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Parents Living with HIV in China:

Family Functioning and Quality of Life

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Abstract

In China, HIV shifts the lifestyle of not only parents living with HIV/AIDS, but also their children, partners, and extended families. We examined factors related to the quality of life of parents living with HIV and the relation between family functioning and individual quality of life. Interviews were conducted with a total of 116 parents living with HIV/AIDS. Analyses of variance, Pearson correlations, and multiple regression analyses were performed to examine the relation between family functioning and quality of life. We found a significant association between family functioning and individual quality of life for parents living with HIV. In particular, family sociability had a strong relationship with the quality of life of parents living with HIV. Parents living with HIV from families where both parents are HIV-positive reported a lower level of family sociability than those from families with only one HIV-positive parent. HIV disclosure, family sociability, and number of children per family were found to be significant predictors of overall quality of life for the population. Study findings underscore the importance of developing interventions that improve family functioning for people living with HIV/AIDS in China.

Keywords

Parents; HIV/AIDS; China; Family functioning; Quality of life

Introduction

The epidemic of HIV/AIDS has spread dramatically in China since the first AIDS case was identified in 1985. By 1998, HIV had reached all 31 provinces and was in a phase of exponential growth. There are currently 650,000 people living with HIV in China, many of whom are parents (China Ministry of Health 2006). When a parent is infected, the impact of HIV radiates throughout the family (Bor et al. 1993; Pequegnat et al. 2001; Rotheram-Borus et al. 2005; Schuster et al. 2000) and influences the next generation (Rotheram-Borus et al. 2001; Wekesa 2000), especially in a family-oriented society such as China (Li et al. 2006; Yang et al. 2006). Parents living with HIV (PLH) must not only cope with their own physical health symptoms, complex medication regimens, stigma, and fear of AIDS-related death, but must also care for their family (Armistead and Forehand 1995; Gwadz et al. 1999; Herek and Capitanio 1993; Lee and Rotheram-Borus 2001; Rotheram-Borus et al. 2003). Such

responsibilities and challenges have the potential to severely impact PLH's quality of life, family relations, and social network.

Previous studies have demonstrated that a PLH's quality of life can be affected by several factors. In order to maintain good health, PLH must frequently visit their health providers and adhere to their medication regimen. Mannheimer et al. (2005) showed that adherence to antiretroviral therapy is associated with better quality of life. Many PLH are not able to work because of poor physical health, creating significant economic hardship (United Nations General Assembly 2005). In addition, individuals with chronic illness experience a great deal of psychological stress. Parents with HIV/AIDS report greater distress than parents with other illnesses (Zayas and Romano 1994). PLH also often face tremendous social pressures and discrimination. In the southeastern United States, stigma towards HIV-infected women limits daily functioning and lowers their quality of life (Sowell et al. 1997). PLH in Cambodia have reported poorer quality of life due to isolation caused by stigma and discrimination (Geurtsen 2005). A study in China showed that companies fired employees because they tested HIV-positive (Cao et al. 2005). The combination of the increasing cost of healthcare for PLH and decreasing family income caused by unemployment may hinder access to basic goods such as food, housing, medication, and education for children ("AIDS Mothers" 2004).

PLH's family relationships can also be affected. Families with chronically ill parents experience more strains than families without an ill parent (West et al. 1991). Chronic illness in the parent can change family roles and isolate family members from each other, causing anger or guilt (Hudgens 1979). In a family affected by HIV/AIDS, the spouse of a PLH experiences the added burden of caretaking demands, which can cause the spouse to feel depressed and to perceive his/her marriage in a negative light (Lewis et al. 1989). The ability of HIV-positive parents to care for their children is also impaired, while poverty induced by HIV/AIDS increases the risk of illness and death among children (Wekesa 2000). When parents are not capable of contributing to housework or providing financial stability because of illness, further burden will rest on their children, who are expected to contribute to the family, either through help with work around the house or monetary support through work outside the house, depending on their age (Stein et al. 1999). This situation affects traditional family roles. In Chinese families, the typical role of an adult is to be a head of the household and a productive person who cares for children and aging parents (Hudgens 1979). Chronic illness reverses this culturally prescribed role, requiring the children to care for the ill adult (Chin and Kroesen 1999). This can significantly strain the relationship between parents, other caregivers and children. Therefore, HIV shifts life patterns not only for PLH, but also for their partners, children, and extended families (Asia News 2005; Lu et al. 2006; United Nations Children's Fund 2004; Wu et al. 2004).

Family relationships also have an impact on a PLH's quality of life. In a study in Thailand, participants reported that family relationships had the greatest influence on their individual quality of life (Jongudomkarn and Camfield 2006). Similarly, HIV-positive men in Taiwan who reported a lack of family support also reported poorer quality of life, indicating the importance of family encouragement and assistance in overall well-being (Yen et al. 2004). Close personal relationships within the family and support from family members contribute directly to improved mental and physical health of chronically ill individuals (Lang 2000). Conversely, family conflict has been shown to be associated with emotional distress (Leslie et al. 2002). Previous studies also reported that family cohesiveness and family sociability contributed to less psychological distress and fewer psychiatric symptoms in mothers with HIV infection (Mellins et al. 2000; Murphy et al. 2002).

The relation between HIV, family functioning, and quality of life have not been well documented in China. This study is the first systematic investigation of the physical, mental,

and social well-being of parents living with HIV in China. The goal of this investigation was to examine the quality of life for parents living with HIV/AIDS in China and its relationship with family functioning. We examined PLH's self-reports of quality of life and family functioning indicators as well as the association between demographics, family functioning, and quality of life.

Method

Data Collection

We collected data from a province in Eastern China with high HIV prevalence, where most existing HIV infections (over two-thirds) were caused by paid plasma donations (Wu et al. 1995, 2001). This region consists of many poor rural counties and a large population of over 63 million people. In 2005, it was estimated that there were between 10,000 and 49,999 HIV-infected individuals living in this area (Lu et al. 2006). The majority of people living with HIV are between the ages of 20 and 50, and the ratio of men to women infected with HIV is roughly equal. Because the spread of HIV through plasma donation primarily occurred in the early 1990s, many HIV-infected individuals are married and have children currently (Ji et al. 2006).

The study participants consisted of parents living with HIV with children from 6 to 18 years of age. Participants were either recruited from the hospital or clinic where they received healthcare services or referred by other PLH already recruited for the study. Recruitment strategy included word-of-mouth and handing out flyers advertising a "Children and Family Health Study." All parents were 18 years of age or older. Interviews were conducted by local project staff at either a community building or the participant's home. A total of 116 parents participated in the face-to-face semi-structured interviews between April and June 2006.

Study protocol, survey instruments, and informed consent forms and procedures were reviewed and approved by the Institutional Review Boards (IRB) of the collaborating sites in the United States and China. Individual informed consent was obtained from participants prior to the survey, and \$7 was given to each study participant for his/her participation.

Measures

The family health survey questionnaire, compiled specifically for this project, contained a total of 147 questions assessing participants' demographics, physical health, mental health, quality of life, family relations, and family experience with HIV/AIDS.

Demographics and Family Background

The demographic information collected in this study included participants' age, gender, education, marital status, occupation, and income. Family background information included the number of children and how many family members were HIV-positive. Disclosure of HIV serostatus was assessed by asking the question, "Have you told others about your/your family member's HIV status?" The participant and spouse's health status was measured with the questions, "What is your health status?" and "What is the child's father (mother)'s health status?" the latter referring to the participant's spouse. If the participant answered "Ill" or "Dead" regarding their spouse, we asked, "What is the illness?" or "What was the cause of death?", accordingly. Using this information, we grouped the participant's family HIV status into three categories: (1) the participant being HIV-positive, the spouse negative, both alive; (2) both the participant and spouse being HIV-positive, both alive; and (3) both the participant and spouse HIV-positive, the spouse having died of HIV.

Quality of Life

Quality of life is defined by the World Health Organization (WHO) as “individuals’ perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards, and concerns” (WHO 1995). In this study, quality of life (QoL) was measured using the Chinese version of the Short Form of the WHO Quality of Life questionnaire (WHOQOL-BREF; WHO 2004). This is a 26-item questionnaire developed from the original 100-item questionnaire, the WHOQOL-100 (WHOQOL Group 1998). The WHOQOL-BREF is an international cross-culturally comparable quality of life assessment instrument and has the same ability as the WHOQOL-100 to discriminate between healthy and sick individuals. Over a 2- to 8-week period, test-retest reliability for the four domains was generally high (0.66-0.87) (WHO 1998). The WHOQOL-BREF has been translated into 19 different languages (WHO 1996). Its validity has been tested among Chinese population and it is proved to be suitable for use in multinational collaborative researches (Jiang et al 2004). The measurement covers four domains, including seven items for physical health, six for psychological health, three for social relationships, and eight for environment domain. Each individual item of the WHOQOL-BREF is scored from 1 to 5 on a response scale. The score of each subscale is the sum of scores from each item within that subscale. The score of the overall quality of life scale is the sum of the scores from the four domains. Higher scores indicate better quality of life. In a validation study conducted among Taiwan-Chinese population, all of the four domains showed high internal consistency (Cronbach alpha range: 0.73-0.81) (Huang et al. 2006). For this study population, the Cronbach alpha values calculated for physical, psychological, social, environmental, and overall quality of life were 0.72, 0.66, 0.55, 0.63 and 0.84, respectively.

Family Functioning

Bloom’s (1985) self-report measures of family functioning based on prior family assessment instruments, is one of the most comprehensive measures available to assess characteristics of family functioning (Grotevant and Carlson 1987). It has been used successfully to differentiate intact versus divorced families (Bloom 1985) and has adequate psychometric properties and discriminant validity (Bloom 1985; Bloom and Naar 1994; Grotevant and Carlson 1987). The original scale is a 75-item survey consisting of 15 scales reflecting family relationship, system maintenance, and personal growth dimensions. For this study, three subscales (family conflict, family cohesion, and family sociability) were chosen based on study interests and culture appropriateness. Each of the subscales consists of five items. For each item, participants were asked to rate how true each statement was for their own family on a 4-point Likert scale. A higher score indicates better family functioning. The Cronbach alpha values for the cohesion, and sociability scales were 0.84 and 0.76, respectively. The Cronbach alpha for the original family conflict scale was as low as 0.54, so one item (“*family members hardly ever lose their tempers*”) was dropped from for conflict scale. This step has increased the Cronbach alpha to 0.62.

Data Analysis

SAS statistical software (Version 9.1) was used for data analyses. First, we descriptively analyzed the distribution of demographics and family background information. Second, we calculated the mean score of each of the four quality of life domains and the mean score of overall quality of life. Differences of these scores were compared between groups with different demographics and family backgrounds using t tests (for independent variable with two levels) or ANOVA (for independent variable with more than two levels). Third, Pearson correlation coefficients were calculated to investigate relationships between the quality of life domains and family functioning scales. Last, three multiple regression models were performed with the family cohesion score, family conflict score and family sociability score. We began with seven

candidate variables, including all the demographic and family background factors. Regression analysis was also conducted with the overall quality of life score. The candidate variables included demographics, family background, and family functioning scores. Then the subset regression method was used to identify the best subset of variables for these four models from a large of number of possible combinations (So et al. 2006). For the variables selected by the model selection procedure, standardized regression coefficients and their significance levels were reported.

Results

Participant Characteristics

Slightly over half of the parent participants were women, and most parents were 45 years old or younger (87.9%). As shown in Table 1, most PLH participants in the study had little or no education, and almost half of the parents were illiterate. The main occupation for parents was farming, with 89% working at least part-time as farmers. More than a third of the families had two children (38.8%), and 43.1% had three or more children in the family. More than half of the families (52.4%) had an annual income of less than 2,501 RMB (\$320). In nearly 60% of the families, both parents were HIV-positive, and in 15.7% of the families one parent had died from AIDS. More than half the participants (52.6%) had disclosed their HIV status to others. Among the 61 participants who disclosed, 60 (98.4%) disclosed to family members, 36 (59.0%) to friends, 34 (55.7%) to health care providers, and 11 (18.0%) to neighbors and/or relatives. The most important reason for not telling was fear of discrimination. The children in this study had a mean age of 13.5 years. 26% of the children were between age 6 and 12. Among all the children, 56% were male, two out of 154 children were HIV positive, and 12% were currently not attending school.

Quality of Life and Family Background

The results of mean comparisons of quality of life by demographic and family background variables are summarized in Table 1. PLH with more children in their family reported significantly lower levels of overall quality of life ($P < 0.05$). Not surprisingly, PLH with more serious family HIV status reported significantly lower quality of life ($P < 0.01$). PLH from families in which the spouse died from AIDS reported the lowest level of quality of life, while PLH from families in which the spouse was HIV-negative reported the best quality of life, compared to the other two groups.

The physical QoL was significantly associated with family income and family HIV status ($P < 0.01$). PLH from families that had lower family income and that were more impacted by HIV reported lower physical QoL scores. The psychological QoL subscale was significantly associated with gender ($P < 0.05$). Mothers living with HIV reported lower psychological QoL scores than the father counterparts. The social QoL subscale was significantly associated with family HIV status ($P < 0.01$). As the impact of HIV on the family increased, PLH were more likely to report a lower level of social QoL. The environmental QoL was significantly correlated with the number of children in the family ($P < 0.001$). Parents with more children in the family reported a lower level of environmental QoL.

Family Functioning and Quality of Life

Correlation coefficients between indicators of quality of life and measures of family functioning, including the family conflict, family sociability, and family cohesion subscales, are presented in Table 2. The family sociability subscale was significantly correlated with all the QoL indicators ($P < 0.001$). The family conflict subscale was negatively correlated with the psychological ($P < 0.05$), social ($P < 0.01$), and environmental ($P < 0.01$) subscales of QoL as well as the overall QoL ($P < 0.01$). Family cohesion was positively correlated with both the

social and environmental subscales ($P < 0.05$) and negatively correlated with the family conflict subscale ($P < 0.01$).

The results of multiple regressions are presented in Table 3. All the demographics and family background variables have gone through the subset regression procedure to identify the best subset of variables for the family conflict, family cohesion, and family sociability regression models. The standardized regression coefficients and the significance levels of the selected variables are reported in the first three columns. Those PLH who reported disclosure of HIV status to other people reported a lower level of family conflict ($\beta = -0.305$; $P < 0.05$). Education was found to be a predictor for family sociability ($\beta = 0.286$; $P < 0.01$), as PLH with higher education tended to report a higher level of family sociability. Those from families where both parents were HIV-positive reported a lower level of family sociability compared with those from families with only one HIV-positive parent ($\beta = -0.282$; $P < 0.01$).

Results of multiple regression analyses for overall quality of life are shown in the last column of Table 3. The full model has 10 candidate variables including family functioning indicators as well as demographic and family background variables. The subset regression suggests the three variables “age”, “both parents HIV+” and “family conflict” to be dropped from the full model. Number of children in the family was significantly negatively associated with the overall quality of life ($\beta = -0.228$; $P < 0.01$) when other variables were controlled. Those PLH who reported disclosure of HIV status to other people were more likely to report a higher level of quality of life than those who did not disclose ($\beta = 0.184$; $P < 0.05$). Family sociability remained strongly positively related to the quality of life score ($\beta = 0.659$; $P < 0.001$) while other variables were held constant. Approximately 65% of variations in the overall quality of life reported by PLH in the study were explained by this final model.

Discussion

We demonstrated that overall there is a strong association between family functioning and individual quality of life for this population. The family system’s concept of interdependency supports the link between family experience and individual well-being (Bloom 1985; Kantor and Neal 1985). The link is unique and important in China. Traditionally, China is a strongly family-oriented society where individuals rarely make decisions without first considering their family (Muller and Desmond 1992). Since families in China are tightly knit, good family functioning becomes an even more critical factor in an individual member’s wellbeing. Families living with HIV face many challenges that can compromise family functioning, such as health-seeking demands, treatment adherence, stress, financial difficulties, and stigma, both within and outside their families. During difficult times, it becomes particularly important for families to stay close and to help and support each other. If the family as a unit is able to successfully overcome these challenges, the quality of life for PLH and family members can be maintained.

Furthermore, we found that family sociability, as a particular aspect of family functioning, has an important relationship with PLH quality of life. Family sociability is defined as the extent to which a family seeks and derives gratification from social interactions with others (Bloom 1985). Chinese culture is highly social. Neighbors often know each other well and have a sense of community. It is not uncommon for families to go over to a friend’s house for dinner or to invite people over to their own homes. Family pride and fear of bringing shame to the family are pervasive motivation-guiding attitudes in Chinese culture (Postgraduate Medical Council 2006). HIV infection poses special challenges for families to function in accordance with this cultural expectation, making it difficult for HIV-affected families to remain integrated into society. Many HIV-affected families are ashamed of their association with the disease, fearing that others will scorn them (Li et al. 2006). The negative impact of HIV is also compounded

by the Chinese tradition of accepting illness stoically and hiding difficulties and hardship behind the family door. This impact of HIV on the family radiates to individual family members including the PLH who also feel shame and, subsequently, less integrated into his/her community. These feelings of isolation reduce the benefits of sociability and hinder adjustment to HIV/AIDS and, in effect, decrease the PLH's well-being. This may explain the strong positive association between family sociability and individual quality of life for this population.

Our study also showed that family sociability is related to the number of parents who are HIV positive. Families consisting of two HIV-positive parents demonstrated lower family sociability than families with one HIV-positive parent. Two explanations may be relevant. First, increased stigma could be associated with a family where both parents are infected; the family may be labeled as an "AIDS family" and is likely to be isolated by others, or the family may choose to be isolated to avoid discrimination. Second, when both parents are ill, there are more medical bills to be paid and an increased burden on the rest of the family, depending on the severity of their illnesses. This is compounded by decreased income due to the difficulty for both adults to work. The resulting decline in the family's financial situation along with increased psychological pressure may prevent the family from the desire to interact with others in the community.

Family burden is also relevant in explaining the finding that the number of children per family was negatively related to PLH quality of life. As the number of children in a family increases, the family burden increases as well. Time and money become scarcer as there are more children requiring the attention of adults. This could be the case in families not affected by HIV (Hesketh and Zhu 1997; Rona et al. 2003). In families living with HIV, resources are already very limited. With each additional child, the family's ability to cope worsens. This can have a detrimental effect on the family unit and on the PLH's mental health.

Moreover, we reported that HIV disclosure has a negative association with family conflict and a positive association with individual quality of life. Family conflict has been linked to negative health outcomes (Semple et al. 1997). The relationship between HIV disclosure and violence against women living with HIV, including being rejected by family, has also been examined (Gielen et al. 2000). Murphy et al. 2001 study reported beneficial effect of disclosure: mothers who disclosed HIV status to their children reported higher levels of social support than mothers who did not. Children who were informed of mother's HIV status displayed lower levels of aggressiveness and negative self-esteem compared to children who were not. In this study, we found that those PLH who disclosed their HIV status to family and others reported a lower level of family conflict than those PLH who did not disclose. It is reasonable to assume that if a PLH disclosed his or her HIV status to family members, there would be fewer secrets between family members; this in turn can reduce potential situations that can instigate conflict within the family. On the other hand, keeping HIV status hidden can be a huge burden on a PLH (Li et al. 2007), increasing anxiety and psychological pressure and leading to a decreased quality of life. However, with a cross-sectional design, the negative association between family conflict and disclosure might be of the other direction. The other possible explanation is that PLH who conceived less family conflict would be more likely to disclose his/her HIV status to the others.

There are some limitations to this study. First, it was conducted in an area with a large concentration of former plasma donors. Results may not be generalizable to HIV-positive individuals that were infected through other transmission routes. Second, our study uses a cross-sectional design which might suffer the limitation of all cross-sectional studies. We may not be able to make causal inferences due to the existence of temporal ambiguity. Third, the reliance on self-report measures, without including youth and/or other family members' perspectives may cause possible information bias. Fourth, only families that had children

between the ages of 6-18 were included in the study. Families with children younger than 6 may face different challenges and other factors may play a role in family functioning and a family member's quality of life. Fifth, the study sample size is not large enough to identify some true relationships. Last but not least, the low Cronbach alpha for some of the subscales is a limitation of the study. However, the validity of the measurement used in this study has been tested elsewhere among Chinese population previously and achieved high internal consistency. We speculate that the inadequate Cronbach alpha in this study is due to small sample size which affects the inter-item correlations.

The results of this study have implications for future HIV intervention in China. The new China policy of providing free anti-retroviral treatment for people with HIV/AIDS and the availability of HIV testing for high-risk groups will identify more families and parents living with HIV/AIDS. Programs and interventions that address the challenges that PLH and their families face and that build and strengthen family relations are needed. Advances in the understanding of family functioning and individual quality of life suggest that program developers and researchers should address the connection between individual and family well-being. Specifically, an intervention that helps parents living with HIV can strengthen the family as a unit, and the strengthening of family resiliency can also have a positive impact on the HIV-infected parents.

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Table 1
Quality of life (subscales and overall scale) by background demographic variables (N = 116)

	Percent (%)	Physical QoL	P	Psychological QoL	P	Social QoL	P	Environmental QoL	P	Overall QoL	P
Gender											
Male	46.6	20.93	0.054	15.85	0.027*	10.06	0.293	21.79	0.118	69.06	0.015
Female	53.4	19.43		14.56		9.65		20.68		64.22	
Age											
40 years or younger	43.1	20.72	0.417	15.10	0.876	9.58	0.441	20.48	0.233	65.87	0.893
41-45 years	44.8	19.69		15.11		10.11		21.67		11.35	
46 years or older	12.1	19.64		15.57		9.84		21.85		8.24	
Education											
Illiterate	48.2	19.48	0.308	14.29	0.147	9.91	0.661	20.12	0.060	63.83	0.237
Elementary not finished	34.1	20.93		15.41		9.76		21.48		67.38	
Elementary or higher	17.7	19.47		15.93		10.33		22.67		68.40	
Number of children in family											
One child	18.1	20.10	0.326	16.00	0.526	10.42	0.172	24.42	0.000***	71.68	0.029*
Two children	38.8	20.98		15.20		9.53		20.67		66.53	
Three children	29.3	19.41		14.82		10.15		20.84		65.12	
Four or more children	13.8	19.31		14.68		9.15		19.12		61.30	
Family annual income											
1,500 Yuan or less	32.4	19.32	0.009**	14.38	0.297	10.11	0.102	20.76	0.209	64.10	0.079
1,501-2,500 Yuan	20.0	18.33		15.1		9.00		21.85		64.28	
2,501-3,500 Yuan	21.9	20.74		15.26		9.73		20.09		65.90	
3,501 Yuan or more	25.7	22.00		15.97		10.38		22.18		70.73	
Family HIV status											
One HIV+, both alive	39.1	21.84	0.002**	15.84	0.196	10.49	0.002**	22.18	0.094	70.36	0.001**
Both HIV+, both alive	45.2	19.08		14.73		9.58		20.69		64.08	
One parent died	15.7	19.06		14.83		8.36		20.39		60.45	
HIV disclosute (N = 115)											
No	47.4	19.88	0.509	14.64	0.058	9.88	0.796	20.85	0.312	65.27	0.195
Yes	52.6	20.40		15.745		9.78		21.57		67.89	

* $P < 0.05$

** $P < 0.01$

*** $P < 0.001$

Table 2
Correlation coefficients among family functioning and quality of life variables

	2	3	4	5	6	7	8
1. Physical QoL	0.491***	0.387***	0.376***	0.792***	-0.086	0.376***	-0.223
2. Psychological QoL		0.434	0.453***	0.786***	-0.222*	0.361***	0.161
3. Social QoL			0.436***	0.655***	-0.258**	0.508***	0.232*
4. Environmental QoL				0.771***	-0.269**	0.500***	0.206*
5. Overall QoL					-0.270**	0.593***	0.181
6. Family conflict						-0.099	-0.247**
7. Family sociability							0.116
8. Family cohesion							

* $P < 0.05$

** $P < 0.01$

*** $P < 0.001$

Table 3
Multiple regressions on family functioning and overall quality of life

	Family conflict β	Family cohesion β	Family sociability β	Overall quality of life β
Female	-0.199	N/A	N/A	-0.127
Age	-0.115	-0.161	N/A	N/A
Years of education	-0.219	0.141	0.286**	-0.113
Number of children in family	N/A	0.179	N/A	-0.228**
Family income (Yuan/year)	0.123	-0.193	N/A	0.141
Both parents HIV+	0.173*	N/A	-0.282**	N/A
HIV disclosed	-0.305*	-0.169	N/A	0.184*
Family conflict			N/A	N/A
Family sociability				0.659***
Family cohesion				0.123
R^2	0.140	0.119	0.154	0.656

N/A: the variable is not selected by the subset regression

* $P < 0.05$

** $P < 0.01$

*** $P < 0.001$