

Running head: QoL in Adolescents with a Disability and their
Parents

Quality of Life in Adolescents with a Disability and their
Parents: The Mediating Role of Social Support and Resilience

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Abstract

The aim of this study was to test whether the effect of the pile-up of demands associated with a disability on quality of life, was mediated by resilience, quantity and quality of social support for adolescents with a disability and their parents. One hundred and thirty two parents, 90 mothers and 42 fathers and 111 adolescents, aged between 16 and 24 years completed measures of the pile-up of demands, social support, resilience and quality of life. Structural equation modeling with the bootstrap resampling method showed that the impact of the disability of their son/daughter on the quality of life of the parents was fully mediated through the parents' resilience and the quantity of social support and that resilience, however only partly, mediates the effect of adaptive skills on the quality of life of the adolescents with a disability. Limitations of the study and clinical implications are discussed.

Quality of Life in Adolescents with a Disability and their
Parents: The Mediating Role of Social Support and Resilience

One of the core notions in the systemic approach is that families form an interactive and interdependent system where what happens to one family member will also affect all the other members of the system (Goldenberg & Goldenberg, 2003; Turnbull & Turnbull, 2001). The disability of a child is such an event that will affect the whole family. Compared to families with typically developing children, a child with a disability poses specific challenges. A multitude of adverse effects of a disability on the family have been found, including higher levels of stress, lower well-being, more negative feelings on parenting, less marital satisfaction, a financial and a caretaker burden (Baker, Blacher, & Olsson, 2005; Blacher & McIntyre, 2006; Hatton & Emerson, 2003; Hunfeld et al., 2001; Maes, Broekman, Dosen, & Nauts, 2003; McIntyre, Blacher, & Baker, 2002; Wilkinson et al., 2001). However, research in families with a child with a disability is inconclusive regarding the impact of the disability on the family. Other studies in families of children with a disability recognize the positive effects these children can have on their family members, including better parent-child interactions, more family cohesion and a stronger life purpose

(Flaherty & Glidden, 2000; Glidden, Bamberger, Turek, & Hill, 2010; Green, 2007; Hastings & Taunt, 2002; Kearney & Griffin, 2001; Taanila, Jarvelin, & Kokkonen, 1999). Thus some families seem to do well despite the extra stressor of the disability of their child, while others struggle and succumb.

There is a large body of literature suggesting several individual and family characteristics that are positively related to the family's adaptation to a child with a disability. Social support, resilience, good family cohesion, effective coping skills and positive cognitive appraisals might all influence the potential negative impact of the disability on the family (Lavee, Hamilton, & Patterson, 1985; Saloviita, Itälina, & Leinonen, 2003; Taanila et al., 1999; Tak & McCubbin, 2002).

It has become apparent that individual and family outcomes due to the impact of a pile-up of demands associated with living with a disability are the result of multiple factors interacting with each other. Therefore a multivariate model incorporating both psychological and social variables that could intervene between the stressor and the outcome is needed. The double ABCX model of McCubbin and Patterson (1983) is one of the most influential theoretical frameworks in this field. The model provides a theoretical basis for examining the effect of a stressor and pile-up of demands (factor aA) on the family adaptation (factor XX) through the

mediation of the existing and expanding family recourses (factor bB), the meaning the family assigns to their situation (factor cC), and the coping strategies employed by the family (factor BC) (Jacques, 2006; McCubbin & Patterson, 1983), whereby mediation should be understood as the process through which a predictor affects a dependent variable indirectly through at least one intervening variable or mediator (Preacher & Hayes, 2008). The double ABCX model formed the theoretical base for the present study, although we did not aim to provide a true model test.

To date, several studies have suggested that resilience and social support positively mediate the effect of a disability on personal and family adaptation (Bromley, Hare, Davison, & Emerson, 2004; Heiman, 2002; Holland & Holahan, 2003; Norizan & Shamsuddin, 2010; Pakenham, Samios, & Sofronoff, 2005; Rolland & Walsh, 2006; Tak & McCubbin, 2002; Weiss, 2002). Resilience has long since been seen as an important factor protecting against life's perils, giving individuals the strength to overcome stressors (Rutter, 1987; Walsh, 2003). Recent conceptual analysis has defined resilience as the process of effectively adapting to significant sources of stress through the use of individual or environmental resources that facilitate the capacity of "bouncing back" in the face of adversity (Windle, 2011, p. 163). Congruent with Windle (2011), resilience is seen as a

adaptation process and not as an adaptation outcome.

Therefore in our model it appears at the same level as the other process variable, namely social support. Social support has been shown to be one of the most important family resources (McCubbin & Patterson, 1983). The literature on social support emphasizes the distinction between the quantity of social support (= amount of actual received support) and the quality of social support (= satisfaction with actual received support) (Haber, Cohen, Lucas, & Baltes, 2007; Renty & Roeyers, 2007). Although both are deemed important, quality of social support is generally considered the stronger predictor of personal wellbeing (Haber et al., 2007; Kessler & McLeod, 1985).

The adaptation of families with a child with a disability has been thoroughly studied. Yet the present paper attempts to complement the existing literature on two accounts. First, most of the research has been executed from a mother's perspective (Seligman & Darling, 2007), since mothers generally are the primary caregivers. Still this practice ignores the fact that family members are mutually interdependent and that a stressor or crisis will have an impact on all family members. Therefore the present study focuses on the adaptation of both parents and children with a disability and on possible differences in the adaptation of these family members. Second, in most disability outcome

studies the outcome has been operationalized in terms of adaptation of the family members, with adaptation ranging on a continuum from negative "maladaptation" to balanced "bonadaptation". Adaptation has been predominantly measured through the stress and psychosomatic symptoms those mothers experience (Saloviita et al., 2003). However, the well-being of family members is more than the absence of negative aspects such as stress. The quality of life concept gives a more comprehensive measure of the family members' well-being (Jozefiak, Larsson, Wichstrøm, & Matthejat, 2010; Turnbull, Poston, Minnes, & Summers, 2007). Therefore we chose to use quality of life as the outcome measure in this study. In international literature, consensus prevails that quality of life is a universal, multidimensional concept containing both an objective and a subjective component (Cummins, 1997; Schalock et al., 2002; Schalock & Felce, 2004). Within the scope of this study we adhere to the definition by Cummins (1997):

Quality of life is both objective and subjective, each axis being the aggregate of seven domains: material well-being, health, productivity, intimacy, safety, community, and emotional well-being. Objective domains comprise culturally-relevant measures of objective well-being. Subjective domains comprise domain satisfaction weighted by their importance to the individual. (p.6)

In sum, the purpose of this study is to test whether the effect of the pile-up of demands associated with a disability on quality of life is mediated by resilience, quantity and quality of social support for adolescents with a disability and their parents. Based on previous research we expect the quality of life of adolescents with a disability and their parents to be lower than the population average, especially on the objective dimension (Cummins, 2005; Sands & Kozleski, 1994). Additionally, we expect to find a negative relation between the pile-up of demands associated with a disability and quality of life and we hypothesize that this relationship will be mediated by resilience and social support, especially quality of social support.

Method

Procedure

The families of adolescents with a disability participating in this study were participants in a larger research project of the Centre of Expertise for Welfare, Public Health and Family commissioned by the Ministry of the Flemish Community (Department of Welfare, Public Health and Family). Families ($N = 912$) of adolescents (16-24 years old) registered by the Flemish Agency for Disabled Persons (FADP) were selected to participate in this study. Registration by the FADP is required to have access to support services. One hundred and

seventy six families participated in the present study. In each family one of the parents and the adolescent with a disability, sometimes assisted by a proxy¹, were asked to complete a set of questionnaires. Adolescents and parents were free to participate: in some families ($N = 65$) only a parent participated and in others ($N = 44$) only the adolescent with a disability completed the questionnaires. Therefore we have two levels with individual participants who are nested within the families. The participants completed an elaborate Internet-based query as part of the research project of the Centre of Expertise for Welfare, Public Health and Family. Because of comparability, all studies of the research project were asked to use the same measurements where possible. In order to keep the workload as low as possible the length of the questionnaires was a major criterion in the selection of the measures.

Participants

The participating sample consisted of 132 parents, 90 mothers and 42 fathers, ranging in age from 37 to 68 years ($M = 48.97$, $SD = 5.71$) and 111 adolescents, 65 boys and 46 girls, their ages ranging from 16 to 24 years old ($M = 19.40$, $SD = 2.27$). The majority of the participants are from intact families (78.8% of the parents and 83.6 % of the adolescents with a disability). The types and severity of the disability of the

adolescents were singular physical disabilities (47.2%), singular intellectual disabilities (6.7%), multiple physical disabilities (13.5%) or multiple intellectual disabilities (32.6%). The parents in our sample had a son/daughter with a singular physical disability (44.6%), a singular intellectual disability (9.2%), a multiple physical disability (11.5%) or a multiple intellectual disability (34.6%). Physical disabilities are somewhat overrepresented in our sample, most likely due to the fact that we also asked the adolescents with a disability to participate.

Measures

Pile-up of demands

Two concepts were used to assess the pile-up of demands associated with a disability: (1) the adaptive skills of the adolescent with the disability; and (2) the impact of the disability on the caregiver and family.

The adaptive skills of the adolescent with a disability were measured using a 15-item scale based on the frequently used and psychometrically sound Supports Intensity Scale (SIS, Thompson et al., 2004). Ten of the SIS items referencing the

Activities of Daily Living (ADL) most frequently studied in several other existing ADL-scales (e.g., washing, dressing, using the bathroom, eating, etc.) were maintained, the remaining 39 items were recapitalized in five items in order to minimize the workload (e.g., the items of the life-long learning subscale were recapitalized under in the item school and learning). For every item the respondents had to fill in if the adolescent could do the activity: *completely autonomous, autonomous with the exception of some small aspects, needed assistance but could do some parts of it, or was totally dependent on others for this activity or if the activity was not applicable*. The sum score of the 15 items is used as a total score of adaptive skills. Cronbach's alpha's in this study were .95 for the parents as well as for the adolescents with a disability.

The Caregiver Reaction Assessment (CRA, Given et al., 1992; van Exel, Brouwer, van den Berg, Koopmanschap, & van den Bos, 2004) aims to assess the informal caregivers' experiences with the perceived impact of providing support to a family member. Logically, only the parents completed this questionnaire. The scale contains 24 items on five subscales; four scales measuring burden: disrupted schedule, financial problems, lack of family support and health problems (e.g., "my activities are centered around the care for my son/daughter";

"caring for my son/daughter puts a financial strain on me"; "it is very difficult to get help from my family in taking care of my son/daughter"; "my health has gotten worse since I've been caring for my son/daughter"). The fifth subscale measures the possible positive aspects of caregiving (e.g., "I feel privileged to care for my son/daughter"). All items are rated on a five-point Likert scale (ranging from *completely disagree* to *completely agree*). Subscale scores are the average of the item scores, ranging from 1 to 5. Analogous to Grov, Fosså, Tønnessen, and Dahl (2006), we establish a CRA total score for the parents, reflecting the total caregiver situation. In order to calculate the total CRA score the 24 items were summed after inversely recoding the positive impact subscale, so that a high score would indicate a negative impact of caring for a child with a disability the same as with the other subscales. This CRA total score could be interpreted as a dimensional scale of the caregiver situation where higher scores reflect the experience of a higher burden. In the present sample Cronbach's alpha for the total scale was .81.

Social support

Quantity of social support of both the parents and the adolescents was measured by the Medical Outcome Study Social Support Survey (MOS-SSS, Sherbourne & Stewart, 1991). The MOS-

SSS is a 19-item measure of perceived availability of social support that was developed as part of the Medical Outcome Study. The availability of the 19 functional forms of support (e.g., How often is each of the following kinds of support available to you if you need It: someone whose advice you really want; someone to help you if you were confined to bed; someone who shows you love and affection; and someone to get together with for relaxation) is rated on a five-point Likert scale (ranging from *none of the time* to *all of the time*). The MOS-SSS consists of four subscales: emotional/informational, tangible, affectionate, and positive social interactions. Summed scores on these four scales indicate an overall quantity of the social support. The reliability of this survey as measured by Cronbach's alpha was .96 for parents and .95 for adolescents with a disability.

The quality of social support was measured using one item of the Belgian Health Interview Survey (Demarest et al., 2001) addressing satisfaction with received social support. The quality of people's social support was rated on a four-point Likert scale (ranging from *really satisfying* to *really unsatisfying*).

Resilience

Resilience of both parents and adolescents with a disability was measured using a questionnaire constructed for a campaign ("fit in je hoofd") of the Flemish government (Willaert & Van den Brande, 2008). The scale, conceptually related to the Resilience Scale (RS-NL, Portzky, Wagnild, De Bacquer, & Audenaert, 2010; RS, Wagnild & Young, 1993), showed sound psychometric properties (Willaert & Van den Brande, 2008). The resilience of the respondents is measured through 14 items (e.g., "I deal with my problems"; "I can count on myself") which are rated on a five-point Likert scale (ranging from *totally disagree* to *totally agree*). Higher scores indicate higher levels of resilience. In this study the alpha coefficient was .90 for parents and .86 for adolescents with a disability.

Quality of life

The Comprehensive Quality of Life Scale (ComQoL, Cummins, 1997) is a multidimensional measure that evaluates quality of life (QoL) both on an objective and subjective subscale.

Quality of life is measured across seven broad domains:

Material Well-being, Health, Productivity, Intimacy, Safety, Place in Community, and Emotional Well-being. The subjective QoL or satisfaction with each domain is rated on a 10-point Likert scale (ranging from *delighted* to *terrible*). Objective

scores are calculated through the sum of the three items for each domain (e.g. ' "How many times have you seen a doctor over the past three months?"; "How often do you talk with a close friend?"; "How often do you sleep well?"). Alpha coefficients for the subjective dimension were .89 for the parents and .83 for the adolescents with a disability. Similar to other studies (Cummins, 1997) we found the Cronbach's alpha of the objective dimension of QoL to be lower than that of the subjective dimension (.72 for the parents and .62 for the adolescents)².

Method of analysis

All analyses were performed using the statistical package Mplus (Muthén & Muthén, 1998-2010). Preliminary to the analyses, missing data were imputed through multiple imputation by the R-package "mi" (Gelman, Hill, Su, Masanao, & Pittau, 2011). This resulted in 10 imputed³ data sets. Correlations were performed to examine the bivariate relationship between the pile-up of demands (impact of the disability and adaptive skills of the adolescent) and the well-being of the respondents (objective and subjective QoL). To test the mediation model, structural equation modeling was used. Structural equation modeling allows us to decompose the total effect of one variable onto another into a direct and

one - or more - indirect effects (Preacher & Hayes, 2008). This test, together with a graphical representation of the effects, provides an insight into if and how a third variable mediates the effect of one variable onto another. Given our causal assumptions, structural equation modeling shows us the different effects in the model, examines these effects separately and tests the likelihood of the whole model.

Given our relatively small sample and the complexity of the mediation model with multiple mediators, the bootstrap resampling method was used to test the proposed mediators (Shrout & Bolger, 2002). A significant indirect effect in the model indicates mediation through that variable. To perform correct hypothesis tests the bootstrap procedure repeatedly samples ($N = 500$) from the original data set and estimates the indirect effects in each of the resampled data sets (Preacher & Hayes, 2008). Separate analyses were conducted for the data of the parents and the adolescents and for both outcome variables (subjective QoL and objective QoL)⁴.

Results

Means and standard deviations are provided for each measure in Table 1. Participants' scores for subjective and objective QoL were compared with the "gold-standard" population averages in Western societies (Cummins, 1997; 1998). The mean score for

the subjective QoL of the parents was within the normal range between 70 and 80. The mean subjective QoL of the adolescents with a disability fell below the "gold-standard". However, the variance of the subjective QoL scores was rather large for parents as well as for adolescents with a disability. When individual scores were compared to the "gold-standard", 37.12% of the parents and 42.61% of the adolescents with a disability fell below the normal range and therefore showed low subjective QoL. The mean scores for objective QoL of the parents and the adolescents were significantly lower than the mean (71.8) found in a norm group of adults from all major geographic regions (Cummins, 1997; 1998).

INSERT TABLE 1 ABOUT HERE

Preliminary analyses were conducted to determine whether the independent and dependent variables varied as a function of demographic information. Gender and age of the adolescents and gender of the parents were significantly associated with the (in)dependent variables. However, none of them was found to confound the results significantly; considering the small sample size we chose not to include these variables in the tested model.

Intercorrelations among the variables in the model

Bivariate associations between the pile-up of demands and the objective and subjective QoL were explored using Pearson's correlations (Table 2). With respect to the QoL of the parents, the analyses revealed that a higher perceived impact of the disability of their child was related with less QoL on the objective ($r = -.21, p = .001$) as well as the subjective dimension ($r = -.26, p = .012$). The adaptive skills of their son/daughter with a disability were not significantly related with the objective nor with the subjective QoL of the parents. However, the adaptive skills correlated rather high with the perceived impact of the disability ($r = -.39, p < .001$). The analysis demonstrated, that for the adolescents, less adaptive skills were moderately correlated with lower levels of quality of life, both objectively ($r = .30, p = .004$) and subjectively ($r = .43, p = .063$).

INSERT TABLE 2 ABOUT HERE

Model tests

Parents

The goodness of fit indices suggested that the tested model (Figure 1)⁵ provided a good fit for the objective QoL data ($\chi^2 = 2.72, p = .256$; CFI = .99; RMSEA = .05). With the exception of the RMSEA, the goodness of fit indices suggested our model (Figure 2) also provided a good fit for the subjective QoL data ($\chi^2 = 5.52, p = .063$; CFI = .97; RMSEA = .11). The models

explained respectively 36% and 53% of the variance in objective and subjective quality of life.

INSERT FIGURE 1 AND 2 ABOUT HERE

Examining the mediation model for objective quality of life, we see that the perceived impact of the disability of their son/daughter is significantly related to the quantity of social support ($\beta = -.39, p < 0.001$) and to the parents' resilience ($\beta = -.27, p = .007$). The adaptive skills of their son/daughter are significantly related to the quantity of social support ($\beta = -.18, p = .046$) but not to any of the other proposed mediator variables. The quantity of social support ($\beta = .35, p < 0.001$) and resilience ($\beta = .30, p < 0.001$) are significantly associated with the objective dimension of quality of life. Mediators are indicated by the coefficients of the indirect effects in the model. The relation between the perceived impact of the disability of their son/daughter and the objective quality of life of the parents is fully mediated by the quantity of social support ($\beta = -.14, p = .013$) and the parents' resilience ($\beta = -.08, p = .036$). No mediators are found for the link between the adaptive skills of their son/daughter and the objective QoL of the parents (β ranged from $-.01$ to $-.07, p > 0.10$).

The mediation model generates very similar results when considering the parents' subjective QoL. Since all the

variables in this model are the same as in the previously tested model, with the exception of the dependent variable, the associations between perceived impact of the disability, adaptive skills, resilience and quantity and quality of social support are exactly the same as in the previous model. All three proposed mediator variables, quantity ($\beta = .29, p = 0.001$) and quality of social support ($\beta = .22, p = 0.005$) and resilience ($\beta = .45, p < 0.001$) are significantly associated with the parents' subjective QoL. As with objective QoL, the relationship between perceived impact of the disability of their son/daughter and the subjective quality of life of the parents is fully mediated by both quantity of social support ($\beta = -.11, p = .023$) and resilience ($\beta = -.17, p = .047$). None of the proposed mediators mediate the association between the adaptive skills of their son/daughter and subjective QoL (β ranged from $-.01$ to $-.06, p > 0.10$).

Adolescents

In both models (Figure 3 and 4) tested for the adolescents we had to relax one of our constraints to improve the model's fit. We chose to free the path from the adolescents' adaptive skills on both dimensions of QoL. This left us with no degrees of freedom, resulting in two fully saturated models. Therefore the goodness of fit indices can't help in the

assessment of the model fit. The two models nevertheless still provide us with the opportunity to formally test the indirect or mediation effects through a series of regressions. Following Bollen (1989), we evaluate the saturated models on the sign and the significance of the coefficient estimates and the R^2 s⁶. The models explained respectively 48 % and 64% of the variance in objective and subjective quality of life.

Insert Figure 3 and 4 about here

Examining the model for objective QoL of the adolescents with a disability, we see that their adaptive skills are significantly related to the adolescents' resilience ($\beta = .51$, $p < 0.001$) and the quantity of social support ($\beta = -.20$, $p = 0.05$). Resilience ($\beta = .43$, $p < 0.001$) and the quantity of social support ($\beta = .34$, $p = 0.001$) are significantly associated with the objective QoL. Resilience partly mediates ($\beta = .22$, $p = 0.005$) the relation between the adolescents' adaptive skills and the objective dimension of their QoL.

Concerning the model on the adolescents' subjective QoL, the associations between adaptive skills, resilience and quantity and quality of social support are exactly the same as for the model presented earlier. Resilience is the only proposed mediator variable that is significantly associated

with the adolescents' subjective QoL ($\beta = .73, p < 0.001$). As with objective QoL the relationship between the adaptive skills of the adolescent with a disability and their subjective QoL is partly mediated through resilience ($\beta = .37, p = 0.002$).

Discussion

The purpose of this study was to test whether the effect of the pile-up of demands associated with a disability on quality of life was mediated by resilience, quantity and quality of social support for adolescents with a disability and their parents.

On average, parents of a child with a disability perceive their quality of life as satisfactory although on the objective dimension they score below what we can expect in the global population. Adolescents with a disability, on the other hand, show a rather low quality of life, both subjectively and objectively. The difference between parents and adolescents illustrate the importance of studying them separately. However, the QoL scores of both adolescents and their parents revealed quite a large range. The next question is, therefore, what predicts these variations?

Congruent with previous studies (Han, 2003; Olsson & Hwang, 2008; Patrick, Kinne, Engelberg, & Pearlman, 2000), the perceived impact of the disability of the adolescent was

inversely related with objective and subjective parental QoL. Less adaptive skills were significantly related with lower QoL for the adolescent on the objective dimension. However, somewhat unexpectedly the adaptive skills of their son/daughter were not significantly related to parental QoL. Considering the strong correlation between the adaptive skills of the son/daughter and the perceived impact of the disability, it might be that the proposed relationship is confounded by the perceived impact of the disability. This is in line with the finding that the effect of the pile-up of demands on adaptation is stronger than that of the initial stressor (Lavee et al., 1985; Renty & Roeyers, 2007).

Our results confirmed for the most part the mediating role of resilience and social support found in previous studies (Alriksson-Schmidt, Wallander, & Biasini, 2007; Bromley et al., 2004; Heiman, 2002; Holland & Holahan, 2003; Norizan & Shamsuddin, 2010; Pakenham et al., 2005; Rolland & Walsh, 2006; Tak & McCubbin, 2002; Weiss, 2002). The effect of the impact of the disability of their son/daughter on the QoL of the parents is fully mediated through the parents' resilience and the quantity of social support. It is through the negative effect on the resilience and the amount of received social support that the impact of the disability influences the parental QoL. Resilience only partially mediates the effect of adaptive skills on both dimensions of QoL for

adolescents. A direct effect of their adaptive skills on their QoL remains. Quantity of social support does not mediate the negative effect on adolescents' QoL, although it remains important as it directly enhances their objective QoL. Although quality of social support is generally considered the stronger predictor of personal wellbeing (Haber et al., 2007; Kessler & McLeod, 1985), we find no mediating and few direct effects of the quality of social support on the two dimensions of QoL. This could, however, be a methodological artifact as quality of social support was only measured through a single item, potentially revealing less differential effect than other constructs.

In sum, our results generally confirmed the well-studied mediating role of resilience and social support and complement the literature in at least two ways. First, we studied parents as well as adolescents with a disability themselves and found differences between them in both the kind of mediators and the amount of mediation. Second, as wellbeing is more than the absence of negative aspects such as stress, we used QoL as the outcome measure, operationalized through both a subjective and an objective measure. Subjective QoL alone has been shown to be insufficient to report the quality of specific living conditions (Hatton & Ager, 2002; Schalock & Felce, 2004). Our results for the parents subscribed to this reasoning, since they showed a rather precarious objective QoL

whilst on average showing normal levels of subjective QoL. Cummins (2001) explains this discrepancy from a homeostatic perspective. Here, subjective wellbeing is considered to be influenced by personality factors and cognitive buffering processes maintaining it within a narrow, positive range for each individual person. Therefore it is seen as stable to external changes and over time, unless the situational changes are sufficiently aversive to defeat the homeostatic processes.

Although this study makes some interesting contributions to the existing literature, some limitations need to be noted. First, our sample size was rather small, leading us to make some pragmatic choices such as not including demographic variables or latent constructs in our models. Future research could benefit from testing the models with larger samples of mothers, fathers and adolescents with a disability. Second, the cross-sectional design of the present study does not allow us to make conclusions regarding causality. A longitudinal study is needed to assert the QoL over time and to assert the temporal and causal relations between the constructs. Third, as mentioned before, the use of a single item measure of the quality of social support might have impacted the results. In future studies a more nuanced measure of quality of social support is needed. Fourth, our sample was made up of adolescents with a disability and one of their parents. Caution is therefore needed in generalizing the findings of

this study to children with a disability in a different age range and their parents. Future research might focus on children with a disability from a different age range or might even aim to search for differences in the adaptation process of children with a disability and their parents from different ages.

Despite these limitations, the findings of this study yield some important research and clinical implications. In sum, our findings illustrate the importance of focusing not only on the aversive effects of a disability but also on more positive outcomes such as wellbeing. Moreover, the significance of studying the influence of a disability on several family members separately instead of only through the mother is endorsed. Furthermore, our results suggest that resilience and social support quantity are mediators of the negative effect of the pile-up of demands associated with living with a disability on QoL and can therefore play an important buffering role. The importance of the buffering role of these variables for practitioners working with families with an adolescent with a disability lies in their susceptibility to change. Measures specifically directed at improving the resilience of families with an adolescent with a disability and expanding the social networks of these families can be taken to positively influence their QoL. First, practitioners in school and healthcare systems should take

measures specifically directed at improving the resilience of adolescents with a disability and their families. Daniel and Wassell (2002) suggest measures on six domains to positively influence adolescents' resilience: (1) offering a secure base for attachment; (2) providing possibilities for training and education; (3) supporting friendships; (4) drawing on the adolescent's talents and interests; (5) focusing on positive values and (6) promoting social competencies. Interventions directed at improving family resilience should focus on three key processes: family belief systems; organizational patterns; and; communication/problem-solving (Walsh, 2003). Second, practitioners and services should take measures to expand the social networks of adolescents with a disability and their families. This seems especially important since persons with a disability and their family members are known to have smaller social networks and are at risk for social isolation (Forrester-Jones et al., 2006; Hodapp, 2002; Robertson et al., 2001).

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Appendix

Addaptive skills scale as constructed for this study

Respond for every activity below how much help the adolescent needs to complete this activity succesful.

	Completely autonomous	Autonomous with the exception of some small aspects	Needs assistance but can do some parts of it	Totally dependent on others	not applicable
Personal hygiene	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Getting dressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Moving (transferring from one place to another)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Using the bathroom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Eating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Housekeeping/cleaning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Taking care of own clothing (washing, ironing)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Running	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

errands/Shopping					
Preparing a meal	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Leisure activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Activities in the community (e.g. visiting friends, going to the movies,...)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Going to school	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Working	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Minding own health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Building and maintaining social relationships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

References

- Alriksson-Schmidt, A. I., Wallander, J., & Biasini, F. (2007). Quality of life and resilience in adolescents with a mobility disability. *Journal of Pediatric Psychology*, 32(3), 370-379. doi: 10.1093/jpepsy/jsl002
- Baker, B. L., Blacher, J., & Olsson, M. B. (2005). Preschool children with and without developmental delay: behaviour problems, parents' optimism and well-being. *Journal of Intellectual Disability Research*, 49(8), 575-590. doi: 10.1111/j.1365-2788.2005.00691.x
- Blacher, J., & McIntyre, L. L. (2006). Syndrome specificity and behavioural disorders in young adults with intellectual disability: cultural differences in family impact. *Journal of Intellectual Disability Research*, 50(3), 184-198. doi: 10.1111/j.1365-2788.2005.00768.x
- Bollen, K. A. (1989). *Structural Equations with Latent Variables*. New York: Wiley.
- Bromley, J., Hare, D. J., Davison, K., & Emerson, E. (2004). Mothers supporting children with autistic spectrum disorders. *Autism*, 8(4), 409-423. doi: 10.1177/1362361304047224
- Cummins, R. A. (1997). *Comprehensive Quality of Life Scale—Intellectual/cognitive disability. Manual, 5th edition*. School of Psychology, Deakin University. Melbourne.
- Cummins, R. A. (1998). The second approximation to an international standard for life satisfaction. *Social Indicators Research*, 43(3), 307-334. doi: 10.1023/A:1006831107052
- Cummins, R. A. (2001). Living with support in the community: Predictors of satisfaction with life. *Mental Retardation & Developmental Disabilities Research Reviews*, 7(2), 99-104. doi: 10.1002/mrdd.1014

- Cummins, R. A. (2005). Moving from the quality of life concept to a theory. *Journal of Intellectual Disability Research*, 49, 699-706. doi: 10.1111/j.1365-2788.2005.00738.x
- Daniel, B., & Wassell, S. (2002). *Adolescence: Assessing and promoting resilience in vulnerable children*. Londen: Jessica Kingsley.
- Demarest, S., Van der Heyden, J., Gisle, L., Buziarsist, J., Miermans, P., Sartor, F. (2001). Gezondheidsenquête door middel van Interview, België. Retrieved May, 2011, from Wetenschappelijk Instituut Volksgezondheid <http://www.iph.fgov.be/epidemiologie/epinl/crospnl/hisnl/table01.htm>
- Flaherty, E. M., & Glidden, L. M. (2000). Positive adjustment in parents rearing children with Down Syndrome. *Early Education and Development*, 11, 407-422. doi: 10.1207/s15566935eed1104_3
- Forrester-Jones, R., Carpenter, J., Coolen-Schrijner, P., Cambridge, P., Tate, A., Beecham, J. (2006). The social networks of people with intellectual disability living in the Community 12 Years after resettlement from long-stay hospitals. *Journal of Applied Research in Intellectual Disabilities*, 19(4), 285-295. doi: 10.1111/j.1468-3148.2006.00263.x
- Gelman, A., Hill, J., Su, Y.-S., Masanao, Y., & Pittau, M. G. (2011). mi: Missing Data Imputation and Model Checking. R package version 0.09-14., from <http://CRAN.R-project.org/package=mi>
- Given, C. W., Given, B., Stommel, M., Collins, C., King, S., & Franklin, S. (1992). The caregiver reaction assessment (CRA) for caregivers to persons with chronic physical and mental impairments. *Research in Nursing & Health*, 15(4), 271-283. doi: 10.1002/nur.4770150406

- Glidden, L. M., Bamberger, K. T., Turek, K. C., & Hill, K. L. (2010). Predicting mother/father-child interactions: Parental personality and well-being, socioeconomic variables and child disability status. *Journal of Applied Research in Intellectual Disabilities, 23*(1), 3-13. doi: 10.1111/j.1468-3148.2009.00549.x
- Goldenberg, I., & Goldenberg, H. (2003). *Family therapy: an overview* (6th ed.). Pacific Grove, CA: Brooks/Cole.
- Green, S. E. (2007). "We're tired, not sad": Benefits and burdens of mothering a child with a disability. *Social Science & Medicine, 64*(1), 150-163. doi: 10.1016/j.socscimed.2006.08.025
- Grov, E. K., Fosså, S. D., Tønnessen, A., & Dahl, A. A. (2006). The Caregiver Reaction Assessment: psychometrics, and temporal stability in primary caregivers of Norwegian cancer patients in late palliative phase. *Psycho-Oncology, 15*(6), 517-527. doi: 10.1002/pon.987
- Haber, M., Cohen, J., Lucas, T., & Baltes, B. (2007). The relationship between self-reported received and perceived social support: A meta-analytic review. *American Journal of Community Psychology, 39*(1), 133-144. doi: 10.1007/s10464-007-9100-9
- Han, H.-R. (2003). Korean mothers' psychosocial adjustment to their children's cancer. *Journal of Advanced Nursing, 44*(5), 499-506. doi: 10.1046/j.0309-2402.2003.02833.x
- Hastings, R. P., & Taunt, H. M. (2002). Positive perceptions in families of children with developmental disabilities. *American Journal on Mental Retardation, 107*(2), 116-127. doi: 10.1352/0895-8017(2002)107<0116:PPIFOC>2.0.CO;2
- Hatton, C., & Ager, A. (2002). Quality of life measurement and people with intellectual disabilities: a reply to Cummins. *Journal of Applied Research in Intellectual*

- Disabilities*, 15(3), 254-260. doi: 10.1046/j.1468-3148.2002.00124.x
- Hatton, C., & Emerson, E. (2003). Families with a person with intellectual disabilities: stress and impact. *Current Opinion in Psychiatry*, 16, 497-501. doi: 10.1097/00001504-200309000-00002
- Heiman, T. (2002). Parents of children with disabilities: Resilience, coping, and future expectations. *Journal of Developmental and Physical Disabilities*, 14(2), 159-171. doi: 10.1023/A:1015219514621
- Hodapp, R. M. (2002). Parenting children with mental retardation. In M. H. Bornstein (Ed.), *Handbook for parenting Vol.1. Children and parenting* (pp. 355-381). London: Lawrence Erlbaum.
- Holland, K. D., & Holahan, C. K. (2003). The relation of social support and coping to positive adaptation to breast cancer. *Psychology & Health*, 18(1), 15-29. doi: 10.1080/0887044031000080656
- Hunfeld, J. A. M., Perquin, C. W., Duivenvoorden, H. J., Hazebroek-Kampschreur, A. A. J. M., Passchier, J., van Suijlekom-Smit, L. W. A. (2001). Chronic pain and its impact on quality of life in adolescents and their families. *Journal of Pediatric Psychology*, 26(3), 145-153. doi: 10.1093/jpepsy/26.3.145
- Jacques, R. (2006). Family issues. *Psychiatry*, 5(10), 337-340. doi: 10.1053/j.mppsy.2006.08.011
- Jozefiak, T., Larsson, B., Wichstrøm, L., & Mattejat, F. (2010). Quality of Life as reported by children and parents: a comparison between students and child psychiatric outpatients. *Health and Quality of Life Outcomes*, 8, 136. doi: 10.1186/1477-7525-8-136
- Kearney, P. M., & Griffin, T. (2001). Between joy and sorrow: Being a parent of a child with developmental disability.

- Journal of Advanced Nursing*, 34, 582-592. doi: 10.1046/j.1365-2648.2001.01787.x
- Kessler, R., & McLeod, J. (1985). Social support and psychological distress in community surveys. In S. Cohen & S. Syme (Eds.), *Social support and health* (pp. 19-40). New York: Academic Press.
- Lavee, Y., Hamilton, I. M., & Patterson, J. M. (1985). The double ABCX model of family stress and adaptation: An empirical test by analysis of structural equations with latent variables. *Journal of Marriage and the Family*, 47(4), 811-825. doi: 10.2307/352326
- Maes, B., Broekman, T. G., Dosen, A., & Nauts, J. (2003). Caregiving burden of families looking after persons with intellectual disability and behavioural or psychiatric problems. *Journal of Intellectual Disability Research*, 47(6), 447-455. doi: 10.1046/j.1365-2788.2003.00513.x
- McCubbin, H. I., & Patterson, J. M. (1983). The family stress process: The Double ABCX Model of adjustment and adaptation. In H. I. McCubbin, M. B. Sussman & J. M. Patterson (Eds.), *Social Stress and the Family: Advances and Developments in Family Stress Theory and Research* (pp. 7-37). New York, NY: Haworth Press.
- McIntyre, L. L., Blacher, J., & Baker, B. L. (2002). Behaviour/mental health problems in young adults with intellectual disability: the impact on families. *Journal of Intellectual Disability Research*, 46(3), 239-249. doi: 10.1046/j.1365-2788.2002.00371.x
- Muthén, L. K., & Muthén, B. O. (1998-2010). *Mplus User's Guide*. Sixth Edition. Los Angeles, CA: Muthén & Muthén.
- Norizan, A., & Shamsuddin, K. (2010). Predictors of parenting stress among Malaysian mothers of children with Down syndrome. *Journal of Intellectual Disability Research*, 54, 992-1003. doi: 10.1111/j.1365-2788.2010.01324.x

- Olsson, M. B., & Hwang, C. P. (2008). Socioeconomic and psychological variables as risk and protective factors for parental well-being in families of children with intellectual disabilities. *Journal of Intellectual Disability Research*, 52(12), 1102-1113. doi: 10.1111/j.1365-2788.2008.01081.x
- Pakenham, K. I., Samios, C., & Sofronoff, K. (2005). Adjustment in mothers of children with Asperger syndrome. *Autism*, 9(2), 191-212. doi: 10.1177/1362361305049033
- Patrick, D. L., Kinne, S., Engelberg, R. A., & Pearlman, R. A. (2000). Functional status and perceived quality of life in adults with and without chronic conditions. *Journal of Clinical Epidemiology*, 53(8), 779-785. doi: 10.1016/S0895-4356(00)00205-5
- Portzky, M., Wagnild, G., De Bacquer, D., & Audenaert, K. (2010). Psychometric evaluation of the Dutch Resilience Scale RS-nl on 3265 healthy participants: a confirmation of the association between age and resilience found with the Swedish version. *Scandinavian Journal of Caring Sciences*, 24, 86-92. doi: 10.1111/j.1471-6712.2010.00841.x
- Preacher, K. J., & Hayes, A. F. (2008). Asymptotic and resampling strategies for assessing and comparing indirect effects in multiple mediator models. *Behaviour research methods*, 40(3), 879-891. doi: 10.3758/BRM.40.3.879
- Renty, J., & Roeyers, H. (2007). Individual and marital adaptation in men with autism spectrum disorder and their spouses: The role of social support and coping strategies. *Journal of Autism and Developmental Disorders*, 37(7), 1247-1255. doi: 10.1007/s10803-006-0268-x

- Robertson, J., Emerson, E., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A. (2001). Social networks of people with mental retardation in residential settings. *Mental Retardation*, 39(3), 201-214. doi: 10.1352/0047-6765(2001)039<0201:SNOPWM>2.0.CO;2
- Rolland, J. S. a., & Walsh, F. b. (2006). Facilitating family resilience with childhood illness and disability. *Current Opinion in Pediatrics*, 18(5), 527-538. doi: 10.1097/01.mop.0000245354.83454.68
- Rutter, M. (1987). Psychosocial resilience and protective mechanisms. *American Journal of Orthopsychiatry*, 57(3), 316-331. doi: 10.1111/j.1939-0025.1987.tb03541.x
- Saloviita, T., Itälänmäki, M., & Leinonen, E. (2003). Explaining the parental stress of fathers and mothers caring for a child with intellectual disability: a Double ABCX Model. *Journal of Intellectual Disability Research*, 47(4-5), 300-312. doi: 10.1046/j.1365-2788.2003.00492.x
- Sands, D. G., & Kozleski, E. B. (1994). Quality of life differences between adults with and without disabilities. *Education and Training in Mental Retardation and Developmental Disabilities*, 29, 30-101.
- Schalock, R. L., Brown, I., Brown, R., Cummins, R. A., Felce, D., Matikka, L. (2002). Conceptualization, measurement, and application of Quality of Life for persons with intellectual disabilities: Report of an international panel of experts. *Mental Retardation*, 40(6), 457-470. doi: 10.1352/0047-6765(2002)040<0457:CMAAOQ>2.0.CO;2
- Schalock, R. L., & Felce, D. (2004). Quality of life and subjective well-being: conceptual and measurement issues. In E. Emerson, C. Hatton, T. Thompson & T. Parmenter (Eds.), *The international handbook of applied research in intellectual disabilities* (pp. 261-279). Chichester, UK: Wiley.

- Seligman, M., & Darling, R. (2007). *Ordinary families, special children: A systems approach to childhood disability*. New York: the Guilford press.
- Sherbourne, C. D., & Stewart, A. L. (1991). The MOS social support survey. *Social Science & Medicine*. doi: 10.1016/0277-9536(91)90150-B
- Shrout, P. E., & Bolger, N. (2002). Mediation in experimental and nonexperimental studies: New procedures and recommendations. *Psychological methods*, 7(4), 422-445. doi: 10.1037//1082-989X.7.4.422
- Taanila, A., Jarvelin, M. R., & Kokkonen, J. (1999). Cohesion and parents' social relations in families with a child with disability or chronic illness. *International Journal of Rehabilitation Research*, 22(2), 101-110. doi: 10.1097/00004356-199906000-00004
- Tak, Y. R., & McCubbin, M. (2002). Family stress, perceived social support and coping following the diagnosis of a child's congenital heart disease. *Journal of Advanced Nursing*, 39(2), 190-198. doi: 10.1046/j.1365-2648.2002.02259.x
- Thompson, J. R., Bryant, B., Campbell, E. M., Craig, E. M., Hughes, C., Rotholz, D. (2004). *Supports Intensity Scale*. Washington, DC: American Association on Mental Retardation.
- Turnbull, A. P., Poston, D. J., Minnes, O., & Summers, J. A. (2007). Providing supports and services that enhance a family's quality of life. In I. Brown & M. Percy (Eds.), *A comprehensive guide to intellectual and developmental disabilities* (pp. 561-571). Baltimore: P.H. Brookes.
- Turnbull, A. P., & Turnbull, H. R. (2001). *Families, professionals, and exceptionality* (4th ed.). Upper Saddle River, NJ: Merrill/Prentice Hall.

- van Exel, N. J. A., Brouwer, W. B. F., van den Berg, B., Koopmanschap, M. A., & van den Bos, G. A. M. (2004). What really matters: an inquiry into the relative importance of dimensions of informal caregiver burden. *Clinical Rehabilitation, 18*(6), 683-693. doi: 10.1191/0269215504cr743oa
- Wagnild, G. M., & Young, H. M. (1993). Development and psychometric evaluation of the Resilience Scale. *Journal of Nursing Measurement, 1*(2), 165-178.
- Walsh, F. (2003). Family resilience: A framework for clinical practice. *Family Process, 42*(1), 1. doi: 10.1111/j.1545-5300.2003.00001.x
- Weiss, M. J. (2002). Hardiness and social support as predictors of stress in mothers of typical children, children with autism, and children with mental retardation. *Autism, 6*(1), 115-130. doi: 10.1177/1362361302006001009
- Wilkinson, B. J., Newman, M. B., Shytle, R. D., Silver, A. A., Sanberg, P. R., & Sheehan, D. (2001). Family impact of Tourette's syndrome. *Journal of Child & Family Studies, 10*(4), 477-483. doi: 10.1023/A:1016713508665
- Willaert, K., & Van den Brande, I. (Producer). (2008). Valideringsstudie Vlaams publiekscampagne 'Fit in je hoofd'. Validiteit en betrouwbaarheid van de zelfbeoordelingstest. Retrieved from <http://www.iswlimits.be/isat/website/publicatie2.pdf>
- Windle, G. (2011). What is resilience? A review and concept analysis. *Reviews in Clinical Gerontology, 21*, 152-169. doi: 10.1017/S0959259810000420

Footnotes

¹ Concerning data validity, family members acting as proxy for the adolescent with a disability only completed the objectively identifiable measures.

² This difference in internal consistency would contraindicate comparison of the results of objective and subjective QoL. However, as we make no such comparison in terms of goodness of fit or strength of correlations, this has no implications for our analyses.

³ Hierarchical regression analyses were carried out on the unimputed data; this did not generate significantly different results.

⁴ Parents' QoL proved to be independent of adolescents' QoL, $r = -.01$ for subjective QoL and $r = .19$ for objective QoL.

⁵ In all model tests the mediating variables were allowed to correlate. However, as they are not important for the hypotheses, the estimated correlation coefficients are not represented in the figures in order not to clutter them.

⁶ In contrast to Bollen (1989, p.116), it is impossible to evaluate the coefficient of determinancy due to the multiple imputation technique.

Table 1 Descriptives for Measures of the Model Predictors and Outcomes.

Variables	Parents			Adolescents	
	<u>Min-Max</u>	<u>Mean</u>	<u>SD</u>	<u>Mean</u>	<u>SD</u>
Disability					
Adaptive skills	0-60	35.71	15.50	38.39	14.46
Perceived impact	1-5	2.82	0.59		
Social support					
Quantity	18-90	67.81	14.39	70.75	14.52
Quality	1-4	3.05	0.63	2.88	0.78
Resilience	14-70	39.02	8.85	30.46	10.94
Quality of Life					
Subjective	0-100	72.68	17.02	65.97	22.30
Objective	0-100	56.99	10.34	54.32	9.58

Table 2 Correlation matrix for Predictors and Outcome variables.

Variables	Parents							Adolescents						
	1	2	3	4	5	6	7	2	3	4	5	6	7	
1 Perceived impact	___							___	___	___	___	___	___	
2 Adaptive skills	-.39***	___						___						
3 Quantity of social support	-.31***	-.03	___					-.20*	___					
4 Quality of social support	.14	-.04	.45***	___				.26	.23	___				
5 Resilience	-.25**	.08	.30**	.26*	___			.51***	.26*	.36*	___			
6 Objective QoL	-.21*	-.10	.50***	.37**	.44***	___		.30**	.24	.33**	.61***	___		
7 Subjective QoL	-.26**	-.11	.53***	.47***	.60***	.65***	___	.43	.45***	.25	.77***	.56***	___	

* $p < .05$; ** $p < .01$.; *** $p < .001$.

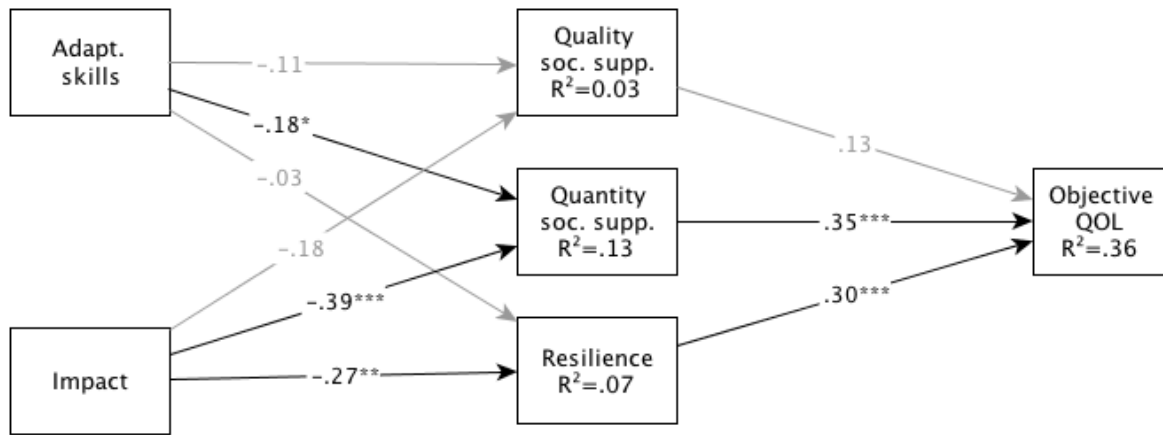


Figure 1: Mediation model tested for parents objective QoL

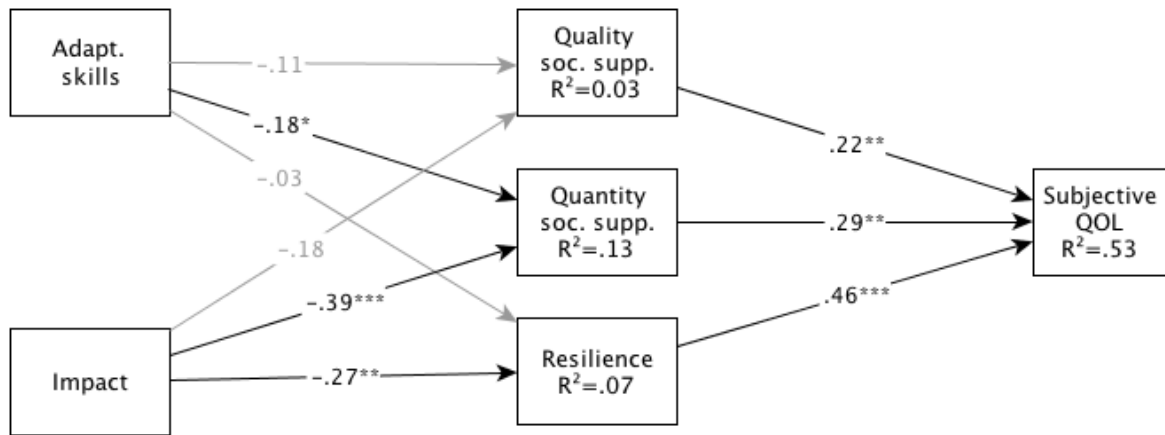


Figure 2: Mediation model tested for parents subjective QoL

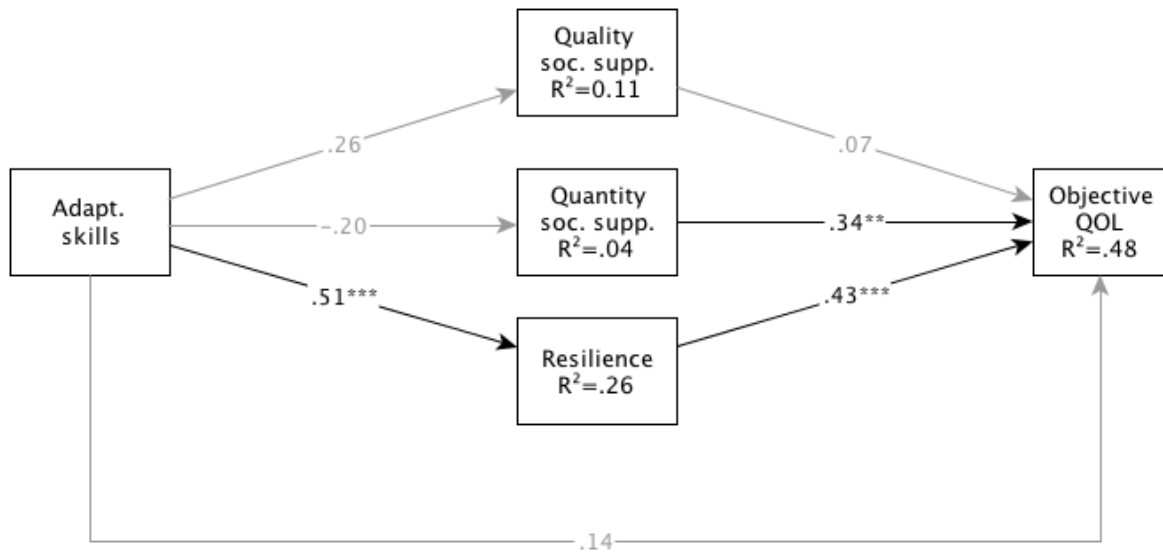


Figure 3: Mediation model tested for adolescents objective QoL

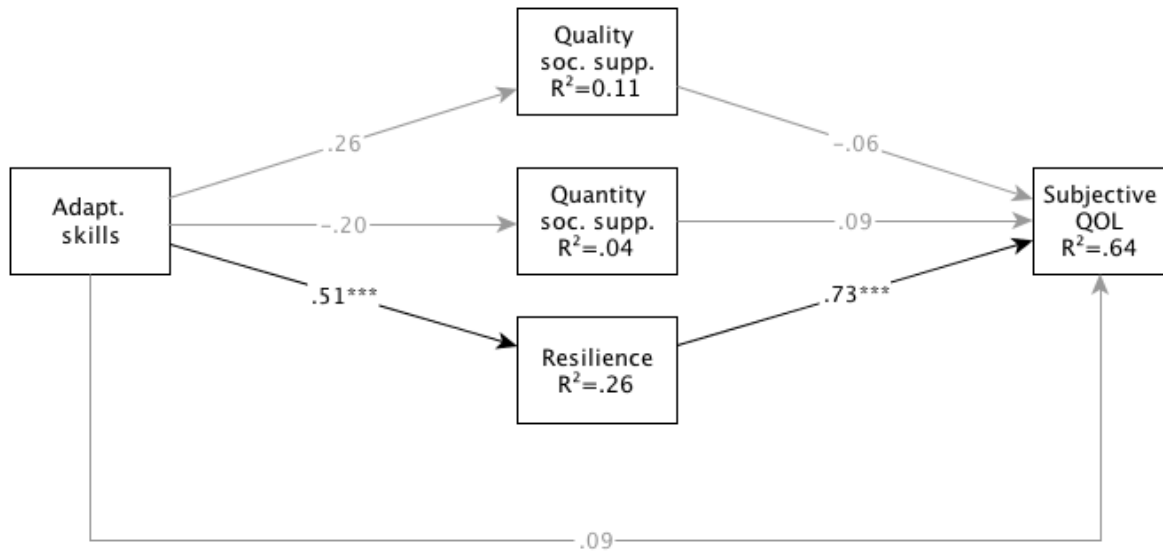


Figure 4: Mediation model tested for adolescents subjective QoL

