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Research Article

Association between Health-Related Quality of Life and Coping Strategies of Gastrointestinal Cancer Caregivers: A Rasch Analysis

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ABSTRACT

The number of Gastrointestinal (GI) cancer patients in Malaysia is rising. Caregivers need to perform their responsibilities as they spend most of their time providing care for the patient in their homes. To what extend does Health-Related Quality of Life (HRQOL) of GI caregivers relates to coping strategies of caregivers are unknown and yet to be investigated. This study investigates the caregivers' response pattern towards HRQOL and coping strategies survey items across several domains and the association between HRQOL and coping strategies of the caregivers. This study used Rasch measurement model in the analysis of survey data gathered from 323 GI cancer caregivers from three public hospitals. Data were collected using HRQOL and Coping strategies instruments administered to the GI caregivers. It was found that four items (QOL_9, QOL_20, QOL_25 and QOL_31) under the Burden domain are among the most difficult to endorse by GI caregivers in the HRQOL items. Meanwhile, two items (COPE4 and COPE11) under the Substance Use domain in the coping strategies constructs are most difficult to endorse by GI cancer caregivers. This study also discovered that majority of caregivers who have issues with mental strain, disruptiveness, daily focus and sleep disruption applied positivity adaptation and use of emotional support as their coping strategies.

Keywords: Gastrointestinal cancer, Caregivers, Health-Related Quality of Life (HRQOL), Coping strategies, Rasch measurement model

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INTRODUCTION

Gastrointestinal (GI) cancer is a group of cancer that influence the digestive system that involves stomach or gastric cancer, liver cancer, oesophageal cancer, bower or colorectal cancer, pancreatic cancer, anal cancer, bile duct cancer, Gastrointestinal carcinoid tumor, small intestine cancer and gallbladder cancer (ACRF, 2017). One of GI cancer which is colorectal cancer has been one of the most common cancers for both genders in Malaysia. This type of cancer is being the number one cancer in men and the second in women following breast cancer (Azizah AM, *et al*., 2015).

There are rising numbers of cancer patients are being treated as outpatients due to the rising frequency of GI cancer (Abdullah NN, *et al*., 2019). Hence, the part of caregivers is getting more important since they are the closest person to the patient. According to Hunt GH, *et al*., 2016, caregivers of the cancer patients go through an average of 32.9 hours per week to take care of their loved one and 43 percent doing nursing jobs without any guidance.

Certain studies reviewed in the literature investigate the associated factors related to Quality of Life of caregivers with advanced GI cancer using correlation and linear regression analysis. However, the study did not look into the detail association between Health-Related Quality of Life (HRQOL) and coping strategies of the caregivers. Therefore, in revisiting the study, a response theory approach will be used to explore the association between HRQOL of caregivers and their coping strategies by using Rasch measurement model.

Health-Related Quality of Life (HRQOL) of caregivers

According to Lim HA, *et al*., 2017, the caregiver's culture was a noteworthy indicator of their QOL. The QOL of the Asian caregivers have been discovered to be lesser than the caregivers in European nations since the western nations have more reachable healthcare support system. The characteristics of the caregivers are actually linked with their HRQOL. Men caregivers frequently have better health both physically and mentally (Gibbons C, *et al*., 2014). In addition, the age of the caregiver also affects their HRQOL. This is because the elder caregivers of patients with stroke or dementia were reported to have a potential living with chronic diseases compared to the young caregivers (Lim YM, *et al*., 2008; Carter JH, *et al*., 2010). The physical well-being of elder caregivers can be conceded by the demands of caregiving and psychological issues such as thoughts of loss and sorrow.

In a study by Lua PL, *et al*., 2013, they stated that the Quality of Life of the caregivers was evaluated by *via* Malay Caregiver Quality of Life scale (MCQOL) and this is an adjustment of the English version of the Caregiver Quality of Life scale (Weitzner MA, *et al*., 1999). According to Abdullah NN, *et al*., 2019, this questionnaire involves of 35 items in total. These items evaluate disturbance of sleep, sexual functioning satisfactions', daily focus, mental strain, getting enough information regarding the illness, patient's protection, managing of the patient's pain and concern of family in caregiving. The QOL of the caregivers has 0.90 of reliability (Cronbach's alpha) which means this instrument provide greater degree of consistency and stability. The Cronbach's alpha for all domains was high that range from 0.78 to 0.84 where the value of Cronbach's alpha for disruptiveness was 0.83, positive adaptation was 0.78 and burden was 0.84. However, the financial concern has the lowest Cronbach's alpha value which is 0.43 as the items on insurance coverage did not utilize to all respondents. So, the item on insurance coverage was deleted and the Cronbach's alpha increased to 0.73. The greatest score of the domains denoted a good HRQOL (Lua PL, *et al*., 2013).

Coping strategies of caregivers

The function of coping strategy is to resolve the issue or control

the emotional reaction in the hectic circumstances (Penley JA, *et al*., 2002). However, coping strategies alone are inefficient for the caregiver's stress (Folkman S, 2008). Coping strategies are appeared to be related to variables like burden of the caregivers, involvement of caregiving, expressed reactions, community bolster, mental morbidity in the caregivers, Quality of Life (QOL) of the caregivers (Grover S and Chakrabarti S, 2015). Coping strategies was applied for handling with issues while the caregivers do not have sufficient time to provide care for patient with serious mental illness (Li J, *et al*., 2007). While in the study from García-Alberca JM, *et al*., 2012, it indicates that coping strategies were related to anxiety and depressed in caregivers of patient with Alzheimer's Disease (AD). The caregivers who applied detachment coping strategies often have greatest degree of anxiety and depression while caregivers who applied more attachment coping strategies have lesser degree of anxiety and depression. Thus, coping is the most significant indicator of mental distress on the caregivers.

A study from Yusoff N, *et al*., 2009, uses Brief Cope in order to evaluate a wide scope of coping behaviour of adults for all circumstance, illnesses and non-illnesses. There are 14 dimensions and two items for every dimension in their study. The items in their study were about self-distraction, active coping, denial, use of substance, use of emotional support, use of instrumental support, behavioural disengagement, venting of emotion, positive reinterpretation, planning, humour, acceptance, religion and self-blame. Moreover, the Malay Version of Brief Cope Scale was tested on the sample of female with breast cancer. The reliability of Malay Version of Brief Cope Scale was ranged from 0.51 to 0.99 which is reliable and valid instrument that can be used for the population of Malaysia due to its acceptable internal consistency.

Rasch measurement model

Rasch models are suitable for evaluating and measuring psychological variables such as capabilities, attitudes, and personality characters where the goal is to acquire an accurate and objective measurement. Rasch model would be a helpful instrument for calibration of items that provides a condition for successful measurement (Ferrari PA and Salini S, 2011). Rasch measurement model is a model that is established two parameters which are the ability of person who answered the questions in the instruments and the difficulty of every single item (Rasch G, 1980). Each person is categorized based on ability and items are categorized based on difficulty. Both of the parameters can be evaluated in logits or log odd value.

Rasch polytomous or also known as rating scale model ascertains the relative difficulty of every item from the smallest to the greatest levels that the instrument can record (Mahmud Z and Porter AL, 2015). Items in this study consists of five categories of response for Health-Related Quality of Life (HRQOL) such as from 0=Not at all to 4=Very much. While for coping strategies consists of four categories of response such as from 1=I haven't been doing this at all to 4=I've been doing this a lot. I've been doing this a lot. The Rasch rating scale model that developed by Andrich D, 1978:

$$P_{ni}\{X_{ni}=x\}=\frac{\exp\sum_{k=0}^{x}[\beta_n-(\delta_i-\tau_k)]}{\sum_{j=0}^{m}\exp\sum_{k=0}^{j}[\beta_n-(\delta_i-\tau_k)]}$$

Where; β_n=Person ability, δ_i=Item difficulty to endorse, τ_k=Response threshold estimated for the m+1 rating category and m=Maximum score and identical for all items.

METHODOLOGY

Study design

This is a secondary data study. Data was acquired from a survey study on HRQOL and coping strategies of the GI cancer caregivers as provided by the principal researcher at the Department of Population Health and Preventive Medicine (PHPM), Faculty of Medicine, UiTM Shah Alam. The data was gathered from a survey on 323 respondents who were caregivers of the GI cancer patients. In the survey, the caregivers were asked to provide feedback about their Health-Related Quality of Life and coping strategies based on the HRQOL for caregiver and Brief Cope scales instruments.

Data analysis procedure

This study was essentially focusing on data collected from Part A (Demographic), Part D and Part F (*Figure 1*). Using Winsteps 3.90.2 software, logit scales from the HRQOL and Brief Cope constructs were distributed in a Wright map (also called as Person-Item Distribution Map (PIDM) and Item Characteristics Curve (ICC). *Figure 1* describes the methodological process and data analysis of the study. The measurement includes summary statistics based on the logit scales.

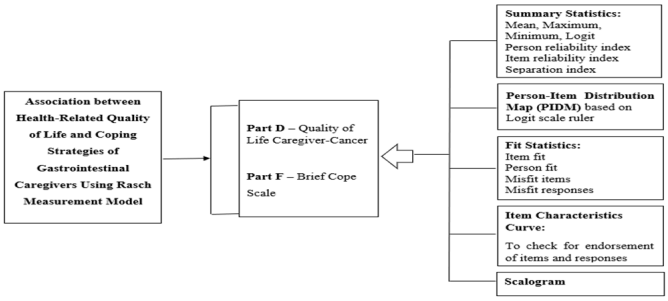

Figure 1: Methodological process and data analysis

RESULTS

Reliability of HRQOL items

Figure 2 shows the person reliability index for HRQOL items at 0.85 is good and consistent. The mean square infit and outfit for persons are 1.04 and 1.03, respectively. Both mean standardized infit and outfit for persons are 0.0. The cut-off value of primary standard deviation for mean square infit and outfit for person is 2.0. This is shown by the person mean square infit and outfit at 0.39 and 0.43, respectively. All these infit and outfit logit measurement shows an overall acceptable fit of data to the Rasch model. The person separation index is 2.41, an indication of two levels of person responses. Person separation indices of two are considered as fairly good (Duncan PW, *et al*., 2003).

```
SUMMARY OF 323 MEASURED Person
-------------------------------------------------------------------------------
|          TOTAL                          MODEL          INFIT        OUTFIT   |
|          SCORE     COUNT     MEASURE     S.E.      MNSQ   ZSTD   MNSQ   ZSTD |
|-----------------------------------------------------------------------------|
| MEAN      92.6      35.0         .45      .15      1.04     .0   1.03     .0 |
| P.SD      20.8        .0         .44      .02       .39    1.7    .43    1.5 |
| S.SD      20.8        .0         .44      .02       .39    1.7    .43    1.5 |
| MAX.     134.0      35.0        2.04      .36      2.40    3.8   3.37    4.5 |
| MIN.      25.0      35.0        -.93      .13       .27   -5.0    .30   -4.6 |
|-----------------------------------------------------------------------------|
| REAL RMSE    .17 TRUE SD     .41  SEPARATION  2.41  Person RELIABILITY   .85 |
|MODEL RMSE    .15 TRUE SD     .42  SEPARATION  2.69  Person RELIABILITY   .88 |
| S.E. OF Person MEAN = .02                                                   |
-------------------------------------------------------------------------------
Person RAW SCORE-TO-MEASURE CORRELATION = .99
CRONBACH ALPHA (KR-20) Person RAW SCORE "TEST" RELIABILITY = .89  SEM = 6.92
```

Figure 2: Summary statistics on person ability for Health-Related Quality of Life (HRQOL)

Figure 3 shows an extremely high item reliability index at 0.99. If the data fits the model well, the meansquare infit and outfit for item will be close to 1.00. This concurs with the mean square infit and outfit for items at 1.03 logit and the mean standardized infit and outfit at 0.0 logit. If the cut-off value of primary standard deviation for mean square infit and outfit for items is 2.0, then data shows an overall acceptable fit. This is indeed shown in the primary standard deviation of the mean square infit and outfit for items at 0.27 and 0.34 logit, respectively. Finally, the item separation index is 8.21, an indication that items are separated into eight levels of difficulty (Linacre JM, 2012).

SUMMARY OF 35 MEASURED Item

	TOTAL SCORE	COUNT	MEASURE	MODEL S.E.	INFIT MNSQ	INFIT ZSTD	OUTFIT MNSQ	OUTFIT ZSTD
MEAN	854.2	323.0	.00	.05	1.03	.0	1.03	.0
P.SD	201.2	.0	.44	.01	.27	3.5	.34	3.6
S.SD	204.2	.0	.45	.01	.27	3.6	.35	3.7
MAX.	1115.0	323.0	1.16	.07	1.58	7.4	1.82	7.9
MIN.	304.0	323.0	-.69	.04	.64	-6.7	.62	-6.3
REAL RMSE	.05	TRUE SD	.44	SEPARATION	8.21	Item	RELIABILITY	.99
MODEL RMSE	.05	TRUE SD	.44	SEPARATION	8.73	Item	RELIABILITY	.99
S.E. OF Item MEAN = .08								

Item RAW SCORE-TO-MEASURE CORRELATION = -1.00
Global statistics: please see Table 44.
UMEAN=.0000 USCALE=1.0000

Figure 3: Summary statistics on item difficulty for HRQOL

Wright map for HRQOL caregivers

The illustration of the persons and items distribution for HRQOL of GI cancer caregivers on a common logit scale is shown in *Figure 4*. The position of persons with high ability to endorse is located above person mean logit scale at 0.45 whereas the positions of persons with low ability are located below the mean logit scale.

In *Figure 4*, about 60% who responded to burden domain items QOL_9 "I fear my loved one will die", QOL_31 "It upsets me to see my loved one deteriorate", QOL_25 "I fear the adverse effects of treatment on my loved one" and QOL_20 "I have difficulty dealing with my loved one's changing eating habits" could hardly endorse these items which are located above the person mean logit. On the other hand, 98% could easily endorse items QOL_17 "I do not feel guilty" and QOL_18 "I do not feel frustrated".

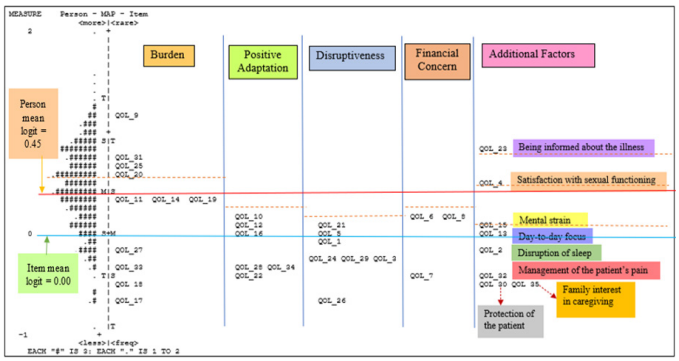

Figure 4: Person-Item Distribution Map (PIDM) for HRQOL

For positive adaptation, disruptiveness and financial concern domains, between 74% and 78% of the respondents could easily endorse items which are located below the person mean logit scale. The easiest item to endorse for positive adaptation is QOL_22 "I have developed a closer relationship with my loved ones"; for disruptiveness is QOL_26, for "The responsibility I have for my loved one's care at home is overwhelming" and for financial concern is QOL 7 "I am concerned about our insurance coverage".

Item Characteristic Curve (ICC) for HRQOL

Figure 5 shows the expected empirical ICC for item logit measure QOL_9 which states "I fear my loved one will die" indicates a fairly difficult item to endorse among the HRQOL constructs. About two third of the points lies below 50% on the expected ogive curve and within 95% confidence interval which indicates majority of caregivers feared that their loved ones will die.

On the other hand, *Figure 6* shows the expected empirical ICC for item logit measure for QOL_17 which states "I feel guilty". This item is the easiest to endorse by GI caregivers among other HRQOL constructs. About two third of the points lies above 50% on the expected ogive curve and within 95% confidence interval which indicates majority of caregivers do not feel burden and guilty while caring for their loved ones.

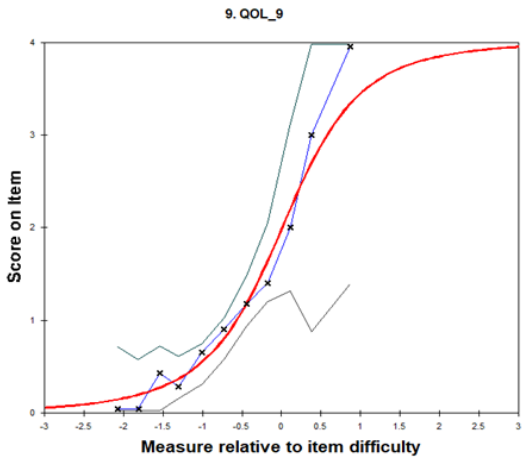

Figure 5: The expected empirical Item Characteristics Curve (ICC) for item QOL_9 (Quality of Life), difficult item to endorse on HRQOL

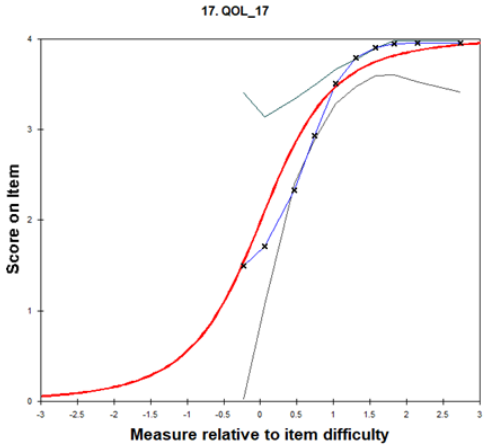

Figure 6: The expected empirical ICC for item QOL_17, easiest item to endorse on HRQOL

Reliability for coping strategies

Figure 7 shows the person reliability index for coping strategies is highly reliable and consistent at 0.87 logit. Higher person reliability indicates a wide range of responses provided by the caregivers. The mean square infit and outfit for persons are 1.00 and 1.10, respectively. The expected value for mean standardized infit and outfit are 0.0 and the mean standardized infit and outfit for persons are -0.2 and 0.1, respectively. All these infit and outfit logit measurement indicates that the data fits the Rasch model well. The standard deviation infit and outfit reflects an overall fit for persons at a 2.0 cut-off value. Here the primary standard deviation for person infit and outfit is 0.53 and 1.16, respectively. This also indicates that the data is within the acceptable range of Rasch model. *Figure 7* also shows that the person separation index is 2.61 suggesting an approximately three levels of caregivers coping strategies.

Figure 8 indicates a high item reliability index at 0.99 logit. This indicates items are replicable for evaluating similar traits. The mean square infit and outfit for item mean squares are 1.06 and 1.12, respectively. The mean standardized infit and outfit for items are -0.1 and 0.3, respectively which is within the acceptable range of Rasch measurement. The standardized infit standard deviation for item is 0.28 and the item separation index shows that the items were separated into 12 levels of difficulty.

```
    SUMMARY OF 323 MEASURED Person
-------------------------------------------------------------------------------
|          TOTAL                          MODEL          INFIT        OUTFIT    |
|          SCORE     COUNT     MEASURE    S.E.      MNSQ   ZSTD    MNSQ   ZSTD |
|-----------------------------------------------------------------------------|
| MEAN      66.0      28.0        -.42     .25      1.00   -.2    1.10    .1 |
| P.SD      12.4        .2         .76     .03       .53   1.7    1.16   1.3 |
| S.SD      12.4        .2         .76     .03       .53   1.7    1.16   1.3 |
| MAX.     106.0      28.0        3.26     .54      3.65   5.3    9.90   8.5 |
| MIN.      31.0      27.0       -3.17     .23       .16  -5.0     .15  -2.0 |
|-----------------------------------------------------------------------------|
| REAL RMSE    .27 TRUE SD     .71  SEPARATION  2.61  Person RELIABILITY  .87 |
|MODEL RMSE    .25 TRUE SD     .72  SEPARATION  2.90  Person RELIABILITY  .89 |
| S.E. OF Person MEAN = .04                                                   |
-------------------------------------------------------------------------------
Person RAW SCORE-TO-MEASURE CORRELATION = .99
CRONBACH ALPHA (KR-20) Person RAW SCORE "TEST" RELIABILITY = .88 SEM = 4.33
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Figure 7: Summary Statistics on person ability for coping strategies

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SUMMARY OF 28 MEASURED Item
-------------------------------------------------------------------------------
|          TOTAL                          MODEL          INFIT        OUTFIT    |
|          SCORE     COUNT     MEASURE    S.E.      MNSQ   ZSTD    MNSQ   ZSTD |
|-----------------------------------------------------------------------------|
| MEAN     761.7     322.6         .00     .09      1.06   -.1    1.12    .3 |
| P.SD     270.7       .8        1.47     .07       .28   2.7     .31   2.4 |
| S.SD     275.7       .8        1.50     .07       .28   2.7     .32   2.4 |
| MAX.    1138.0     323.0        3.91     .37      1.65   5.0    1.77   4.7 |
| MIN.     330.0     320.0       -1.84     .06       .67  -4.8     .71  -3.5 |
|-----------------------------------------------------------------------------|
| REAL RMSE    .14 TRUE SD     1.46  SEPARATION 10.58  Item   RELIABILITY  .99 |
|MODEL RMSE    .12 TRUE SD     1.47  SEPARATION 12.67  Item   RELIABILITY  .99 |
| S.E. OF Item MEAN = .28                                                     |
-------------------------------------------------------------------------------
Item RAW SCORE-TO-MEASURE CORRELATION = -.94
Global statistics: please see Table 44.
UMEAN=.0000 USCALE=1.0000
```

Figure 8: Summary Statistics on item difficulty for coping strategies

Person-Item Distribution Map (PIDM) for coping strategies

Figure 9 illustrates the persons and items distribution map for coping strategies of GI cancer caregivers on a common logit scale.

In *Figure 9*, the ability of persons is normally distributed within ± 2.0 standard deviation from the mean person logit scale. The coping items are categorized across 14 sub-domains according to the type of coping strategies. Most caregivers stated substance use which are COPE11 "I've been using alcohol or other drugs to help me get through it" and COPE 4 "I've been using alcohol or other drugs to make myself better" are difficult to endorse. For the acceptance domain, about 98% of the caregivers can easily endorse items COPE 20 "I've been accepting the reality of the fact that it has happened" and COPE 24 "I've been trying to live with it". The caregivers have mainly accepted the reality of their situation and have been trying to live with the caregiving tasks.

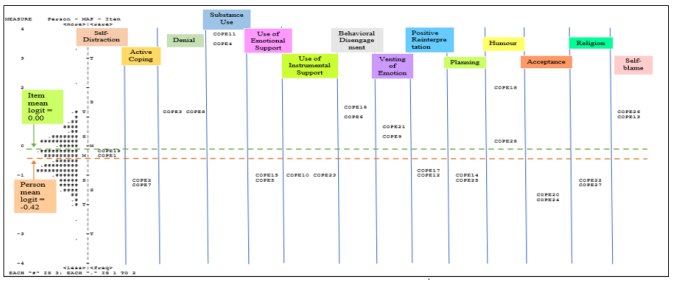

Figure 9: Person-Item Distribution Map (PIDM) for coping strategies

Item Characteristic Curve (ICC) for coping strategies

Figure 10 illustrates the expected empirical ICC the corresponding item logit measure for COPE11 "I've been using alcohol or other drugs to help me get through it" is difficult to endorse by caregivers. About all points lies below 50% on the expected curve and within 95% confidence interval which shows that caregivers had been using alcohol or drugs to help them get through the caregiving job.

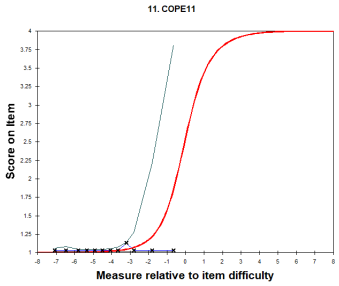

Figure 10: The expected empirical ICC and frequency table for COPE11

In contrast, the expected empirical ICC and frequency table for COPE24 "I've been trying to live with it" is shown in *Figure 11*. This item is easily to endorse by GI caregivers on coping strategies. Around two third of the points lies above 50% on the expected ogive curve and within 95% confidence interval which explains the majority of caregivers have been trying to live with the caregiving job.

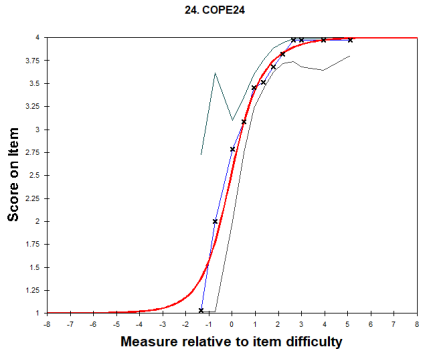

Figure 11: The expected empirical ICC and frequency table for COPE24

Person-Item Distribution Map (PIDM) between HRQOL and coping strategies of GI cancer caregivers

Figure 12 illustrates the comparison of Person-Item Distribution Map (PIDM) between HRQOL and coping strategies of GI cancer caregivers items.

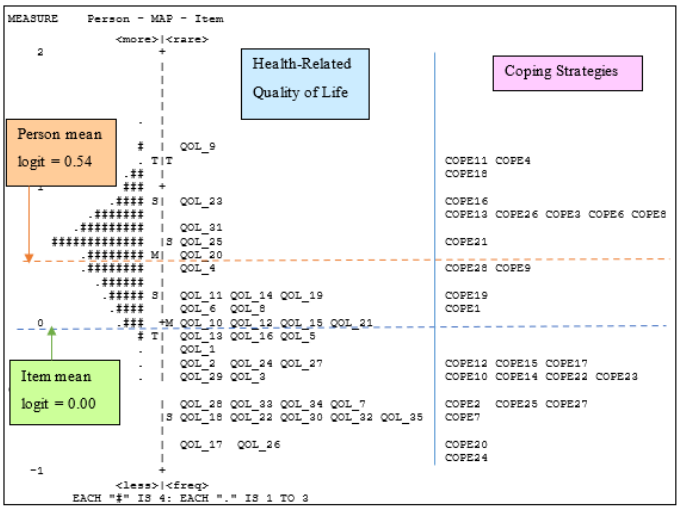

Figure 12: Person-Item Distribution Map (PIDM) between HRQOL and coping strategies of GI cancer caregivers

The HRQOL and Coping Strategies items are plotted side by side on the interval logit scale ranging from -0.93 to 1.33 logits. The description shall focus on the mapping of few items in HRQOL and Coping Strategies. For item QOL_9 "I fear my loved one will die", majority found this to be easily endorsed. In spite of this, majority find it difficult to endorse COPE11 "I've been using alcohol or other drugs to help me get through it" and COPE4 "I've been using alcohol or other drugs to make myself feel better". These caregivers feared about losing their loved ones but not to the extent of taking alcohol and drugs to make them feel better. Mapping of item QOL_9 with COPE 24 "I've been trying to live with it" seems acceptable as well. Even though they fear of losing their loved ones, they have been trying to live with the situation.

For items which are located below the item mean logit, about 98% of respondents reported three items in positive adaptation (QOL_10 "I have more of a positive outlook on life since my loved one's illness", QOL_12 "My sense of spirituality has increased" and QOL_16 "I get support from my friends and neighbours"), an item in mental strain (QOL_15 "I feel under increased mental strain), four items in disruptiveness (QOL_1 "It bothers me that my daily routine is altered", QOL_5 "It is a challenge to maintain my outside interest", QOL_21 "I have difficulty dealing with my loves one's changing eating habits", QOL_24 "It bothers me that I need to be available to chauffeur my loved one to appointments), an item in day-to-day focus (QOL_13 "It bothers me, limiting my focus day-to-day") and an item in disruption of sleep (QOL_2 "My sleep is restful").

Upon mapping these HRQOL items with positive reinterpretation (COPE12 "I've been trying to see it in a different light to make it seem more positive and COPE17 "I've been looking for something good in what is happening") and an item in use of emotional support (COPE15 "I've been getting comfort and understanding from someone"), it can be gathered that caregivers were trying to adapt with positivity and require emotional support as their coping strategies even though they have issues with mental strain, disruptiveness, daily focus and sleep disruption.

DISCUSSION AND CONCLUSION

In examining HRQOL, respondents have high burden but maintain the positivity in adapting to the caregiving situation. They are concerned with maintaining financial stability and less disruptiveness. Meanwhile, respondents tend to use acceptance as their coping strategies to maintain good HRQOL. They have been accepting the reality and been trying to live with the caregiving task as they already adapted with the caregiving job for a long period. Hence, this study is able to discover the caregiver's Health-Related Quality of Life (HRQOL) and their difficulties in performing their caregiving tasks while demonstrating their strategies in coping with the caregiving situation.

DECLARATIONS

Availability of data and material

The data that support the findings of this study are available from the corresponding author Abdullah NN upon reasonable request.

Code availability

This study used Winsteps software to analyze the data.

Authors' contribution

NNA collected the data for her study as citied in the article of Abdullah NN, 2019. Meanwhile, NAI and ZM drafted and designed the study. NAI wrote the manuscript, analyze the data and interpreted the findings. All authors approved the final version of the manuscript.

Ethics approval

This study was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards. This study was approved by the Ethics committee of the National University of Malaysia and the Medical Research and Ethics Committee, Ministry of Health Malaysia.

Consent to participate

Informed consent was obtained from all individual participants included in the study.

Consent publication

The participants have consented to the submission of the study to the journal.

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