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Variables associated with communicative participation in Parkinson's disease and its relationship to measures of health-related quality of life

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Abstract

Purpose: Communication disorders associated with Parkinson's disease (PD) often lead to restricted participation in life roles, yet there is a limited understanding of influencing factors and few quantitative measurement tools available. This study aimed to identify variables associated with communicative participation in PD, and to examine the relationship between the Communicative Participation Item Bank (CPIB) and existing health-related quality of life (HRQOL) measures.

Method: Self-report data from 378 participants with PD from the United States and New Zealand were analysed. Data included responses to the CPIB, PD Questionnaire-8, sub-scales of the Global Health instrument from the Patient Reported Outcomes Measurement Information System (PROMIS), and additional self-report instruments.

Result: Greater perceived speech disorder, lower levels of speech usage, fatigue, cognitive and emotional problems, and swallowing difficulties were associated with lower levels of communicative participation. Participants' age significantly influenced findings, interacting with country of residence, sex, and speech usage. Scores on the CPIB were moderately correlated with HRQOL measures.

Conclusion: Communicative participation in PD is complex and influenced by both demographic and disease-based variables, necessitating a broader view of the communicative experiences of those with PD. Measurement of communicative participation as a separate construct to existing HRQOL measures is recommended.

Search terms

Parkinson's disease; speech; communication; participation; quality of life

Introduction

Communicative participation refers to communication that takes place in the context of daily activities, such as that associated with work, leisure, social activities, household management, and community involvement. It is defined as "taking part in life situations where knowledge, information, ideas or feelings are exchanged" (Eadie et al., 2006, p. 309). The current study focuses on the communicative participation of individuals with Parkinson's disease (PD). Firstly, it investigates which demographic and self-report variables are most strongly associated with communicative participation in PD. Secondly, the study examines the relationship between a measure of communicative participation, the Communication Participation Item Bank (CPIB), and other health-related quality of life (HRQOL) measures commonly used with people with PD.

Speech disorder is common in those with PD. Approximately 50 – 89% of people with PD will develop speech motor disorder and reduced speech intelligibility as the disease progresses (Hartelius & Svensson, 1994; Johnson & Pring, 1990; Miller et al., 2007). However speech production, and degree of speech impairment, form only one component of the broader communication disorder experienced by people with PD (e.g. Donovan, Kendall, Young, & Rosenbek, 2008; Dykstra, Adams, & Jog, 2015; Miller, Noble, Jones, Allcock, & Burn, 2008; Miller, Noble, Jones, & Burn, 2006). Deficits in high-level complex language function (i.e. at sentence or discourse level) may be present, particularly reductions in information content and impairments to verbal fluency (Altmann & Troche, 2011). Furthermore, co-occurring cognitive decline, neuropsychiatric disturbance (e.g. depression, apathy, anxiety, hallucinations, and impulsivity), sleep difficulties, and sensory problems (Jankovic, 2008) are also likely to impact communication and HRQOL in the longer term. In combination, the communicative consequences and general symptoms of PD appear to have significant effects on the ability to maintain everyday life roles.

A number of qualitative studies have investigated the effects of PD on individuals' everyday communicative lives. Participants commonly describe feelings of communication frustration, loss of independence, and feelings of inadequacy associated with the disease process (Baylor, Burns, Eadie, Britton, & Yorkston, 2011; Donovan et al., 2008; Frost, Tripoliti, Hariz, Pring, & Limousin, 2010; Miller, 2012; Miller et al., 2008; Miller et al., 2006; Shih et al., 2012; Spielman et al., 2011). For example, qualitative interviews reported that individuals with dysarthria, seven of whom exhibited PD, described dysarthria as resulting in significant social and psychological effects that proved restrictive to participation in their life roles (Walshe & Miller, 2011). Furthermore Miller et al. (2006) in semi-structured interviews with 37 people with PD, noted that both speech and language (e.g. word retrieval, sentence formulation and comprehension) changes occurring in PD affected the individual and their family life; even before obvious speech impairment was present. These communication changes had direct effects on participants' abilities to socialise, resulting in apprehension regarding communication through to social withdrawal (Miller et al., 2006). Similarly, in a later analysis of perception of communication change in 104 people with PD, Miller et al. (2008) demonstrated that PD exhibited a negative influence on communication for nearly all participants. Levels of depression and disease severity were most strongly associated with poorer communication outcomes.

From the above studies it is clear that restricted communicative participation is a significant issue for those with PD. However Miller, Deane, Jones, Noble, and Gibb (2011), in their survey of 185 speech-language pathologists[1] in the United Kingdom, reported that while maximising participation in communication was a key goal of intervention, few speech-language pathologists undertook formal measurement of this construct as part of their suite of assessment or outcome measurement tools. Interestingly, some speech-language pathologists who participated in the survey included measures of HRQOL in their assessment battery, including the Medical Outcomes Study 36-item Short Form Health Survey (Ware & Sherbourne, 1992) (i.e. the SF-36) and the Parkinson's Disease Quality of Life (PDQ39) scale (Jenkinson, Fitzpatrick, Peto, Greenhall, & Hyman, 1997a). While these assessments contribute valuable information regarding an individual's overall perspective on health, they collapse data over a wide range of topics (e.g. physical symptoms, mobility, self-care, emotional coping, and resources for managing health). As a result, they may not be specific enough to capture meaningful changes in focused areas such as the impact of communication disorders on daily activities. Overall, the findings of Miller et al. (2011) highlight a considerable challenge for the profession. Increasingly, healthcare providers are encouraged to collect quantitative data from patients regarding the "real life" impact of health conditions—yet there are few valid and reliable tools available to measure this, particularly those dedicated to the communication aspects of participation in everyday life. However, a recently developed tool, the CPIB, addresses this lack of participation-focused measures in outcomes measurement.

The CPIB is a patient-report outcome measure that provides valid and reliable measurement of the effect of communication disorders on participation in the communication aspects of daily life activities (Baylor et al., 2013). The CPIB asks patients to rate how much their condition interferes with participation in a variety of everyday verbal communication situations such as talking to people you know, talking on the telephone to get information, ordering a meal in a restaurant, having a conversation in a small group, and a range of other situations. The CPIB was developed with Item Response Theory (IRT), and like many IRT instruments consists of a larger item bank from which smaller item subsets can be drawn for administration (Fries, Bruce, & Cella, 2005; Reeve et al., 2007). Currently a 10-item disorder-generic short form is available for clinical use for people with speech and language disorders, with additional short forms and computerised adaptive testing targeted for future development (Baylor et al., 2013). Importantly, the CPIB has been specifically calibrated for use with people with PD (see Baylor et al. (2013) for details of this process). While originally developed based on a cohort from the United States (US), a cross-cultural applicability study has also demonstrated its suitability for use with respondents from New Zealand (NZ) with PD (see Baylor et al., 2014, for full details).

Regarding the CPIB and people with PD, two things are not yet clear – firstly, which demographic and self-report variables are most strongly associated with CPIB scores; and secondly, how does the CPIB relate to existing HRQOL measures that cover a range of constructs. For speech-language pathologists and other healthcare providers to best identify

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[1] In keeping with the Journal convention, the term "speech-language pathologist" is used throughout.

individuals at risk for negative communicative participation outcomes and social isolation, a clear understanding of the variables associated with communicative participation in individuals with PD is needed. Communication intervention outcomes are optimised if treatment is delivered prior to symptoms becoming insurmountable, and/or maladaptive strategies developed (Miller, 2012). Hence, early identification is vital to ensuring accurate and time-efficient recognition of the effects of communication disorders upon those with PD.

Next, while it seems intuitive to advocate for the use of the CPIB as a validated and quantitative measure of communicative participation in those with PD, it is also likely that the CPIB shares commonalities with existing HRQOL measures. For example, the CPIB may be highly correlated with existing general measures of HRQOL and, if so, there is little need for clinicians to include more than one measure in their assessment battery. Alternatively, existing HRQOL measures cover a wide range of topics and are influenced by many variables not related to communication. Thus, they may not be specific enough to capture meaningful changes in communicative participation. In this case the inclusion of a dedicated measure of communicative participation in an assessment battery is important. Understanding the relationship between the CPIB and existing HRQOL tools will enable clinicians to select measurement tools sensitive to their client’s goals for communication-based intervention and to assist in efficient and effective decision-making.

As a result, this study aims to examine: (1) which commonly available demographic and self-report variables are most strongly associated with communicative participation in a group of individuals with PD; and (2) what is the relationship between communicative participation and HRQOL measures commonly used with individuals with PD. The hypothesis is that multiple variables beyond speech disorder severity will affect communicative participation in PD, highlighting the multifaceted nature of communicative participation. It is also hypothesised that a relationship will exist between CPIB scores and selected HRQOL measures, but that these measures will not be interchangeable.

Method

Study methods were approved by the Institutional Review Board at the University of Washington (US) and the Multi-region Ethics Committee of the Ministry of Health (NZ).

Participants

Data are reported from 378 participants with PD, diagnosed at least three months prior to participation—200 participants from the US and 178 from NZ. Participants were selected from a larger cohort of 428 individuals as reported in Baylor et al. (2014). Our earlier study used a differential item function (DIF) analysis to examine the cross-cultural applicability of the CPIB. In contrast, this secondary analysis presents previously unpublished patient-report data and examines its relationship to individual CPIB scores. Participants from the US were recruited from across the country with approximately 50% from western states, 24% from southern states, and the remaining from northeastern and midwestern states. Participants from NZ were recruited nationally and approximately 75% of respondents resided in urban areas. To be included in this study, participants were required to: (a) have completed all self-report questionnaires included in this report, (b) use speech as their primary mode of communication, and (c) report that PD had negatively affected their ability to communicate. There were no exclusionary criteria related to treatment history for either PD or speech symptoms. Participants who resided in nursing homes were excluded as the CPIB is yet to be validated on that population. Descriptive data regarding participants is presented in Table I.

Data Collection and Analysis

Data collection methods were identical across the US and NZ samples. All data were self-report measures. Participants completed all questionnaires either online or on paper, depending on their preference. Further details regarding data collection methods are available in prior papers (Baylor et al., 2014; Baylor et al., 2013). All survey instruments employed are described in further detail below. Participants' completed questionnaire data were either downloaded from our online collection portal to spreadsheets, or entered manually by trained research assistants at both sites. To ensure accuracy, manually entered data were double-coded and any differences corrected prior to data analysis. The survey instruments and statistical analyses related to each component are described below.

Communicative participation.—The CPIB is a unidimensional patient-reported outcome (PRO) instrument specific to communicative participation. For full details of development and testing of the CPIB the reader is directed to Baylor et al. (2013). The CPIB consists of a 46-item bank, but only subsets of that item bank are administered for assessment. Currently, one 10-item short form applicable across speech and language disorders is available. In brief, to complete the CPIB, participants are asked to rate how much their condition, in this case PD, interferes with their participation in a range of daily speaking situations. Sample questions include "Does your condition interfere with talking with people you know?" and "Does your condition interfere with asking questions in a conversation?" For each question there are four response choices: 'not at all,' 'a little,' 'quite a bit,' and 'very much', with scores typically reported in T-scores (mean = 50, SD = 10) (Baylor, Hula, et al., 2011; Baylor, Yorkston, Bamer, Britton, & Amtmann, 2010).

Question one: Predictors of communicative participation in Parkinson's disease—measures.—To examine the influence of demographic and other self-report symptoms on communicative participation, a suite of measurement tools were chosen as independent variables to represent the specific domains of severity of speech disorder, individual speech needs, hearing, cognition, physical activity, fatigue, pain, emotional problems, and swallowing. These included *(i) Self-rated communication disorder severity*: Using the Amyotrophic Lateral Sclerosis-Functional Rating Scale (ALS-FRS) (Cedarbaum et al., 1999), participants were asked to choose, from a list of five statements, one that best described their speech intelligibility. Responses ranged from 'normal' through to 'not understandable – I do not use speech for communication' (see Appendix A, item F, for details of the statements); *(ii) Individual speech usage/needs*: Participants were asked to select their level of everyday speech usage on a categorical scale from the options: 'undemanding', 'intermittent', 'routine', 'extensive', and 'extraordinary'. Full details of the scale, including rating descriptions, are reported in Baylor, Yorkston, Eadie, Miller, and

Amtmann (2008); *(iii) Hearing*: Participants were asked to respond to the yes/no question, “Do you currently have any problems with your hearing?”; *(iv) Cognition*: Eight items were selected with permission from the NeuroQOL item bank (visit www.neuroqol.org). The eight selected items examined how much difficulty a participant had with memory, reading, writing, and problem solving. Items were rated on a five point categorical scale with 1 = cannot do and 5 = none (in response to the question “how much difficulty do you have…”). Possible scores ranged from eight through to 40, with higher scores representative of better cognition[2]; *(v) Physical activity, fatigue, pain, and emotional problems*: Four individual items related to pain, fatigue, emotional problems, and the individual’s ability to carry out physical activities were extracted from the PROMIS Global Health questionnaire (Hays, Bjorner, Revicki, Spritzer, & Cella, 2009). See Appendix A, items H through K, for item wording and response options; and *(vi) Swallowing*: The swallowing-related question from the ALS-FRS (Cedarbaum et al., 1999) was selected with participants asked to choose, from a list of statements (see Appendix A, item M), which best described any problems they had with swallowing.

In addition to the above listed measurement tools, demographic information was also collected including: country of residence, number of years since diagnosis, sex, years of education, employment status, and living situation.

Question two: Relationship between CPIB & related PROs—measures.—The second aim was to examine the relationship between the CPIB and HRQOL measures commonly employed for people with PD. Two instruments were selected: the Parkinson’s Disease Questionnaire-8, or PDQ-8 (Jenkinson, Fitzpatrick, Peto, Greenhall, & Hyman, 1997b), and the Global Health instrument from the Patient Reported Outcomes Measurement Information System (PROMIS) for comparison. PROMIS is an initiative funded by the U.S. National Institutes of Health (NIH) to advance the science of patient reported outcome measures (www.nihpromis.org). The PROMIS Global Health instrument is divided into two subscales, a physical health subscale and a mental health subscale, both of which were compared to the CPIB scores in this study. As the PROMIS Global Health Instrument does not contain any items specifically related to communication, one further item was singled out for separate comparison to the CPIB. This item asks how well the individual feels s/he carries out usual social roles and activities such as at home, at work, in social activities, etc. This item was chosen based on the hypothesis that due to the pervasiveness of communication in most daily activities, this item might have the strongest association with the CPIB.

Statistical analysis

Backward stepwise linear regression was undertaken to address the first research question. This approach was deemed appropriate given the large number of predictor variables and possible interaction between these variables and the parameter of age. Preliminary analyses indicated that the NZ and US samples differed in average age; participants from NZ were

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[2] The NeuroQOL items were selected and used with permission for this study before the NeuroQOL instruments were finalised; hence the scoring format used for this custom item set is different than the now-published NeuroQOL forms and scoring.

significantly older than those from the US, $t(376) = -4.18$, $p < .001$. Given the known age differences between the two groups, and the possibility of age influencing other included variables, model testing began with all variables of interest entered into the model interacting with age. The following variables were included in the initial model: country of residence, number of years since diagnosis, sex, years of education, employment status, living situation, self-rated speech severity, speech usage, fatigue, pain, physical activity, emotional activities, cognition, swallowing, and history of hearing loss. Non-significant interactions followed by individual factors were pruned as warranted based on a p-value of .05, and those with coefficients significant a $p < .05$ retained in the final model. All statistical analysis was completed in R (R Core Team, 2015). To ensure that the model obtained through backwards selection was the best fit for the data, we also compared the fit of this model to other hypotheses-derived models using Akaike information criterion (AIC) model comparisons (Wagenmakers & Farrell, 2004).

For question two, Pearson product-moment correlation coefficients examined the strength of the relationship between the CPIB and the PDQ-8, CPIB and PROMIS physical subscale, and CPIB and PROMIS mental subscales respectively. A Spearman's rank correlation coefficient was used to determine the strength of relationship between the CPIB and PROMIS Social Roles data. The conventions of Cohen (1988) were used to guide interpretations regarding strength of the correlations. Regression analyses were conducted separately for each variable to calculate an adjusted R-squared value.

Result

For reference, Appendix A contains descriptive results of participants' scores on all measures included in the study sub-grouped into US and NZ cohorts. Items A through E detail results across the CPIB, PROMIS Global Health sub-scales, and PDQ-8. Items F through N pertain to individual self-report items.

Question One: Variables Associated with Communicative Participation

Backwards stepwise linear regression was undertaken to examine which demographic and self-report variables were most strongly associated with CPIB scores. As previously stated, model testing began with all variables of interest entered into the model interacting with age. Analysis proceeded, pruning non-significant factors as warranted based on a p-value of .05 until a final model was reached. To further validate our model selection, additional hypotheses-derived models were generated and compared, using Akaike information criterion (AIC) model comparisons to the final model (Wagenmakers & Farrell, 2004). This process confirmed that the backward stepwise regression derived model was the best fit for the data. Model diagnostics were run on the final model and no cases were excluded. The final regression model is presented in Table II. The final model accounted for approximately 43% of the variance in CPIB score ($F = 24.18$, $p < .001$, adjusted $R^2 = .425$).

The model indicated that country of residence was significantly associated with communicative participation. Participants from NZ exhibited significantly higher levels of communicative participation than their US counterparts, but this interacted with age. Younger participants with PD in NZ reported significantly higher levels of communicative participation than their US counterparts. This effect lessened with older age, with older participants from both countries tending to have reported similar communicative participation outcomes. Speech severity was also significantly associated with communicative participation; people who reported less severe speech symptoms had higher communicative participation scores. Similarly, those who reported higher levels of speech usage also exhibited increased CPIB scores. Interestingly, this also interacted with age. Older participants within the group who reported higher speech usage reported more favourable communicative participation. Higher levels of fatigue, the presence of cognitive and emotional issues, and swallowing difficulties all had significant negative associations with communicative participation. Furthermore, increasing age was associated with significantly enhanced communicative participation generally; however this interacted with sex—women did not exhibit the increases in communicative participation shown in men.

Question Two: Relationship Between the CPIB & Related PROs

Table III details the relationships between the CPIB and HRQOL measures. As can be seen, moderate significant relationships existed between the CPIB and PROMIS sub-scales, and between the CPIB and the single social roles question. However, a strong and significant relationship was evident between the CPIB and PDQ-8. Adjusted R-squared values indicated little shared variance between the CPIB and PROMIS Global Health subscales (< 20%), with approximately one-third of the variance shared between the CPIB and PDQ-8.

Discussion

This study investigated communicative participation, the effect of a communication disorder on participation in daily life activities, in 378 individuals with PD from NZ and the US. It examined which demographic and self-report variables were most strongly associated with communicative participation in people with PD, and how the CPIB, a validated measure that focuses specifically upon communicative participation, related to existing commonly used HRQOL measures.

As expected, the findings revealed that communicative participation was influenced by a complex set of variables. The presence of greater perceived speech impairment, lower levels of speech usage, cognitive symptoms, emotional issues, fatigue, and swallowing difficulty were all negatively associated with communicative participation. Standardised beta coefficients indicated that perceived level of speech impairment was the greatest contributor to communicative participation (though it should be noted that these coefficients were not considerably larger than a number of other contributors). Prior research has reported minimal or no relationship between objective measurements of speech intelligibility or vocal intensity and communicative effectiveness in those with PD (Donovan et al., 2008; Dykstra et al., 2015). Considered in relation to the current findings, it appears that an individual's *perception* of their speech production may have a greater influence on communicative participation than the results of objective measurement of the adequacy of speech.

The perceived presence of cognitive symptoms was also significantly associated with communicative participation outcomes. Individuals noting cognitive symptoms such as having difficulty remembering where things were placed (e.g. keys), difficulty reading and following complex instructions (e.g. for new medications), or problems planning for and keeping appointments[3] reported significantly lower levels of communicative participation. The current study did not include a self-report measure specifically directed at high level language function, however, the relationship between cognitive symptoms and high-level language problems in PD (Altmann & Troche, 2011) provides support for the consideration of language ability in assessment and treatment planning.

Demographic factors also influenced perceptions of communicative participation. When controlling for associated variables, older participants in the cohort reported significantly higher levels of communicative participation. This appeared to fit with epidemiological research reporting that increasing age may be associated with greater quality of life, when issues such as disease or disability are controlled for (Layte, Sexton, & Savva, 2013; Netuveli, Wiggins, Hildon, Montgomery, & Blane, 2006). However in the current study this effect was complicated by an interaction with sex—women did not experience the same age-related benefit of increased communicative participation experienced by men. It has previously been noted that with advancing age, women may exhibit reductions in HRQOL (Kirchengast & Haslinger, 2008), self-concept and psychological well-being (Pinquart & Sörensen, 2001) compared with men. The current study highlights the possibility that as they age, perception of communicative participation is also experienced differently for men and women with PD.

The effect of ageing upon communicative participation interacted with country of residence. Participants from NZ reported significantly higher levels of communicative participation. This effect was most salient in the younger age ranges of the study participants, with differences between the two groups lessening with increasing age. Currently we do not have a good explanation for this result. Both countries rank similarly on the Organisation for Economic Co-operation and Development (OECD) Better Life Scale Index, which compares well-being across countries (Organisation for Economic Co-operation and Development, 2015). Consequently differences in general levels of well-being across the two countries are unlikely to play a major role. Cultural bias of the tool itself can also be excluded as an influencing factor; our earlier work demonstrated an absence of CPIB response bias across participants from the US and NZ (Baylor et al., 2014). It appears feasible that general differences in culture and attitudes to disability may have influenced these findings. A further possibility is that the two countries' differing healthcare systems may play some part. NZ has a universal health care system, whereas the US does not; and total healthcare spending per capita in the US is approximately 2.35 times that of NZ (Squires & Anderson, 2015). Whether these across-country differences effect communicative participation in PD, and whether the results could be replicated, remains to be seen. Replicating this study, and extending to countries such as Canada or Australia (that have similarities in health care systems and culture) may further clarify any potential differences. Furthermore, examination of urban versus rural dwelling participants may be of interest.

Level of speech usage was also associated with communicative participation. Overall, higher levels of speech usage were associated with improved perception of communicative

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[3] All three examples relate to questions from the NeuroQol Item Bank (see www.neuroqol.org).

participation. That is, participants who communicated more reported higher levels of communicative participation, though this was also associated with ageing. Older people who communicated more tended to report improved communicative participation relative to those who did not. Social participation has been associated with greater quality of life in those aged 65 plus years (e.g. Layte et al., 2013) and the current finding supports the general concept that staying active plays a protective factor in ageing—the more an individual communicates, the more satisfied he/she may be with their involvement in life activities.

To our knowledge this is the first study to investigate demographic and self-report variables underpinning CPIB scores in people with PD, and the largest study to look at general predictors of communication participation outcomes in PD. Overall, the findings support the growing recognition of the complexity of influences on communicative participation (e.g. Baylor, Burns, et al., 2011; Baylor et al., 2010; Eadie et al., 2015; Yorkston, Baylor, & Amtmann, 2014) and specifically communicative participation of those with PD. This complexity should be considered in the light of current approaches to assessment and treatment of communication problems in people with PD. Current assessment and treatments aim primarily to improve intelligibility, speech production and voicing (e.g. Miller et al., 2011; Sapir, Ramig, & Fox, 2011), with the notion that these changes will enhance participation/quality of life. However, results from the current study and others (Donovan et al., 2008; Dykstra et al., 2015; Miller et al., 2008; Miller et al., 2006) highlight the importance of considering the multifaceted nature of communicative participation in assessment and treatment planning for clients with PD. Participation-driven approaches to assessment and intervention are used more commonly in aphasia and, perhaps, this approach should also be considered when working with clients with PD. These comments echo, to an extent, those of Miller (2012) who, in discussing PD, stated “assessments must cover activity, participation and impact aspects of functioning, not merely impairment dimensions. In parallel, interventions should also encompass these dimensions.” (p. 285).

The numerous influences on communicative participation identified in the current study also adds weight to the call for routine referral of people with PD to speech-pathology services early in the disease process (Miller, 2012). The results of this study suggest that speech-language pathologists, physicians, and referrers should look to people who report speech problems, limited speech usage, cognitive and emotional issues, fatigue, and swallowing issues as “at risk” for poorer communicative outcomes and hence, candidates for referral to speech-language pathology services. If referral occurs only once obvious speech difficulties have arisen, opportunities to enhance and maintain communicative participation may be being missed.

The second focus of this investigation was the relationship between the CPIB and other HRQOL measures used commonly with people with PD. The study revealed moderate relationships between the CPIB and the PROMIS Global Health physical sub-scale, PROMIS Global Health mental sub-scale, and the PROMIS social roles question from the Global Health questionnaire. This was not unexpected, given that the CPIB is a self-report psychosocial measure that focuses on the individual’s experiences in life situations. However, while significant moderate relationships existed, measures of shared variance demonstrated that the CPIB and PROMIS measures were not interchangeable. Indeed, each of the PROMIS measures accounted for less than 20% of the shared variance in CPIB scores. Thus while a relationship existed between an individual's perceived communicative participation and their HRQOL (as measured by the PROMIS), these measures did not overlap entirely. The broader focus of the PROMIS items, and lack of communication-orientated questions, would seem to be the likely reason for the limited shared variance between this measure and the CPIB. This interpretation appears reasonable given that a strong association was found between the PDQ-8 and CPIB. The PDQ-8 was developed for and focuses on individuals with PD. It also contains two items specific to communication and cognition. This appears to be a likely reason for the greater overlap between the CPIB and PDQ-8, as compared with the PROMIS measures. However, again these measures were not interchangeable, with approximately 33% of variance shared between the two measures.

Overall, it appears that HRQOL measures commonly used with individuals with PD do not provide a satisfactory substitute for an independent measure of communicative participation. HRQOL focuses specifically on the individual's perception of his or her physical and mental health (Centers for Disease Control and Prevention, 2000), but participation is more circumscribed construct, focusing specifically on an individual's involvement in and fulfilment of his or her specific required and discretionary life roles (World Health Organization, 2001). It is possible that a measure of quality of life related to communication such as the Quality of Communication Life Scale (Paul et al., 2004) may bear a stronger relationship to the CPIB. Alternatively, in those with PD, the Voice Handicap Index (Jacobson et al., 1997) may also share a considerable component of variance in scores. Follow up studies could investigate these relationships. However, in line with the current findings, it is suggested that for clients with PD, communicative participation be investigated as a separate construct clinically and in research.

Conclusion

This study has highlighted the complexity of issues affecting communicative participation in individuals with Parkinson's disease. While self-reported speech difficulty and cognitive symptoms were associated with communicative participation, other variables including country of residence, age, speech usage, fatigue, emotional issues, and the presence of co-occurring swallowing problems were also involved. This study has raised a number of issues and challenges as we move forward in understanding the complexity of communication difficulties faced by clients with Parkinson's disease in undertaking their everyday life activities. Research investigating cross-cultural differences and further exploration of the role of language and cognition appears warranted. The study also provided evidence that the Communication Participation Item Bank offers a different perspective than other measures of health-related quality of life, and that changes in communicative participation are not fully captured by existing health-related quality of life measures. Therefore, it is suggested that communicative participation should be measured separately, and routinely, in clients with Parkinson's disease.

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Appendix A.

Response categories and summary of participant results across the suite of measures employed.

Construct/Question	Response/Scoring	NZ (*n* = 178)	US (*n* = 200)
A. Communicative Participation (Baylor et al., 2013).	Mean (SD) Range	−0.008 (0.88) −2.48 to 2.61	−0.230 (0.91) −3.24 to 2.61
B. PROMIS Physical (Hays, Bjorner, Revicki, Spritzer, & Cella, 2009)	Mean (SD) Range	43.20 (6.54) 23.5 to 67.7	43.54 (7.27) 23.5 to 57.7
C. PROMIS Metal (Hays et al., 2009)	Mean (SD) Range	44.04 (6.55) 31.3 to 62.5	43.41 (7.87) 25.1 to 67.6
D. PROMIS Social Roles (Hays et al., 2009)	Poor	4 (2.2%)	8 (4.0%)
	Fair	57 (32.0%)	64 (32.0%)
	Good	78 (43.8%)	79 (39.5%)
	Very good	35 (19.7%)	40 (20.0%)
	Excellent	4 (2.2%)	9 (4.5%)
E. Health-related quality of life: PDQ-8 (Jenkinson, Fitzpatrick, Peto, Greenhall, & Hyman, 1997)	Mean (SD) Range	9.85 (4.82) 1 to 24	10.95 (5.68) 0 to 29
F. Self-rated speech severity (Cedarbaum et al., 1999)	Normal	20 (11.2%)	30 (15.0%)
	Sounds different but people understand me	40 (22.5%)	40 (20.0%)
	Sometimes have to repeat words to be understood	113 (63.5%)	126 (63.0%)
	Use gestures, writing or drawing	4 (2.2%)	4 (2.0%)
	Not understandable	1 (0.5%)	0 (0.0%)
G. Speech Usage (Baylor, Yorkston, Eadie, Miller, & Amtmann, 2008)	Undemanding	51 (28.7%)	59 (29.5%)
	Intermittent	73 (41.0%)	73 (36.5%)
	Routine	44 (24.7%)	56 (28.0%)
	Extensive	10 (5.6%)	10 (5.0%)
	Extraordinary	0 (0.0%)	2 (1.0%)
H. Fatigue (Hays et al., 2009) In the past 7 days, how would you rate your fatigue on average?	None	3 (1.7%)	4 (2.0%)
	Mild	42 (23.6%)	56 (28.0%)
	Moderate	112 (62.9%)	102 (51.0%)
	Severe	20 (11.2%)	34 (17.0%)
	Very severe	1 (0.6%)	4 (2.0%)
I. Pain (Hays et al., 2009) In the past 7 days, how would you rate your pain on average?(0–10 scale re-coded to 105 scale)	5 = No pain	25 (14.0%)	32 (16.05)
	4	92 (51.7%)	89 (44.5%)

Construct/Question	Response/Scoring	NZ (*n* = 178)	US (*n* = 200)
	3	43 (24.2%)	60 (3.0%)
	2	17 (9.6%)	19 (9.5%)
	1 = Worst pain imaginable	1 (0.6%)	0 (0.0%)
J. Physical Activities (Hays et al., 2009) To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?	Completely	33 (18.5%)	47 (23.5%)
	Mostly	66 (37.1%)	68 (34.0%)
	Moderately	52 (29.2%)	54 (27.0%)
	A little	25 (14.0%)	27 (13.5%)
	Not at all	2 (1.1%)	4 (2.0%)
K. Emotional Activities (Hays et al., 2009) In the past 7 days, how often have you been bothered by emotional problems such as feeling anxious, depressed, or irritable?	Never	22 (12.4%)	14 (7.0%)
	Rarely	45 (25.3%)	60 (30.0%)
	Sometimes	82 (46.1%)	70 (35.0%)
	Often	28 (15.7%)	50 (25.0%)
	Always	1 (0.6%)	6 (3.0%)
L. NeuroQOL[#] – 8 items selected asking how much difficulty with tasks related to memory, reading, writing, and problem solving[**]	Mean (SD) Range	30.62 (6.31) 11 to 40	28.84 (6.58) 12 to 40
M. Swallowing (Cedarbaum et al., 1999) Which statement best describes any problems you have with swallowing?	No problems	75 (42.1%)	90 (45.0%)
	Occasional problems – can eat most foods	100 (56.2%)	109 (54.5%)
	Limited to soft foods / liquids	2 (1.1%)	0 (0.0%)
	Eat some but also have tube feeding	1 (0.6%)	1
	No eating by mouth – all nutrition via tube feeding	0 (0.0%)	0 (0.5%)
N. History of hearing loss	Yes	81 (45.5%)	73 (36.5%)
	No	97 (54.5%)	127 (63.5%)

Note. NZ = New Zealand, US = United States. PROMIS = Patient Reported Outcomes Measurement Information System.

[**] The NeuroQOL items were chosen and used with permission prior to publication of the final NeuroQOL item banks. The specific items used are available from the authors.

[#] Possible range 8 – 40, with higher scores better.

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Table I.

Demographic details of the 378 participants with Parkinson's disease. For the variables sex, education, employment, living situation and ethnicity, data is presented as number of participants in that particular category, with proportion of participants in parentheses.

Descriptor	**Data**	**NZ Participants *n* = 178**	**US Participants *n* = 200**
Age (years)	Mean (SD)	69.47 (7.68)	65.69 (9.69)
	Range	47 to 89	43 to 89
Years since diagnosis	Mean (SD) Range	8.11 (5.95) 0 to 32	8.00 (6.32) 0 to 45
Sex	Male	131 (73.6%)	108 (54.0%)
	Female	47 (26.4%)	92 (46.0%)
Education	Did not compete high school	35 (19.7%)	0 (0.0%)
	High school graduate	34 (19.1%)	13 (6.5%)
	Vocational/technical/some college	50 (28.1%)	42 (21%)
	College or postgraduate	59 (33.1%)	145 (72.5%)
Employment	Currently in paid employment	33 (18.5%)	40 (20.0%)
Living situation	Alone	26 (14.6%)	16 (8.0%)
	Family	148 (83.1%)	179 (89.5%)
	Other	4 (2.2%)	5 (2.5 %)
Ethnicity	Caucasian or NZ European	171 (96.1%)	193 (96.5%)
	Hispanic	-	2 (1.0%)
	Black	-	1 (0.5%)
	Māori	1 (0.6%)	-
	Asian	5 (2.8%)	1 (0.5%)
	More than one	-	3 (1.5%)
	Other	1 (0.5%)	-

Note: NZ = New Zealand, US = United States.

Table II.

Final model detailing predictors of communicative participation in PD. Estimate (Est.) is a standardised beta coefficient.

	Est.	**Std. Err**	***t*-value**	***p*-value**
(Intercept)	−0.01	0.08	−0.15	0.883
Country: New Zealand	0.23	0.08	2.70	0.007
Age	0.22	0.07	3.29	0.001
Sex: Female	0.13	0.09	1.50	0.135
Speech severity #	0.28	0.04	6.58	< 0.001
Speech Usage	0.21	0.04	4.76	< 0.001
Fatigue	0.09	0.04	2.09	0.038
Cognitive symptoms	0.24	0.05	5.18	< 0.001
Emotional problems	0.15	0.05	3.18	0.002
Some/ocassional swallow problems	−0.20	0.08	−2.48	0.014
Age * Country: New Zealand	−0.24	0.09	−2.78	0.006
Age * Sex: Female	−0.19	0.08	−2.28	0.023
Age * SpUsage	0.09	0.04	2.22	0.027

Note: The dependent variable was Communicative Participation Item Bank (CPIB) score.

#For speech severity, low scores represent perceived speech difficulties and higher scores more normal sounding speech. Hence this coefficient should be interpreted that people with less severe speech disorder reported higher communicative participation.

Table III.

Relationship between the Communicative Participation Item Bank (CPIB) and common measures of health-related quality of life (HRQOL), as well as the shared variance between CPIB and each variable.

Variable	Correlation with CPIB	Adjusted R^2
PROMIS Physical	.337[*]	.111
PROMIS Mental	.414[*]	.169
PROMIS Social Roles	.413[*]	.169
PDQ-8[#]	−.573[*]	.327

Note: PROMIS = Patient Reported Outcomes Measurement Information System;

[*] = significant at $p < .001$;

[#] Higher scores on the Parkinson's Disease Questionnaire-8 (PDQ-8) indicate that Parkinson's disease has had a greater effect on overall health status whereas higher scores on the CPIB indicate better communicative participation outcomes. Therefore, a negative correlation is expected.