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Quality of life for carers and spouses of those with familial intellectual disability

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Quality of life and IDMOD

1. Familial ID and QoL
2. Primary data collection
3. QoL in carers and spouses
4. Next steps

Familial Intellectual Disability (ID)

- Intellectual disability (ID) is estimated to effect approximately 1% of the world
- ID has significant impacts on the individuals, with lower life expectancy and many other comorbidities
- Familial ID is where ID affects more than one person in the immediate family
- Advances in genetic testing and genomic sequencing has increased the diagnostic rate of ID to approximately 60% (de Ligt J, et al 2012, Rauch et al 2012)
- However, with limited data on the impacts of the disease on individuals and their families, decision makers require these data for funding decisions and to direct resources to where services can be best targeted
- Previous studies have found lower QoL in those caring for ID, however they did not use a validated instrument with health utilities, limiting their use in cost-effectiveness analysis
- In this presentation I will discuss how we will use QoL data with a microsimulation model, as well as some results from our analysis on factors associated with QoL in those caring for people with ID

Primary data collection

- Participants recruited as part of the Australian Economic and Psychosocial Impacts of Caring for Families Affected by Intellectual Disability (EPIC-ID) (Schofield et al 2020)
- Tailored questionnaire to carers of those with ID and their spouses
- Participants recruited through the Genetics of Learning Disability (GoLD) clinics in New South Wales, Australia
- Presently, 111 carers have been interviewed, who are caring for 174 with ID in total
- Quality of life analysis forms part of the larger IDMOD model, a microsimulation model of the costs and impacts of familial ID

QoL data

- For carers and spouses, we assess QoL through the AQoL-8D, a validated instrument for QoL with associated health utility values
- The AQoL-8D has 8 domains; independent living, senses, pain, mental health, happiness, self-worth, coping and relationships

Primary data collection

Socio-demographic data

- EPIC-ID collects substantial data on carers, spouses and family members they are caring for with ID
- For carers, this includes socio-demographic variables such as age, gender, location, education, employment status, health conditions and caring responsibilities
- Spouses complete their own AQoL-8D
- For those with ID, their surveys are completed by their carers
- Data on those with ID include age, gender, severity of ID, relationship to carer, QoL and living situation

Estimating QoL in carers and spouses

- For all carers and spouses, AQoL-8D utility values were estimated using the associated algorithm with the instrument
- 1 sided t-tests were performed against population norms
- For individuals with ID, utility values were estimated via the proxy responses from their carers. These were using the Health Utilities Index 2 and 3

Multivariate analysis

- Literature review on potential control variables
- Variables for analysis included severity of ID, mental health of carer, physical health, financial stress and number of people caring for
- The model is estimated with AQoL-8D utility value of the carer as the dependent variable
- To consider the impacts of caring for more than one person, counts of variables of those cared for are used, e.g. number living at home, number with severe ID etc.

Descriptive statistics - carer

A SELECTION OF SUMMARY STATISTICS

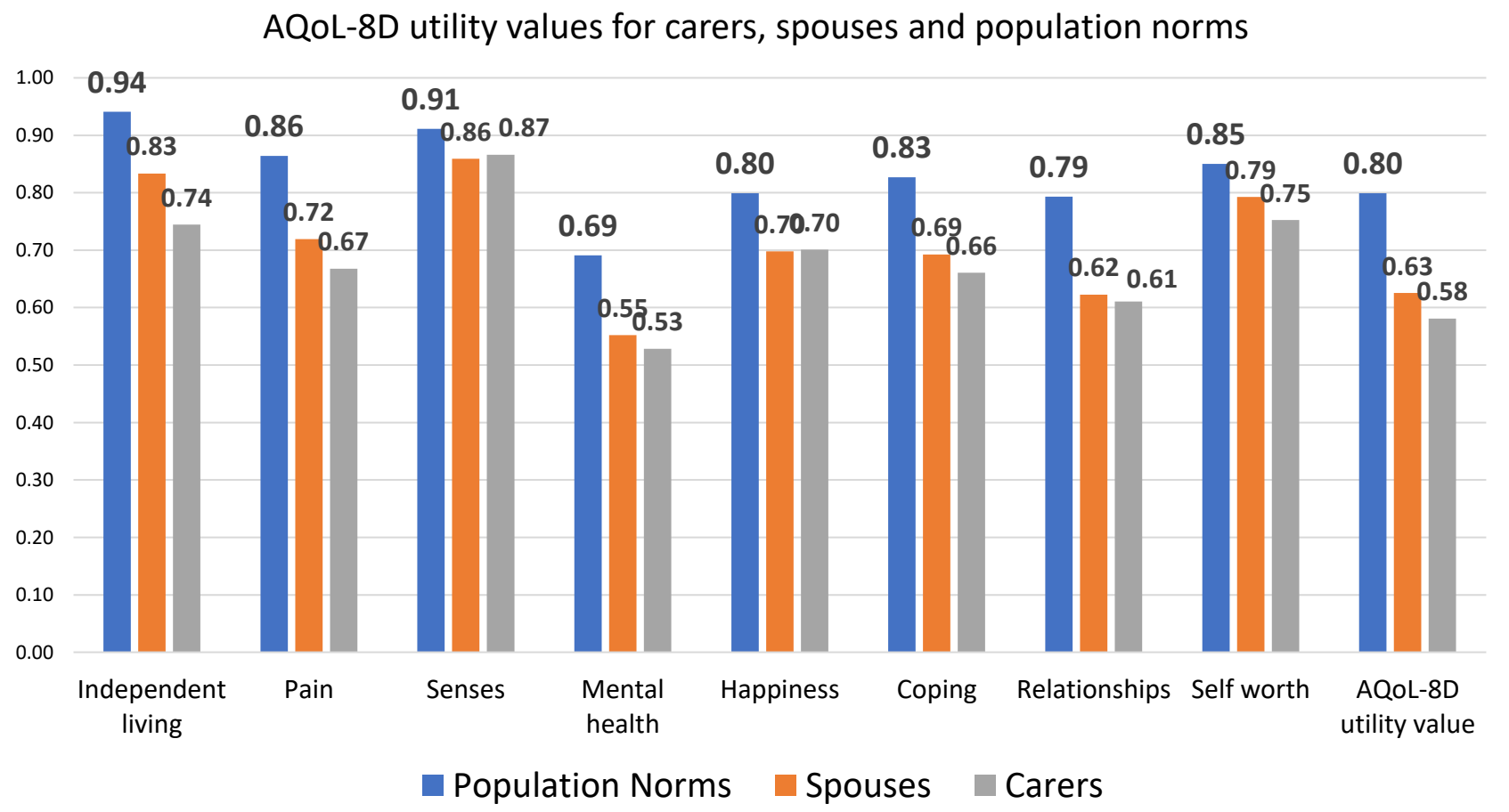
Variable	Carer (N=111)
Age	50.8 (12.0)
Gender	
Female	100 (90%)
Male	11 (10%)
Has spouse	
Yes	83 (75%)
No	27 (25%)
Primary school	5 (5%)
Partially completed secondary school (less than Year 12)	35 (32%)
Completed secondary school (Year 12)	10 (9%)
Trade/apprenticeship (e.g. hairdresser, chef)	4 (3%)
Certificate/diploma (e.g. child care, technician)	31 (28%)
University degree	15 (14%)
Higher university degree (e.g. Masters, PhD)	10 (9%)
Missing	1 (1%)
Number of people with ID they are caring for	
1	56 (50%)
2	47 (42%)
3	8 (7%)
Number of people with ID living at home	
0	50
1	42
2	17
3	2
Number of people living with carer and requiring full time care	
0	33
1	51
2	24
3	3
Had difficulty or could not pay gas, electricity, rent or mortgage on time	
Yes	29 (26%)
No	82 (74%)
Employment	
Full-time paid work (including leave)	12 (11%)
Part-time paid work (including leave)	37 (34%)
Unemployed and looking for work	1 (1%)
Not in the labour force	60 (55%)
Missing	1 (1%)

Descriptive statistics - ID

Variable	N=174
Age (mean)	20.5
Bellow 18	89 (51%)
18 and above	85 (49%)
Gender	
Male	139 (80%)
Female	35 (20%)
Severity	
Mild	50 (29%)
Moderate	72 (41%)
Severe	52 (30%)
Living situation	
At carer's home	131 (75%)
With another relative	4 (2%)
In supported living	11 (6%)
In group accommodation	7 (4%)
In residential care	3 (2%)
In public housing	5 (3%)
Other	9 (5%)
Missing	4 (2%)

Aggressive behaviour	
Yes	39 (22%)
No	135 (78%)
At home and requires full time supervision	
Yes	
No	
Relationship to carer – immediate family	
Yes	160 (92%)
No	14 (8%)
Financial dependent	
Yes	50 (29%)
No	124 (71%)

AQoL-8D utility values



Multivariate regression output

ASSOCIATIONS WITH AQOL-8D OF CARERS

- OLS multivariate regression with AQoL-8D as dependent variable

Variable	Estimate	SE	P value
Intercept	0.75	0.17	<.0001
Age	0.00	0.00	0.71
Gender	-0.04	0.07	0.51
Financial dependence	0.00	0.04	0.92
Financial stress	-0.10	0.04	**0.01**
Mental health condition	-0.13	0.04	**0.00**
Full time supervision (count)	-0.03	0.05	0.57
Aggression (count)	-0.09	0.04	**0.01**
In paid work	0.01	0.04	0.83
Severe ID (count)	0.05	0.03	0.17
Number caring for	0.01	0.04	0.68

Discussion of results

- Similar to previous literature, severity of ID is not correlated with QoL of a carer
- Financial stress and mental health are correlated with QoL
- This is expected and suggests that the impact of caring for people with ID may impact QoL through these mechanisms
- Aggression is negatively correlated with QoL
- Consistent with literature and feedback from clinicians and genetic counsellors, this behaviour can be challenging for carers
- Age of those being care for is complicated

Next steps

Integrating QoL with IDMOD cost outputs

- Familial ID clearly has significant impacts on carers of those with familial ID and their spouses
- IDMOD is a microsimulation model of lifetime economic and social costs of familial ID, using the same EPIC-ID cohort
- IDMOD produces cost of ID by age group of those being cared for
- To understand the potential benefits of any interventions for those with familial ID (or their carers), data on QoL through health utilities will be used
- Diagnosing the cause of ID is crucial for families. For individuals it can improve prognosis and use and access of support services, while for families it can assist with reproductive planning
- Combining QoL data with cost outputs will allow IDMOD to estimate the cost effectiveness of new interventions, such as advances in genetic testing, as well as use of reproductive planning and technologies

References

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