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Title: The development and validation of the Brief Experience of Caregiving Inventory (BECI)

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Authors

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Abstract

Background: The social network supporting an individual with psychosis may be adversely affected by the experience of caregiving. The Experience of Caregiving Inventory (ECI) is 66 item self-report measure of the impact of caregiving for carers of people diagnosed with psychotic disorders. This study aimed to create a brief version of the ECI, and evaluate its reliability and validity (n=626). Methods: The validation process was conducted through a multidimensional item response theory (MIRT) approach, using a graded response model and a complementary network approach. Results: This resulted in a 19 item, four factor inventory with a good model fit, displaying good reliability and validity. Conclusion: The BECI is a valid measure. The simplicity, ease of application and robust psychometric properties further enhances its acceptability and usefulness as a brief measure in clinical research and trials, as well as in routine practice providing reliable and valid data on experience of caregiving in families of an individual with psychosis.

Keywords: Carers, Psychosis, Questionnaire Development, Psychometrics, Item Response Theory

1. Introduction

Experts in the treatment of schizophrenia and related psychotic disorders increasingly recognise the impact of the social and psychological context on the progression of the illness [1,2]. One such factor that has been shown to impact on the course of the disorder is the caregiving relationship. “Carers” such as family members, friends, partners, and children, provide day-to-day care for individuals with psychosis that is estimated to save governments/ health care systems more than £1.24 billion a year [2]. It is well established that the interactions between such carers and individuals with psychosis can have both positive and negative impacts on the patients’ illness [3], for example, carers can facilitate help-seeking in the individuals they care for [4] and well-functioning families may also reduce the chances of relapse/hospital admission [5]. In recognition of the importance of this caregiving relationship, assessment of carer needs and in some cases interventions for carers are now amongst the treatment guidance for individuals with psychosis in several countries e.g., [6,7]. For example, in 2014, the National Institute of Clinical Excellence in the UK, included guidance for specific carer interventions, including assessment of the impact of the service user’s illness on the carer themselves.

Carers may experience positive aspects of caregiving (see [3] for a review). However, recent estimates suggest that carers of individuals with psychotic conditions may experience high levels of ‘burnout’ [8], loss and grief [9], and increased health service use [10]. Additionally, it is estimated that between 30-40% experience clinical levels of depression [11]. In this context, it is important that clinicians and researchers routinely assess the impact of this provision of care on the carers. Additionally, considering the important positive impacts carers can have on the individual with psychosis [12], it is important that clinicians provide targeted support to ensure this relationship does not break down.

To facilitate the assessment of carers, there are several measures of carer experiences (e.g., Burden Index of Caregivers [13], Carers needs assessment for schizophrenia (CNA-S) [14], however, perhaps the most widely used measure is the Experience of Caregiving Inventory (ECI) [15]. Developed with carers of individuals with psychotic conditions, it is the one of the

few measures that includes both positive and negative aspects of caregiving. However, the length of the ECI at 66 items, makes its application impractical in many contexts and may be overly burdensome for carers to complete especially in clinical settings. Creating shorter and simpler status /outcome measures is a critical step in supporting their use in clinical care [16]. In this context, we aimed to develop a brief version of the ECI using the original dataset and comprehensive statistical techniques to produce a measure that firstly, has a reduced number of items to facilitate its use in routine clinical care, secondly, has strong psychometric properties to ensure the validity of the measurement and finally, highlights the specific areas which would may benefit from direct clinical intervention.

2. Methods

2.1 Analysis

Summary sample characteristics are presented in Table 1. Further details can be found in the original paper [15]. The original paper used principal components analysis to derive a 10 factor solution with 66 items. The ECI comprises of 8 'negative' and 2 'positive' factors. We followed a confirmatory approach in order to retain the original 10 factor solution. A Multidimensional Item Response Theory (MIRT) approach was used for item selection. Pertinent to developing a brief measure MIRT analysis provides more information at item level, providing increased precision in measurement estimates. This method addresses the limitation in Classical Test Theory where longer tests are usually more reliable than shorter tests and discrimination is based on correlation between item and total test score. Selecting items through MIRT can identify how underlying latent traits interact with item characteristics, such as 'difficulty' and 'discrimination' (see below) [17]. The high dimensionality of the ECI contributes to model complexity and its interpretation. The latent traits represent the aspects of the latent construct being measured, which we assume independent and influencing all subjects. The traits underlying the experience of caregiving are assumed to fit with a compensatory model whereby being low on one trait (e.g. stigma) can be compensated by being high on another (e.g. dependency). MIRT undertakes a process not dissimilar to confirmatory factor analysis,

while also including item and model fit estimation [17]. MIRT can help validate the proposed theoretical structure of the test, and thus provide evidence regarding the validity of test scores [18]. The intention was to represent each item by a vector of item statistics on the same dimensions needed to fit the data. Best fit items would then be retained in the model until a satisfactory brief inventory was constructed.

Discrimination parameters represent the degree to which an item discriminates between persons with different levels of the latent trait and can be interpreted like factor loadings in factor analysis, representing the strength of the association of the item with the latent trait. Each component of the vector represents the “loading” of each latent trait on the response probability. Items with a high discrimination on a latent trait are more likely answered in different ways by individuals with different latent traits.

The *difficulty* parameter can be interpreted as the severity of the symptom described in the item, for instance, if the difficulty of ECI item 6 (risk of committing suicide) is high, it means that it takes an elevated value of the latent traits in order to obtain an endorsement of the individual to the existence of the symptom [19].

The item parameters, item information curves (IIC), *MDIFF* (item difficulty index) and *MDISC* (item discrimination index) were used [20]. *MDIFF* indicates the point on the scale of the latent trait where a person has .5 probability of responding positively to an item category. Large positive values of *MDIFF* indicate greater item difficulty, while large negative values indicate less difficulty. Each value represents the difficulty of the *k*th step (moving between ratings on the scale e.g. from often to nearly always) of the graded response item. In the present context, “difficulty” refers to the value of the latent trait for which an item gives the most information. *MDISC* is related to the slope of the item response surface in the steepest direction, capturing the ability of an item to discriminate between people with different levels of the latent trait - higher values indicate greater discrimination ability of the item. IICs relate the reliability and precision of an item where the curve indicates the level on a given trait continuum that the item provides the most information. Items reaching maximum information levels were considered against items with more precision across levels.

Given the polytomous data and large number of dimensions, we used a graded response model, with Metropolis-Hastings Robbins-Monro (MHRM) algorithm (maximum likelihood estimation) for parameter calculations. Analyses were conducted in R package “mirt” [17].

Item selection was conducted by assessing the factor loadings (Λ) and item parameters (IIC, MDIFF, MDISC, outfit). Item-fit statistics (signed chi-squared test: 'S_X²' [21]), were also assessed. Factor correlations, a MIRT-based index: empirical reliability (a calculation of latent trait estimates and their associated standard errors using a Bayesian modal estimation procedure: MAP) and the classical measure of reliability (Cronbach's α) were used to compare to overall reliability of measure.

To complement the reliability and validity analysis, a graphical ‘least absolute shrinkage and selection operator’ (lasso) network model [22] was conducted in R package ‘qgraph’ [23] to visually inspect the strength, closeness and betweenness of item associations. The use of network modelling with the BECI not only visualises the clustering of dimensions but also the network of interacting evaluation of carers which can arise through direct causal influences. This is fitting with the Causal Attitude Network model [24].

Sex of person with psychosis	66% male
Main caregiver	74%
Relationship to relative	59% mother 11% father 16% spouse 10% sibling 3% other
Age of relative M(SD)	33.47 (10.72)
Age of caregiver M(SD)	53.83(12.95)
Length of illness (years) M(SD)	11.52(8.86)
Relatives diagnosis	Schizophrenia 79.4% Schizoaffective disorder 2.6% Bipolar disorder 9.7% Schizophrenia & Epilepsy 1% Unknown 7.3%
Relative lives with caregiver	60.9% yes

Table 1. Summary demographic details n = 626

2.2 Measures

A number of measures from the original study were used to assess construct validity. The sum of the eight ECI negative scales (ECIneg) were included for comparison purposes.

The Positive and Negative Affect Schedule (PANAS) [25] comprises two mood scales, one that measures positive affect and the other which measures negative affect. Only the Positive scale was used in the current analyses, as the negative affect scale did not display a normal distribution within the sample.

The Provision of Social Relations (PSR) [26] is a 15 item scale measuring components of social support with two dimensions: family and friend support.

An Adapted Ways of Coping (WOC) checklist [27,28] is a 28 item measure, covering cognitive and behavioural strategies for coping. Szmukler et al. replicated the subscales within the ECI sample, labelling them practical coping, emotional coping and detachment where higher scores for practical and detachment, and lower scores on emotional coping are considered adaptive. Relative scores (percentage of total efforts for each coping type) were used [29].

The Pearlin Mastery Scale (Mastery) [30] is a 7 item scale, measuring an individual's level of mastery; the degree to which an individual considers themselves to have control over their own life.

The General Health Questionnaire (GHQ) [31] is a 28 item scale, covering a range of psychiatric symptoms.

3. Results

Initial confirmatory MIRT for the original 66 item ECI for a 10 factor model (n=626) displayed poor model fit ($M^2(1881)=21962.53$, $p=0.13$, $RMSEA = 0.131$, $SRMSR=0.324$, $CFI=0.61$ and $TLI=0.597$). Factor loadings (oblimin rotation method) ranged between 0.191 to 0.831 and items slopes (α) between 0.58 to 3.74 (see supplementary material for MIRT analysis of ECI-66).

3.1 Brief Experience of Caregiving Inventory

Local independence assumption was investigated through the residual covariance matrix, revealing excess item covariation (25 pairwise violations) which can indicate local dependence. Our preference was to calibrate the final item set in the context of the entire questionnaire [32].

Intra-class correlations (ICCs) were generated and items were compared within factor groupings, against slope and location parameters to gain most information from items. High discrimination values for *MDISC* (>1.5) and items displaying equal spread across *MDIFF* values with those with high positive values at β_3 and β_4 were retained. S_X^2 values were also assessed however these were all significant; statistical power is a function of sample size [21]. As such values for item fit were converted to a standardised 'outfit' mean squared index (S_X^2/df). 26 items provided the best information / discrimination against these criteria.

Following selection of items, the 26 items were re-investigated for local dependence, based on multiple pairwise violations, item 1 and 55 were removed, leading to local independence for the remaining items. Analyses of the number of factors to retain [33] suggested a 5 factor solution (optimal co-ordinates and parallel analysis) for the remaining 24 items. An exploratory MIRT for 5 factors was conducted and an iterative process was conducted to find the best fit. At this stage a further 5 items (items 5, 6, 11, 29 and 48) were removed based on Λ and *MDISC*. The remaining 19 item BECI (Table 1) suggested a 4 factor solution (parallel, eigenvalue and optimal co-ordinates analyses).

The model fit for the 19 item, 4 factor model displayed good fit ($M^2(44)=102.65$, $p<0.0001$, $RMSEA = 0.046$, $SRMSR=0.046$, $CFI=0.987$ and $TLI=0.966$). Λ (oblimin rotation method) ranged between 0.487 and 0.887 and α between 1.01 and 3.25.

BECI item (original ECI item)	F1	F2	F3	F4	MDISC
14 (54) Unpredictable	0.86				1.63
17 (61) Irritable	0.81				1.53
18 (62) Inconsiderate	0.79				1.48
19 (63) Behaving in a reckless way	0.72				1.24
15 (56) Uncommunicative	0.68				1.13
16 (57) Not interested	0.63				1.00
12 (44) I have discovered strengths in myself		0.89			1.90
4 (20) I have become more confident dealing with others		0.84			1.62
5 (23) I have become more understanding of others with problems		0.71			1.06
7 (22) He/she is good company		0.49			0.67
8 (36) How health professionals do not understand your situation			0.84		1.84
6 (26) How to deal with mental health professionals			0.88		1.73
2 (10) How mental health professionals do not take you seriously			0.83		1.55
3 (16) Dealing with psychiatrists			0.83		1.37
11 (42) How to make complaints about his care			0.64		1.10
9 (39) How to explain his illness to others				0.59	1.08
10 (40) Others leaving home because of the effects of the illness				0.65	1.01
13 (47) The illness causing a family breakup				0.58	0.95
1 (02) Feeling unable to tell anyone about his illness				0.71	0.85
<u>Factor correlations</u>	<u>F1</u>	<u>F2</u>	<u>F3</u>	<u>F4</u>	
Difficult behaviours (F1)		-0.12	0.53	0.48	
Positive Personal Experiences (F2)			-0.20	-0.19	
Problems with services (F3)				0.47	
Empirical Reliability	0.88	0.81	0.88	0.70	
Cronbach's α	0.87	0.76	0.87	0.69	

Table 2: Factor loadings, factor correlations, reliability and discrimination (MDISC) for the BECI, F4=Stigma / Effects on family

3.2 Reliability

Both measures of reliability of the BECI displayed good overall internal consistency (Cronbach's $\alpha = 0.84$) and for subscales (see Table 2). Factor correlations were medium to large between difficult behaviours, problems with services and Stigma/Effects on the family.

Positive personal experiences displayed small negative correlations with the other factors. These findings suggest good overall reliability.

3.3 Construct validity

The mean score on the BECI was 33.2 (SD=12.2), range 1-68, where a higher score is indicative of greater 'burden'. The factor, Positive Personal Experiences, is reverse scored, when summing the total score. An excel calculator for extracting the score for the BECI from original ECI and scoring the BECI has been included in supplementary material.

Factor loadings were strong and did not cross load indicative of convergent validity [34] with factor correlations suggestive of good discriminative validity between dimensions.

A number of associated measures were collected in the original study. Correlations between measures are reported (Table 3). The BECI and ECIneg were strongly correlated ($r=0.881$). Correlations between the BECI and other measures displayed significant correlations with practical and emotional coping, with less adaptive coping correlating with a more negative experience of caregiving. The BECI was positively correlated with the PANAS positive affect. At a factor level this relationship appeared to be related to a significant positive correlation ($r=0.159$) between positive affect and problem with services (which in turn was negatively correlated with positive personal experiences). No significant relationship existed between the BECI detached coping, mastery and PSR. These findings mirrored the correlations between these measures and the ECIneg. Comparison of significance of the difference between correlations [35] between the measures and both the BECI and ECIneg revealed only one significant difference: a stronger correlation between BECI and practical coping (ECIneg $r=-0.85$, Stegier's $Z = -2.7$). The GHQ and physical health (self-rated on a 4 point scale) were significantly correlated with the BECI but not with the number of visits to their GP (for the carer's own health) in the last year. No predictive relationships were observed.

No group differences were found for specific diagnosis, number of admissions, or having the carer living with the patient. This corresponds with the findings for the original ECI.

3.4 Network Analysis

The network graph (Figure 1) highlights the relationship between items both within and across dimensions. A LASSO network is similar to the predictive associations obtained in multiple regression and thus, the strength of a connecting line indicates the strength of the predictive relationship between two items (while controlling for all other items). The wider and more saturated the line, the stronger the correlation. The Extended Bayesian Information Criterion (EBIC) hyperparameter was set at 0.5 for a more parsimonious model.

The clustering of items reflects the distinction between the dimensions, and strength of relationships within dimensions, obtained through the MIRT analyses. As expected there is a structural gap between positive personal experiences and the other dimensions. The network highlights a dynamic relationship between items suggesting a direct relationship or a feedback loop. Overall, items were positively connected within the network, with a clear negative connection between item 12 (I have discovered strengths in myself) and item 19 (behaving in a reckless way).

To estimate the influence of items within the network and identify more 'important' items, where centrality may indicate the influence of a single item on the rest of the network, node strength centrality [36] was calculated (a stable centrality metric defined as the sum of all associations: degree, closeness, and betweenness). Bootstrapped centrality stability analysis demonstrated a high proportion of statistically significant comparisons. Correlation stability coefficients computed for the centrality metrics (betweenness = 0.05, closeness = 0.21, strength = 0.44), show strength centrality metrics surpassed the recommended cut off of 0.25 [37] while the betweenness and closeness centrality metric did not, and were therefore not interpreted (details in the supplementary material).

The items with the highest node strength centrality were items 6 (How to deal with mental health professionals), 8 (How health professionals do not understand your situation), 12 (I have discovered strengths in myself) 14 (Unpredictable) and 17 (Irritable), suggesting these may be of greatest clinical significance. These correspond with the items with high discrimination (MDISC).

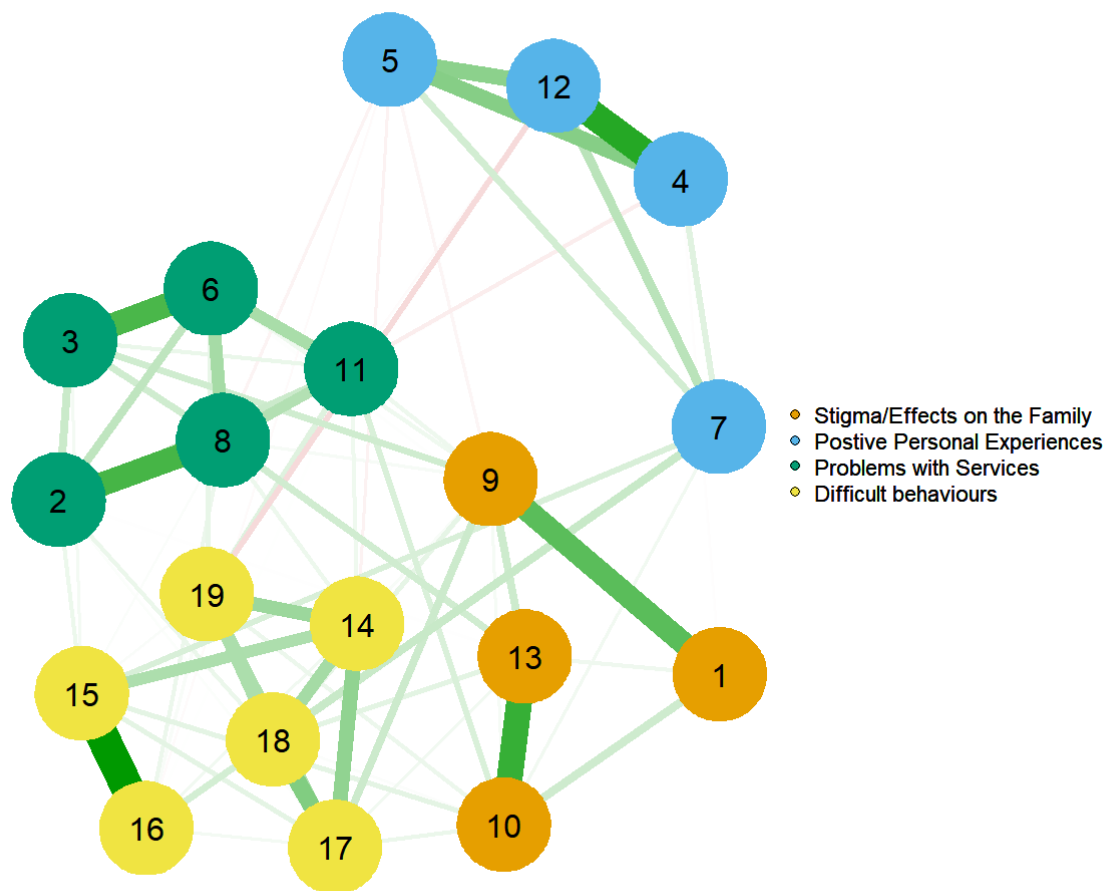


Figure 1: Glasso network of items in BECI, grouped by factors. Green lines represent positive connections, red lines negative connections. Numbers refer to items as labelled in Table 2.

	Pract.	Emo.	Detach.	Mastery	Panas+	Physical Health	PSR	GHQ	ECIneg
BECI	-0.138 ***	0.133 ***	0.014	0.035	0.125 **	0.155 ***	-0.035	0.291 ***	0.881 ***
Pract.	—	-0.422 ***	-0.569 ***	0.016	0.027	-0.199 ***	0.021	-0.256 ***	-0.085 *
Emo.		—	-0.345 ***	0.057	0.087 *	0.170 ***	0.064	0.287 ***	0.111 **
Detach.			—	-0.087 *	-0.059	-0.025	-0.093 *	-0.068	-0.020
Mastery				—	0.389 ***	0.085 *	-0.300 ***	0.041	0.010
Panas+					—	0.041	-0.271 ***	0.052	0.110 **
Physical Health						—	0.032	0.475 ***	0.155 **

Table 3: Pearson Correlations between associated measures * $p < .05$, ** $p < .01$, *** $p < .001$. Pract. = Practical Coping, Emo=Emotional Coping, Dist. = Detachment Coping

4. Discussion

4.1 Overview of results

This is the first empirical study to develop a brief version of the original 66-item ECI using item response theory which is considered gold standard for refining and reducing the length of existing scales in the social, medical, and educational sciences. We reanalysed the original data used in the development of the ECI [15] in the present study and carried out analyses based on MIRT. The original 10 factors appeared to be a poor fit to the data and we identified 19 items mapping onto 4 new factors to create BECI, namely 'difficult behaviours', 'positive personal experiences', 'problems with services' and 'stigma/effects on the family'. A copy of the BECI is included in a supplementary file. Results confirm sufficient reliability, factorial and construct validity and discriminant validity of the BECI. We have therefore successfully reduced scale length without compromising its psychometric properties.

Furthermore, network analysis and MIRT revealed individual items (item numbers: 6; 8; 12 14, 17) based on node strength and discrimination (MDISC) which may have particular clinical importance and relevance when interpreting appraisals of caregiving. These reflect the perceived impact of mental health professionals' helpfulness and level of understanding, their loved ones perceived 'unpredictability' and 'irritability' and also a carer discovering strengths in themselves. It is often assumed that caregiving appraisal is heavily influenced by patient factors and burden of caring [38], however, these results suggest that carers' perception of mental health professionals is also central to this association.

Importantly, the relationship between the GHQ and experience of caregiving was significant, indicating that the subjective experience is associated with psychological distress and wellbeing. Poorer physical health that can also be considered a proxy for wellbeing was related to poorer experience of caregiving in this sample, but not to the number of GP visits. This might be related to help seeking behaviours in carers and it is likely that carers put the needs of their relative with psychosis ahead of themselves. Positive affect was not related to the BECI, and instead related to increased mastery and more problems with services. This finding may indicate that difficulties experienced by carers may positively contribute to a greater sense

of agency and having an active role in caregiving especially in relation to accessing support from clinical services.

These results have direct implications on clinical practise and highlight the importance of providing support and information to families and carers of individuals affected by psychosis and fostering a family inclusive approach to clinical care. Furthermore, given that perceived communication has been highlighted important in the context of caregiving appraisal, family intervention work targeting communication between carers and their loved ones is of direct value.

4.2 Limitations

Findings from the current study should be viewed in light of important limitations. Despite its advantage as a shorter instrument, the BECI should not be considered a replacement for the original scale. The decision to produce a short version could be seen as a loss of the multidimensional construct, for example the dimension stigma is not fully represented in the BECI. Nonetheless, BECI has retained at least 1 item from each of the original domains, and qualitative loss of items has not comprised the psychometric value of the brief version. The ECI differentiated between positive and negative appraisals of caregiving although only the overall negative score was used to assess the instruments validity thus it seems reasonable to assume the positive subscale was only used for qualitative purposes. The BECI provides a total composite score thereby integrating the positive and negative elements.

The data used in this analysis was collected in 1996 from a cohort of carers of individuals with psychosis. While the structure of providing psychiatric care has improved over the years, and present day services such as Early Intervention Services seek to address the factors contributing to the burden of caregiving, the experience of caregiving itself has not changed substantially. The levels of caregiver burden [8, 39], poor understanding of psychosis [40] and caregiver mental health issues [11] remain high across the globe. Recognition of these issues has led to the development of targeted interventions [7] to improve understanding of psychosis and the experience of caregiving by reducing burden [41]. Nonetheless the experience of

caregiving appears to remain the same. It is likely that experience of caregiving varies depending on severity, chronicity and stage of illness and therefore some constructs might better capture carers' experiences at particular time points. In order to reduce the potential that the items were selected due to specifics of the sample, the findings need to be replicated in a second sample, and across the trajectory of psychosis. We contacted authors of recent published research using the ECI, however, we were not able to attain a large enough sample to run this analysis.

As such, the psychometric properties of the BECI warrant further scrutiny. Independent validation in other samples should take into account varying chronicity of illness. Larger sample sizes and a greater representation of carers of individuals with psychosis should be aimed for, helping to improve the reliability of our results, the robustness of factorial structure and the amount of evidence of validity.

Furthermore, the extent to which clinicians find the BECI helpful in clinical practice is yet to be investigated and future research examining the psychometric properties of the BECI may help to determine the degree to which BECI can be used to assess and predict clinical outcomes.

4.3 Conclusions

The findings of the present study suggest that the BECI, at a third the length of the original, is a reliable and valid instrument to measure the caregiving experience of a carer of a person with psychosis. The BECI will serve as a potentially helpful tool for researchers, clinicians, health care systems where brevity is needed. These results also suggest four particular areas that clinicians should focus on to reduce carer burden.

5. References

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