

**Data Supplement****Screening for Caregiver Psychosocial Risk in Children with Medical Complexity**

Rahul Verma MD, Yasna Mehdian, Neel Sheth, Kathy Netten, Jean Vinette, Ashley Edwards, Joanna Polyviou, Julia Orkin MD, MSc, Reshma Amin MD, MSc

**Appendix 1:** STROBE checklist

**Appendix 2:** Revised Psychosocial Assessment Tool (PATrev)

**APPENDIX 1:  
STROBE CHECKLIST**

	<b>Item No</b>	<b>Recommendation</b>	<b>Page No</b>
<b>Title and abstract</b>	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	OK 2
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	OK 2
<b>Introduction</b>			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	OK 4
Objectives	3	State specific objectives, including any prespecified hypotheses	OK 4
<b>Methods</b>			
Study design	4	Present key elements of study design early in the paper	OK 5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	OK 5
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants	OK 5
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	OK 5-6
Data sources/ measurement	8	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	OK 7
Bias	9	Describe any efforts to address potential sources of bias	OK 7
Study size	10	Explain how the study size was arrived at	OK 5
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	OK 7
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	OK 7
		(b) Describe any methods used to examine subgroups and interactions	OK 7
		(c) Explain how missing data were addressed	OK 7
		(d) If applicable, describe analytical methods taking account of sampling strategy	OK 7
		(e) Describe any sensitivity analyses	N/A

<b>Results</b>			
Participants	13	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	OK 9
		(b) Give reasons for non-participation at each stage	OK 9
		(c) Consider use of a flow diagram	OK
Descriptive data	14	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	OK 9
		(b) Indicate number of participants with missing data for each variable of interest	OK 9
Outcome data	15	Report numbers of outcome events or summary measures	OK 9
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	OK 9
		(b) Report category boundaries when continuous variables were categorized	OK 9
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	N/A
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	OK 10
<b>Discussion</b>			
Key results	18	Summarise key results with reference to study objectives	OK 11
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	OK 13
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	OK 11-13
Generalisability	21	Discuss the generalisability (external validity) of the study results	OK 13-14
<b>Other information</b>			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	OK 15



**PSYCHOSOCIAL ASSESSMENT TOOL<sup>©</sup>**  
(adapted all-literacy version – for all ages – general version)

About the child (the patient):																																											
Child's name:		Today's date:																																									
First Last	Middle	Month Year	Day																																								
Child's date of birth:		Is the child: <input type="checkbox"/> Male / Boy																																									
Month Day		Year																																									
Child's diagnosis (illness):		Date of diagnosis: Month Day Year																																									
<p>What are the ethnic or cultural origins of your child's ancestor's? (An ancestor is usually more distant than a grandparent. You can provide more than one answer.)</p> <table border="0"> <thead> <tr> <th align="center">Biological Mother</th> <th align="center">Biological Father</th> </tr> </thead> <tbody> <tr> <td><input type="checkbox"/> Eastern European (Polish, Russian, Croatian, etc)</td> <td><input type="checkbox"/> Eastern European (Polish, Russian, Croatian, etc)</td> </tr> <tr> <td><input type="checkbox"/> Western European (English, French, Portuguese, etc)</td> <td><input type="checkbox"/> Western European (English, French, Portuguese, etc)</td> </tr> <tr> <td><input type="checkbox"/> East Asian (Chinese)</td> <td><input type="checkbox"/> East Asian (Chinese)</td> </tr> <tr> <td><input type="checkbox"/> East Asian (Korean)</td> <td><input type="checkbox"/> East Asian (Korean)</td> </tr> <tr> <td><input type="checkbox"/> East Asian (Japanese)</td> <td><input type="checkbox"/> East Asian (Japanese)</td> </tr> <tr> <td><input type="checkbox"/> South Asian (East Indian, Pakistani, Sri Lankan, etc)</td> 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About you:																																											
Are you: <input type="checkbox"/> Biological Parent <input type="checkbox"/> Step-parent <input type="checkbox"/> Adoptive parent <input type="checkbox"/> Foster parent <input type="checkbox"/> Grandparent <input type="checkbox"/> Legal Guardian																																											
<input type="checkbox"/> Aunt / Uncle / Other relative <input type="checkbox"/> Other (describe):																																											
Your role with the child <input type="checkbox"/> Main (daily) caregiver <input type="checkbox"/> Supporting or back-up caregiver <input type="checkbox"/> Occasional (off and on) caregiver																																											
(✓one box): <input type="checkbox"/> Other (describe):																																											
About the main caregiver(s) in the child's home (if you are not the main caregiver, please provide as much information, as you know):																																											
Age of main caregiver(s) (✓all that apply): <input type="checkbox"/> Under age 21 <input type="checkbox"/> Age 21 or over <input type="checkbox"/> One is over 21 and the other is under 21																																											
How far did the main caregiver(s) get in school? (✓all that apply)																																											
<input type="checkbox"/> Started school but didn't finish		<input type="checkbox"/> Finished high school / got GED																																									
<input type="checkbox"/> Started college or trade school		<input type="checkbox"/> Finished college or trade school																																									
<input type="checkbox"/> Started master's or doctoral program		<input type="checkbox"/> Finished master's or doctoral program																																									
Marital status of caregiver(s): (✓one) <input type="checkbox"/> Single <input type="checkbox"/> Married / Partnered <input type="checkbox"/> Separated / Divorced <input type="checkbox"/> Widowed <input type="checkbox"/> Other																																											

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1. Tell us who lives in the child's home: (include the child; yourself - if you live in the home - and other children or adults in the home)						
First and Last Names	Age	Relationship to the child		First and Last Names	Age	Relationship to the child
		The child/patient				

2. Tell us about who helps out with the child's care: (✓all boxes that apply)									
	My spouse / partner	Child's main / other caregiver(s)	Child's grand-parents	Other family members	Friends	People at work	Church / spiritual community	Other (list)	No One
a. Childcare / Parenting									
b. Emotional Support									
c. Money / Financial Support									
d. Information									
e. Everyday tasks (for example: meals, errands, transportation)									

3. How will you or other caregivers get to the hospital or clinic for appointments? (✓all boxes that apply)			
<input type="checkbox"/> Own Car	<input type="checkbox"/> Rides from Others	<input type="checkbox"/> Public transportation (bus, subway, train)	<input type="checkbox"/> Not Sure / Don't Know

4. What type of healthcare coverage does your child receive: (✓all boxes that apply)		
<input type="checkbox"/> OHIP	<input type="checkbox"/> Private Health Insurance	<input type="checkbox"/> IFHP

5. What other income / supports does your family receive: (✓all boxes that apply)						
<input type="checkbox"/> OW	<input type="checkbox"/> ODSP	<input type="checkbox"/> ACSD	<input type="checkbox"/> SSAH	<input type="checkbox"/> Enhanced Respite	<input type="checkbox"/> ADP	<input type="checkbox"/> Easter Seals

6. Is the family having money problems? (✓ one box)			
<input type="checkbox"/> No problems	<input type="checkbox"/> Some problems	<input type="checkbox"/> Many problems	<input type="checkbox"/> It's hard for the family to meet its needs

7. In what areas are there money problems? (✓all boxes that apply)					
<input type="checkbox"/> None	<input type="checkbox"/> Phone/heat/light bills	<input type="checkbox"/> Rent/mortgage	<input type="checkbox"/> Buying food	<input type="checkbox"/> Car (upkeep /gas /insurance)	
<input type="checkbox"/> Medical(bills, supplies, equipment)		<input type="checkbox"/> Child care			

8. Child's day care / schooling status: (✓all boxes that apply)			<input type="checkbox"/> Too young (go to next question)		
<input type="checkbox"/> In Day Care	<input type="checkbox"/> Preschool / Pre-K	<input type="checkbox"/> K-12; Grade? _____	<input type="checkbox"/> Home schooled	<input type="checkbox"/> Homebound	
<input type="checkbox"/> Gifted	<input type="checkbox"/> Special Education	<input type="checkbox"/> Dropped out of school	<input type="checkbox"/> Finished high school	<input type="checkbox"/> Not attending by parent's choice	
<input type="checkbox"/> Not currently receiving school or homebound services		<input type="checkbox"/> Has IEP			

9. In general, does she or he: (✓ one box for each question) →				10. A problem for other children at home?	
	No	Some times	Yes OR Getting Help	<input type="checkbox"/> No other children	
	No	Yes		No	Yes
a. Seem moody / change moods a lot?					
b. Seem sad or keeps to herself / himself?					
c. Have developmental problems compared to kids the same age?					
d. Been a victim of crime, abuse or violence in / outside the home?					
e. Have other medical problems - now or before? (List)					
f. Have a mental health problem? (List)					

If the child is <u>under</u> 2 years old, does she or he...				Is this a problem for other children at home under 2?	
g. Cry a lot?					
h. Have trouble with a sleeping routine?					
i. Have trouble with feeding habits?					
j. Act like she/he doesn't want to be close to you?					
If the child is <u>2 years or older</u> , does she or he...				Is this a problem for other children at home 2 or older?	
k. Get upset about going to the doctor or dentist?					
l. Seem overly active (if applicable) ?					
m. Have problems paying attention?					
n. Cry or get upset easily?					
o. Get distracted easily?					
p. Worry a lot (if applicable)?					
q. Have learning problems / problems in school?					
r. Use drugs, alcohol, or other substances?					
s. Act shy or cling to you or other adults?					
t. Have problems making or keeping friends?					
u. Steal, lie, or act aggressively toward others?					
v. Have trouble falling asleep / staying asleep?					
w. Talk about suicide or has made a suicide attempt (if applicable)?					
x. Take medication for any of the issues above?					

<b>11. About the adults caring for the child...</b> (✓one box for each question)		No	Yes
a.	Has anyone had a lot of worry, fear, or anxiety at times?		
b.	Have drugs or alcohol caused problems for anyone in the family?		
c.	Has anyone been sad or depressed at times?		
d.	Does anyone have problems paying attention / staying focused / concentrating for periods of time?		
e.	Have there been relationship problems, fights, or talk about breaking up or divorce?		
f.	Has anyone been in trouble with the law or in jail – now or before?		
g.	Has anyone been told that she or he drinks too much alcohol?		
h.	Have there been legal problems with child custody or with who should raise the child?		
i.	Has anyone talked about or made a suicide attempt?		
j.	Did anyone see a crime or has anyone been a victim of crime, abuse, or domestic violence?		
k.	Is anyone really sick or have a serious medical problem? (List)		
l.	Does anyone have other mental health problems? (List)		
m.	Has anyone in the family died during the past year?		
n.	Are there other family problems or stresses? (List)		

  

<b>12. At any time during the child's illness have you . . .</b> (circle one number for each question)		Not at all	Some times	Often	Very much
a.	Had unwanted memories or upsetting dreams about the child being sick?	0	1	2	3
b.	Stayed away from people, places, or things that remind you that the child is sick?	0	1	2	3
c.	Been on the lookout for signs that the illness is getting worse or happening all over again?	0	1	2	3
d.	Felt more jumpy, easily angered, or more likely to act without thinking as a result of the illness?	0	1	2	3
e.	Lost interest in being with family and friends, or doing regular activities as a result of the illness?	0	1	2	3

  

<b>13. How certain are you that you (or other caregivers) can . . .</b> (circle one number )		Not at All	Some -what	Fairly	Very
a.	Find the time for her / his medical appointments (ex: time off, child care, arranging travel)?	0	1	2	3
b.	Follow through on her / his medical treatment plan (including medications)?	0	1	2	3
c.	Cope with the upsetting and worrying parts of treatment?	0	1	2	3

  

<b>14. As a caregiver for the child, how much do you believe. . .</b> (✓one box for each statement below)		Not true for me	A little true for me	Mostly true for me	Very true for me
a.	The doctors and nurses know how to help				
b.	I can express my concerns to the medical team				
c.	I can make good treatment decisions				
d.	I am a good caregiver through all of this				
e.	Our family will be closer because of this				
f.	There are people I can turn to for help				
g.	This is a disaster				
h.	She / he will face a lot of complications or challenges				
i.	She / he will never be able to manage this				
j.	I /we must have done something wrong for her / him to have this				
k.	Her / his outcome depends on me (or other caregivers) doing all the right things				
l.	This will make me a stronger person				

**Thank you for your time!**