Patient and Caregiver Priorities for Outcomes in Peritoneal Dialysis: Multinational Nominal Group Technique Study

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Supplementary Material TOC

Supplemental File 1: Mathematical formula for nominal group technique ranking

The rankings from the nominal group technique produced ordinal data. We used a measure of importance (i.e. importance score) for each outcome to prioritize the outcomes, based on the attributed rankings. To calculate this measure, the distribution of the ranking for each outcome was obtained by calculating the probability of each rank for each outcome. Using mathematical notation, this is written as $P(O_j \; in \; rank \; i)$, i.e., the probability of the outcome O_j being assigned the rank i. Thus, for each outcome, we obtained the probability of being ranked in first place, in second place, and so on. By the total law of probabilities, these probabilities were decomposed as:

$$P(O_j \; in \; rank \; i) =$$

$$= P(O_j \; in \; rank \; i \; | O_j \; is \; nominated) \times P(O_j \; is \; nominated)$$

$$+ P(O_j \; in \; rank \; i \; | O_j \; not \; nominated) \times P(O_j \; not \; nominated)$$

where "nominated" meant the outcome was given a rank by the participant. We assumed that the $P(O_j \; in \; rank \; i \; | O_j \; not \; nominated)$ was 0, because if the participant did not rank the outcome O_j, then the probability of any rank was 0. Therefore, the expression above simplified to:

$$P(O_j \; in \; rank \; i) = P(O_j \; in \; rank \; i \; | O_j \; is \; nominated) \times P(O_j \; is \; nominated)$$

We therefore observed that the probability had two components: 1) the importance given to the outcome by the ranking and 2) the consistency of being nominated by the participants. We then used these probabilities and computed the weighted sum of the reciprocal ranking $\left(\frac{1}{i}\right)$ to obtain the importance score (IS):

$$IS = \sum_{i=1}^{nr \; of \; outcomes} P(O_j \; in \; rank \; i) \times \frac{1}{i}$$

The importance score can be interpreted as a summary measure of importance of the outcome that incorporates the consistency of being nominated and the rankings given by participants. The ranks were inverted to give more weight to higher ranks and less to lower ranks. Scores ranged between zero and one, and higher scores identified outcomes that were more valued by participants. This measure had a similar motivation to the Expected Reciprocal Rank Evaluation Metric proposed in a different context.[24] The importance scores were also calculated separately by country, gender, age, and for patients and caregivers. The analysis was conducted using the software package R version 3.2.3 (*R Foundation for Statistical Computing, Vienna, Austria*).

Supplemental Table 1: Focus group question guide

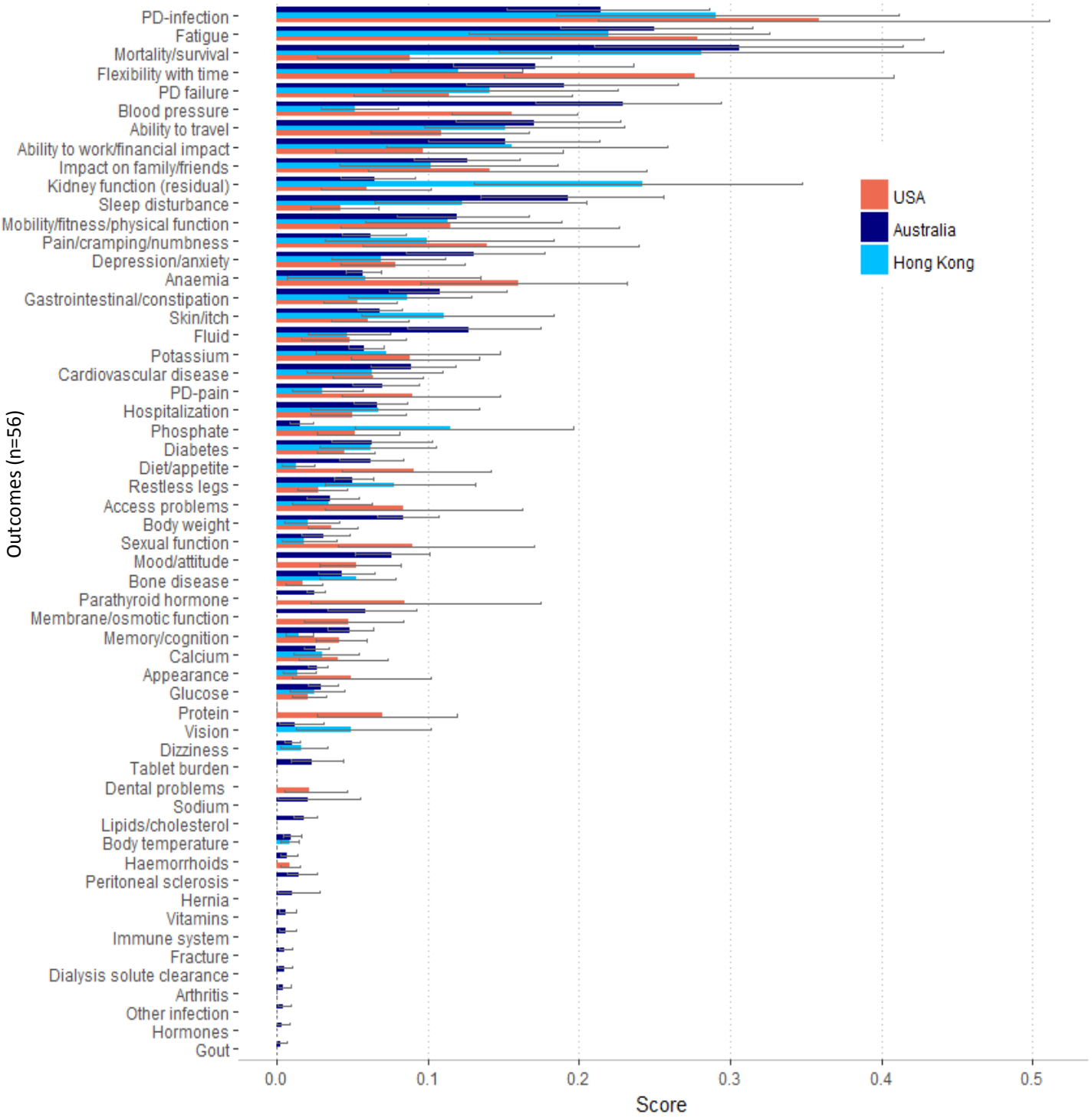
Time	Details	
	Welcome and introductions, ice-breaker and objectives	
20 mins	**Focus Group** As a group we would firstly like to invite you to share your ideas and experiences of peritoneal dialysis: 1) What aspects of peritoneal dialysis or PD treatment are important to you - why? *(medications, time of dialysis, location)* 2) Do these treatments affect your life - in what ways? • What specific outcomes *(impacts)* are important to you than other outcomes – why? • What outcomes most challenging to deal with - why and how do you cope with it?	
	Nominal group Technique (Part 1)	
40 mins	**Nominal Group (Part 1)** Now we are going to have a more focused discussion and an activity to find out what outcomes *(complications, symptoms)* matter to you most and why. I am going to read you a question. After I have read, I would ask that you take a couple of minutes to write down **three** ideas (by yourself) on the paper provided to the question shown on the flip chart. This is the question: "If researchers wanted to evaluate two different types of treatments for people on peritoneal dialysis (e.g. CAPD vs APD, different length of dialysis, different types of medication, different diet, types of catheter); what do you think they need to study (measure) in order to determine which one is 'better' for you/your family/for other patients?" *[Restate definition if needed]* *A simple definition of an "outcome" is anything that arises/changes as a result of a health condition or treatment [medications, surgical, type of dialysis, lifestyle management])* *[Give examples discussed in focus group if needed]* *For example, you may want to know about the specific side effects such as cramping, nausea, vomiting or headaches etc. You may want to know about your chance of infection. You may also want to know you can travel freely with this treatment. Or possibly whether this treatment could increase your life expectancy.* Please write down your 3 ideas now and then we will share them with each other. Now, I would like you to share your ideas. I am going to go around the table and ask each of you to give me one or two ideas from your worksheet, summarized in a few words. After the entire list is on the board, we will discuss and clarify the ideas. Please do not repeat an idea already listed on the board. You can offer a different idea or you can pass. We will now briefly discuss each idea, to clarify the meaning of each item on the chart. We should feel free to express different points of view. The person who suggested the idea does not have to clarify or explain the item. [The facilitator will point to the first item] Are there any questions or comments group members would like to make about this first item?	

	We are now going to include some things other patients have told us in the past. The additional items included that were not raised by the group are *[write them on the flip chart, read them out and clarify].*	
Break		
10 mins	**<u>Break</u>** *Print list of outcomes for ranking.*	
Nominal group Technique (Part 2)		
25 mins	**<u>Nominal Group Part 2</u>** Now we are going to look at all the ideas raised by the group and I will ask you to rank them in order of most important to least important to you. Now we will have a discussion to discuss any similarities and differences in ranking. What did everyone put as: number 1, number 2, number 3, least important? Would anyone like to explain why they ranked [outcome] or how they made their decisions about ranking? Why do you think most people ranked [outcome] high/low? Why do you think there are differences in ranking of [outcome]?	

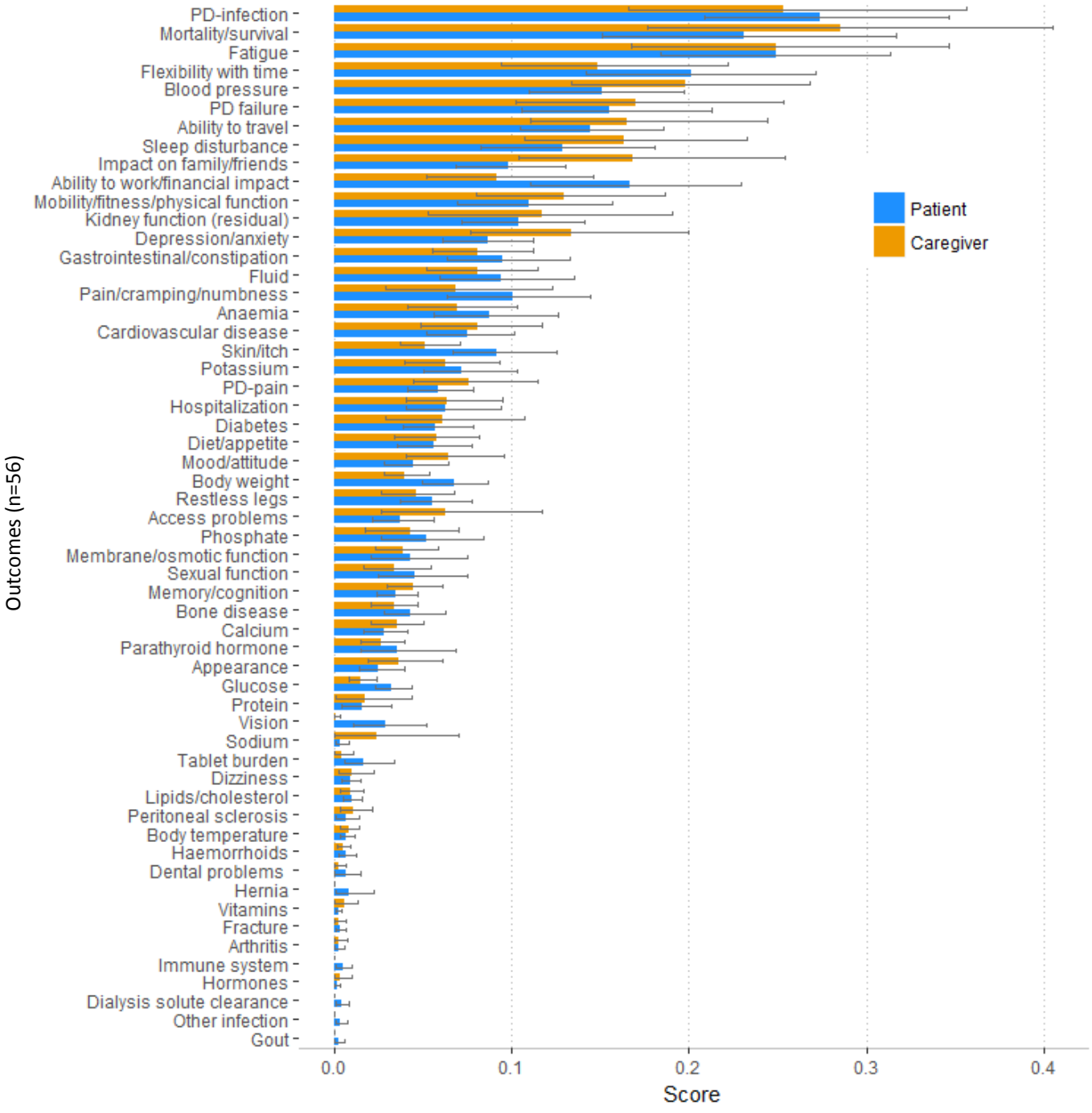
Supplemental Table 2: Location and number of participants in each nominal group

Group ID	City	Language of group	Patients (n=81)	Caregivers (n=45)	All, n=126 (%)
1	Sydney	English	6	3	9
2	Sydney	English	4	2	6
3	Sydney	English	5	4	9
4	Melbourne	English	5	3	8
5	Melbourne	English	4	2	6
6	Brisbane	English	4	6	10
7	Brisbane	English	5	3	8
8	Brisbane	English	7	1	8
9	Los Angeles	English	6	4	10
10	Los Angeles	English	4	4	8
11	Los Angeles	Spanish	8	4	12
12	Hong Kong	English	10	2	12
13	Hong Kong	English	7	2	9
14	Hong Kong	English	6	5	11

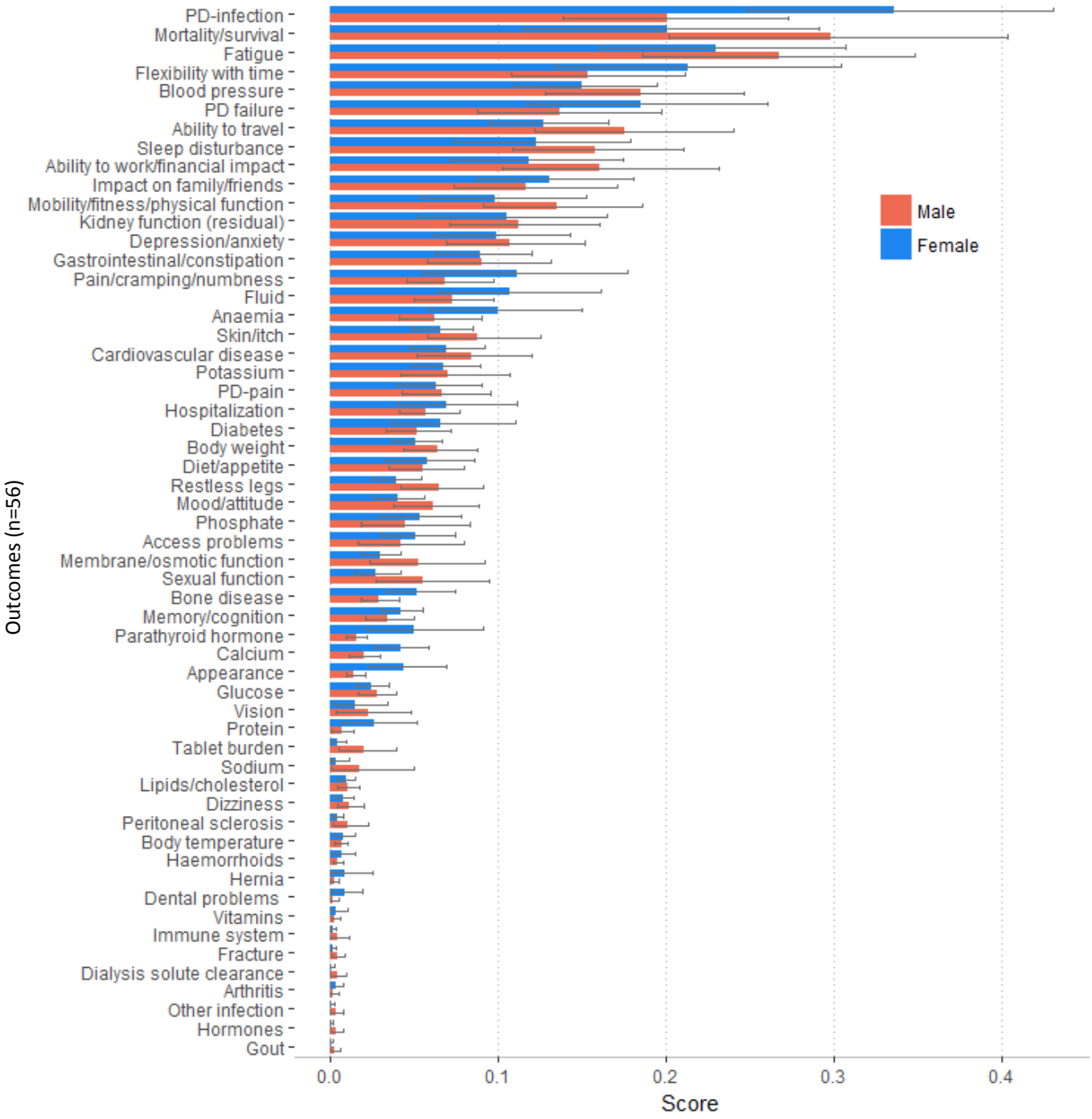
Supplemental Figure 1: Importance scores for outcomes by country – Australia, Hong Kong and the United States



Supplemental Figure 2: Importance scores for outcomes between patients and caregivers



Supplemental Figure 3: Importance scores for outcomes between male and female participants



Supplemental Figure 4: Importance scores for outcomes between participants over and under the age of 55 years