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ABSTRACTS

31st Annual Conference of the International Society for Quality of Life Research

Cutting Edge Research Plenary Session

(CERP1) Explainable AI predicting Alzheimer's Disease with Multimodal Deep Neural Networks

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Aims: Alzheimer's Disease (AD) is a neurodegenerative disorder characterized by progressive cognitive decline. Recent advances in deep learning offer promising avenues for improving the prediction of cognitive outcomes in AD. Latent factor analysis can capture the multidimensional nature of cognitive impairment free from measurement errors. We propose a novel latent multimodal deep learning framework to predict AD cognitive status using neuroimaging and clinical data. **Methods:** Five hundred and eighty-one (581) patients aged between 55 and 92 from the ADNI database (ADNI1 – ADNI10) were included in the study, among which 300 (52%) were males, 538 (93%) were white, 426 (73%) were married, and 405 (70%) had more than 16 years of education. Seventy-one (71) were diagnosed with AD, 383 patients had varying degrees of cognitive impairment, while the rest were cognitively normal. Confirmatory factor analysis (CFA) was applied to derive the latent scores based on various neural cognitive tests, as the outcome of our study. A multimodal deep neural network with two modalities, for image data and clinical data respectively, was constructed to predict the latent cognitive scores. Attention layers were added on top of the two modalities to improve prediction and interpretation. The data was split into a 0.80 training set and a 0.20 testing set. Mean absolute error (MAE) and mean squared error (MSE) were used to evaluate the model performance. An image-only model, a clinical data-only model, and a multimodal model without attention layers were also built for comparison purpose. **Results:** The CFI, TLI, and RMSEA of the CFA were 0.994, 0.989, and 0.071 respectively, demonstrating a good fit to the data. The multimodal neural network with attention layers achieved an MAE of 0.371 and an MSE of 0.248, outperforming other models. The latent cognitive score revealed a positive correlation of 0.732 with AD diagnostic status. **Conclusion:** Our results demonstrated the attention multimodal model's superior performance in predicting the latent cognitive status of AD, introducing attention layers into the model contributed to the prediction AD using neuroimaging and clinical data.

(CERP2) Launch of the Rare Disease Clinical Outcome Assessment Resource, a Tool to Aid in COA-derived Endpoint Selection

Lindsey Murray, PhD, Critical Path Institute, Tucson, Arizona, United States; Naomi Knoble, PhD, U.S. Food and Drug Administration, Silver Spring, Maryland, United States; Michelle Campbell, PhD, U.S. Food and Drug Administration, Silver Spring, Maryland, United States; Dawn Phillips, PhD, Regnexbio, Rockville, Maryland, United States; submitted on behalf of The Rare Disease Clinical Outcome Assessment Consortium

Aims: For most rare diseases, endpoints to measure clinical benefit of treatment have not been identified. Critical Path Institute's Rare Disease Clinical Outcome Assessment (COA) Consortium seeks to accelerate development of therapies to treat rare diseases via the creation and curation of a Rare Disease COA Resource (RD-COAR). The RD-COAR aims to simplify COA selection by providing information on published COAs that have the potential to be used to support efficacy endpoints in treatment trials for rare diseases. **Methods:** Based on input from FDA, biopharmaceutical representatives, and clinical researchers, a domain-level approach was selected to begin populating the RD-COAC. The first iteration focused on daily function assessment in pediatric, non-oncologic populations, divided into subdomains of self-care, gross motor function, fine motor function, and communication. A landscape analysis was conducted to identify potential COAs. This COA list was winnowed to identify measures to include in a detailed gap analysis that evaluated each COA against evidentiary expectations. A subcommittee including FDA, clinical researchers, and COA development experts was formed to evaluate results of each round of literature review. Two external advisory panels, consisting of an occupational therapist, physical therapist, caregiver representatives, and a speech and language pathologist reviewed the results of the gap analyses. A consensus process between the advisory panels and subcommittee determined final COAs for inclusion in the RD-COAR. **Results:** The RD-COAR was launched in September 2023. COAs included represent tools most commonly used in rare disease research, published in the literature, and available to examine against evidentiary criteria. In total, 34 gross-motor function, 16 fine-motor function, 15 self-care, and 23 communication/language COAs were included in the initial RD-COAR. A single COA could be categorized across multiple domains. Evidence from the gap analysis can be viewed at https://rdcoas.c-path.

experiences of partners, also related to type of PCa treatment. Overall, couples seem to be able to communicate openly about PCa with their nearest and more than half of the spouses continue their own leisure and social activities. Time between diagnosis and survey completion may have learned partners how to cope and adapt to the PCa of their partner.

Table: characteristics of respondents (N=1135) and questionnaire items

Median age of partner of PCa patient at time of questionnaire completion (median, IQR)	68 (62-73)
Median age of partner of PCa patient at time of PCa diagnosis (median, IQR)	61 (55-67)
Countries with >7.5% of responses	N (%)
France	97 (8.6%)
Germany	161 (14%)
Norway	212 (19%)
The Netherlands	224 (20%)
General health – SF12v2*	Median, IQR
Physical component summary (PCS) score	41 (37-45)
Mental component summary (MCS) score	51 (42-59)
Communication	
My partner and I can openly talk about his cancer	N (%)
Strongly agree	665 (59.6%)
Agree	324 (29.0%)
Neither agree nor disagree	80 (7.2%)
Disagree	38 (3.4%)
Strongly disagree	9 (0.8%)
Unknown	19
Our communication is worse since his PCa diagnosis	N (%)
Strongly agree	43 (3.9%)
Agree	99 (8.9%)
Neither agree nor disagree	161 (14.4%)
Disagree	351 (31.4%)
Strongly disagree	464 (41.5%)
Unknown	17
We talk (or can talk) about death	N (%)
Strongly agree	264 (24.0%)
Agree	388 (35.2%)
Neither agree nor disagree	234 (21.2%)
Disagree	140 (12.7%)
Strongly disagree	76 (6.9%)
Unknown	33
We have shared the diagnosis of PCa with our children	N (%)
Strongly agree + Agree	985 (91%)
We have shared the diagnosis of PCa with close family	N (%)
Strongly agree + Agree	996 (89%)
We have shared the diagnosis of PCa with friends and/or neighbours	N (%)
Strongly agree + Agree	879 (79%)
Relationship	
The PCa has an effect on our relationship	N(%)
Strongly agree	180 (16.2%)
Agree	332 (29.8%)
Neither agree nor disagree	214 (19.2%)
Disagree	213 (19.2%)
Strongly disagree	175 (15.7%)
Unknown	21
I am worried about our relationship	N (%)
Strongly agree	54 (4.9%)
Agree	108 (9.7%)
Neither agree nor disagree	156 (14.0%)
Disagree	381 (34.3%)
Strongly disagree	412 (37.1%)
Unknown	24
The PCa of my partner has brought us closer together	N (%)
Strongly agree	139 (12.6%)
Agree	334 (30.1%)
Neither agree nor disagree	450 (40.6%)
Disagree	142 (12.8%)
Strongly disagree	43 (3.9%)
Unknown	27
I feel lonely since my partner got the diagnosis of PCa	N (%)
Strongly agree	62 (5.6%)
Agree	153 (13.9%)
Neither agree nor disagree	239 (21.7%)
Disagree	356 (32.4%)
Strongly disagree	290 (26.4%)
Unknown	35
Social functioning	
I have reduced participation in my own leisure activities since the diagnosis of PCa of my partner	N (%)
Strongly agree	47 (4.2%)
Agree	160 (14.4%)
Neither agree nor disagree	164 (14.8%)
Disagree	410 (36.9%)
Strongly disagree	329 (29.6%)
Unknown	25
I have reduced participation in my social activities since the diagnosis of PCa of my partner	N (%)
Strongly agree	49 (4.4%)
Agree	157 (14.2%)
Neither agree nor disagree	170 (15.3%)
Disagree	410 (37.0%)
Strongly disagree	322 (29.1%)
Unknown	27

*SF12v2 – general population score is 50 for both the PCS and the MCS.

(1043) Analyzing Citation Patterns of New Investigators Special Interest Group Members

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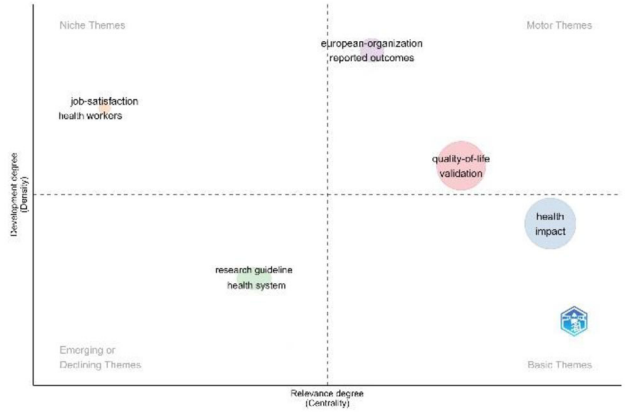
Aims: New investigators, including graduate students, recent doctoral graduates and early-career faculty (within 5 years of their terminal degree) play a pivotal role in advancing Quality of Life QoL) within the International Society of Quality of Life Research (ISOQOL). In this study, we analyzed the citation patterns of research outputs from ISOQOL New Investigators Special Interest Group (NI SIG) members to identify research trajectories and emerging areas of interest, fostering collaboration among the next generation of QoL researchers. **Methods:** We focused on NI SIG members, excluding 16 who did not meet the eligibility criteria. Among the remaining 61 members, we examined published documents (including peer-reviewed articles, books, editorials, and meeting abstracts) authored or co-authored by NI SIG members. Our search spanned the Web of Science databases from 2019 to 2023. We conducted bibliometric descriptive analysis to explore publication trends and citations. Additionally, we performed thematic analysis of extracted documents using the Bibliometrix package in R. **Results:** Our analysis encompassed 784 documents, revealing an average of 11 co-authors and 34.7% international collaborations per document. Document publication peaked in 2022 (211) but declined in 2023 (183), with a corresponding drop in average citations per article from 5.24 to 1.03. Most documents were published in the Quality of Life Research (144), BMJ Open (23), and Journal of Patient-Reported Outcomes (14) with many clinical-focused journals being cited only once (243). Thematic mapping highlighted established themes such as QoL research or instrument validation, health or impact of intervention, and the use of the European Organization for Research and Treatment of Cancer (EORTC) questionnaire. Emerging research areas included job satisfaction, health workers, and research guidelines (see Fig. 1). The corresponding authors of published documents were primarily from high-income countries including the United States, Canada and the United Kingdom. **Conclusion:** This study underscores the robust international collaborations among NI SIG members, yet highlights avenues for increased engagement, particularly among low and middle-income countries. It also elucidates the entrenched themes such as evaluating the impact of health and instrument validation in QoL research while unveiling niche or emerging areas for further exploration and collaboration.



(1044) Postoperative quality of life in thoracic surgery patients using electronic patient-reports outcomes

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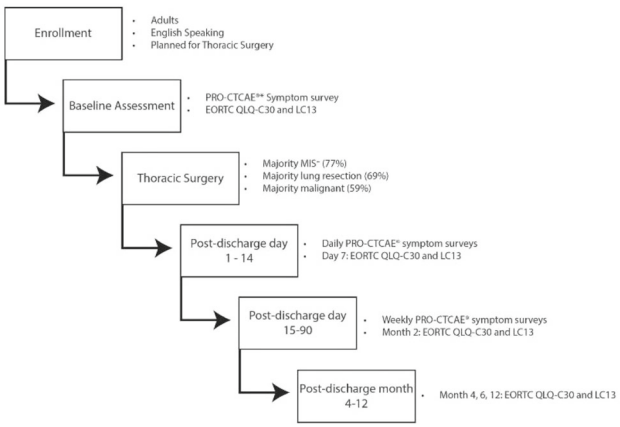
Aims: Prior studies have shown quality of life (QOL) after lung resection is persistently reduced for up to 1 year, even after minimally invasive surgery. We examined whether post-discharge remote electronic patient-reported outcome (ePRO) symptom measurement with and without alerts to providers impacts QOL after thoracic surgery. **Methods:** From 2020–2022, we enrolled patients planned for thoracic surgery to a randomized controlled trial on measuring symptoms remotely using ePROs (NCT04342260). All participants received web-based ePRO surveys on symptoms (e.g. pain) using the PRO-CTCAE® and physical functioning (PROMIS® SF4a) after discharge (daily surveys day 0–14 then weekly day 15–90) (Fig. 1). Providers received alerts for severe/worsening symptoms in the alerting arm. Change from baseline at each time point was compared between arms. Minimally important difference (MID) was set at 10 points. The study was powered to detect a difference in global health status between arms. **Results:** Of 113 participants randomized, 99 began post-discharge ePROs measurement. The arms were similar in demographics (Table 1). Alerts were trigged in 88% of participants in the alerting arm. Clinical action (e.g. prescribing meds) was made in response to 64% of alerts. Global health status (-11.9, sd = 19.2), physical function (-11.8, sd = 14.5), social function (-12.4, sd = 18.7), and fatigue (13.7, sd = 21.8) from the QLQ-C30; and pain in chest (23.7, sd = 32.4) from the LC13 showed statistically significant worsening at Day 7 and returned to baseline by month 2 in the alerting group. Physical function (-12.3, sd = 20.9), role function (-23.2, sd = 35.5), social function (-22, sd = 32.1), and pain (19, sd = 33.2) from the QLQ-C30 showed statistically significant worsening at Day 7 in the measurement only group with return to baseline by month 2 (Fig. 2). No differences in QOL between arms were observed. **Conclusion:** While alerting providers about concerning ePROs had no influence on QOL, thoracic surgery patients engaged in ePRO measurement had shorter durations of deterioration in QOL than described in previous studies; suggesting measurement of PROs postoperatively enhances outcomes. Future studies should aim to elucidate the mediators of the influence of ePROs on QOL after surgery.

Figure 1: Study Schema



*PRO-CTCAE = Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events
^MIS = Minimally Invasive Surgery

Table 1: Demographics

Characteristics	Alerting (N = 50)	Measurement only (N = 49)	Total (N = 99)	P value
Female gender, n (%)	29 (58.0%)	32 (66.7%)	61 (62.2%)	0.63
Age, mean (SD)	56.9 (14.2)	62.5 (13.3)	59.6 (14.0)	0.16
Race, n (%)				0.94
Black	11 (22.9%)	8 (17.0%)	19 (20.0%)	
White	32 (66.7%)	35 (74.5%)	67 (70.5%)	
Other	5 (10.4%)	4 (8.5%)	9 (9.5%)	
Hispanic, n (%)	2 (4.3%)	0 (0.0%)	2 (2.1%)	0.70
Current or previous smoker, n (%)	29 (58.0%)	34 (69.4%)	63 (63.6%)	0.52
BMI, mean (sd)	30.1 (7.3)	28.8 (6.7)	29.5 (7.0)	0.61
FEV1, mean (sd)	88.4 (20.4)	79.4 (23.8)	83.8 (22.5)	0.19
Married/Partnered, n (%)	23 (59.0%)	30 (71.4%)	53 (65.4%)	0.49
Education, n (%)				0.45
College or more	17 (44.7%)	13 (32.5%)	30 (38.5%)	
Some college or associate degree	11 (28.9%)	14 (35.0%)	25 (32.1%)	
High school or GED	6 (15.8%)	12 (30.0%)	18 (23.1%)	
Employed, n (%)	15 (37.5%)	9 (22.5%)	24 (30.0%)	0.45
Technology use				
Never use email	1 (2.6%)	2 (5.0%)	3 (3.8%)	1.00
Never use computer	0 (0.0%)	3 (7.5%)	3 (3.8%)	0.46
Never use internet	0 (0.0%)	2 (5.0%)	2 (2.6%)	0.70
Diagnosis				
Lung cancer	13 (26.5%)	24 (49.0%)	37 (37.8%)	0.14
Other malignancy (e.g metastatic lung nodule, mediastinal tumor)	10 (20.0%)	11 (22.4%)	21 (21.2%)	0.92
Procedure type				0.94
Biopsy	7 (14.0%)	4 (8.2%)	11 (11.1%)	
Chest wall repair	3 (6.0%)	3 (6.1%)	6 (6.1%)	
Diaphragm repair	4 (8.0%)	2 (4.1%)	6 (6.1%)	
Lung resection	33 (66.0%)	35 (71.4%)	68 (68.7%)	
Thymectomy	2 (4.0%)	3 (6.1%)	5 (5.1%)	
Other	1 (2.0%)	2 (4.1%)	3 (3.0%)	
Minimally invasive surgery	40 (83.3%)	35 (71.4%)	75 (77.3%)	0.58