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TITLE: Do mothers and fathers hold similar views about their child's arthritis?

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Abstract

Objective

Evaluations of the wellbeing of children with Juvenile Idiopathic Arthritis (JIA) typically rely on parents as proxy respondents. An assumption of several studies appears to be that mothers' and fathers' ratings are interchangeable, as reports do not always specify which parent completed the assessments nor, in repeated measures, if they were completed by the same parent. The aim of this study was to examine the level of agreement between mothers' and fathers' ratings of their child's quality of life (QoL) and to identify possible predictors of disagreement.

Methods

82 mothers and fathers of children with JIA completed ratings of their child's symptoms, QoL, and measures of their mood and beliefs about their child's illness and treatment. The number of active and limited joints and physician global assessment were also recorded.

Results

Intra-class correlations between mothers' and fathers' ratings of physical and psychosocial QoL were high (0.824 and 0.755 respectively). However, calculation of difference scores revealed that 70.6% and 65.9% respectively were classified as discordant. Where parents differed, the direction of difference was not systematic. Discordance in parents' mood states and in their illness and treatment beliefs explained a small amount of variance in discordance in QoL.

Conclusion

It should not be assumed that proxy ratings of a child's wellbeing can be generalised from one parent to the other. Studies that take repeated assessments should ensure that the same parent completes assessments at all time-points. Other factors that may explain discordance between parents' ratings need to be explored.

Understanding parents' responses to their child's arthritis is crucial as their judgements of the wellbeing of their child are used in part to determine the relative success of therapy. Parents act as proxy respondents, particularly in the case of younger children. In juvenile idiopathic arthritis (JIA), two of the six core outcome variables (COV) that are used to define improvement in clinical trials (rating of overall wellbeing and the Child Health Assessment Questionnaire (CHAQ)) (1), are often completed by parents. Parents' evaluations of their child's wellbeing are not only important in clinical assessment but they also drive health care utilisation (2).

Studies of proxy reporting in childhood chronic disease have usually focused on the level of agreement between parent and child or between parent and physician. Several studies have suggested poor to moderate correlations between parent and child ratings, with parents generally reporting the impact on the child to be greater than that reported by the children themselves (see reviews (3;4). In JIA, studies have compared parent and child on ratings of pain and physical function (5-9), overall well-being (6;8) and quality of life (QoL) (6;8;10-12). Agreement between parent and child has tended to be moderate and there is some indication that the level of agreement varies with disease severity and the particular health domain being assessed.

Studies have also compared parent and physician on their ratings of the child's pain (9) physical function (13;14) and overall wellbeing (15;16). Agreement between parent and physician ranged from 40% - 69% in these studies (13-16). Where the raters differed, there was no consistent finding across studies for either parent or physician to give poorer ratings.

An issue that has not had much attention is the assumption in many studies that it is not important whether a mother or father completes the ratings as their responses are seen as interchangeable. In several of the studies quoted above, it was not stated which of the parents provided the rating. The issue is particularly important in studies that require repeated parent ratings to be provided at more than one time-point. It is striking that this information is not necessarily reported in clinical trial reports, which may specify only that a parent assessment was obtained, without specifying from which parent, or if it was the same parent each time (e.g. (17)). **The assumption that mothers and fathers are interchangeable appears to have been made but this has rarely been tested (an exception being Garcia-Munitis et al 2006 who compared patients' ratings with those of their mothers, fathers and physicians (9)).**

Our study aimed to examine the relationship between mothers' and fathers' ratings of their child's QoL in JIA and also to examine factors that might help to explain the level of agreement or disagreement between them. Other studies have suggested that factors such as parents' illness beliefs and mood are likely to influence their assessments (e.g. **(8;9)). This hypothesis is consistent with Leventhal's theoretical model(18;19) which proposes that people's cognitive and emotional responses to their illness influence how well they cope with it, which in turn impacts on health outcomes such as quality of life. Our study aimed to examine the role of these variables when applied to a proxy measure.** In this study we compared mothers' and fathers' ratings of their child's QoL and examined whether the level of agreement between them is influenced by demographic characteristics, disease-related variables, agreement in parents' beliefs about their child's arthritis and its treatment and their mood.

Participants and Methods

Participants were mothers and fathers of children with juvenile idiopathic arthritis (JIA), defined by ILAR criteria (20), who were under the care of the rheumatology service at Great Ormond Street Hospital for Children or University College Hospital, London, UK. Children and parents were recruited as part of the Childhood Arthritis Response to Medication Study (CHARMS). All children were either currently taking methotrexate (MTX) or had been prescribed it in the past for at least 6 months. As part of the CHARMS study, data were collected from parents about their child's response to treatment for JIA. In this paper we report data only in cases where both parents completed the study questionnaires. The study had full ethical approval from ICH/GOSH LREC, reference 05/Q0508/95 and all participants gave full, informed written consent. The study conforms to the principles outlined in the Declaration of Helsinki.

Measures

In addition to demographic information on the parents and child, the following measures were collected:

- Clinician assessed measures from the JIA core outcome variables (1) i.e. number of active and limited joints and physician global assessment were collected as indices of **current** JIA disease severity. JIA subtype, age at diagnosis, and disease duration were also recorded.
- Parents' ratings of their child's quality of life were assessed using the Pediatric Quality of Life Inventory (PedsQL) Generic and Rheumatology scales (10), both of which have parallel scales relating to children aged 2-4, 5-7, 8-12 and 13-18. The generic measure produces 2 composite scores of Physical and Psychosocial QoL. The Rheumatology scale consists of 5 subscales – pain and hurt, daily activities, treatment, worry and communication. The two latter subscales appear only in the scales relating to children aged 5 and over. Scores

on all subscales of the generic and rheumatology scales are transformed to 0 – 100 scales where a higher score signifies a better quality of life. **The PedsQL has been found to have good internal consistency and to distinguish between healthy children and those with rheumatic disease (10).** Varni et al (2003)(21) have reported a clinically meaningful difference on the PedsQL Generic Scale of ±4.5 points.

- Parents' ratings of their child's symptoms were assessed with 10cm visual analogue scales (VAS) for severity of pain, stiffness and fatigue in the last week.
- Parents' beliefs about their child's arthritis were assessed with the Revised Illness Perceptions Questionnaire (IPQ-R) (22), which was adapted to assess a proxy's beliefs about the patient's illness, rather than the patient's beliefs. **The IPQ-R has been found to have good internal consistency, acceptable test-retest reliability and to be able to discriminate between acute and chronic pain patients (20).** The IPQ-R assesses beliefs in 9 domains, 7 of which are analysed in this paper: The 2 not analysed are (i) identity – the symptoms the person perceives to be related to the illness and (ii) cause - beliefs about what caused the illness. The 7 items assessed in this study were iii) personal control – beliefs about their ability to control the illness. For this study, parent beliefs about the child's and the parent's ability to control the illness were assessed (iv) treatment control – beliefs about the ability of treatment to control or cure the illness v) timeline acute/chronic – perception of the likely time course of the illness (vi) timeline cyclical – perception of the degree of unpredictability of the illness viii) consequences – perception of the impact of the illness. Parent beliefs about the consequences of the illness both for themselves and their child were assessed vii) coherence – how much respondents understand the illness. Again, these items were duplicated to assess parent beliefs about coherence of the illness to themselves and to their child ix) emotional representation – the emotional responses generated by the illness. This scale was also duplicated to assess parent beliefs about the emotional response generated in themselves and

in their child. Each subscale provides a score from 1-5, with a higher score representing a stronger belief.

- Parents' beliefs about their child's treatment were assessed with the Treatment Representations Inventory (TRI) (23), which was adapted to assess a proxy's beliefs about the patient's treatment, rather than the patient's beliefs. **The TRI has been found to have good internal consistency and to discriminate between patients undergoing different treatments (21).** The TRI assesses beliefs in 4 domains: (i) treatment value – beliefs about the positive effects of the treatment in controlling and arresting the progress of the illness, (ii) concerns –beliefs about the emotional impact of treatment (on the child) and parents' concerns about treatment, (iii) cure – beliefs about the ability of the treatment to resolve the illness and return their child to their normal life, (iv) decision satisfaction – parents' evaluation of the decision process for choosing their child's treatment. Each subscale provides a score from 1-5, with a higher score representing a stronger belief.
- Parental mood was assessed with the Hospital Anxiety and Depression Scale (24). This scale provides separate scores for anxiety and depression, both ranging from 0-21, with higher scores indicative of greater depressed/ anxious mood.

Statistical Analysis

Levels of agreement between mothers' and fathers' assessments were calculated using intra-class correlations (ICC**). ICC values of <0.40 are considered to reflect poor agreement, 0.4 - <0.75 = moderate agreement and ≥0.75 = good agreement.** Differences between mothers' and fathers' scores were also calculated for all measures to provide continuous difference-scores between mothers and fathers on all variables. Agreement in QoL was also analysed using the Bland and Altman method(25).

To explore possible determinants of the level of discordance between parents in assessment of QoL, two multiple regression analyses were performed in which the dependent variables were parent difference scores on the PedsQL Generic Physical and Psychosocial subscales. Potential predictor variables were child age and gender, disease duration, disease severity as indicated by the number of active and limited joints and physician VAS, parent age and education level, and difference scores on parent mood, illness and treatment beliefs. The relationship between potential predictor variables and the QoL difference scores was examined initially by correlations (Pearson r correlations for continuous variables, Spearman's rho (r_s) for ordinal variables). To examine which variables accounted for most variance in QoL difference scores, all significant variables ($p< 0.01$) identified from the univariate analyses were included in hierarchical multiple regressions using enter method. The criterion level of $p<.01$ was used to ensure that the number of predictor variables did not exceed recommendations for power calculation in multiple regression analysis(26).

The independent variables were entered into the regression in blocks in the following order: demographic variables, disease variables, illness and treatment beliefs, and mood. This order was used because it enables examination to be made as to whether psychosocial variables add to the explanation of discordance in parents' assessment of QoL, once demographic and clinical variables have been taken into account.

Results

Eighty two parent dyads completed all assessments. Demographic and disease variables are shown in Table 1. All 82 children had been treated with MTX for their JIA for 6 months or more and at the time of the assessment they were relatively well as indicated by the low disease activity scores such as active joint count, physicians global assessment (Table 1).

Assessment of the degree of concordance between mothers and fathers.

Mothers' and fathers' ratings of their child's QoL are shown in Table 2.

Intra-class correlations between mothers' and fathers' evaluations of generic QoL were good (see Table 2) with a slightly higher correlation in Physical than in Psychosocial QoL. However on the rheumatology scale, ICCs ranged from poor on the worry subscale to good on the pain subscale. On mothers' and fathers' ratings of their child's symptoms, ICCs were moderate for stiffness and fatigue and good for pain (Table 2).

There was greater variation in the level of agreement between parents on their beliefs about their child's JIA and its treatment (Table 3). ICCs ranged from poor on beliefs about the level of personal control the child or parent had over the illness, to moderate for beliefs about the ability of treatment to cure or control the illness.

Mean (SD) scores on anxiety and depression were 7.43 (4.07) and 4.01 (3.47) respectively for mothers and 6.35 (3.77) and 3.84 (3.02) for fathers. These are within the normal, non-clinical range for the scale. Paired t-tests found no significant differences between mothers and fathers on anxiety or depression **(results not shown).**

Although ICCs on the PedsQL Generic scale were good, plotting of difference scores shows that there was nonetheless a **relatively** high degree of discordance between parents on these scales (Figure 1). A difference of ± 4.5 points on the generic scale is considered clinically significant (21) and Figure 1 shows that only 29.4% of mothers' and fathers' scores fell within this range on generic physical QoL and 34.1% on psychosocial QoL. Although a clinically meaningful difference has not been reported for the rheumatology scale we have

taken the same criteria for this scale as applied in the general scale to establish discordant judgements. Figure 1 shows that the greatest agreement between mothers and fathers was on the daily activities subscale and the poorest on the worry subscale.

It can also be seen from Figure 1 that the direction of difference in the parents' assessments was not systematic. For example, the proportions for whom QoL was rated better by the mother were fairly similar to those for whom QoL was rated better by the father.

Factors that may help to explain the degree of concordance/discordance between mothers and fathers

Bland and Altman plots (supplementary data) show that the level of concordance/discordance did not vary by level of QoL.

Univariate analysis:

To determine whether the level of discordance in parents' assessments of their child's QoL was related to demographic or clinical variables, a series of univariate correlations were performed. These showed that the level of discordance was not related to the child's age or gender, JIA subtype, disease duration, or disease severity assessed by active joints, limited joints and physician VAS.

To determine whether the level of discordance in parents' assessments of their child's QoL was related to differences in their **age, education,** mood and perceptions of symptoms and beliefs regarding their child's JIA and its treatments, a further set of correlations were performed between the difference scores on these variables. Table 4 shows the significant

correlations between these difference scores. Greater discordance between parents in their ratings of their child's physical QoL was related to greater discordance in: their assessment of pain and stiffness, their belief about the emotional impact of JIA on their child and their level of depressed mood. So, for example, where one parent had a higher level of depressed mood than the other, their rating of their child's physical QoL was also worse.

Multivariate analysis:

The significant variables shown in Table 4 were entered into two multiple regression analyses, with discordance in Physical QoL and Psychosocial QoL as the dependent variables (Table 5). These variables explained 21% and 14% of the variance in Physical and Psychosocial QoL, respectively. Only discordance in pain rating and depressed mood remained significant predictors of discordance in Physical QoL in the final equation. Discordance in mothers' and fathers' treatment concerns and in their beliefs about the cyclical nature of JIA were significant predictors of discordance in their ratings of Psychosocial QoL.

Discussion

This study has shown that the correlations found between mothers and fathers in their ratings of their child's QoL can mask high levels of discordant responses. This indicates that where parental proxy reports are used in JIA, any assumption that mothers' and fathers' ratings are interchangeable may not be correct. Although it has been asserted previously by Jozefiak et al (2008)(27), based on a study of parents' ratings of QoL of healthy school-children, that it is reasonable to generalise from mothers to parents, those findings appear not to generalise to parents of children with JIA.

Any assumption that parents would display a systematic difference in their ratings of QoL was not supported by the data in this study. Consequently it is not possible to simply apply a correction factor to enable generalisation from one parent to the other. It would seem that where possible, obtaining the ratings of both parents may be informative but, as this will often be impractical, repeated assessments in studies examining changes in QoL should at least be completed by the same parent and studies should report who has provided the proxy rating. It is important that the classification of discordance in this study was based on a difference score in the PedsQL that is considered clinically meaningful (21). Therefore the findings indicate that where repeated proxy assessments by parents in a trial are not provided by the same parent, it is possible that clinically important bias may enter study findings.

To our knowledge, only one previous study has compared in detail mothers' and fathers' ratings in JIA (9). This study compared mother, father, child and physician on ratings of the child's pain, and reported moderate levels of agreement of pain intensity between the child and parents and poor levels of agreement between the child and the physician. Comparison of

mothers and fathers found moderate to good agreement in their ratings of their child's present pain, pain in the previous week and Child Health Assessment Questionnaire (CHAQ), with intra-class correlations (ICC) of 0.73, 0.77 and 0.8 respectively. However our study performed further analyses of parent responses and we suggest that although some data indicate fairly good levels of agreement between parents, correlational analysis may mask underlying differences.

Studies have reported that proxy ratings tend to be in greater agreement with child reports for more observable phenomena, such as daily activities, than for cognitive and emotional attributes (3). This study provides some evidence to suggest this is also the case between parent reports, in that the highest level of agreement was for daily activities and the lowest for pain and worry (Figure 1). Such findings are probably to be expected but it is helpful to be aware of where the discrepancies exist between raters as symptoms and emotional variables are important areas of the assessment of children with JIA.

Given the differences found between parents, our study aimed to identify variables that could help to explain the level of difference. Some studies that have compared parent and patient proxy reports have found higher levels of agreement at extreme ends of the scale but more disagreement midscale i.e. raters are more likely to be in agreement if the child is very well or very unwell. This does not appear to be the case in comparison of ratings between mothers and fathers, in which discordance was not influenced by disease severity. Neither did demographic characteristics of the parents and children help to explain levels of discordance.

We also examined whether discordance between parents in their mood and beliefs about the illness and its treatment might help to explain discordance in their ratings of QoL. In the

multivariate analysis of discordance between parents' ratings of physical QoL, discordance in pain rating and parents' level of depressed mood were significant explanatory variables however, discordance in illness and treatment beliefs did not contribute to the explanation of discordance in ratings of physical QoL. An association between mothers' ratings of their child's functioning and their levels of depressed mood has been found in another study of JIA (28). Child's depressive symptoms have also been found to be predictive of parent-child disagreement about child's pain (7). The causal direction of the findings in the current study remains unknown however. It is possible that a poorer perception of one's child's QoL increases the likelihood of depressed mood. On the other hand, a more depressed mood could lead to perceiving one's child's QoL in a more negative way. It is likely that both could be valid but longitudinal analysis would be required to tease out the relationship.

The variables that helped to explain discordance in psychosocial QoL were different from those that were significant in physical QoL. Discordance in parents' beliefs about the unpredictable nature of JIA (timeline cyclical) and concerns about treatment were significant variables in the multiple regression analysis of discordance in psychosocial QoL. Concerns about medication have been reported as one of the greatest stressors by mothers of children with JIA (28) and the unpredictable disease course has been associated with parental anxiety (29). It would appear that where these perceptions differ between parents they are reflected in different ratings of the child's psychosocial QoL. Again, the causal direction is unknown in that a poorer perception of the child's psychosocial QoL may result in greater concerns about their treatment and the unpredictable nature of the disease however the opposite causal route is also feasible.

The amount of variance in discordant ratings of both physical and psychosocial QoL explained by these variables (Table 5) was fairly small, indicating that other factors that were not assessed in this study must be important in explaining discordance between parents. The findings suggest the need for further research to understand the underlying factors related to parental discordance and one may speculate that factors such as family functioning, parental characteristics such as optimism and parents' coping abilities may be important.

The study findings must be considered in the light of some limitations. The patients in the study had all been treated with MTX for 6 months or more and mostly had low disease severity at the time of assessment, shown by joint count and physician VAS scores so the extent to which they are generalisable to the JIA population as a whole is unknown. Although the study examined only parent ratings and could have been enriched with the inclusion of child data, this would have excluded parents of very young children who cannot complete self-report measures.

In conclusion, we suggest that studies of JIA , which use parent proxy reporting to assess QoL and well being in children, need to detail which parent provides the reports and where possible to use the same parent, or both, throughout any study that uses repeated sampling of parents proxy ratings.

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Table 1. Demographic and disease variables

Variable		
Child details		
Gender, n (%) female	53 (65%)	
Age, in years mean (S.D.)	8.3 (3.9)	
Time since diagnosis, in years median (IQR) (data for n=78)	3.3 (1.7 – 5.7)	
JIA subtype, n (%)		
Systemic	9 (11.0)	
Oligoarticular persistent	11 (13.4)	
Oligoarticular extended	13 (15.9)	
Polyarticular, RF–ve	34 (41.5)	
Polyarticular, RF+ve	4 (4.9)	
Polyarticular, RF status unknown	1 (1.2)	
Psoriatic	4 (4.9)	
Enthesitis related	6 (7.3)	
Core outcome variables, median (range, **inter-quartile range** (IQR))		
Number of active joints (data for n=77)	0 (0 – 10, 0 – 1.5)	
Number of limited joints (data for n=77)	0 (0 – 10, 0 – 1.5)	
Physician VAS (data for n=65)	0 (0 – 5.8, 0 – 1))	
Parent details	**Mother**	**Father**
Age in years, mean (S.D.)	38 (6.3)	40 (6.3)
Highest academic qualification, n (%)		
None	2 (2.5)	6 (7.4)
GCSE/O Level	46 (56.8)	35 (43.2)
A level equivalent	11 (13.6)	17 (21.0)
Degree	10 (12.3)	14 (17.3)
Postgraduate	9 (11.1)	5 (6.2)
Missing data	3	4

Table 2. **Mean (S.D.) scores and** intra-class correlations between mothers' and fathers' assessments of QoL and symptoms

QoL subscale	n	Mother	Father	Intra class correlation	p
Generic:					
Physical	82	75.8 (24.5)	74.2 (24.0)	.824	<.001
Psychosocial	82	64.2 (16.4)	64.8 (18.6)	.755	<.001
Rheumatology:					
Pain	82	72.7 (24.2)	69.9 (25.5)	.751	<.001
Daily activity	82	88.0 (19.6)	86.3 (19.6)	.730	<.001
Treatment	82	63.2 (23.8)	66.0 (25.0)	.694	<.001
Communication	63*	71.4 (28.5)	71.0 (29.8)	.551	<.001
Worry	63*	73.0 (25.4)	74.5 (24.3)	.328	<.01
Symptoms:					
Pain	82	1.81 (2.37)	2.36 (2.53)	.809	<.001
Stiffness	82	1.95 (2.35)	2.29 (2.49)	.724	<.001
Fatigue	82	3.37 (2.88)	2.84 (2.61)	.685	<.001

* smaller n on these subscales as they are not completed for children aged <5 years
QoL Scales 0-100 – a higher score signifies a better quality of life e.g. a higher score on pain signifies less frequent pain-related problems
Symptoms 10cm VAS, a higher score signifies more severe symptoms in the past week

Table 3. Intra-class correlations between mothers' and fathers' illness and treatment beliefs

	Mother mean (SD)	Father mean (SD)	Intra class correlation	p
Illness Perceptions Questionnaire-Revised (IPQ-R) subscales:				
Treatment control	3.05 (.46)	3.06 (.34)	.661	<.001
Consequences for parent	3.03 (.80)	3.00 (.84)	.590	<.001
Consequences for child	3.12 (.77)	3.24 (.68)	.584	<.001
Child's emotional representation	2.84 (.70)	2.87 (.71)	.440	<.001
Parent's emotional representation	3.42 (.78)	3.19 (.71)	.440	<.001
Timeline cyclical	3.29 (.92)	3.05 (.89)	.438	<.001
Coherence to parent	3.70 (.92)	3.62 (.67)	.437	<.001
Coherence to child	2.98 (.57)	2.98 (.61)	.318	.002
Timeline (acute/chronic)	3.03 (.31)	3.01 (.32)	.281	.005
Child's personal control	2.76 (.44)	2.80 (.40)	.199	.036
Parent's personal control	3.32 (.68)	3.21 (.66)	.192	.041
Treatment Representations Inventory(TRI) subscales:				
Cure	3.57 (.65)	3.55 (.59)	.616	<.001
Decision satisfaction	3.89 (.44)	3.77 (.49)	.465	<.001
Concerns	3.45 (.70)	3.40 (.65)	.427	<.001
Value	4.12 (.44)	4.11 (.48)	.397	<.001

Scale 1-5, higher scores = stronger belief in ability of treatment to control the illness, more severe consequences, more severe emotional response, stronger belief in an unpredictable disease timeline, more coherent, belief in a longer disease duration, greater sense of personal control over the illness, stronger belief in power of treatment to cure the illness, greater satisfaction with treatment decisions, greater concerns about treatment, stronger belief in the value of treatment.

Table 4. Significant correlations (p<.01) difference between fathers and mothers on evaluation of child's QoL

Discordance in:	Physical QoL	Psychosocial QoL
VAS Pain	-.289	ns
VAS Stiffness	-.290	ns
Treatment concerns	ns	-.309
Belief about disease uncertainty	ns	-.288
Belief about emotional impact on child	-.299	ns
Parental depressed mood	-.309	ns
Parental age	**ns**	**ns**
Parental years education	**ns**	**ns**

Table 5. Multiple regression analyses

		Discordance in Physical QoL			**Discordance in Psychosocial QoL**		
Block	**Predictor variables** Discordance in:	β	t	Adj R^2	β	t	Adj R^2
1	*Symptoms*			.11			
	Pain	**-.237**	**-2.291***		-	-	
	Stiffness	.185	1.848		-	-	
2	*Illness beliefs*			.14			.14
	Emotional impact on child	-.169	-1.604		**-.260**	**.2.520***	
	Timeline cyclical	-	-				
	Treatment beliefs	-	-		**-.294**	**-2.847****	
	Concerns						
3	*Mood*			.21			
	Depression	**-.274**	**-2.704****		-	-	

* p<.05, ** p<.01
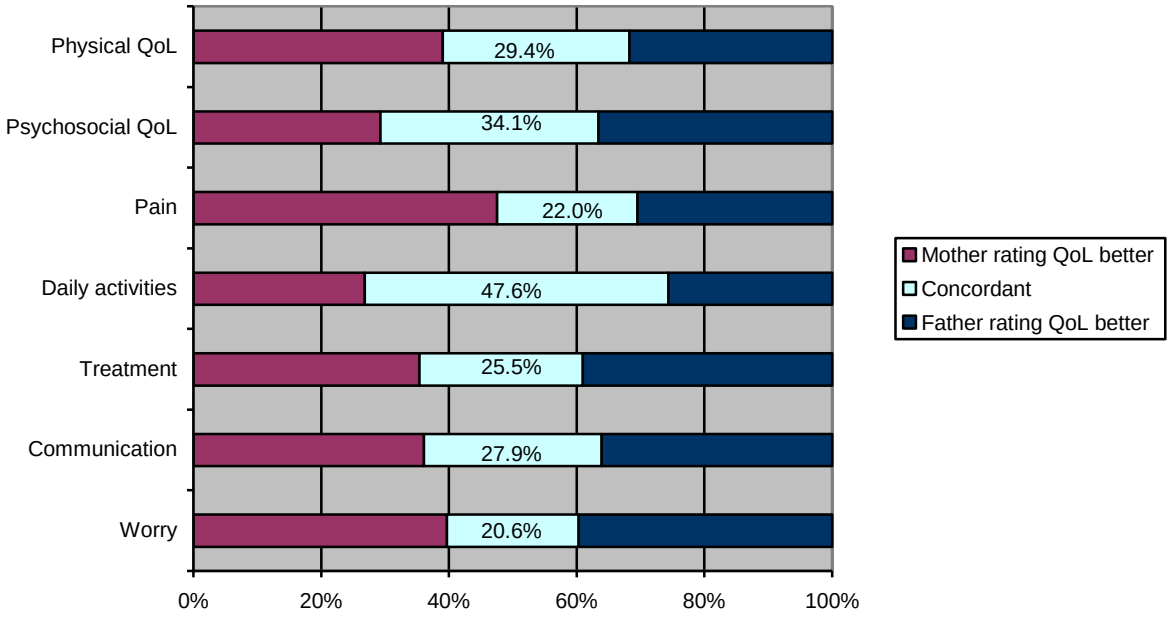
Figure 1. Difference between parents in ratings of child's Quality of life