## **Marshall University**

## **Marshall Digital Scholar**

Theses, Dissertations and Capstones

1997

# Religion and coping with chronic illness: a comparison of rural and urban communities

Christina Mullins

Follow this and additional works at: https://mds.marshall.edu/etd

Part of the Child Psychology Commons, Comparative Psychology Commons, Experimental Analysis of Behavior Commons, Human Factors Psychology Commons, Religion Commons, and the Social Psychology Commons

Religion and Coping with Chronic Illness:
A Comparison of Rural and Urban Communities

Thesis submitted to the Graduate School of Marshall University

In partial fulfillment of the requirements for the Degree of Master of Arts in Clinical Psychology.

by

Christina Mullins

Marshall University

Huntington, West Virginia

July 23, 1997

THIS THESIS WAS ACCEPTED ON July 23, 1997 as meeting the research requirement for the Master's degree.

Thesis Advisor Manaina Lato 27
Dept. Of Psychology

Thesis Committee Durks Milander Dept. of Psychology

Aheart Thomas Dept. of Psychology

### Table of Contents

	P	age
I.	Abstract	. 4
II.	Introduction	.5
	A. Effects of Chronic Illness on the Child	l
	and Family	.6
	B. Coping	.7
III.	Method	.10
	A. Subjects	.10
	B. Procedures	.10
IV.	Results	.11
V.	Discussion	.12
VI.	Tables	.15
	A. Table One	.15
	B. Table Two	.16
	C. Table Three	.17
VII.	References	.18
	Appendix A: Demographic Sheet	.21
	Appendix B: Belief Questionnaire	.24
	Appendix C: CICI:PQ	.26

### Abstract

This study compared 45 rural and urban families in their use of religion as a means of coping with the stress of a chronically ill child. Parents reported no differences between their actual use of religion as a means of coping. However, urban families were more likely to believe they should turn to their clergy for emotional support.

Religion and Coping with Chronic Illness:
A Comparison of Rural and Urban Communities

At least one fifth of the United States' population is rural (Sherman, 1992). The differences between rural and urban communities go beyond living in the "city" versus living in the "country". Not only are those who live in rural areas more likely to be poor and have less education than their urban counterparts (Sherman, 1992), but since they are spread out over large geographical regions they often have limited access to physicians and medical facilities as well.

In recent years health care in rural America has been an issue not only for the people living in these areas, but also for health providers and politicians. Rural Americans live in areas where there are few jobs, and as a result there may be little money to finance high quality medical care. In contrast, those who live in urban areas have better job opportunities, and are more likely to be in a position to afford good health care. Unfortunately, parents who reside in rural locations who are suffering or have a child suffering from an illness may find their problems are multiplied. They may find it difficult to travel to a doctor, or since there are fewer jobs in rural areas, may have difficulty affording care. Social support systems, such as family, friends, or support groups may also be difficult to utilize, because they are unavailable or located too far away to travel.

When any child is diagnosed with a chronic illness, such as cancer, spina bifida, or asthma, life changes for the whole family. The severity of the illness may differ, but regardless of the severity, the family members must learn to

cope with the demands that the illness will place on them as part of the family. Since the very nature of a chronic illness is that it is ongoing, families may not experience any relief from their situation. Some families may only have to deal with the inconvenience of doctor's appointments and medications, while others may eventually have to cope with the loss of the child. Each family will experience the illness of a child differently, but some type of adjustment will be common to all.

The adjustment that a rural family may have to make to a chronically ill child will be compounded by the greater distance and unavailability of medical care. In addition, the family may not live near support services. Overall, this could make living with chronic illness a greater burden for the family living in an rural area.

Effects of Chronic Illness on the Child and Family

It is important to examine how a child's illness will impact the functioning of the child and his/her family. The child's illness may present many new difficulties for him/her. The child may have to be hospitalized, endure painful medical procedures, miss school, and even face the possibility of death. One study suggested children with spina bifida may have difficulty developing independence, coping skills, and the ability to meet care needs (Monsen, 1992). These characteristics may be common to children with other types of illnesses. It is evident that these concerns will present problems for the child.

It is a challenge to balance the special care that the sick child needs with the everyday demands of life. These demands can make life difficult for one or both parents. For example, mothers often report feelings of depression. As a

result of these difficulties, parents may experience changes in their marriage. Dealing with these changes may cause more stress than the marriage can bear, resulting in divorce. On the other hand, some couples are brought closer together by the common stress (Varni and Wallander, 1988). Parents may also have to miss work which could create financial difficulties for the family, particularly if the absenteeism results in the loss of a job or failure to receive a promotion.

The ill child's siblings are also affected by the illness. They may feel worried or scared that something bad will happen to them or their brother/sister as well as displaced, unimportant, lonely, jealous, and neglected (Martinson, Gilliss, Colaizzo, Freeman, & Bossert, 1990), because their parents are so focused on the ill child.

#### Coping

As the family struggles to deal with the child's illness it becomes important to find ways to cope. Lefton (1991, p. 481) defines coping as the "Process by which a person manages environmental and internal demands that do or even might cause stress." The family with a chronically ill child must learn to cope with the medical concerns, changes in the family routine, as well as painful thoughts and emotions.

Some studies suggest that one of the first steps toward coping may be that all members of the family need to understand what is happening (Hymovich & Baker, 1985; Ritchie, Caty, & Ellerton, 1988). Ill children may find peer relations important in dealing with their illness (Monsen, 1992). Friends may help to provide support or simply help the child feel more like other children. They may also try to control events, reduce tension, protect themselves, and

accept or elicit help (Ritchie et al, 1988).

Some families may find support in friends, family, or even professionals, while others may rely heavily on religious beliefs and the church community. Most studies that have considered religion as a variable relating to health have pointed out that differing religious groups approach health and medicine differently (Schiller & Levin, 1988). However, fewer studies address whether religion is helpful in coping with illness. Throughout history, many people have believed that their faith is more effective than medicine in healing (Byrne, 1979). For example, the snake handlers of Appalachia may refuse medical aid if bitten, because they believe that God will heal them if they possess the necessary faith.

Religion is often associated with coping in stressful events such as death. Studies confirm that many people do find religion helpful in dealing with stressful life events (McIntosh et al., 1993; Carver et al., 1993; Leyser, 1994). Religion may help people suffering in stressful situations find meaning and/or understanding (Hall, 1994:; Dull & Skokan, 1995). It may provide a sense of control for sufferers, as well as optimism that somehow things will turn out for the best (Dull & Skokan, 1995). Spilka, Hood, & Gorsuch (1985) suggest that religion may be the only way to make sense of the pain and suffering. Church attendance may be a way for some families to meet with friends for emotional support, and some congregations may even offer financial assistance to offset medical expenses.

Ebmeier, Lough, Huth, & Autio (1991) suggest that a child's relationship with God may be helpful in coping with their illness. Children may see God as watching over and protecting them as well as helping and giving comfort. These

perceptions may help children relax and feel more comfortable when having to endure painful procedures or when they feel frightened.

In the past some clinicians have suggested that religion in itself may be pathological, while others have suggested that it may be important for good mental health (Ventis, 1995). The question still remains, however: should religious beliefs be included in treatment if the person perceives it as helpful?

For many years, it has been assumed that people who live in rural areas are more religious than their urban counterparts. In fact, Ford (1967) suggests that religion is so pervasive throughout southern Appalachian culture that it nearly impossible to consider any aspect of life without it. If this is true, would rural families with chronically ill children use religion as a way of coping more often than their urban counterparts? One study suggested that rural subjects caring for spouses with chronic illness use religion as part of a support system only moderately (Weinert & Long, 1993). However, this data was not directly compared to an urban population, which makes it difficult to determine whether there would have been a difference between the two groups.

If years of assumptions are not incorrect, people living in rural areas may use religion as a means of coping more than their urban counterparts. If true, this study should find that rural families utilize religion and religious organizations in coping with the demands of chronic illness more frequently than urban families. This information would be helpful to health care providers when making treatment plans that include treating the whole person/family.

This study compared rural and urban families with a

chronically ill child on several variables concerning religion, to assess if there is a difference in their use of religion as a way of coping. It was expected that rural families would utilize religion as a means of coping more than urban families.

#### Method

#### Subjects

The sample included volunteers from community health services and patients attending health fairs, representing both rural and urban populations. All families contained at least one ill child with one family containing two. There were 45 families, 26 families from rural areas, and 19 families from urban areas. The age in years of the children ranged from 3 - 17 years, with an average age of 9.6. See Table One for frequency information regarding gender and illness.

Insert Table One About Here

#### Procedure

Researchers distributed questionnaires to subjects who agreed to participate in this study. The children and their parents were asked to read and complete the information.

A demographic sheet was included in the packet (appendix A). This form asked for information such as the child's diagnosis, age of the child, as well as whether they live in an urban or rural community.

A belief questionnaire (Mulder et al, 1994) (appendix B) was also included. Subjects were able to mark a scale

between 1 and 6 to indicate their level of agreement or disagreement with various statements.

The Chronicity Impact and Coping Instrument: Parent Questionnaire (CICI:PQ) (appendix C) (Hymovich, 1983) was given to parents as a measure of their use of religion in coping with chronic illness. Construct validity for the instrument was established by consulting relevant professionals, in the areas of chronic illness, as well as parents of chronically ill children (Hymovich, 1983). Most questions were posed in a Lickert format with responses ranging from 1 to 6. At this time standard scoring was not available. Therefore, items were examined individually.

It was expected that there would be differences between rural and urban samples on items that addressed religion. These items included beliefs or statements such as: people should consult their pastor when emotionally troubled, the Bible is the true word of God, God wants us to be happy with what we have, God helps those who help themselves, the poor will be rich in heaven, religion is the most important source of comfort, actual pastoral counseling, turning to the clergy and church for emotional and financial support, prayer during times of stress, and actual church attendance.

The following statistical procedures were used: Chi Square, analyses of variance (general linear models procedure), and correlation analyses (Pearson product moments).

#### Results

It is important to mention that differences approaching significance were found between rural and urban subjects in regard to the ages of the children. The mean age for rural subjects was 8.1 and the mean age for urban subjects was

10.6. However, correlation statistics show no correlation between ages of the children and variables considered in the study.

An ANOVA using the general linear models procedure showed that urban families were more likely to think that emotionally troubled people should see the pastors of their church, F(1,39) = 8.05, p<.05.

Urban subjects were also more likely to believe that the Bible is the true word of God, F(1,39) = 3.98, p<.05. See Table Two for means of rural and urban groups in regard to the opinion questionnaire.

Insert Table Two About Here

No differences were observed between rural and urban subjects for: God wants us to be happy with what we have, God helps those who help themselves, the poor will be rich in heaven, religion is the most important source of comfort in my life, pastoral counseling, turning to the clergy or church for emotional or financial support, prayer during times of stress, and actual church attendance. See Table Three for frequency data from the CICI:PQ and the demographic questionnaire.

Insert Table Three About Here

#### Discussion

This study contained a rather small sample. Therefore,

results should be interpreted cautiously, and be used as a starting point for further research.

Although the ages of the children approach a statistically significant difference, age does not appear to be a factor in the way that their parents answered the questions.

It was unexpected that urban subjects would believe more than rural subjects that emotionally troubled people should turn to the pastors of their church. This may be partly explained by the fact that it has been found that people living in urban areas are more likely to use mental health services (Goldstrom & Mandersheid, 1982). Future research should also address the possibility that urban dwellers have better access to clergy trained in pastoral counseling, or that urban pastors may be more likely to offer counseling services.

It was also unexpected that urban subjects would believe more than rural subjects that the Bible is the true word of God. It is unclear why this was observed. It may be related to the small sample size or the limited geographical region of the sample. Further study is warranted.

No observed differences between other items may indicate that there is truly no difference between rural and urban subjects in regard to these issues, or it may be the result of our small and restricted sample. Further study with a larger sample is necessary.

The results of this study appear to indicate that there are no differences between rural and urban subject in their actual use of religion in coping with a child's illness. However, urban subjects may believe more than their rural counterparts that pastors could be helpful in coping during

times of emotional distress. It is possible that the results of this study would change if more life threatening illnesses were included in the sample. Families who have the potential to lose their child to an illness may differ from a sample comprised of almost all asthma.

The results of this study are not consistent with widely held beliefs about rural versus urban cultures, and should be used with care. Further research is necessary before making firm conclusions.

Religion and Illness 15

Table One

Descriptive frequency data for gender, illness, and age

	rural	urban	total
male	15	10	25
female	11	9	20
cancer	1	2	3
diabetes	2	1	3
seizures	1	0	1
asthma	22	16	38
age	8.1	10.6	9.6

Table Two

Means and standard deviations (SD) for variables on Opinion Questionnaire (maximum = 6, with 1 = disagreement and 6 = strong agreement)

	rural	(SD)	urban	(SD)
*Consulting pastor	3.5	(2.0)	4.8	(1.0)
*Bible is word of God	4.5	(1.9)	5.4	(1.0)
Content with what we have	4.8	(1.7)	5.2	(1.4)
God helps those who help themselves	4.6	(2.0)	5.2	(1.4)
Poor will be rich in heaven	4.6	(1.8)	3.7	(1.8)
Religion most important comfort	4.2	(1.7)	4.7	(1.4)

<sup>\*</sup> Statistically significant

#### Table Three

## Frequency data from the CICI:PQ and Demographic questionnaire

_	Praye	er in tir	mes of	stress
		l urban 2 2 2	total 3 4	
		Church At	ttendar	nce
	ru frequently occasional rarely never		6	14 13
		Denomi	nation	
	rur Catholic Jewish Protestant Other None	al urban 1 1 20 3	1 0	2 1 37 4
	Past	pastora	l coun	seling
	rural yes 10 no 10			
	*Clerg	y for emo	otional	l support
	rural yes 4	urban t 3 7		

\*35 subjects did not indicate clergy

#### References

Byrne, J. T. (1979, January/February). In sickness and in health: The effects of religion. Health Education. 6-12.

Carver, C. S., Pozo, C., Harris, S. D., Noriega, V., Scheier, M. F., Robinson, D. S., Ketcham, A. S., Moffat, F. L., & Clark, K. C. (1993). How coping mediates the effect of optimism on distress: A study of women with early stage breast cancer. <u>Journal of Personality and Social Psychology</u>, 65 (2), 375-390.

Dull, D. T., & Skokan, L. A. (1995). A cognitive model of religion's influence on health. <u>Journal of Social Issues</u>, 51, (2), 49-64.

Ebmeier, C., Lough, M. A., Huth, M. M., & Autio, L. (1991). Hospitalized school-age children express ideas, feelings, and behaviors toward God. <u>Journal of Pediatric Nursing</u>, 6, (5), 337-349.

Ford, T. (1967). The passing of provincialism. In T. Ford (Ed.), <u>The Southern Appalachian Region A Survey</u>. Lexington: University of Kentucky Press.

Goldstrom, I. & Manderscheid, R. (1982). The chronically mentally ill III: A descriptive analysis from the uniform client data instrument. <u>Community Support Service Journal</u>, 2, 4-9.

Hall, B. A. (1994). Ways of maintaining hope in HIV disease. Research in Nursing and Health, 17, 283-293.

Hymovich, D. P., (1983). The chronicity impact and coping instrument: parent questionnaire. <u>Nursing Research</u>. 32, (5), 275-281.

Hymovich, D. P., (1984). Development of the chronicity impact and coping instrument: parent questionnaire. <u>Nursing</u> Research. 33, (4), 218-222.

Hymovich, D. P., & Baker, C. D. (1985). The needs, concerns and coping of parents of children with cystic fibrosis. Family Relations. 34, 91-97.

Lefton, L. (1991). Psychology. Boston: Allyn and Bacon.

Leyser, Y. (1994). Stress and adaptation in orthodox Jewish families with a disabled child. <u>American</u> <u>Journal of Orthopsychiatry</u>, 64, (3), 376-385.

Martinson, I. M., Gilliss, C., Colaizzo, D. C., Freeman, M., & Bossert, E. (1990). Impact of childhood cancer on healthy school-age siblings. <u>Cancer Nursing</u>, <u>13</u>, (3), 183-190.

McIntosh, D. N., Silver, R. C., & Wortman, C. B. (1993). Religion's role in adjustment to a negative lifeevent: Coping with the loss of a child. <u>Journal of Personality and Social Psychology</u>, 65, (4), 812-821.

Monsen, R. B., (1992). Autonomy, coping, and self-care agency in healthy adolescents and in adolescents coping with spina bifida. <u>Journal of Pediatric Nursing</u>, 7, (1), 9-13.

Mulder, P., Daughterty, A., Teel, W., Midkiff, J., Murray, K., & Smith, L. (1994). Rural West Virginia: a cross cultural perspective with implications for clinical intervention. The West Virginia Journal of Psychological Research. 3, 9-25.

Ritchie, J. A., Caty, S., & Ellerton, M. L. (1988) Coping behaviors of hospitalized preschool children. Maternal-Child Nursing Journal, 17 (3), 153-171.

Schiller, P. L., & Levin, J. S. (1988). Is there a religious factor in health care utilization?: A review. Social Science and Medicine, 27, (2), 1369-1379.

Sherman, A. (1992). <u>Falling by the Wayside: Children in Rural America</u>. Washington: Children's Defense Fund.

Spilka, B., Hood, R. W., & Gorsuch, R. L. (1985). <u>The Psychology of Religion an Empirical Approach</u>. New Jersey: Prentice-Hall, Inc.

Varni, J. W., & Wallander, J. L. (1988). Pediatric chronic disabilities: hemophilia and spina bifida as examples. In D. K. Routh (Ed.), <u>Handbook of Pediatric Psychology</u> (pp. 190-219). New York: Guilford Press.

Ventis, W. L. (1995). The relationship between religion and mental health. <u>Journal of Social Issues</u>, <u>51</u> (2), 33-48.

Weinert, C., & Long, K. A. (1993) Support systems for the spouses of chronically ill persons in rural areas. Family and Community Health. 16, (1), 46-54.

## Appendix A

Supplemental Parent Questionnaire Directions: Check the box that most applies to you and your situation.

General Information	Ye	s No	
Has anyone in your family been in any type of counseling o Had problems with their nerves?			
Have you felt lonely during your child's illness?			
Have you tried anything different that your doctor didn't Recommend (i.e. home remedies)?			
Have there been any financial difficulties associated with Your child's illness?			
Do you have medical insurance or a medical card?			
Do other children help in the daily care of their brother Or sister?			
Are your friends supportive of you and your child?			
Do you ever feel stressed out?			
Do you ever feel overwhelmed?			
Have you needed any emotional support due to your Child's illness?			
Does your clergy/pastor counsel your family?			
Do you ever wonder why this happened to your child?			
Do you ever feel like the illness is a punishment?			
Do you believe good people should not have bad things Happen to them?			
Do you feel you treat your child differently because (s)he Is ill?			
Education  1. How often does (s)he miss school?	2. Has your ch	nild ever been ho	mebour
2) 2-3 times per month3) 4-5 times per month4) 5-7 times per month5) Rarely ever6) Other: How often?	If so when a	and how long?	

## Living Situation

I.	Check the one that best describes where you live:
	l) city, near relatives
	2) country, near relatives
	3) city, not near relatives
	4) country, not near relatives
2.	About how long of a drive is it to your child's regular doctor?
	1) less than 30 minutes
	2) 30 minutes to an hour
	3) one hour to two hours
	4) more than two hours: How long?
3.	About how long of a drive is it to the closest hospital?
	1) less than 30 minutes
	2) 30 minutes to an hour
	3) one hour to two hours
	4) more than two hours: How long?
Tre	eatment History
1)	How often does your child go to the doctor's office?
	1) once a year
	2) twice per year
	3) once per month
	4) other: How often?
2)	Is your child currently receiving special academic services? For example, learning disabilities, gifted
2,	program, etc.?
	yesno
	If so what type?
	How long?
3)	Is your child receiving any other special medical treatments such as chemotherapy, radiation
,	treatments, etc.?
	yes no
	If so what type?
	How long?
4)	Do you ever have doctors, nurses, etc. visit your home?
.,	yes no
	How often?
5)	Is it ever hard to understand diagnosis, medications, treatments, or progress reports of your child?
٠,	yes no
6)	Have you ever been upset or frustrated with the care/treatments your child has been given?
	yesno

	Name of medication:	Dosage:	Times:
	Name of medication:	Dosage:	Times:
	Name of medication:	Dosage:	Times:
	Name of medication:	Dosage:	Times:
216	ease check other problems for your f	amily, as they relate to you	ır child's illness
_	_missing work for child's health care		
	_emotional stress on child with illness		
	_child discipline problems		
	_problems with relatives not understan	ding illness	
	_marital problems		
	_problems with child's friends not und	erstanding illness	
	_lack of support		
	_child not taking medications or not w		
_	other: please specify		
			<del></del>
vi	iscellaneous		
I .		nend with your child each d	av?
•	1) less than 10 minutes	pona wim your omia ouon a	-y .
	2) 10-20 minutes		
	3) 20-30 minutes		
	4) more than 30 minutes: ple	ease specify:	
	, p.		
2.	How much time do you spend each d	lay thinking about your child	d's illness?
	11/L	1	
`	Who would you turn to for emotiona	i support?	
3.	clergy		
3.	SDOUGE		
<b>3</b> .	spouse		
3.	boyfriend/girlfriend		
	boyfriend/girlfriend neighbor		
3.	boyfriend/girlfriend neighbor friend		
	boyfriend/girlfriend neighbor friend coworker		
3.	boyfriend/girlfriend neighbor friend		
	boyfriend/girlfriend neighbor friend coworker other: please specify:	al support, who would you t	um to?
1.	boyfriend/girlfriend neighbor friend coworker other: please specify:	al support, who would you t	um to?
	boyfriend/girlfriendneighborfriendcoworkerother: please specify:  If you found that you needed financiaspouse	al support, who would you t	um to?
	boyfriend/girlfriend neighbor friend coworker other: please specify:  If you found that you needed financia spouse boyfriend/girlfriend	al support, who would you t	urn to?
	boyfriend/girlfriend neighbor friend coworker other: please specify:  If you found that you needed financia spouse boyfriend/girlfriend neighbor	al support, who would you t	um to?
	boyfriend/girlfriend neighbor friend coworker other: please specify:  If you found that you needed financia spouse boyfriend/girlfriend neighbor friend	al support, who would you t	um to?
	boyfriend/girlfriendneighborfriendcoworkerother: please specify:  If you found that you needed financiaspouseboyfriend/girlfriendneighborfriendcoworker	al support, who would you t	um to?
	boyfriend/girlfriendneighborfriendcoworkerother: please specify:  If you found that you needed financiaspouseboyfriend/girlfriendneighborfriendcoworkerchurch	al support, who would you t	urn to?
	boyfriend/girlfriendneighborfriendcoworkerother: please specify:  If you found that you needed financiaspouseboyfriend/girlfriendneighborfriendcoworker		um to?

## Appendix B

#### **OPINION QUESTIONNAIRE**

Directions: The following are questions concerning opinions that different people hold about a variety of Things. We are interested in your opinions about these things. Please read each statement. Rate how strongly you agree or disagree with each statement by checking a number from 1 to 6 With 1 being strong disagreement and 6 being strong agreement. If you do not wish to Answer the question or it does not apply to you, please check NA.

	Disa 1	agree 2	3	4	5	<b>A</b> 4	gree NA
When people are emotionally troubled or have problems with their nerves, it would help to talk to the pastor of their church							
Children should be seen and not heard							
Schools need to focus most on science and technology to prepare students for the jobs of the future							
I know most of the families that live within 10 miles of my home				_			
The Bible is the true word of God							
The government should do more to help people							
Children deserve respect and we should pay attention							
People in my county should try to save our special culture							
People who have emotion, mental, or nerve problems are sick just like people who have physical problems							
Life in my county has been changing a lot in the past few years							
It is important to give a child a good education							
God would like us to learn to be content with what he has provided for us							
If a person is unhappy with life, they should talk to someone							
Hard work is the best way to get ahead							
If you want something done right you should do it yourself							
God helps those who help themselves							

	Dis	agree	2		-	Agree 5 6 NA		
	<u> </u>	2	3	4	<u> </u>	0	NA	
If everyone would just volunteer some time to a good cause, we could solve most of society's problems								
If people want a better life they should join together in groups to make changes								
Children have feelings just like adults								
If my community offered free mental health information classes I would go to them								
I have read the Bible								
What I do in my own home is my own business								
Being poor is all right because the poor will be rich in heaven								
Strangers are just friends we have not met yet								
People with high expectations are in for a big let down								
I would like to travel to other places where the people are very different than me								
There are some private or personal subjects that should be spoken of only at home and never in public								
My religion is the most important source of comfort and help in my life								
I would like to put a big, high fence around my yard so that I could have privacy								
I did not have to go through as much as my parents had to go through								

## Appendix C

## CHRONICITY IMPACT AND COPING INSTRUMENT: PARENT QUESTIONNAIRE

TODAY'S DATE: CHILD'S AGE: CHILD'S SEX: (1) MALE		CHILD'S NAME:_ BIRTHDATE: (2) FEMALE	
CHILD 3 3LX. (1) WALL		(2) PEWIALE	
	<b>SECTION A:</b>	YOUR CHILD	
1. What is your child's condit	ion or diagnosis?	(1) Not (2) Mo	ld you say your child's condition severe (slight) derately severe y severe
3. How long ago was your c(1) under 3 mths(2) 3-6 mths(3) 7-11 mths			
4. Does anyone else in your(1) no  If yes, who?(1) myself(2) other parent(3) child's brothe(4) grandparent(5) other: Who?  5. Please indicate your relations.	(2) yes r/sister	7.	What have you done in the past When you have needed help With any of the areas listed in Question 6. (check as many as you want) (1) Have not needed help(2) Wrote away to others(3) Asked the clergy(4) Went to the library(5) Nurse/Doctor
(1) mother (2) father (3) stepmother	(5) foster mother		(6) Friends/Relatives (7) Parents (8) Nothing (9) Talked to others (10) Have not known (11) Other: What?
6. Parents have asked for help			nent and care including those
listed below. Please indicate i following:	t you would or would Would Not Like	Not Sure	with or discuss any of the Would Like
Physical care of child			
Diet/Nutrition			
Sleep Habits			
Genetic Counseling			
Play or recreation activities			
Managing child's behavior			
Providing the right play			
and learning experiences			
Care of minor illness			
Expected child development			
Child's physical development			
Child's social development		<del></del>	

	Would Not Like	Not Sure	Would Like
Emotional Development			
Intellectual Development			
Child's condition			
Other:			

### **SECTION B: YOURSELF**

1. All parents have some areas of concern. During the past 3 months, how much of a concern have the following areas been for you? Check the box that applies to how much concern you have had for each situation.

Concerns	None/Not Apply	Not sure	A little bit	Quite a bit	A great deal
Extra demands on my time					
Feeling worn out					
Enough fun and relaxation as I would like					
Having enough time alone With spouse/partner					
Sexual relationships with Spouse/partner					
Making my child comfortable Or happy					
Enough time or attention From spouse/partner					
Getting out of house Together with spouse/partner But without children					
Getting out of house alone					
Getting to do activities Together as a family					
Whether I am taking care of My child in the best way					
Having to travel too far for Medical help or child care					
Whether influencing what my Child is able to do					
Having enough insurance to Meet expenses of child care					
Wondering what my child's Future is likely to be					
The responsibility of caring For my child worries me					-

- 2. Parents handle their concerns in many different ways. There are times when you may have more problems and concerns Because of your child's condition. In what ways do you do Things differently when these problems come up? Check all That apply to you.
- Parents have different beliefs about things influence their lifestyle.
   Please check whether or not you agree with the beliefs indicated Below.

	Doesn't Apply	i	Do same	Do more	Beliefs	Agree	Not Sure	Disagree
Cry					Parents should Take care of their			/
Busy self with other things					Own needs they			
Talk with someone					Can help their Children			
Ignore/try to forget					It is necessary to Get out of the			
Hide feelings					House often to			
Get away					Relieve the strain Of child care			
Smoke					It is usually better Not to show or			
Yell/scream/slam doors, etc.					Talk about one's Feelings to others			
Exercise					Sometimes just			
Ask for help					Avoiding or trying To forget makes it			
Take alcohol					Easier to handle			
Pray					I usually have			
Take medicine					Control over things			
Are you a member of a parent Child's illness?	s' associat	ion re	lated to	your	That happen to me Or my family			
(1) Yes(2) No					It is lucky that this	1		
a. If yes, how often do you	attend mee	_	?		Is the only			
(1) frequently (2) occasionally	(3) ra (4) n				Condition my child Has			
b. If you go to the meetings,(1) Do not go(2) Very helpful(3) Somewhat helpful	(4) N (5) N				My child's Condition is always Going to be there And there is Nothing I can do			
Do you have someone who co			-		_			
Day in case of an emergency ( Cannot take care of your child(1) No(2)	•	you b	ecome	ill and (3) Yes	I sometimes think Of my child's Condition as a			
Do you have someone who co Week or more in case of an er			your c	hild for a				<u> </u>

A.) What is your marital statu	s?			
(1) married (4)	divorced			
(1) married(4)(5)	single (never n	narried)		
(3) separated				
B.) For how many years have	you been wide	owed, married	I,	
Separated, or divorced?				
(1) under one year	(3) 4-6 ye	ears		
(2) 1-3 years	(4) over (	6 years		
C.) How many times have you	u been married r more	?		
	more			

### **SECTION C: YOUR SPOUSE**

1.	How old is your spouse?	ſ							7
	(1) under 18 years		Problem for sp	oouse	Does	Not	ı	Α	Α
	(2) 19-24 years (3) 25-29 years			Not	sure	little	mod-	great	
				apply	apply	bit erat	егате	deal	
	(4) 30-34 years					<del>                                     </del>		1	
	(5) 35-39 years		Getting to do			j		1	
	(6) 40-44 years		Together as a	family					
	(7) 45-49 years		Whether you	are taking	1				
	(8) 50 years or over		Care of your o	child the				1	1
	(0) 30 ) 64 8 6. 6.6.		Best way				1		
2.	What is your spouse's occupat	tion?	Having to trav	el too far	1		1		
2.	(Please state what your spouse		For medical h						
	not where they are employed)	does,	саге	•					
<b>4</b> . <b>5</b> .	Three months?(1) excellent(3) a	good fair/poor how much of	f a problem		tionshi _(1) no _(2) ver _(3) sor _(4) sor	p with t sure ry sati newh newh	your s	spouse's fied atisfied	?
	roblem for spouse	Does not Apply	Not sure	A little	T	A mo	derate int	A greadeal	at
E	xtra demands on time								
	eeling worn out because of all he family needs								
N	ot enough fun and relaxation s spouse would like								
	ot enough time or attention rom you								
	aving enough time alone with								
	alking with or understanding								

Sexual relationship with you

Directions: Please mark the box that most applies to your spouse and your situation

Problem for spouse	Does not apply	Not sure	A little bit	A moderate Amount	A great deal
Making your child comfortable Or happy					
Getting out of the house together With you, but without children					
Getting out of the house alone					

7. People may do different things when they become upset with their spouse. Please indicate the way in which you do things differently when you are upset with your spouse than when you are not upset.

	Does not apply	Do less	Do about the same	Do more
Сгу				
Busy self with other things				
Talk with someone		·		
Ignore/try to forget				
Hide feelings				
Get away				
Smoke				
Yell/scream/slam doors, etc.				
Exercise				
Ask for help				
Take alcohol				
Pray				
Take medicine		†		

8. In what ways does your spo	use do things differen	ently wher	upset with you than v	when not upset?
C	Does not apply	Do less	Do about the same	Do more
Cry Busy self with other things				
Talk with someone				
Ignore/try to forget				
Hide feelings				
Get away				
Smoke				
Yell/scream/slam doors, etc.		-		
Exercise				
Ask for help				
Take alcohol				
Pray				

#### SECTION D: BROTHERS AND SISTERS

Directions: Please check each box that applies to you, your child, and your situation

1. During the past 3 months, how much have you and your other children talked about the following:

	Not at all/ Does not apply	A little bit	A moderate	A great deal
Information about the child's Condition				
How to take care of the condition				
Their friends				
School				
Activities				
Child's behavior in general				
Their futures				
Growing up in general				

2. Please indicate whether you would like to have help with or discuss any of the following in relation to any of the following in relation to any if your child's brothers or sisters:

	Would not	Not sure	Would like
Information about expected child Development Managing child's behavior			
Physical needs			
Social needs			
Intellectual needs			
Helping child understand the Other child's reaction			
Helping children to get along			

## SECTION F: OTHER

Directions: Please check the best answer that	t applies to you and your situation
1. How many children do you have?	10. Are you satisfied with your current work?
	1) yes2) no
123456 78 or more	
2. How many of your children are under	11. What is your age?
· ·	
Five years of age?	1) under 185) 40-44 years
01234 or more	2) 19-24 years6) 45-59 years
	3) 25-29 years7) 50 or over
3. How many of your children are between	4) 30-34 years
six and twelve years of age?	
01234 or more	12. How much school have you finished?
	1) 9 <sup>th</sup> grade5) some college 2) 10 <sup>th</sup> grade6) college graduate
4. How many of your children are 13 years	2) 10 <sup>th</sup> grade 6) college graduate
or older?	3) 11 <sup>th</sup> grade7)master's degree4) 12 <sup>th</sup> grade8) doctoral degree
01234 or more	4) 12 <sup>th</sup> grade 8) doctoral degree
5 To assess how has the health of some shir	dans 12. How has your consent health been in the last
5. In general how has the health of your chi	
been during the past 3 months?	3 months?
Excellent good fair/	
Child 1 (ill child)	2) very good4) fair/poor
Child 2	
Child 3	14. What is your family's annual income?
Child 4	1) under \$5,000
Child 5	2) \$5,000-10,000
Child 6	3) \$11,000-20,000
Child 7	4) \$21,000-30,000
	5) over \$30,000
Child 8	3) 0 vei \$30,000
6 77 11 1 1 1 1 m	
6. How would you describe yourself?	•
1) white, non-hispanic	
2) Asian	
3) Black	
4) Spanish American	
5) American Indian	
6) Other: specify	
7. What is your religion?	
1) Catholic	
2) Jewish	
3) Protestant (Baptist, Methodist, E	
Presbyterian, Church of God, Ch	
Pentecostal, Holiness, Mormons,	Jehova's
Witness)	
4) Other: specify	
5) No religion	
8. How often have you attended religious	services in
The last three months?	SCI VIOLS III
1) frequently3) rarely	
2) occasionally4) never	
9. Are you working now?	
	yes, where do you work?
	Eves do you work 1) full-time 2) nart-time