Patient perceptions of outcome measures in chronic inflammatory demyelinating polyneuropathy: a study of the I-RODS scale

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Key words: chronic inflammatory demyelinating polyneuropathy; outcome measures; patient perception.

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Data Availability Statement: Anonymised data available upon reasonable request.

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Abstract.

Background: Patients' perceptions of outcome measures used in chronic inflammatory demyelinating polyneuropathy (CIDP) are unknown.

Methods: We performed a cross-sectional evaluation of patient perceptions of the Inflammatory Rasch-built Overall Disability Scale (I-RODS) from 41 subjects with CIDP through a structured questionnaire. We assessed perceived hesitation to provide a response, item importance and relevance, understanding of specific items and factors affecting responses.

Results: Hesitation to provide a categorical answer was reported by 20% of subjects or more, for 5/24 (20.8%) items. Uncertainty was most frequent for "travel by public transport" (22.4%) and "catch an object (e.g. ball)" (24%). Six of 24 (25%) items were perceived as unimportant to their disease by at least a third of participants. Items most commonly perceived as unimportant were "travel by public transport" in 53.7%, "catch an object e.g. ball" in 61%, "dance" in 65.9%. Several items were frequently perceived as irrelevant. These included "move a chair" (39%), "do the dishes" (46.3%), "catch an object e.g. ball" (61%), "travel by public transport" (68.3%), and "stand for hours" (82.9%). The understanding of multiple items such as "read a book", "sit on a toilet" and "take a shower" was found highly variable. Fatigue was perceived more commonly than mood (53.7% vs.17.1%, p=0.001), and more commonly in younger subjects (p=0.037), as influencing responses to the I-RODS.

Discussion: Patient-perceived uncertainty, unimportance, irrelevance and poor understanding of items as well as fatigue and mood, impact on the value of the I-RODS. Greater emphasis on individualized disability assessments require consideration in future.

Introduction.

The use of objective outcome measures in chronic inflammatory demyelinating polyneuropathy (CIDP) is recommended by International Guidelines (1) and has become more widespread in recent years (2). Different outcome measures are in use and despite debate about their validity in different populations or disease subtype, they are generally currently widely accepted and used as the best available means of evaluating treatment effects and monitoring disability in subjects with CIDP (2).

Patient reported outcome measures (PROMs) represent a patient-centred approach to evaluating treatment outcomes (3, 4). However, PROMs may, due to their physician-driven generation methodology, potentially have similar disadvantages to traditional outcome measures. Although wide, early patient involvement is essential in the generation PROMs (5), the degree and timing of such participation is highly variable (6). Lack of resources and time may be a cause of overreliance of PROMs developers on existing disease guidelines, personal experience or practical considerations (7). Decision on items of a scale purely conceived by physicians and not involving patients' views, although subsequently validated on subjects having or having had the disease in question, may result in irrelevance and inappropriateness of components of the scale (8).

Few studies in other areas of medicine have considered post-hoc patients' perspectives on PROMs (9). The I-RODS (Inflammatory Rasch-Built Overall Disability Scale) has become in the last decade a frequently used scale for monitoring patients with CIDP (10). The items of this scale were not obtained from direct patient consultation and were validated on patients with CIDP and other dysimmune neuropathies including Guillain-Barre syndrome. This was done on a patient population exclusively from the Netherlands using the Dutch language version (10).

This study aimed to explore patients' perspectives of the English version of the I-RODS, in a cohort of English-speaking subjects with CIDP through a structured telephone questionnaire. The specific objectives of the current study were to evaluate patient perceptions for each of the 24 items on hesitation to provide a response, importance of items in relation to disease presentation and severity, relevance of items to the individual subject and precise understanding by patients of certain items of the English version wording. We also attempted to determine patients' views on the most important items to them as well as their perception of non-physical factors impacting on their scores.

Methods.

We reviewed electronic records of patients attending our Inflammatory Neuropathy Clinic, at University Hospitals Birmingham, U.K., with a diagnosis CIDP. We considered consecutive patients meeting 2010 European Federation of Neurological Societies/Peripheral Nerve Society (EFNS/PNS) Guidelines criteria for "definite" or "probable" CIDP (1), who had received immunomodulatory treatment and who had previously been evaluated by the

English language version of the I-RODS. The raw I-RODS score (best: 48/48, worst: 0/48) is determined routinely in our practice by physician-administered interview of the 24 items on that scale, rating inability (0/2), difficulty with (1/2), or normal ability (2/2), to perform each task.

We collected demographic data, age at onset, disease duration, and CIDP subtype from electronic patient records. Two investigators (DW and CE) practised implementing the questionnaire, to achieve neutral questioning and for consistency of technique, for each item of the I-RODS and for every other supplementary question asked.

Included patients were then called to complete the telephone questionnaire. The first section consisted of (i) scoring of each one of the 24 items on the scale, (ii) asking about any hesitation or uncertainty for the response provided (yes/no) and (iii) asking about the perceived importance of the item in relation to the patient (yes/no). Patients were then asked to list up to 6 of the most important items to monitor their disease. The second section of the questionnaire required answers to multiple choice questions evaluating the understanding of 5 items as asked in the English version of the I-RODS. These had been selected on the basis of difficulties expressed by patients with these items, in the clinical setting in our unit. This section also consisted of further questions relating to 8 other items of the scale, for which patients were asked, by providing a yes/no answer for each, whether the item was of relevance to them as individuals. The items evaluated in this component of the questionnaire had similarly been selected from the experience of comments from patients in clinical practice. Finally, patients were asked whether or not they felt their responses to the I-RODS items may be influenced by their (i) degree of fatigue on the day and (ii) current mood.

Frequency of responses to questions of the different sections of the questionnaire were determined and compared for the different items of the I-RODS, in the studied cohort. Comparison of proportions were performed by Fisher Exact Tests and comparison of means by independent T-tests. Correlations were performed with Pearson’s correlations. Statistical analyses were done using SPSS Version 24.0. The study was approved and registered by our relevant Institutional Review Board as a prospective Clinical Audit (CARMS no. 15601, 8th November 2019). Clinical Audit does not require Ethics Committee approval in the United Kingdom. All patients provided consent to participate in the project.

Results.

We identified 73 patients with “definite” or “probable” CIDP meeting our inclusion criteria. Of those, 21 could not be contacted by telephone, 2 could not participate due to cognitive difficulties, one could not complete the questionnaire due to linguistic issues, and 4 declined to participate. Four participants were excluded from the study analysis due to a large number (>25%) of missing responses.

We hence included 41 subjects (13 females, 28 males) in the final analysis. Mean age was 62.4 years (S.D.: 15.3). Mean age at disease onset was 55.1 years (S.D.:15.5). Mean disease duration was 7 years (range 0-24). Twenty-nine patients (70.7%) had typical CIDP, and the remainder had atypical variants (Lewis-Sumner syndrome in 9, pure motor in 1, pure sensory in 1 and distal form [DADS- “distal acquired demyelinating sensory and motor neuropathy”] in 1). Mean raw I-RODS score at time of questionnaire administration was 30/48 (S.D. 11.1).

Table 1. summarizes the results, for each of the 24 items of the I-RODS, relating to (i) frequency of perceived hesitation of response to provide (ii) frequency of perceived importance, and (iii) frequency of presence in individual patients’ perceived top 6 items of importance. More than one patient in 6 expressed hesitation to provide a response for 5/24 items (20.8%). In order of frequency, these were “walk outdoors for 1 km” (17.1% of subjects), “go to general practitioner” (19.5% of subjects), “bend and pick up an object” (19.5% of subjects), “travel by public transport” (22% of subjects) and “catch an object e.g. ball” (24.4% of subjects). Six of 24 (25%) items were felt unimportant by at least a third of

participants. These were: “do the dishes” in 34.1%, “stand for hours” in 41.5%, “run” in 46.3%, “travel by public transport” in 53.7%, “catch an object e.g. ball” in 61%, “dance” in 65.9%.

Table 2. shows correlations between patient-perceived hesitation and patient-perceived importance for the above-mentioned, worst-performing items for each of these 2 questions. The 2 items “go the general practitioner” and “catch an object e.g. ball” showed negative inter-correlations for responses about both these perceptions (p=0.002 and p=0.031, respectively), indicating association of perception of hesitation and that of unimportance in the cohort.

With regards to the choice of the perceived (up to a maximum of 6), most important items, 9/24 (37.5%) were selected by <10% of subjects. The 6 items that did poorest were “do the dishes” (7.3%), “catch an object e.g. ball” (7.3%), “travel by public transport” (7.3%), “move a chair” (4.9%), “dance” (4.9%) and “go to general practitioner” (0%). These 6 items were all less frequently selected than any of the 6 most popular items, which were “walk one flight of stairs” (40%; p=0.004), “wash upper body” (52.5%; p<0.001), “dress upper body” (50%; p<0.001), “wash lower body” (47.5%; p<0.001), “walk and avoid obstacles” (47.5%; p<0.001) and “walk outdoor <1 km” (50%; p<0.001).

Five of the 8 assessed items for patient-perceived individual relevance were not selected by more than a third of participants. These were “do the dishes” (39% of participants), “move a chair” (46.3%), “catch an object e.g. ball” (61%), “travel by public transport” (68.3%), and “stand for hours” (82.9%). On the other hand, the items “make a sandwich”, “dance” and “run” were not selected by only 4.9%, 26.8% and 22% of subjects respectively.

Findings of the evaluation of the understanding of the 5 specific items studied are shown in Table 3. Considerable heterogeneity was present for all items, particularly for the following 3. The item “read a book” was perceived as a question about visual deficit by 42.5% and about difficulty holding and turning pages by 47.5% of subjects. In 10% of subjects, this item was perceived as relating to understanding what was being read. Similarly, the item “sit on a toilet” was perceived as a question about being able to sit on the toilet by 36.8%, to rise from the toilet seat by 36.8% and to walk to the toilet by 26.3% of subjects. The item “take a shower” was perceived as evaluating ability to do so without help by 61.5%, the ability to use a shower without adaptations by 20.5% and the ability to use any shower including elsewhere from home (e.g. in a hotel on holiday), by 17.9% of subjects.

Finally, the level of fatigue on the day was felt to influence responses more frequently than current mood (by 53.7% vs. 17.1; p=0.001). Patients reporting an effect of fatigue were younger than those who did not (mean 57.2 years S.D.: 17.1 vs. 67.3 years S.D.: 11.5; p=0.037). A trend was observed for a longer disease duration in subjects reporting an effect of fatigue (8.7 years S.D.:7.3 vs. 5.1 years S.D.:4.2; p=0.06).

Discussion.

PROMs have the potential to bridge the gap between clinical practice and physician-based evaluation and patients' perspectives of their disease, its consequences and treatment effects (3, 4). Figure 1. illustrates the factors that may impact upon the value of the I-RODS as a PROM for CIDP. Clinicians may in practice, be reluctant to use PROMs routinely due to the added workload. However, there is evidence that systematic use of PROMs leads to better communication between doctors and patients and improves decision-making, patient satisfaction and care (3). Patients have been found enthusiastic about self-monitoring using PROMs (11) although conceptual issues may be present with certain items, requiring improvement (12). The quality of PROMs therefore matters considerably. It is important that PROMs remain truly patient-focused and their quality is dependent on patient-perceived importance, relevance, ease of understanding for providing responses and reproducibility from one assessment to another (13). The early involvement of patients in the development of PROMs is, as a result, highly desirable (11). Such patient involvement in the development of PROMs also clearly requires inclusion of subjects within the spectrum of disabilities caused by the disease and exclusion of subjects who have a different, albeit related, disease. Patient participation has in practice, however been frequently lacking in the development of PROMs. A recent literature review however identified only about 10% of 189 developed PROMS, as using patient input for item generation and less than 7% as involving patients in all aspects of their generation (14). The development of the Inflammatory Rasch Built Overall Disability Scale used currently for CIDP, utilized items from the ICF (International Classification of Functioning, Disability and Health) list, selecting those with probable relevance to polyneuropathy patients based on clinical characteristics (10). A diagnostically heterogeneous group of 852 patients (with CIDP, Guillain-Barre syndrome and gammopathy-related polyneuropathy), all members of the Dutch Society of Neuromuscular Disorders, and therefore culturally homogeneous, were then invited to answer the already pre-selected questions. Subsequent Rasch analyses were then conducted to elaborate the 24 item questions of the scale. Only 27.2% of patients had CIDP in the I-RODS derivation study whereas 59.2% had GBS, a monophasic disorder, with many differences to CIDP, no expected progression and no propensity to respond to delayed treatment. Considering the scale is today used for monitoring of the long-term deficits in CIDP, their treatment-induced changes and their fluctuations, the use of a predominantly GBS population for scale derivation may be problematic.

The aim of our study was to ascertain patients' perspectives on the I-RODS. First, we found that > 20% of items caused hesitation with regards to the best choice of answer, in more than 1 in 6 patients. This implies possible low reliability of these items and the final score achieved. van Nes et al. noted in their procedures in their original development of the I-RODS that patients were requested to answer “able to perform, but with difficulty” when special devices or other forms of assistance were needed (10). This is however frequently not explained or understood. Second, over a third of patients considered one item in 4 as being unimportant to their disease. This reached proportions of 50% for 3 items of the scale. Third, of the items considered most important, the least popular 6 were chosen only by 0-7.3% of participants, compared to the most popular 6, chosen by 40-50% of participants, a significant difference. Also, patient-perceived individual relevance was low for 5 of the 8 assessed items, particularly so for “catch an object e.g. ball”, “travel by public transport” and “stand for hours”, with half to over three-quarters of participants considering them as irrelevant. Of note, the irrelevance of both latter items may both be due to lower rates of use of public transport in our studied population, possibly due to geographical and socio-economic factors (15). In this regard, private car travel has been shown to be utilised more in rural and suburban areas than in metropolitan areas by frail subjects, in keeping with the findings in our cohort (16). Cultural variations may also explain results for this and other items, such as the perceived importance of ability to “make a sandwich” or “dance”, which may have been different in other populations. We found correlations suggesting association of perceived hesitation and perceived importance of 2 items, “go the general practitioner” and “catch an object e.g. ball”. This may suggests the poor added value of these 2 items in our cohort. However, it is also possible that other factors such as patients’ fear of answering or embarrassment to provide an answer may have affected these results, in representing potential confounding factors in the analysis of the association between perceived hesitation and perceived importance. Globally, these results may otherwise highlight the disparity between scale items in multiple aspects of patient perceptions and cast uncertainty on the value of the full 24-item scale as currently, and repeatedly, administered in clinical practice.

The examination of patients’ understanding of the 5 items studied demonstrated considerable variations. The findings for the item “read a book” highlight how often an incorrect score could be given, e.g. scoring 0/2 (not possible to perform) for a patient with poor eyesight yet having good upper limb strength (where the score should be 2/2). Similarly, the findings for “sit on a toilet” appeared in effect to instead assess mobility in over a quarter of our patients, while “take a shower” raised the issues of independence performing the task, use of adaptations, and ability to perform the task in all relevant circumstances. This issue may be partly related to the chosen wording, which is known to represent an issue with PROMs due to undocumented translation quality, despite frequent assumptions of validity and reliability (17). This may be of particular consequence when patients are asked to complete the evaluation independently, in clinic waiting areas or at home before attending, as is frequently the case. The impact of this issue may be different in different linguistic versions of the scale, although we believe it is likely this does not only concern the English-language form.

Fatigue was frequently considered by participants as influencing responses. This was more common in younger subjects, who may represent those for whom the I-RODS is best suited, as we found in a previous study (18). Although less commonly, mood was also felt to influence responses. We recently found in a cohort of subjects with CIDP that fatigue correlated with disability scores including the I-RODS, and was independently associated with depression (19). The impact of fatigue and mood on PROMs appears likely but needs to be considered carefully as may impact differently on different components of the scale. This was not further evaluated in the current study.

Our analysis is limited by its single-centre design and number of participants recruited. We did not analyse for associations with CIDP subtype as the numbers of patients were insufficient for meaningful conclusions. In view of the heterogeneity of CIDP, this will be an important question to study in future larger analyses. It is clear that different CIDP phenotypes impact significantly upon the importance and relevance of items of the I-RODS, and, as a result, on patients' perceptions of the questions asked. For example, our patients with Lewis-Sumner syndrome mostly had upper limb deficits, which resulted in the several items evaluating leg function being of little of no relevance to the disease, in contrast to those evaluating arm function and dexterity. As all patients responded to the same questionnaire and had to express their perception of each item, including those of no definite relevance to their CIDP subtype, this may have impacted upon our findings. We did not compare the I-RODS with another outcome measure for CIDP, such as the Overall Neuropathy Limitation Score (20) which may have proved of interest. Although patients are routinely assessed in our service with the ONLS, grip strength and Medical Research Council sum scores (MRCSS), these were not collected at time of the telephone questionnaire administration and were therefore not included in the analysis. The I-RODS itself may appear more suited to research rather than clinical practice and may hence not represent the ideal clinical monitoring tool, although is now extensively used for this purpose (21). Although devised to be patient-friendly and as short as possible, the administration of the telephone questionnaire may also have impacted on the findings. We pre-selected items, from clinical experience, for which further information on patient perceptions were sought. As this was not exhaustively performed for all items, so as to improve time and ease of questionnaire completion, we may have missed out on useful information on other items of the scale. Unfortunately, we also did not have socio-cultural and economic data which would have been of interest in the questions posed on the I-RODS. In this regard particularly, we believe, for example, that local transport methods and habits, food preferences and cultural factors impacted upon patient perceptions of the items “travel by public transport”, “make a sandwich” and “dance”, in the current study. This ultimately may have had consequences on our results and their interpretation, which may as a result, be specific to the U.K. or even, to our region of the U.K. Also, as in any survey, our results are limited by the subjectivity of responses obtained, itself dependent on multiple patient and environmental factors, during and around the time of questionnaire administration. Finally, we did not assess the potential impacts of repeat assessments using the scale, which may lead, in our clinical experience, to automatic responses due to reduced patient willingness to engage in the required thoughtful evaluation of each item. Recent findings about lack of impact of PROMs feedback to patients on their sense of empowerment and satisfaction are in keeping with our clinical experience (22).

In conclusion, we believe, despite the above-mentioned limitations, that our study brings insight into patients’ perceptions, views and considerations about the I-RODS, which is increasingly used in the monitoring of CIDP, although acknowledgedly not devised as a CIDP-specific scale, which is in itself, evidently problematic. The current COVID19 pandemic has resulted in extensive practice of telemedicine worldwide with increased use of remotely-administered PROMs (23). Hence, a re-appraisal of their value for clinical practice is timely and useful. Our findings indicate multiple issues of concern in the different areas assessed by the I-RODS. Whether these may reduce the value of the I-RODS as clinical evaluation tool for disability in CIDP is possible and requires further confirmatory multicentre studies in other populations. Validation for the English-language version as well as other versions would be appropriate, as has been performed rarely so far (24). Early-stage, enhanced, direct and relevant patient involvement, with a focus on age-, gender- and culture-specific individual variations of disabilities and their impact, as well as particular thought to precise item wording and/or translation, require consideration in the development of future scales. In the meantime, use of more patient-tailored monitoring methods may be appropriate for routine practice.

Table 1. Proportion of participants (i) perceiving hesitation about best response for item (ii) perceiving importance of item (iii) selecting item amongst their 6 important items.

ITEM	*Perceived Hesitation about best response*	*Perceived Importance of Item*	*Presence in top 6 items of importance*
Read a newspaper/book	**4/41**	**37/41**	**4/41**
Eat	**3/41**	**40/41**	**9/41**
Brush your teeth	**3/41**	**40/41**	**4/41**
Wash upper body	**4/41**	**40/41**	**21/41**
Sit on a toilet	**2/41**	**41/41**	**6/41**
Make sandwich	**4/41**	**36/41**	**8/41**
Dress upper body	**3/41**	**41/41**	**20/41**
Wash lower body	**4/41**	**41/41**	**19/41**
Move a chair	**6/41**	**36/41**	**2/41**

Turn a key in a lock	2/41	40/41	6/41
Go to general practitioner	8/41	37/41	0/41
Take a shower	5/41	38/41	11/41
Do the dishes	6/41	27/41	3/41
Do the shopping	3/41	35/41	7/41
Catch an object e.g. ball	10/41	16/41	3/41
Bend & pick up an object	8/41	37/41	6/41
Walk 1 flight of stairs	3/41	39/41	16/41
Travel by public transport	9/41	19/41	3/41
Walk and avoiding obstacles	2/41	39/41	19/41
Walk outdoors < 1 km	7/41	38/41	20/41
Carry & put down a heavy object	2/41	30/41	5/41
Dance	5/41	14/41	2/41
Standing for hours	3/41	24/41	8/41
Run	1/41	22/41	4/41

Table 2. Correlations between patient-perceived hesitation and patient-perceived importance of 8 pre-selected items of the I-RODS.

Item	Pearson’s Correlation	p value
“Go to general practitioner”	r = -0.46	*p =0.002*
“Catch an object e.g. ball”	r = -0.338	*p = 0.031*
“Bend and pick up an object”	r = -0.046	p = 0.78

“Travel by public transport”	**r = -0.223**	**p = 0.16**
“Walk outdoor < 1km”	**r = 0.121**	**p = 0.45**
“Dance”	**r = 0.046**	**p = 0.78**
“Stand for hours”	**r = -0.129**	**p = 0.42**
“Run”	**r = -0.17**	**p = 0.29**

Table 3. Patients’ Understanding of 5 pre-selected items of the I-RODS (multiple choice).

	Understanding of ‘ability to read’
Vision-related	17 (42.5)
Understanding	4 (10%)
Holding a book	19 (47.5%)
	Understanding of ‘ability to eat’
Ability to swallow	5 (12.5%)
Ability to chew food	8 (20%)
Ability to use cutlery	27 (67.5%)
	Understanding of ‘ability to sit on a toilet’
Get into a seated position on toilet	14 (36.8%)
Rise from a seated position on toilet	14 (36.8%)
Walk to the toilet	10 (26.4%)
	Understanding of ‘ability to go to your GP’
Being able to do so by yourself (drive, public transport, walk)	30 (76.9%)
Being at all able to do so even with assistance	5 (12.8%)
Getting an appointment/ contacting the surgery	3 (7.7%)
Parking or transport to your GP	1 (2.6%)
	Understanding of ‘being able to take a shower’
Being able to shower without help	24 (61.5%)
Being able to shower without adaptations	8 (20.5%)
Being able to do so in any shower including elsewhere from home (e.g in a hotel)	7 (18%)

Figure 1. Factors impacting upon the value of the I-RODS scale as a PROM for CIDP.

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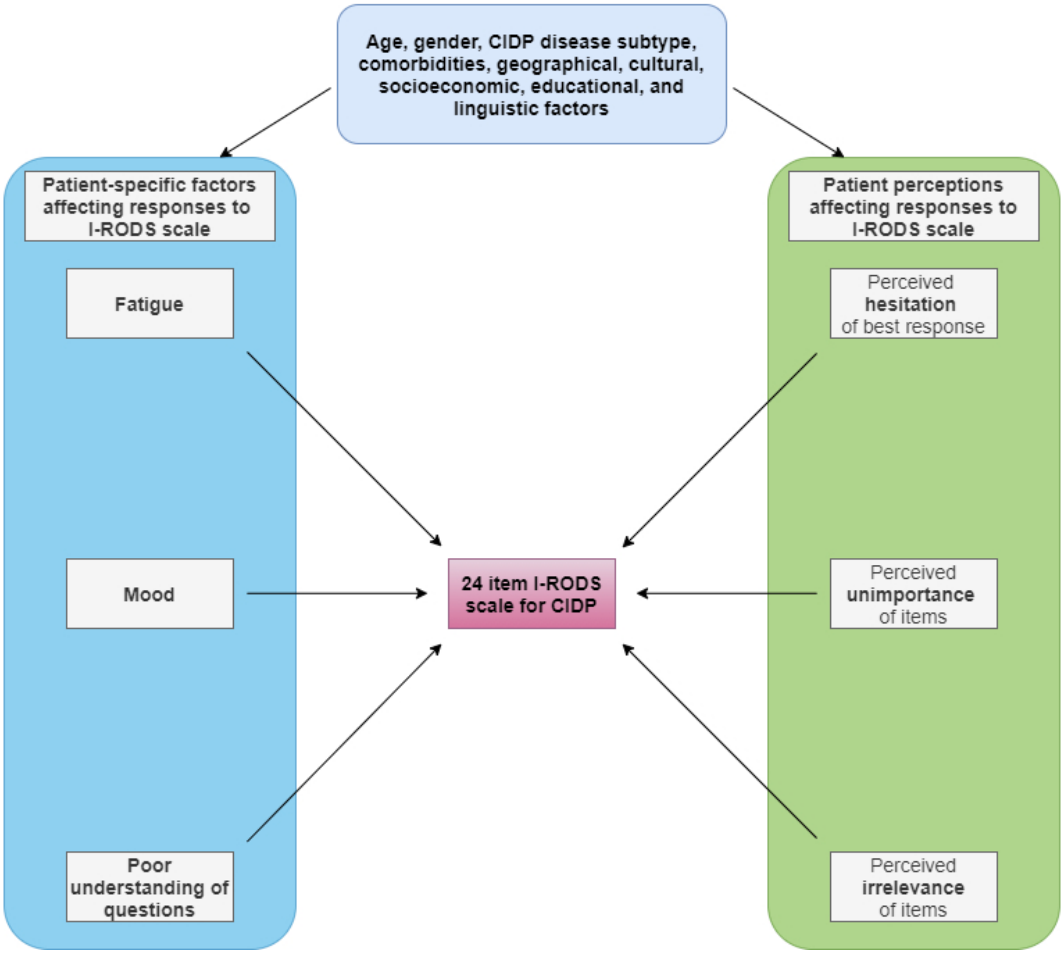
Figure 1.



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