

Using a HRQoL Questionnaire can Improve Communication and Consultations



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Background

- Health-related quality of life (HRQoL) is a multi-dimensional construct that refers to an individual's physical functioning, ability to perform daily activities, sense of well-being, satisfaction with life, perception of psychological status, and social functioning¹. It relates to how an individual's well-being is affected over-time by a disease.
- The aim of measuring HRQoL is to provide a comprehensive assessment of a patient's health status from their perspective².
- HRQoL is often adversely affected in people with Multiple Sclerosis (MS). It tends to be worse in people with MS than the general population³.
- HRQoL has been extensively researched in patients with multiple sclerosis but to date there is little published describing its assessment in routine clinical practice.

The study had the following aims:

- To explore, understand and evaluate whether there is a role for routine assessment of HRQoL in patients with MS in daily clinical practice⁴.
- To determine whether assessing HRQoL routinely in practice is feasible and valuable⁴.

Methods

The study was split into two phases⁴:

- Phase 1: 311 patients completed the MSIS-29v2 before each routine outpatient appointment.
- Phase 2: Fifteen participants who had completed two or more MSIS-29v2 during the research period were selected to be interviewed about their experience of completing the MSIS-29v2 and its use in an outpatient appointment. Two health professionals were also interviewed to determine their views and experiences.

Multiple Sclerosis Impact Scale, MSIS-29v2²

- Questionnaire looking at physical and psychological impact of MS on daily life from the patient perspective².
- Questions 1-20 measure physical impact and questions 21-29 measure psychological impact.
- Higher scores indicate greater impact.
- Takes 5-10 mins to complete.

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Multiple Sclerosis Impact Scale		WI313-23	302)			
Participant Identification number Are you still willing to participate in this research.		cle).				
\$ 05 5 55 500	Torr (picase on	100	100			
Yes • If yes please complete the questionnaire below	DW.	No No				
For each statement, please circle the <i>one</i> nu Please answer <i>all</i> questions.	mber that best	describes	your situatio	n.		
In the past 2 weeks, how much has your MS limited your ability to \dots	Not at all	A little	Moderately	Extremel		
1. Do physically demanding tasks?	1	2	3	4		
2. Grip things tightly (e.g. turning on taps)?	1	2	3	4		
3. Carry things?	1	2	3	4		
	Not at all	A little	Moderately	Extremel		
In the past 2 weeks, how much have you been bothered by		2	3	4		
	1					
bothered by	1	2	3	4		
bothered by 4. Problems with your balance?		2	3	4		
4. Problems with your balance? 5. Difficulties moving about indoors?	1					
bothered by 4. Problems with your balance? 5. Difficulties moving about indoors? 6. Being clumsy?	1	2	3	4		
bothered by 4. Problems with your balance? 5. Difficulties moving about indoors? 6. Being clumsy? 7. Stiffness?	1 1 1	2	3	4		
bothered by 4. Problems with your balance? 5. Difficulties moving about indoors? 6. Being clumsy? 7. Stiffness? 8. Heavy arms and/or legs?	1 1 1	2 2 2	3 3 3	4 4		
bothered by 4. Problems with your balance? 5. Difficulties moving about indoors? 6. Being clumsy? 7. Stiffness? 8. Heavy arms and/or legs? 9. Tremor of your arms or legs?	1 1 1 1	2 2 2 2	3 3 3 3	4 4 4		

In the past 2 weeks, how much have you been bothered by		Not at a	all A little	Moderate	ely Extreme		
13. Limitations in your social and leisure activities at home?			1	2	3	4	
14. Being stuck at hon	1	2	3	4			
15. Difficulties using y	our hands in everyday t	asks?	1	2	3	4	
16. Having to cut down the amount of time you spent on work or other daily activities?			1	2	3	4	
17. Problems using transport (e.g. car, bus, train, taxi, etc.)?			1	2	3	4	
18. Taking longer to d	o things?		1	2	3	4	
19. Difficulty doing things spontaneously (e.g. going out on the spur of the moment)?			1	2	3	4	
20. Needing to go to the toilet urgently?			1	2	3	4	
21. Feeling unwell?			1	2	3	4	
22. Problems sleeping?			1	2	3	4	
23. Feeling mentally fatigued?			1	2	3	4	
24. Worries related to your MS?			1	2	3	4	
25. Feeling anxious or tense?			1	2	3	4	
26. Feeling irritable, impatient or short-tempered?			1	2	3	4	
27. Problems concentrating?			1	2	3	4	
28. Lack of confidence?			1	2	3	4	
29. Feeling depressed?			1	2	3	4	
	Dutcome sula Medical School, Ply nelp to complete this		naire (ple	ase circle):			
Yes			No				
Since you last cocircle):	ompleted a question	naire do yo	ou think t	hat your qual	ity of life ha	as (please	
Significantly Improved	Slightly Improved	No Change S		Slightly Deterio		Significantly Deteriorated	
Please comment							
	v	ersion 1, 2 nd	May 2014				

Acknowledgements

Findings

- Using the MSIS-29v2 empowers patients to consider the physical and psychological impact of MS on themselves and their daily life.
- The MSIS-29v2 provides healthcare professionals with a structured approach to reviewing the impact of MS on an individual.
- Each question is scored 1-4 enabling MS healthcare professionals to identify key priorities to discuss during the appointment.
- The team can use the answers to guide any requirements for therapeutic interventions or referrals to other members of the multi-disciplinary team.
- Physical and psychological impact scores of the MSIS-29v2 before and after interventions can be compared, capturing data on where the service's input has made a real difference to patients.
- Structuring a consultation around the MSIS-29v2 promotes holistic patient-centred care through shared decision-making

Conclusions

The study concluded that the introducing HRQoL assessments using the MSIS-29v2 was:

Feasible

Patients were able to complete the questionnaire quickly and easily before their appointment.

Valuable to patient

The structure of the MSIS-29v2 allowed patients to focus their thoughts so they could provide their healthcare professional with relevant information.

Valuable to healthcare professionals

The assessment helped professionals to identify important issues, suggest interventions and monitor progress over time.

Useful

It improved patient-clinician communication and helped patients become more aware of the impact of their condition.

In summary

In daily practice the real value of the MSIS-29v2 rests in its ability to empower patients to consider the impact of their MS in a structured manner. Also to measure changes in the physical and psychological impact of MS following interventions from the patient perspective.

Next Steps

To embed the use of the MSIS-29v2 into daily clinical practice requires:

- Patience! "At the beginning, using the MSIS-29v2 does take a little bit longer, but I would really encourage people to persevere. Yes, you're changing the way you practice, but it is for the better!"
- Printing facilities and a method of distribution. We post out the questionnaire with the clinic letter and have put some in the leaflet rack in the waiting room.
- Suitable waiting room space where patients can complete the form, ideally with support for those with visual problems and fine motor weakness.

References

- 1. Buchanan, R.J., Huang, C. and Kaufman, M., 2010. Health-related quality of life among young adults with multiple sclerosis. International Journal of MS Care, 12, pp.190-199.
- 2. Hobart, J., Lamping, D., Fitzpatrick, R., Riazi, A. and Thompson, A., 2001. The Multiple Sclerosis Impact Scale (MSIS-29): a new patientbased outcome measure. Brain, 124, pp.962-973.
- 3. Benedict, R., et al., 2005. Predicting quality of life in multiple sclerosis: accounting for physical disability, fatigue, cognition, mood disorder, personality, and behavior change. Journal of the Neurological pp.29-34.
- 4. Willis, H. N., 2018. Assessment of Health-related quality of Life in Patients with Multiple Sclerosis in the Outpatient Setting: A mixed
- methods study.

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