

Title: Psychological distress and convergence of own and proxy Health-Related Quality of Life in carers of adults with an intellectual disability.

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Data availability statement

Data are available on reasonable request from the first or last author.

Abstract

Background

In adults with an intellectual disability, Health-Related Quality of Life (HRQoL) is often measured by proxy-report. This cross-sectional study investigated whether the mental health of proxy-raters impacts the way they rate HRQoL.

Methods

In this study, 110 carers of adults with an intellectual disability completed measures of psychological distress (Kessler-6) and HRQoL (EQ-5D-3L) about their own HRQoL and that of the care-recipient. Differences between HRQoL scores as rated by the carer about themselves and the care-recipient were calculated (convergence scores) and multiple regression models were fitted to estimate the association between proxy psychological distress and convergence scores for subjective/objective HRQoL controlling for support needs of the care-recipient, carer age, and gender of care-recipient.

Results

There was a significant association between psychological distress and subjective HRQoL convergence scores ($r=.92$; $p=0.03$; 95% CI: -1.76 to -0.09). There was no association between psychological distress and objective HRQoL convergence scores ($r=.01$; CI -0.02 to 0.001; $p=0.08$). The association between psychological distress and HRQoL scores was no longer present when models did not include convergence scores.

Conclusions

Carers experiencing more psychological distress tended to rate their own and the care-recipients subjective HRQoL more similarly. Objective HRQoL measures did not show this convergence in scores with increasing carer psychological distress. Findings differed when the analysis approach was changed, suggesting the results above require replication in future studies.

Keywords:

Health-Related Quality of Life, Adults with Intellectual Disability, Learning Disability, Proxy-Reports, Carers, Mental Health, Measurement.

Background

Health-Related Quality of Life (HRQoL) encompasses physical, psychological and social health dimensions and is an important measure for studying illness impacts or intervention outcomes (Cesnales & Thyer, 2014). In intellectual disability research, HRQoL can be measured by either self-report, proxy-report (from a healthcare professional, carer or relative), or both.

Although there is overall poor agreement between self-reported HRQoL and proxy-reported HRQoL in people with an intellectual disability (Zimmermann & Endermann, 2008), many people with an intellectual disability are not able to self-report due to difficulties associated with communication, behaviour, and concentration. Therefore, proxy-reports, especially from family carers, are still often the main source of HRQoL data in intellectual disability research and clinical practice (Scott & Haverkamp, 2018).

Evidence from studies in neurotypical children suggests that parents' own Quality of Life (QoL) tends to resemble QoL scores they provide for their child (Cremeens et al., 2006; Eiser et al., 2005; Lim et al., 2019). Also, evidence from studies involving neurotypical children and their parents suggests that parents with higher psychological distress levels provide poorer proxy-scores for HRQoL (Arnaud et al., 2008; Janicke et al., 2007; Sato et al., 2013; White-Koning et al., 2007) and parents with higher psychological distress levels also typically have poorer QoL themselves (Cesnales & Thyer, 2014).

It is therefore hypothesised that in the presence of psychological distress, the rater's ability to separate their own QoL from that of another person might be impaired, leading to HRQoL ratings that converge. If psychological distress makes convergence more likely, an explanation for this might be that in the presence of psychological distress, cognitive processes interfere with one's perception of the self, others, and the world (Beck, 2002).

Carers for people with an intellectual disability have been shown to have higher levels of psychological distress, anxiety and depressive symptoms than carers of people without an intellectual disability (Burton-Smith et al., 2009; Grey et al., 2018; Seltzer et al., 2011). In particular, parents caring for children with more support needs or parents having cared for their child for longer might face more psychological distress due to longer exposure to chronic stress or the cumulative effects of caring for their child with an intellectual disability who lives with

the family (Seltzer et al., 2010). Therefore, these carers might be more vulnerable to score convergence when proxy-reporting.

Due to proxy-reports often being the main information source in intellectual disability research and clinical practice, it is important to understand any threats to validity. Convergence can be problematic if it indicates that proxy-raters cannot differentiate between their own QoL and their child's QoL. Therefore, this cross-sectional study aimed to investigate whether psychological distress in parents of adults with an intellectual disability is associated with convergence of HRQoL ratings, given by the carer for themselves and the care-recipient. We hypothesised that psychological distress would be associated with a higher convergence between own HRQoL ratings and their ratings for the person with intellectual disabilities.

Method

Procedure

Data for this study were drawn from Grey et al. (2018). The study recruited participants who were the main carer for an adult relative aged 18 years or over with an intellectual disability who was living in the family home. Study participants completed either postal or online questionnaires. Participants were recruited through statutory and voluntary organizations that advertised via email, websites, and newsletters. Ethical approval was obtained from Research Ethics and Governance Committee, Bangor University (ethics number 2012-8242). Approval for re-analysis was obtained from UCL Ethics committee (project ID 18483/001).

Participants

This study included 110 family carers of adults with an intellectual disability. The majority (87.4%) were parents, with a small number of other family relatives. There were 18 (16.2%) males and 92 (82.9%) females. Participants' mean age was 59.8 years (SD 12.0 years, range 24 to 91). Proxy HRQoL data were provided for 65 (58.6%) male and 43 (38.7%) female adults with an intellectual disability. The average age of adults with an intellectual disability was 34.9 years (SD 11.6 years, range 18 to 67). Carer and care-recipient characteristics are summarised in Table 1.

Measures

Psychological distress

The Kessler 6 (K6; Kessler et al., 2002) was used to measure psychological distress of family carers. The K6 is a six-item scale measuring non-specific psychological distress over the past thirty days. Respondents rate each item (so sad nothing could cheer you up; nervous; restless or fidgety; hopeless; everything was an effort; worthless) on a five-point Likert-type scale to reflect how often carers' experienced negative feelings (none of the time; a little of the time; some of the time; most of the time; all of the time). The range of possible scores is 6 to 30, where higher scores indicate greater psychological distress levels. The K6 has very good predictive validity for psychiatric disorders as it has been shown to predict reliably serious mental illness in general population samples in USA (Kessler et al., 2002). The K6 is not gender, age, nor education biased (Kessler et al., 2002). The measure showed excellent internal consistency for the current study sample (Cronbach's $\alpha=0.90$).

Health-Related Quality of Life

The EQ-5D-3L (EuroQol Group, 1990) was used to measure HRQoL of family carers and adults with an intellectual disability (via proxy). The EQ-5D-3L is a generic measure of HRQoL which includes a descriptive scale and visual analogue scale. It is one of the most widely used instruments for measuring HRQoL in clinical trials, population studies and real-world clinical settings, having proven to be valid, reliable and responsive in numerous conditions and populations, including with parents of children with autism (Khanna et al., 2013).

In the descriptive scale, HRQoL is rated across five domains (mobility; self-care; usual activities; pain/discomfort; anxiety/depression), with each dimension scored at 3 levels (no problems; some problems; extreme problems). Higher scores indicate poorer health in a particular domain.

The descriptive score is converted into a single index value by applying a UK specific index-weighting. This produces an objectively rated single index health-score based on country-

specific preferences for health states. Single index scores run from '0' representing extreme health difficulties to '1.0' representing no health difficulties.

The EQ-5D-3L Visual Analogue Scale, is a subjective HRQoL measure ranging from 0 (worst imaginable health state) to 100 (best imaginable health state). Participants indicate their health state by marking a line where they view their overall health to be.

HRQoL convergence scores were calculated by subtracting carers' own HRQoL scores from their HRQoL scores for the care-recipient. This was done separately for objective and subjective HRQoL scores.

Socio-Economic Position

A composite variable indicating families' socio-economic position was created by combining five dichotomous indicators: 1) Family living in 20% most deprived area according to UK Index of Multiple Deprivation (0=yes, 1=no); 2) Carers' employment status (0=unemployed, 1=employed either full or part time); 3) Educational status (0=no education/GCSE equivalent, 1=A-level equivalent and above); 4) Income poverty (0=Families weekly net income at/or below poverty line, 1=Families weekly net income above poverty line); 5) Hardship as derived from the Family Resources Scales (Dunst & Leet, 1986) as described in Grey et al. (2018). The resulting socio-economic position composite scores ranged from zero to five, with higher scores representing a higher socio-economic position.

Support needs

Five questions were used to assess care-recipients' support needs 1) Able to speak/sign 30 words or more; 2) Presence of visual or hearing impairment; 3) Incontinent during day or night; 4) Presence of epileptic seizure; 5) Needs support to eat (0=not applicable/not a support need, 1=applicable/present) A support needs score was calculated by summing the total number of needs present, with higher scores representing higher support needs. The measure showed acceptable internal consistency (Kuder Richardson coefficient=0.64).

Approach to Analysis

All analyses were conducted using SPSS Statistics 25.0™. Multiple regression models were fitted to estimate the association between family carer psychological distress with subjective

and objective HRQoL convergence scores, controlling for other factors likely to be associated with HRQoL. Potential confounders were initially identified based on literature search: care-recipient gender (Bianchini et al., 2013; Lundberg et al., 2012), age (Helseth et al., 2015; Petsios et al., 2011; Rajmil et al., 2013; Sattoe et al., 2012) and support needs (Upton et al., 2008); and family carer gender (Rensen et al., 2019), age (Seltzer et al., 2011), and socioeconomic position (Petsios et al., 2011).

Pearson's correlation between convergence scores and potential confounders were examined to determine variables that would be taken forward to the final models. Care-recipient gender was associated with objective HRQoL convergence score ($r=-0.24$, $p=0.01$) and subjective HRQoL convergence score ($r=0.28$, $p<0.01$). The care recipient support needs score was associated with objective HRQoL convergence score ($r=0.36$, $p<0.01$) and subjective HRQoL convergence score ($r=0.20$, $p=0.04$). Family carer age was associated with objective HRQoL convergence scores ($r=-0.24$, $p=0.01$). Care-recipient age, family carer gender and socio-economic position had near-zero correlations with both outcomes. Due to the sample size being modest a parsimonious approach to covariate selection and only variables with a significant association ($p<0.05$) or non-zero ($r>0.2$) correlation with either outcome were included in the regression models. Bivariate analyses between all potential confounders to look for multicollinearity identified no strong correlations, except for care-recipient age ($r= 0.55$) with family carer age. Given that family carer age was associated with the outcomes, this was included in the regression model along with support needs and care-recipient gender.

Finally, for each family carer, the mean value for the HRQoL score for the carer and care-recipient was calculated. The subjective HRQoL score mean was used in the subjective analysis and the objective HRQoL score mean was used in the objective analysis to control for the amount of measurement error, akin to the Bland-Altman method that was proposed for looking at agreement between two methods that measure the same quantity. (Giavarina, 2015)

On the recommendation of an anonymous reviewer, regression models were re-run substituting convergence scores for proxy-rated HRQoL scores as the dependent variable with proxy raters' own HRQoL scores as the predictor alongside carer psychological distress and their interaction (also controlling for potential confounders as described above).

Results

The distribution of convergence scores is shown in Figure 1. The values are normally distributed, with those closer to zero showing more convergence, whilst further from zero show less convergence between family carer own HRQoL and that of the care recipient.

Examining the main research question, the regression models showed a significant association between family carer psychological distress and subjective HRQoL convergence scores with carers with higher psychological distress showing more convergence in subjective HRQoL scores (regression coefficient: -0.92; $p=0.03$; 95% CI -1.76 to -0.09). Figure 2 demonstrates this association in a line graph where the predicted convergence values of subjective HRQoL scores are plotted against the carer psychological distress scores, showing that convergence increases (scores closer to zero) for higher levels of psychological distress. There was no association between carer psychological distress and objective HRQoL convergence scores (regression coefficient -0.01; CI -0.02 to 0.001; $p=0.08$).

Incidentally, there was a significant association between carer age and objective HRQoL score, with older carers showing more convergence of scores (-0.01 ; $p=0.003$; 95% CI -0.01 to -0.003). The results of the regression models for both outcomes are summarised in Table 2.

Table 3 presents the results of the linear regression models with proxy-rated HRQoL scores as the outcome, controlling for carer HRQoL scores. The models indicate no significant effects for the interaction term (psychological distress by carer HRQoL) scores for objective HRQoL ($b=0.01$, $p=0.870$) and subjective HRQoL ($b= -0.01$, $p=0.803$).

Discussion

This study explored the association between mental health of proxy-respondents and HRQoL convergence scores. Findings indicate evidence of an association between proxy psychological distress and convergence in subjective HRQoL scores. Proxy-raters with higher psychological distress levels tend to provide ratings of care-recipient subjective HRQoL which are more similar to the proxy's subjective ratings of their own HRQoL. No such association was found for objective HRQoL.

This study builds on the concept of convergence in HRQoL scores that carers provide for themselves and for the care-recipient. The findings suggest that psychological distress makes convergence more likely for subjective, rather than objective, HRQoL scores. An explanation for this might be the cognitive fusion between the self and the rest of the world in depression (Beck, 2002) is susceptible to subjective scoring. On the other hand, shared environmental factors which increase psychological distress in the parent and impact QoL of both the parent and care-recipient might be better captured by the more holistic subjective rating scale.

There was a significant association between carer age and objective, though not subjective, HRQoL convergence score, with older carers reporting more similar objective HRQoL scores between themselves and the care-recipient. Older carers may have cared for their child for longer and the exposure to chronic stress (Seltzer et al., 2010) might have made them more vulnerable to convergence in objective proxy-reporting.

To our knowledge, this study is the first to examine the association between family carer mental health and the convergence of HRQoL scores, drawing from a homogenous group of adult offspring living with their parents. The findings have significant implications in the reliance on proxy-family-raters for HRQoL reports in intellectual disability research and clinical practice. It highlights that complex processes can influence family carer reports. This shows the importance of enabling people with an intellectual disability to self-report wherever possible. The use of carer reports should include objective measures alongside any subjective reports. If using subjective measures, the clinician/researcher should measure the mental health status of the carer and carefully consider how this may influence the information being obtained.

This study has several limitations. There is a potential sampling bias as participants self-selected to take part. The cross-sectional, correlational design only provides a 'snap-shot' of processes in family carers of adults with an intellectual disability within the UK (Grey et al., 2018). The modest sample size reduces the power of the findings. The survey was designed to be primarily a carer survey and, for this, consent for participation and self-report measures were not obtained by care recipients with an intellectual disability. Future research is needed to replicate the approach with self-reported EQ-5D data. In addition, the study did not include diagnostic ascertainment of intellectual disability or carer mental health problems. The support a care-recipient receives from outside sources was not measured, which might be related to

convergence either as an independent predictor or a moderator. There is no comparison to care-recipient own ratings in order to indicate whether the convergence indicates more or less reliable information. Crucially, the alternative regression models did not identify a significant interaction effect, suggesting that the effect of carers' own HRQoL scores on proxy-rated HRQoL scores may not differ at different levels of psychological distress. However, the two modelling approaches make different assumptions about the data (e.g., Mansournia *et al* 2021). Differences in statistical results should make us more aware of how differences in assumptions could lead to different results, and call for replication of the approach adopted here in future studies.

Further research is needed into the factors associated with proxy-reporting processes, so that we can account for these in understanding of the QoL of people with an intellectual disability. This includes replicating the study on a larger scale with comparisons to care-recipient self-ratings and including staff who also provide proxy-reports to determine if their reporting is influenced by the same factors as family carers. The association between carer age and convergence in proxy-reports requires further investigation. There is also a need to develop validated measures for proxy-reporting of HRQoL for people with an intellectual disability, that take into consideration factors that are important to this population, such as the psychological distress in carers and levels of support a person needs.

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Tables

Table 1: Carer characteristics and care-recipient characteristics

Carer characteristics		
Gender	Male	18 (16.2)
	Female	92 (82.9)
Age (years) mean (SD)	59.8 (12.0)	
Relationship to care- recipient	Mother/step-mother	81 (73.0)
	Father/step-father	16 (14.4)
	Siblings/step-siblings	6 (5.4)
	Other relative (aunt/uncle, cousin, daughter, spouse)	6 (5.4)
Level of education	No formal qualification/General education/High school	53 (47.7)
	Higher education	51 (45.9)
Employment Status	Paid employment (FT/PT)	36 (32.4)
	Unemployed	73 (65.8)

Care-recipient characteristics		
Gender	Male	65 (58.6)
	Female	43 (38.7)
Age (years) mean (SD)	34.9 (11.6)	
Support Needs		
1) Able to speak/sign 30 words or more	Yes	79 (71.2)
	No	27 (24.3)
2) Presence of visual or hearing impairment	Yes	31 (27.9)
	No	74 (66.7)
3) Incontinent during day or night	Yes	34 (30.6)
	No	76 (68.5)
4) Presence of epileptic seizure	Yes	19 (17.1)
	No	86 (77.5)
5) Needs support to eat	Yes	37 (33.3)
	No	70 (63.1)
Abbreviations: N, number of respondents; SD, standard deviation; FT, full time; PT, part time. Data are n (%) unless otherwise specified. 1) -5) Questions indicating care-recipients' support needs		

Table 2: Regression results for examining the association between psychological distress (K6 scores) and subjective and objective HRQoL convergence scores

	Objective HRQoL Convergence Score				Subjective HRQoL Convergence Score			
Model Summary	R square		P value		R square		P value	
	0.41		<0.001*		0.20		0.001*	
	regression coefficient *	P value	95.0% Confidence Interval		regression coefficient *	P value	95.0% Confidence Interval	
			Lower bound	Upper bound			Lower bound	Upper bound
K6 score	-0.01	0.08	-0.02	0.001	-0.92	0.03	-1.76	-0.09
Support needs score	0.03	0.10	-0.01	0.07	2.45	0.09	-0.41	5.30
Proxy Age	-0.01	0.003	-0.01	-0.003	-0.06	0.75	-0.45	0.32
Gender of care-recipient	-0.05	0.32	-0.16	0.05	-8.01	0.06	16.50	0.49
Mean of own and proxy HRQoL score	-0.79	<0.001	-1.09	-0.50	-0.43	0.001	-0.69	-0.17

K6 = Kessler 6 Score
*Unstandardised scores

Table 3: Alternative regression models with care recipient HRQoL scores as the outcome

	Objective HRQoL Proxy-rated Score				Subjective HRQoL Proxy-rated Score			
Model Summary	R square		P value		R square		P value	
	.34		<0.001*		.27		<0.001*	
	regression coefficient *	P value	95.0% Confidence Interval		regression coefficient *	P value	95.0% Confidence Interval	
			Lower bound	Upper bound			Lower bound	Upper bound
K6 score	-0.01	0.690	-0.06	0.04	0.59	0.824	-4.62	5.79
Support needs score	-0.09	<0.001	-0.13	-0.05	-2.31	0.112	-5.17	0.55
Proxy Age	0.00	0.104	-0.00	0.01	0.11	0.718	-0.47	0.68
Gender of care-recipient	-0.10	0.066	-0.21	0.01	-10.48	0.018	19.11	1.84
Carer's HRQoL	0.27	0.331	-2.79	0.82	0.62	0.024	0.08	1.15
K6* Carer's HRQoL interaction	.007	0.870	-0.05	0.06	-0.01	0.803	-0.08	0.07

K6 = Kessler 6 Score
*Unstandardised scores

Figure legends:

Figure 1: Graphs to show convergence scores for objective (left) and subjective (right) HRQoL scores. Values closer to zero show more convergence, whilst further from zero show less convergence between family carer ratings of their own HRQoL and that of the care recipient.

Figure 2: Predicted subjective HRQoL convergence scores for different values of carer psychological distress (K6) scores.