Author’s response to reviews

Title: A Sociodemographic Variables Questionnaire (Q-SV) for Research on Family Caregivers of Children with Chronic Disease

Authors:

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Author’s response to reviews:

December 3, 2018

Dear editors of BMC Psychology,

Thank you for providing us the opportunity to resubmit our manuscript (PSYO-D-18-00117) entitled “Sociodemographic Variables Questionnaire (Q-SV) for research on family caregivers of children with chronic disease”. We appreciate the opportunity to publish in BMC Psychology and have carefully reviewed your comments and the valuable comments of the reviewers. To ensure that all of your concerns were fully addressed, we made the following major changes to the revised manuscript based on the reviewers’ suggestions.

Thank you again for the opportunity to submit, and I appreciate any assistance that you can provide.

Sincerely,

Filiberto Toledano-Toledano, Ph.D.

Children’s Hospital of Mexico Federico Gómez National Institute of Health.
Dr. Márquez 162, Doctores, Cuauhtémoc, México City, 06720, México.

Below are our responses to the comments.
Reviewer reports:

Reviewer 1

Comment 1:

Your study did not differentiate or define what chronic diseases were included, or excluded. Please clearly define.

Response 1: We agree, and this information has been added. Thank you very much for the suggestion.

Change 1:

We define what a chronic disease is and describe the diseases suffered by children whose parental caregivers were included in the study.

As the line 60-67, first paragraph of the Introduction section:

A chronic disease can be defined as a medical condition that continues or occurs again and again for a long time and may worsen over time [Bernell & Howard, 2016]. The most common types of chronic disease in children are asthma, diabetes, obesity, migraine, epilepsy, developmental disabilities, and cancer [Bai, Herten, Landgraf, Korfage, & Raat, 2017].


In the results of the second study:

The hospitalization time of 446 children whose family caregivers were included in the study ranged from one month to six months, with an arithmetic mean of 1.71 (95% CI, 1.59, 1.82) and a standard deviation of 1.23. Regarding the clinical diagnoses, 74% (330 out of 446) suffered from oncologic disease, with acute lymphocytic leukemia as the most frequent cancer, 7% (31) had abnormal blood flow due to congenital heart defect, 4.7% (21) had nephrotic syndrome, 4% (4) had end-stage renal disease, 2.9% (13) had asthma, 2.7% (12) had tricuspid atresia, 2% (9) had Down syndrome, 0.9% (4) had tetralogy of Fallot, 0.7% (3) HIV/AIDS, 0.7% (3) had received an organ transplant, and 0.4% (2) had cystic fibrosis.

Table not included in the manuscript
<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oncological diseases</td>
<td>330</td>
<td>74.0</td>
</tr>
<tr>
<td>Abnormal blood flow due to congenital heart defect</td>
<td>31</td>
<td>7.0</td>
</tr>
<tr>
<td>Nephrotic syndrome</td>
<td>21</td>
<td>4.7</td>
</tr>
<tr>
<td>End-stage renal disease</td>
<td>18</td>
<td>4.0</td>
</tr>
<tr>
<td>Asthma</td>
<td>13</td>
<td>2.9</td>
</tr>
<tr>
<td>Tricuspid atresia</td>
<td>12</td>
<td>2.7</td>
</tr>
<tr>
<td>Down syndrome</td>
<td>9</td>
<td>2.0</td>
</tr>
<tr>
<td>Tetralogy of Fallot</td>
<td>4</td>
<td>0.9</td>
</tr>
<tr>
<td>HIV/SIDA</td>
<td>3</td>
<td>0.7</td>
</tr>
<tr>
<td>Organ transplant</td>
<td>3</td>
<td>0.7</td>
</tr>
<tr>
<td>Cystic Fibrosis</td>
<td>2</td>
<td>0.4</td>
</tr>
<tr>
<td>Total</td>
<td>446</td>
<td>100</td>
</tr>
</tbody>
</table>

Comment 2:

Were your judges’ evaluation of 3 criteria chosen a priori? Please explain.

Response 2: We agree with this suggestion and have added this information. Thank you very much for the suggestion. The categories were defined a posteriori to classify the judgments of the expert evaluators.

Change 2:

The judges’ evaluations were classified into three categories, which were generated a posteriori through a thematic content analysis: 1) Relevance: it is necessary, essential and fundamental to ask these items in the context of pediatric chronic disease; 2) Utility: it is beneficial to ask these items to investigate pediatric chronic disease in this institution; and 3) Permanence: these SVs should continue to be assessed over time in research with families experiencing chronic health conditions".
Comment 3:

Why does one of your validation criteria in Table 2 include Suggestion, yet this was never described in text or defined? This also suggests to me that your criteria were not a priori.

Response 3: We agree with this suggestion and have added this information. Thank you very much for the suggestion.

Change 3:

The third column of Table 1 on the suggestions provided by the reviewers or judges has been removed since the percentages were always zero and this category is not necessary to classify the reviewers' answers.

Table 1. Validation of the first version of the Q-SV 20 items by 335 expert reviewers in Social Work.

<table>
<thead>
<tr>
<th>Validation of the 20 items</th>
<th>Relevance (%)</th>
<th>Utility (%)</th>
<th>Permanence (%)</th>
<th>Final decision</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sociodemographic variables of the caregiver</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td>68</td>
<td>66</td>
<td>75</td>
<td>*</td>
</tr>
<tr>
<td>Age</td>
<td>81</td>
<td>76</td>
<td>74</td>
<td>*</td>
</tr>
<tr>
<td>Education</td>
<td>93</td>
<td>86</td>
<td>86</td>
<td>*</td>
</tr>
<tr>
<td>City of origin of caregiver</td>
<td>11</td>
<td>31</td>
<td>41</td>
<td>Eliminated</td>
</tr>
<tr>
<td>Religion</td>
<td>67</td>
<td>61</td>
<td>67</td>
<td>*</td>
</tr>
<tr>
<td>Marital status</td>
<td>65</td>
<td>77</td>
<td>80</td>
<td>*</td>
</tr>
<tr>
<td>Years married</td>
<td>19</td>
<td>34</td>
<td>46</td>
<td>Eliminated</td>
</tr>
<tr>
<td>Number of children</td>
<td>60</td>
<td>80</td>
<td>78</td>
<td>*</td>
</tr>
<tr>
<td>Occupation</td>
<td>83</td>
<td>93</td>
<td>96</td>
<td>*</td>
</tr>
<tr>
<td>Monthly household income</td>
<td>99</td>
<td>97</td>
<td>100</td>
<td>*</td>
</tr>
<tr>
<td>Sociodemographic variables of the children</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>93</td>
<td>67</td>
<td>63</td>
<td>*</td>
</tr>
</tbody>
</table>
Sex  
67  83  83  *

Medical variables of the patient

Diagnosis  
89  98  97  *

Medical service  
66  55  58  Eliminated

Amount of time hospitalized  
78  70  70  *

Time since diagnosis  
82  72  70  *

Family variables

Family role of caregiver  
87  86  95  *

Family type  
82  71  69  *

Family life cycle  
92  89  93  *

Support networks  
100  97  99  *

Note: * Items kept in the questionnaire.

Comment 4:

It's surprising that sex of caregiver was removed as a question, in addition to other variables. There's no discussion about why this was done, or what potential impact it may have on this or future studies who would use these recommendations. For example, perhaps time since diagnosis and duration of hospitalization are proxies for age of child. Or it could be that there is not enough variation in sex of caregiver.

Response 4:

We agree with the reviewer and are grateful for the suggestion. The omission of the variable sex of the caregiver was corrected according to the criterion of retention of variables.

Change 4:

The analysis of the information of the expert judges in Social Work was performed again, and Table 1 now shows the frequency of response of the relevance, utility and permanence of the sex variable, which are also included the final version of Sociodemographic Variables Questionnaire (Q-SV) for research on family caregivers of children with chronic disease.
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<td>*</td>
</tr>
</tbody>
</table>

Comment 5:

What about multiple caregivers per child?

Response 5: We agree with this suggestion and have added this information. Thank you very much for the comment.

Change 5:

The question pertaining to the family role of caregiver in the Sociodemographic Variables Questionnaire (Item 12): What family relationship do you have with the patient? Mother, Father, Grandmother, Uncle, Sibling. This item remains in the final version: A Sociodemographic Variables Questionnaire (Q-SV 17 Items).

12. You: What family relationship do you have with the patient?

Mother ___________
Comment 6:

Table 3: There is F and p-value, but not all of these can be ANOVAs since age appears as continuous (would be a correlation r or linear regression t statistic).

Response 6:

The data analysis was re-analyzed in such a way that the appropriate tests were used according to the level of measurement of the variables (metric or non-metric).

Change 6:

The changes were made in the results section of the manuscript.

Comment 7:

My greatest concern that must be addressed is that for your ANOVA results, none of these p-values tell us the results you are suggesting. For example, you state that "Finally, caregivers with a lower quality of life had lower levels of education (F =5.63, M = 83.63, p <.001). This p-value demonstrates that there is a difference in mean health indicators (e.g. quality of life) between the levels of your variables (e.g. education), but without showing the results of the post-hoc multiple comparisons tests, the readers cannot assess if lower quality of life had lower levels of education, etc. Please comment on this.

Response 7:

The reviewer is right. In the analysis of variance, a posteriori pairwise mean comparisons must be performed and significant results must be presented.

Change 7:

The changes were made in the results section of the manuscript.
Reviewer 2

Comment 1:

Introduction

The knowledge gap that this study fills should be clarified. What is the relevance of this information to Spanish-speaking or Mexican population? What is the relevance beyond those populations? While the reader can decide some of this based upon the methods and results, it would be helpful for the authors to outline the field as a whole and then any particular knowledge gaps that might exist for Spanish-speaking population (e.g., no similar measures validated in Spanish) and/or individuals who operate within Mexico (perhaps a brief description of the systems that social workers, caregivers and their children work within). Please help the reader contextualize this study.

Response 1:

We agree with this suggestion and have added this information. Thank you very much for the information.

Change 1:

Additional details were provided explain why a questionnaire that includes sociodemographic variables is necessary, the gaps in knowledge were defined, and the affiliation of the expert judges in the field of Social Work with the National Institutes of Health and families was included.

Comment 2:

I suggest different organization:

Introduction

Study 1: Describe Methods and present Results,

Study 2: Describe Methods and present Results

Discussion

Response 2: We agree with this comment and have revised the manuscript as suggested. Thank you very much.
Two studies were included in the manuscript, and each has its own method and results.

Methods

Study 1

Please provide additional details on participant recruitment: How many reviewers were invited? How were they contacted? What was the participation rate? Was there any compensation for participation?

Provide additional details on procedure: were they mailed the survey? Was this done in person? What language was it delivered in? Etc.

Provide some information on how items were scored - for example: on a scale of 1 to 5, or yes/no, etc.

Study 2

Again please provide additional details on how participants were recruited: How were they identified and contact? How many invited? What was the participation rate? Other details, such as compensation, language, etc.

Response 3: We agree with this suggestion and have added this information in study 1 and study 2. Thank you very much for the information.

Details about the sample, recruitment strategies, compensation and other requested details were provided. In the revised manuscript, we described the methods of both studies, the method of collecting data from the expert reviewers in Social Work (these data were used to generate the final version of the sociodemographic variables questionnaire with 17 items); and the methodological processes for investigating the psychosocial variables among the 446 family caregivers.

Comment 4:

Result
The reported results are all bi-variate. While the analyses presented in Table 3 are interesting, I think it would be more informative to create and present multivariate models, so that the reader can learn something about which variables are most important (as they all relate to one another). Bi-variate analyses are often sufficient when the only goal is to validate a measure, but if you would like to present results based on a measure, we should see some multivariate modeling.

Table 2: Provide additional information on what the %'s represent - are these % agreement? Are they % who said the items was: relevant, had utility, etc? (see comment in

Table 3: This is difficult to read. I'm not sure if the authors are making comparisons between caregiver characteristics and psychosocial variables for the patient? Or the caregiver? If both, they should be presented separately. Also, rather than presenting the F-statistic and p-value for each psychosocial variable and characteristic relationship, it might be more helpful to present the mean (s.d.) and overall p-value for differences (and pair-wise comparisons when relevant)

This is a study 1) validating a questionnaire assessing sociodemographic variables for research on family caregivers of children with chronic disease; 2) assessing relationship between these sociodemographic variables and psychosocial care. Aim #1 was adequately fulfilled, however, Aim #2 still requires additional work and clarification.

Response 4: The text was modified based on this suggestion by the reviewer.

Change 4:

Considering the reviewers' suggestions, the methods and results of study 1 and 2 were rewritten. Based on the current results, multivariate analyses were not appropriate.

Sincerely,

Filiberto Toledano-Toledano, Ph.D.