PCR105

The Impact of Caring for Juvenile Idiopathic Arthritis on Caregivers' Quality of Life

Fuhrmann AC[1], Marshall DA[1], Dal Ben R[1], Currie GR[1], Yeung RSM[2], Vastert S[3], Wulffraat N[3], Swart J[3], Benseler SM[1], On behalf of the UCAN CAN-DU and UCAN CURE Consortia

[1]University of Calgary, Calgary, Canada [2]University of Toronto, Toronto, Canada [3]University of Medical Center Utrecht, Utrecht, Netherlands

UNIVERSITY OF CALGARY

INTRODUCTION

- Juvenile Idiopathic Arthritis (JIA) affects patients and their families, increasing caregivers' burden and decreasing quality of life, as explored by qualitative studies.
- However, quantitative research using standardized measures and utility scores is limited.

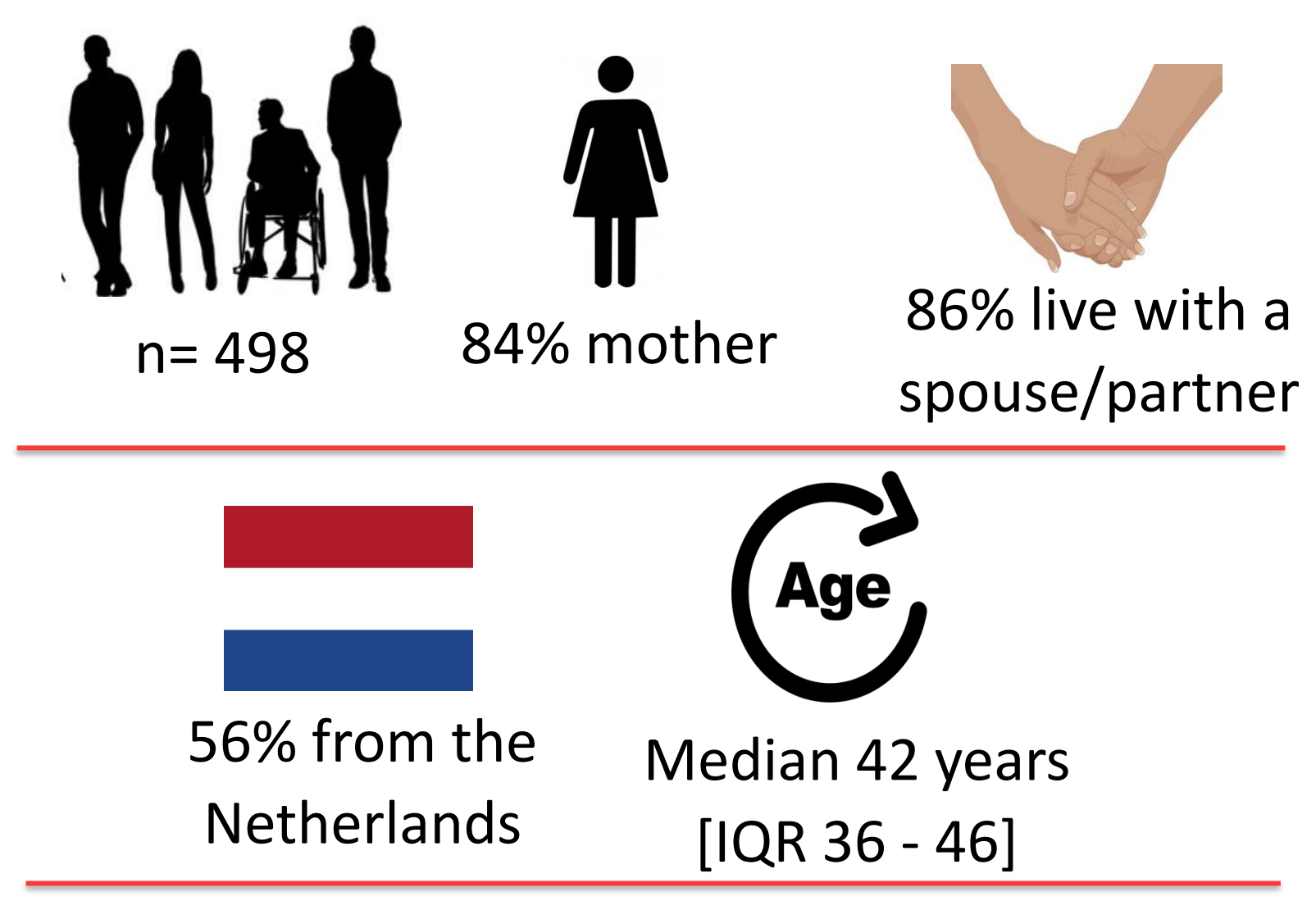
OBJECTIVE

To assess the relationship of care-related quality of life of caregivers of children with JIA with demographic and clinical factors.

METHODS

- **Study**: The Canada-Netherlands Personalized Medicine Network in Childhood Arthritis and Rheumatic Diseases (UCAN CAN-DU) & Precision Decisions for Childhood Arthritis (CURE), carried out in all pediatric rheumatology clinics in Canada and the Netherlands, including all subtypes of JIA, and patients across the disease trajectory from new diagnosis to starting or stopping biologics.
- **Sample**: All patients with a completed CarerQol-7D measured at baseline.
- **Data**: Demographic and clinical information, and the standardized and validated CarerQol-7D instrument, collected between July/2019 and September/2024.
- **Instrument:** CarerQol-7D contains seven dimensions with a utility score from 0 (worst caregiving situation) to 100 (best caregiving situation) and a well-being visual analog scale (VAS) score from 0 (completely unhappy) to 10 (completely happy).
- **Data analysis**: Linear regression models explored associations between CarerQol-7D utility and VAS scores with demographic and clinical factors using a stepwise process, and the final model was selected via Akaike Information Criterion for model fit.

RESULTS



n= 498

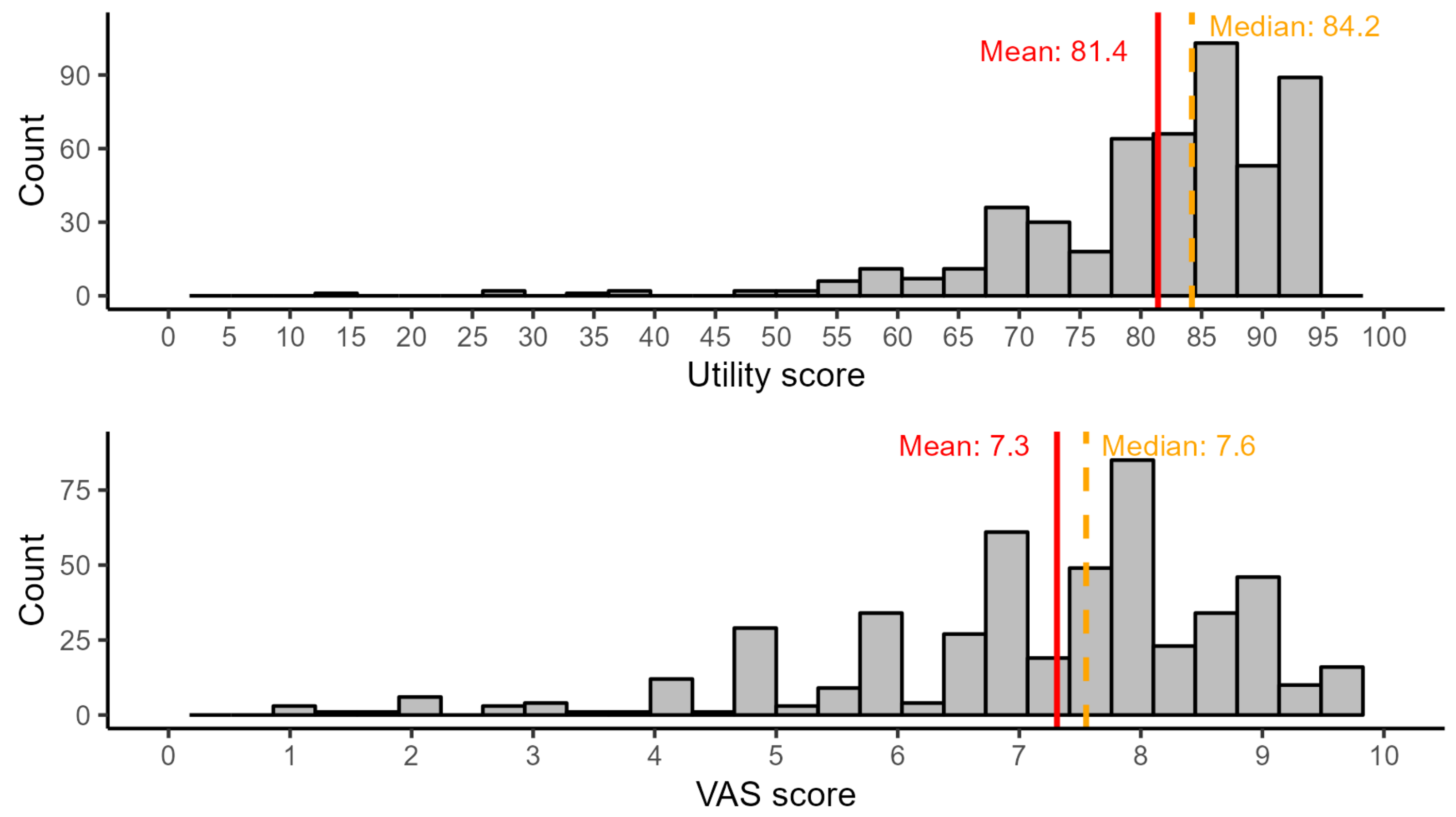
84% mother

86% live with a spouse/partner

56% from the Netherlands

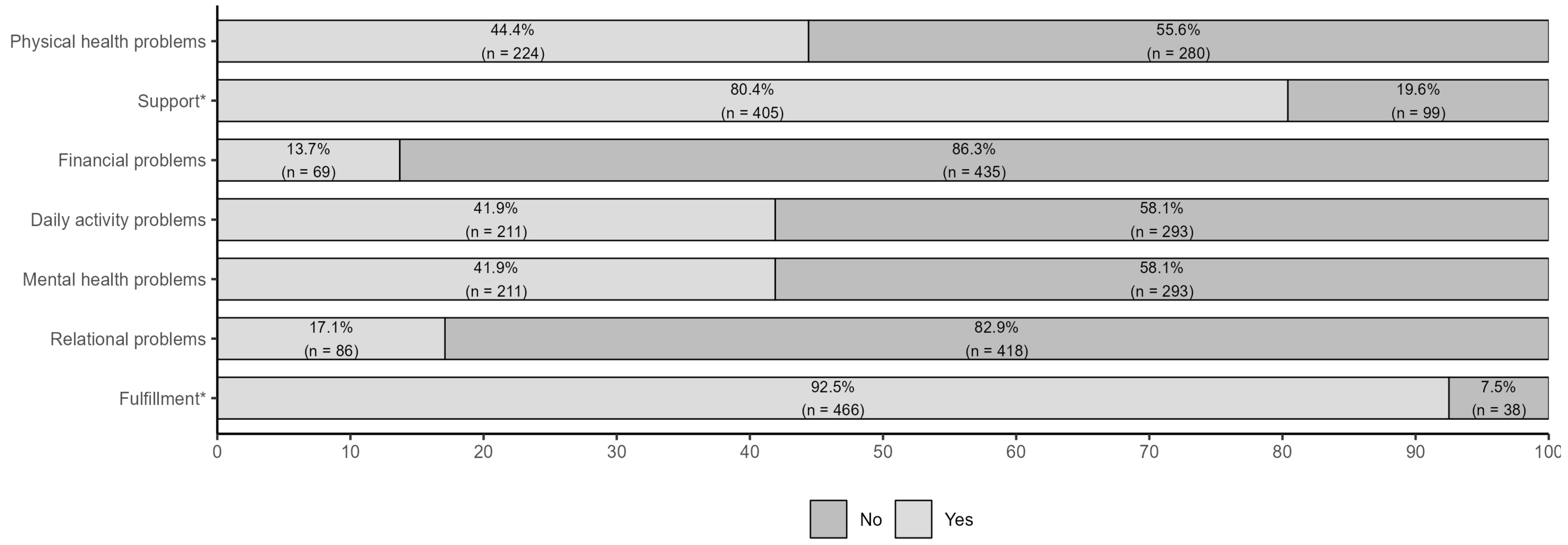
Median 42 years [IQR 36 - 46]

Figure 1 - CarerQol-7D utility and VAS scores at baseline



Utility score ranges from 0 (the worst caregiving status) to 100 (the best caregiving status).
VAS ranges from 0 (completely unhappy) to 10 (completely happy).

Figure 2 - Distribution of caregivers response by CarerQol-7D dimensions



n are the number of participants for each response category. Percentages (%) indicate the proportion of participants selecting each response.
*Positive dimensions.

Table 1 - Regular regression models for CarerQol-7D utility and VAS scores (n= 446)

Predictors	*Estimates*	*CI*	*p*
	Utility scores		
(Intercept)	84.35	81.26 – 87.43	**<0.001**
Children's biological sex [male]	-1.98	-3.90 – -0.05	**0.045**
Mental health condition caregiver	-9.35	-11.97 – -6.73	**<0.001**
Caregiver received extra help	-3.88	-6.05 – -1.71	**<0.001**
R^2 / R^2 adjusted	0.189 / 0.176		
	VAS scores		
(Intercept)	9.56	8.25 – 10.88	**<0.001**
Country [Netherlands]	-1.07	-1.73 – -0.41	**0.002**
Children age group [10-15]	0.50	0.08 – 0.92	**0.019**
Children age group [16-18]	0.71	0.17 – 1.24	**0.010**
Children with other comorbidities	-0.42	-0.74 – -0.10	**0.010**
Children with musculoskeletal signs and symptoms	-0.30	-0.56 – -0.04	**0.023**
Caregiver gender [male]	0.39	0.01 – 0.76	**0.043**
Physical health condition caregiver	-0.27	-0.53 – -0.02	**0.035**
Mental health condition caregiver	-1.22	-1.59 – -0.85	**<0.001**
Mental health condition spouse/partner	-1.00	-1.48 – -0.51	**<0.001**
Caregiver received extra help	-0.36	-0.67 – -0.05	**0.023**
R^2 / R^2 adjusted	0.249 / 0.224		

CONCLUSION

- UCAN CAN-DU & CURE is the **first study** to use the CarerQol-7D to explore the care-related quality of life in JIA.
- **Novel insights** from a large (n= 498), multicenter cohort (n= 18), across all JIA subtypes, various treatment regimes, and age groups.
- Despite high average scores, the distribution reveals a considerable portion of caregivers face substantial **burdens**.
- Although most caregivers reported fulfillment and support, many struggle with **physical and mental health** and **unmet assistance needs**.
- Targeted interventions, particularly in mental and physical health, and daily support, are needed to mitigate caregivers' burden and enhance their quality of life.

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This work was supported by the Canadian Institutes for Health Research (Canada) [grant number 381280]; Genome Canada (Canada) [grant number OGI-150]; Genome Alberta (Canada), Ontario Genomics (Canada); The Arthritis Society (Canada) [grant number GC-18-001]; the Hospital for Sick Children (Canada); the University of Calgary (Canada); ZonMw [(848006001)](the Netherlands); and ReumaNederland (the Netherlands); One Child Every Child.

Contact Information: ana.fuhrmann@ucalgary.ca
https://cumming.ucalgary.ca/research/health-economic/home