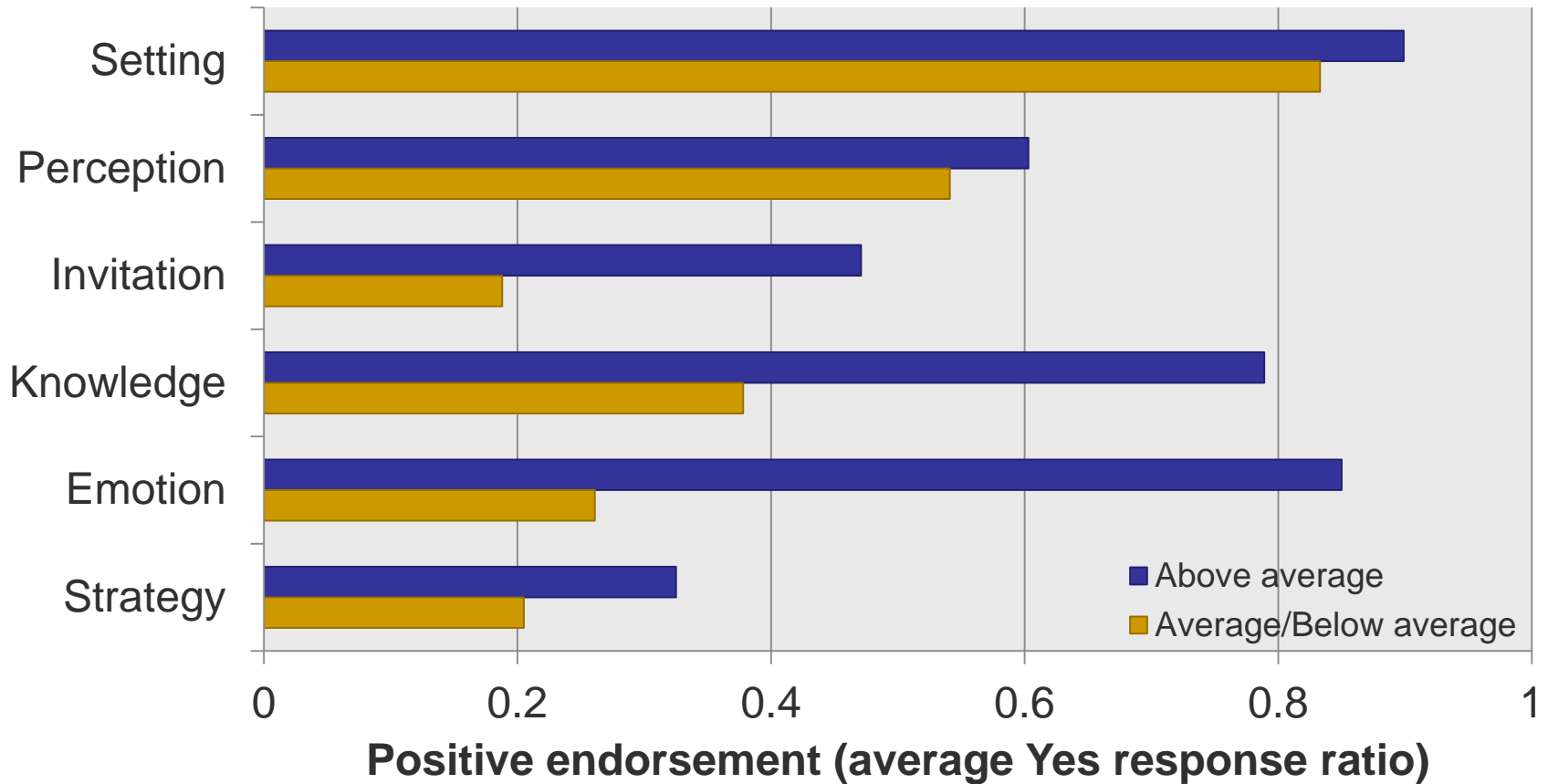
Low: *“It was just a diagnosis to the neurologist and no emotional support or ongoing guidance was given.” (P341)*

**SPIKES
domains**

**Rating of ability of neurologist by people
with MND**

	Above average		Average/ Below average		p-value	Cronba ch's α
	n=156		n=87			
	Mean	SD	Mean	SD		
Setting	0.90	± 0.16	0.83	± 0.22	0.031	0.047
Perception	0.60	± 0.29	0.54	± 0.30	NS	0.029
Invitation	0.47	± 0.43	0.19	± 0.31	<0.001	0.636
Knowledge	0.79	± 0.34	0.38	± 0.43	<0.001	0.731
Emotion	0.85	± 0.31	0.26	± 0.38	<0.001	0.897
Strategy	0.32	± 0.17	0.20	± 0.15	<0.001	0.473

Rating of neurologists' ability/skills under the six SPIKES domains



Discussion

- First national Australian study to provide a comprehensive insight into the process of receiving the MND diagnosis from the patients' perspective
- Rating of ability/skills of neurologist was proportional to length of consultation for diagnosis
- Overall rating of ability/skills was closely associated with performance within the SPIKES domains

Discussion

The largest significant differences in performance were in four domains:

- Responding with empathy to the feelings of patient/family;
- Sharing the information and suggesting realistic goals;
- Exploring what patient/family are expecting or hoping for;
- Making a plan and following through.



Comparison to European Guidelines (Anderson et al, 2007)

	Present study	Guidelines
Length of consultation	30 min	45-60 min
First follow up visit after diagnosis	7 weeks	2-4 weeks or sooner
Referral to MND association	40%	always
Communication of diagnosis	70% had 2 or more visits	Stepwise fashion
Completely private space	96%	always
No interruptions	91%	always
Relative present	70%	always

Limitations

- Representativeness of sample to general MND population- however a third in each of five states
- Representativeness of neurologists involved
- Survey based on one protocol (SPIKES)- however results also compatible with European guidelines
- Formal validation of instrument-however good face validity and internal consistency of SPIKES

Conclusions

- The manner in which patients learn of their diagnosis can have implications for:
 - The way they move on from the news of their diagnosis
 - The actions required for support throughout their illness
- The longer the patients spent with their neurologists during breaking this bad news, the more they were satisfied.

Conclusions

- With over a third of patients dissatisfied, there is room for improvement in the practice of delivering the diagnosis in Australia
- Greater adherence to certain attributes of effective communication of bad news may improve the way neurologists perform this difficult task
- Such improvements may be attainable through educational programs and the development of best practice protocols



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