Exercise

HTA: Policies and Principles Week 6

The purpose of this practical exercise is to illustrate the application of some of the quality of life measures covered in the lecture. You will be presented with 3 scenarios – each one detailing the presentation of a person with Parkinson's disease. Imagine you are in each of the scenarios and complete the questions below, using the EQ-5D-3L, ICECAP-O and PDQ-39 questionnaires. (There are no specific right answers, so if there are details missing from the scenario, make an educated guess as to what the response would be for a patient filling out the questionnaire).

Scenario 1

You can walk, but sometimes suffer from stiffness and muscle pain. You do not fall. You sometimes cannot control the movement of your arms, so you try to reduce your number of outings in public, for example dining in a restaurant, or going to the leisure centre. You also avoid getting together with your friends and family members as you don't want them to see that you are unable to control your limbs. You start gambling due to the impulse control problems associated with Parkinson's. You struggle to fall asleep at night, which causes you to often feel depressed. You live together with your husband; he has had to reduce his working hours by four hours per day to look after you, and thus your household income is reduced. Your husband is currently doing most of the housework for you.

Scenario 2

You can walk but suffer stiffness and muscle pain quite often. You usually fall more than three times per day, but you have managed to cope with near-fall strategies so that you don't get severe injuries from falling. You sometime cannot control the movement of your arms, but it doesn't stop you from trying new restaurants as you still enjoy food especially innovative cuisines. You like to have family and friends around in your house and you like to cook for everybody. You try to play golf every day and are making a new golf cart from using old spare parts. You have a hard time falling asleep at night, approximately three times a week. Your wife cares for you so you don't have to worry about getting help from people outside your family. You like to participate in Parkinson's research and community support groups to help other people with Parkinson's.

Scenario 3

You have been admitted to hospital A&E twice in the last month for fractures due to falls. You suffer from muscle pain quite often. You feel very worried about the progression of the disease. You cannot speak clearly, so people have a hard time understanding you. As a result, you avoid contact with other people or going to public places. You are more likely to fall when you walk in a hurry or when going upstairs with somebody following behind you. While you are eating, sometimes you cannot control your saliva, so you are embarrassed to eat together with relatives or friends. Your sleep is fine at night. You live alone so you have to do all the housework yourself. You are not well-informed of the knowledge and treatment in Parkinson's. You live far away from community-based Parkinson's support group, and you feel lonely, insecure and uncomfortable when talking about this disease to other people.

Question 1

Give a score between 0-100 for the overall quality of life for each of the above scenarios. Think about your reasons behind each score.

	Scenario 1	Scenario 2	Scenario 3
Quality of life			

Question 2

Fill in the PDQ-39 questionnaire for the 3 scenarios. Using the formula provided with the questionnaire in the Appendix, calculate the dimension scores and the summary index for each of the 3 scenarios.

PDQ-39 dimensions	Scenario 1	Scenario 2	Scenario 3
Mobility			
Activities of daily living			
Emotional wellbeing			
Stigma			
Social support			
Cognition			
Communication			
Bodily discomfort			
Summary index			

Question 3

Fill in the EQ-5D-3L questionnaire for the 3 scenarios (provided in the Appendix). Using the scoring table provided for the EQ5D in the lecture (the table with coefficients for TTO tariffs), calculate the utilities for each of the 3 scenarios.

EQ5D Domains	Scenario 1	Scenario 2	Scenario 3
Mobility			
Self-care			
Usual activities			
Pain/discomfort			
Anxiety/depression			
Utility score			

Question 4

Fill in the ICECAP-O questionnaire for the 3 scenarios (provided in the Appendix). Use the below value set table to calculate capability scores for each of the 3 scenarios.

| Attributes | Four levels | | | | Example | |
	Able to do all / without any concern (4)	Be able to do many / with a little concern (3)	Able to do a few / with some concern (2)	Unable to do / with a lot of concern (1)	Response	Dimension index
Attachment	0.2535	0.2325	0.1340	-0.013	3	0.2325
Security	0.1788	0.1071	0.0661	0.032	2	0.0661
Role	0.1923	0.1793	0.1296	0.015	2	0.1296
Enjoyment	0.1660	0.1643	0.1185	0.017	3	0.1643
Control	0.2094	0.1848	0.1076	-0.051	4	0.2094
				ICECAP-O value		**0.8019**

Source: Coast J et al. Valuing the ICECAP capability index for older people. Social Science and Medicine 2008; 67(5):874-882.

ICECAP-O response	Scenario 1	Scenario 2	Scenario 3
Attachment			
Security			
Role			
Enjoyment			
Control			
Anxiety/depression			
ICECAP-O score			

Question 5

Now complete the following table with the scores you obtained in Questions 1-4.

ICECAP-O response	Overall QoL	PDQ-39	EQ-5D-3L	ICECAP-O
Scenario 1				
Scenario 1				
Scenario 1				

How do the scores from the instruments compare to the initial score out of 100 you assigned each of the scenarios?

How do the scores for each of the instruments compare to one another?

Do these measures adequately capture quality of life for the scenarios presented?

What would your outcome measure recommendation be for a researcher designing a trial of a treatment for Parkinson's?

Post your thoughts on these questions in the discussion forum.