

# Validation of the Family Inventory of Needs (FIN) for family caregivers in palliative care

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## ABSTRACT

**Objective:** Caregivers of cancer patients are faced with significant demands that can seriously impact their physical and mental health. It is important for healthcare professionals to be aware of caregivers' support needs in order for these to be adequately addressed. Our study develops a German version of the Family Inventory of Needs (FIN) and provides a comprehensive evaluation of its acceptability and psychometric properties.

**Method:** Cross-sectional data from 308 participants were taken from the baseline assessment of an ongoing prospective study. Retests were completed by 46 participants approximately one week after baseline. Informal caregivers of terminally ill cancer patients were recruited from three hospitals in Vienna. Questionnaires for hope (IHS), traumatic stress (IES-R), and depression and anxiety (HADS) were employed together with the translated FIN to assess concurrent and discriminant validity.

**Results:** The internal consistency of FIN–Importance had a Cronbach's  $\alpha$  of 0.94, and that for FIN–Fulfillment was  $\alpha = 0.96$ . Retest reliability for FIN–Importance was  $r = 0.97$ , while that for FIN–Fulfillment could not be calculated due to missing responses to this subscale. Concurrent and discriminant validity tests for the scale and the discriminative power of items were adequate. However, missing responses may limit the feasibility of using this scale in research settings. We identified six questions that could be excluded from the scale in order to increase its acceptability and further improve its psychometric properties.

**Significance of results:** Our results suggest that the FIN is suitable for clinical settings. For use in research, we suggest four adaptations to increase the scale's acceptability and psychometric properties. The FIN can be a valuable tool for informing the emotional, physical, and psychological support provided to family carers of people who are terminally ill with cancer.

**KEYWORDS:** Palliative medicine, Caregivers, Family, Validation, Questionnaires, Translations

## BACKGROUND

Palliative care considers the physical, psychosocial, and emotional needs of patients, offering a unique concept of care for terminally ill and dying persons (Wanzer et al., 1989). Importantly, palliative support

is not supposed to focus on patients as isolated individuals but to include their families and informal caregivers in the caring process (Borasio, 2011). There is growing evidence that informal caregivers are at high risk of suffering emotional and physical distress due to the substantial demands associated with caregiving (Scott et al., 2001; Sanderson et al., 2013). They are at risk for developing disabling mental health problems—such as depression, anxiety, and posttraumatic stress disorder—during both the times of caring for their loved one and in the

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subsequent phase of bereavement (Williams & McCorkle, 2011; Robinson et al., 2013).

Today, both the significant role of family caregivers as well as their potential vulnerability is widely accepted by palliative care professionals (Borasio, 2011), and increasing research activity is focusing on caregivers' experiences (Kogan et al., 2013), needs (Hannon et al., 2012), and preferences (Lee et al., 2013), and on caregiving outcomes such as physical, social, or emotional problems (Stenberg et al., 2010). In practice, caregivers' needs, such as information, support, and communication, are acknowledged but often not adequately met (Hwang et al., 2003). This has considerable clinical consequences. For caregivers, unmet needs are associated with impaired work performance (Park et al., 2010) and higher levels of burden and anxiety (Sharpe et al., 2005), as well as distress (Hirdes et al., 2012). It has also been shown that caregivers' unmet needs predict poor mental health during the time of diagnosis and treatment and for years after (Kim et al., 2010).

In order to adequately address caregivers' needs, they must first be reliably identified (Henriksson et al., 2011; Hudson, 2013). Numerous assessment tools have been developed to systematically measure caregiver variables, including support needs (Hudson et al., 2010), but often they are not properly validated or sufficiently tested for clinical use and may need further refinement (Wen & Gustafson, 2004). No thoroughly validated assessment tool for caregiver needs exists in German. The Family Inventory of Needs (FIN) (Kristjanson et al., 1995) has been considered a promising instrument for clinical practice since it encompasses a wide range of needs, measuring both their perceived importance and whether they have been met (Deeken et al., 2003). However, in research the scale has been applied using variable scoring rules, which makes it difficult to appraise its practical applicability and psychometric properties (Friethriksdottir et al., 2011; Hannon et al., 2012).

This study has two aims: (1) to add to the establishment of the psychometric properties of the FIN, and (2) to provide a validated German version of the instrument.

## METHODS

### Translation and Content Validation

The FIN was translated from English into German according to the World Health Organization's recommendations for developing equivalent versions of assessment tools in different languages (WHO, 2013). This involved professional translation of the

original scale into German followed by having the translation checked by three bilingual German-/English-speaking researchers. Additionally, 30 unilingual German speakers from different sociodemographic backgrounds, including relatives of palliative care patients and nurses and doctors, reviewed the translated scale. The translation was amended according to their comments and back-translated to English by a different professional translator. The back-translation was then sent to the author of the original scale for approval.

### Setting and Participants

This validation study was part of a larger research program. It employs data from the baseline assessments of an ongoing prospective study that screens for a range of psychiatric diagnoses (including prolonged bereavement) and their predictors in caregivers before and after the death of the patient. Informal caregivers of terminally ill cancer patients were recruited from the Medical University of Vienna and two major Viennese city hospitals. Participants were self-identified primary caregivers of terminally ill cancer patients, defined by the presence of advanced metastasis or an estimated life expectancy of less than six months, aged at least 18, fluent in German, and capable of giving written informed consent. After an initial information letter, eligible family members were contacted via telephone and informed about the study. Following their assent to participate, they received the questionnaires, information, and consent form, together with a prepaid return envelope. Some 50 participants were randomly chosen to receive the FIN again after a target interval of one week to establish retest reliability. The study was approved by the ethics committee of the Medical University of Vienna (905/2010).

### Measurement Tools

The **Family Inventory of Needs (FIN)** measures the support needs of family caregivers of advanced cancer patients and the extent to which these are met (Kristjanson et al., 1995). It contains 20 items, each of which is rated on two subscales. In its original version, the first subscale (FIN–Importance) measures the importance of each care need on a scale between 0 (not at all important) and 10 (very important). The second subscale (FIN–Fulfillment) asks respondents to indicate whether each need scoring above 0 on FIN–Importance is met by healthcare professionals, allowing ratings of 0 (not met) and 1 (met). The original scale-development study reported a Cronbach's alpha of 0.83 for the FIN–Importance subscale. For the FIN–Fulfillment subscale, a percentage of met and unmet needs was calculated.

Other authors scored the scale differently. The Icelandic version rates FIN–Importance between 1 (not important) and 5 (very important), and FIN–Fulfillment as “not met,” “partly met,” or “met” whenever a score of at least 4 is chosen on the FIN–Importance subscale. This approach resulted in an alpha of 0.92 for FIN–Importance and 0.96 for FIN–Fulfillment (Fridriksdottir et al., 2006). For the present study, we combined the two approaches using ratings between 1 (not important) and 5 (very important) for FIN–Importance and 0 (not met), 0.5 (partly met), and 1 (met) for the FIN–Fulfillment subscale, including all items with a score of at least 2 (somewhat important) on FIN–Importance.

The **Integrative Hope Scale (IHS)** contains 23 items rated on a 6-point Likert-type scale from “strongly agree” to “strongly disagree.” The six negatively anchored items are reverse scored. The overall score is the sum of all items, ranging from 23 (low hope) to 138 (high hope). The scale’s internal consistency has a Cronbach’s alpha of 0.92 and a retest reliability of  $r = 0.84$  (Schrank et al., 2011).

The **Impact of Event Scale–Revised (IES–R)** contains 22 items estimating subjective distress caused by traumatic events. Items are rated on a 4-point Likert-type scale from “not at all” to “frequently” and assess the domains of intrusion, avoidance, and hyperarousal. Cronbach’s alpha for the scale is between 0.78 and 0.82, and retest reliability is  $r = 0.87$  (Horowitz et al., 1979; Creamer et al., 2003).

The **Hospital Anxiety and Depression Scale (HADS)** is the most commonly used method for assessing depression and anxiety in palliative care, both for patients and their relatives. The scale’s 14 items assess the levels of depressive and anxiety symptoms on a scale ranging from 0 to 3. Cronbach’s alpha lies between 0.80 and 0.93 and retest reliability between  $r = 0.70$  and 0.85 (Herrmann, 1997).

## DATA ANALYSIS

Questionnaire acceptability and comprehensibility were estimated by analyzing missing responses, including the percentage of missing responses per item, the frequency of missing responses per subscale, and the frequency of the questionnaire being unusable for analysis due to missing responses. We used a conservative rule for classifying questionnaires as unusable, that is, more than two missing responses per subscale. After analyzing missing data, we replaced missing responses on the FIN–Fulfillment subscale with the item-specific population mean whenever there was a maximum of two missing values per person. For analyzing FIN–Fulfillment only, those items are used that received a correspond-

ing value of at least 2 on the FIN–Importance subscale. Items with a missing value or a value of 1 on the FIN–Importance subscale are not included in the analysis of FIN–Fulfillment. Hence, missing items on the FIN–Importance subscale cannot be replaced. The discriminative power was calculated for each item using the Item Discrimination Index (Schwierigkeitsindex) (Kubinger, 2009). Internal consistency was calculated for each subscale using Cronbach’s alpha. Concurrent and discriminant validity for FIN–Fulfillment were established using Pearson’s correlation coefficient. It is not possible to adequately test or interpret concurrent or discriminant validity for FIN–Importance since, to the best of our knowledge, no validated measurement tool in the German language exists that could be applied for this purpose. Nevertheless, to approach this task, we tested the correlations between FIN–Importance and hope, distress, depression, and anxiety, hypothesizing a lack of relationship. Retest reliability was assessed using Pearson’s correlation coefficient between the first and second assessment times for both subscales. All statistical analyses were computed using IBM® Statistical Product and Service Solutions (SPSS, version 17.0), and  $p$  values of 0.05 were considered statistically significant.

## RESULTS

### Participants

A total of 308 caregivers supplied written informed consent and participated in the assessment. Their characteristics are shown in Table 1.

### Questionnaire Acceptability

On the FIN–Importance subscale, 45 questionnaires (15.1%) had at least one missing response, 31 (10.4%) more than one, and 22 (7.4%) more than two. On the FIN–Fulfillment subscale, 124 questionnaires (41.6%) had at least one missing response, 96 (32.2%) more than one, and 75 (25.2%) more than two. This means that on the FIN–Importance subscale 14 of the 20 items remained below the 5% threshold for missing responses, while on FIN–Fulfillment all items showed missing response rates above 10%. Overall, the number of missing responses increased toward the end of the questionnaire. Table 2 shows the raw item means and missing responses per item.

Participants often did not adhere to the instructions when completing questionnaires. The most frequent deviation was that only one of the subscales (FIN–Importance or FIN–Fulfillment) was answered throughout. Other questionnaires showed

**Table 1.** Sociodemographic characteristics of participants [*n* (%)]

Variable		
Caregiver age ( <i>n</i> = 308)		53.7 years mean
Caregiver gender ( <i>n</i> = 308)	Female	185 (60.1%)
Marital status ( <i>n</i> = 305)	Partnership/marriage	251 (82.3%)
	Single (including divorced, widowed)	54 (17.7%)
Relationship to patient ( <i>n</i> = 308)	Spouse/partner	159 (51.6%)
	Child	94 (30.5%)
	Parent	16 (5.2%)
	Other	39 (12.7%)
Living situation ( <i>n</i> = 306)	Same household	177 (57.8%)
	Different household	129 (42.2%)
Length of overall caring time ( <i>n</i> = 303)	<6 months	89 (29.4%)
	6–12 months	63 (20.8%)
	1–2 years	52 (17.2%)
	2–3 years	31 (10.2%)
	>3 years	68 (22.4%)
Hours caring per week ( <i>n</i> = 302)	<10 hours	34 (11.3%)
	10–20 hours	55 (18.2%)
	20–40 hours	44 (14.6%)
	>40 hours	169 (56.0%)
Educational level ( <i>n</i> = 307):	Primary education (up to age 14)	25 (8.1%)
	Secondary education (age 15–18)	128 (41.7%)
	Vocational training	93 (30.3%)
	Higher education (above age 18)	61 (19.9%)

**Table 2.** Item means and missing responses per item for both subscales (*n* = 298)

Items	FIN–Importance		FIN–Fulfillment	
	Mean	Missing Responses <i>n</i> (%)	Mean	Missing Responses <i>n</i> (%)
I need to:				
1 Have my questions answered honestly	4.6	11 (3.7)	0.8	33 (11.1)
2 Know specific facts concerning the patient's prognosis	4.4	13 (4.4)	0.6	36 (12.1)
3 Feel that the health professionals care about the patient	4.6	12 (4.0)	0.8	33 (11.1)
4 Be informed of changes in the patient's condition	4.6	13 (4.4)	0.7	35 (11.7)
5 Know exactly what is being done for the patient	4.3	12 (4.0)	0.7	32 (10.7)
6 Know what treatment the patient is receiving	4.2	13 (4.4)	0.7	36 (12.1)
7 Have explanations given in terms that are understandable	4.5	14 (4.7)	0.8	30 (10.1)
8 Be told about treatment plans while they are being made	4.3	13 (4.4)	0.6	41 (13.8)
9 Feel there is hope	4.3	19 (6.4)	0.6	48 (16.1)
10 Be assured the best possible care is being given to the patient	4.5	12 (4.0)	0.8	36 (12.1)
11 Know what symptoms the treatment or disease can cause	4.4	13 (4.4)	0.6	34 (11.4)
12 Know when to expect symptoms to occur	4.3	13 (4.4)	0.5	37 (12.4)
13 Know the probable outcome of the patient's illness	4.4	13 (4.4)	0.6	32 (10.7)
14 Know why things are being done for the patient	4.3	14 (4.7)	0.7	33 (11.1)
15 Know the names of health professionals involved in the patient's care	3.7	15 (5.0)	0.7	39 (13.1)
16 Have information about what to do for the patient at home	4.5	23 (7.7)	0.6	49 (16.4)
17 Feel accepted by the health professionals	3.9	25 (8.4)	0.8	53 (17.8)
18 Help with the patient's care	3.7	25 (8.4)	0.8	61 (20.5)
19 Have someone be concerned with my health	3.2	20 (6.7)	0.5	65 (21.8)
20 Be told about people who could help with problems	3.9	20 (6.7)	0.6	45 (15.1)

erratic response patterns, with individual questions often rated on only one of the subscales. Consequently, 70 questionnaires (23.5%) had more than 2 missing responses per subscale and were hence classified as unusable. Mean values were 4.0 ( $SD = 0.7$ ,  $n = 254$ ) for FIN–Importance and 0.6 ( $SD = 0.2$ ,  $n = 223$ ) for FIN–Fulfillment. Given the flawed response styles (e.g., FIN–Fulfillment ratings also provided for items with low or missing FIN–Importance scores), existing responses needed to be excluded from the analysis when using only items with a FIN–Importance rating above 1. This increased the percentage of excluded responses (i.e., together with missing responses) per item to between 15.1 and 31.2% on the FIN–Fulfillment subscale.

We subsequently decided to include all questionnaires in further analyses irrespective not only of the overall number of missing responses per questionnaire but also the corresponding FIN–Importance rating for analysis of the FIN–Fulfillment subscale. This was considered appropriate because of the high number of missing responses overall, their unequal distribution among the two subscales, and the fact that no overall score covering both subscales could be calculated. Most importantly, excluding a high number of questionnaires due to complex rating methods would have constituted a loss of available clinically relevant information. For comparison, using all available data, mean values were 4.2 ( $SD = 0.7$ ,  $n = 288$ ) for FIN–Importance and 0.7 ( $SD = 0.2$ ,  $n = 275$ ) for FIN–Fulfillment.

### Discriminative Power of Items

In order for a test to be equally discriminative across all possible scores, item discrimination indices (Schwierigkeitsindizes) should be equally distributed between 0.2 and 0.8 (possible values ranging between 0 and 1). An index of 1 indicates that all respondents answered the question on the extreme positive end of the scale, while an index of 0 indicates that all respondents answered the question on the extreme negative end of the scale. In both cases, the item provides no statistically relevant information and should be removed from the item pool (Kubinger, 2009). Our results show that, for all items in both subscales, item discrimination indices were equally spread between 0.4 and 0.7. There were no items with very low or very high indices.

### Internal Consistency and Subscale Correlation

The internal consistency of FIN–Importance had a Cronbach's alpha of 0.94 and that of FIN–Fulfillment 0.96. The two subscales showed a significant

but small linear relationship ( $r = 0.27$ ,  $p = 0.000$ ,  $n = 203$ ).

### Validity

For FIN–Importance, a lacking relationship was confirmed for hope, distress, and depression, all showing nonsignificant correlations between  $r = 0.07$  and  $0.09$  with FIN–Importance. However, anxiety scores did show a low but significant correlation with FIN–Importance ( $r = 0.14$ ). As expected, a significant positive correlation was found between FIN–Fulfillment and hope ( $r = 0.40$ ) and a significant negative correlation with distress ( $r = -0.30$ ), as well as with anxiety and depression (both  $r = -0.25$ ).

### Test–Retest Reliability

Overall, 46 participants returned their retest questionnaires after a mean of 5 days. None of the participants had completed sufficient responses on the FIN–Fulfillment subscale, making it impossible to calculate its retest reliability. The data quality for FIN–Importance was adequate, with a retest reliability of  $r = 0.97$ .

## DISCUSSION

Our study provides a German translation and validation of the FIN. In terms of acceptability, the FIN–Importance subscale showed satisfactory results, with missing responses for 14 of the 20 items below the 5% threshold. By contrast, for FIN–Fulfillment, all items showed missing response rates above 10%. There were no missing data in the original scale-development paper (Kristjanson et al., 1995). Other applications of the scale do not mention missing responses. However, the Icelandic version, for which no formal validation study has been published, uses the FIN–Fulfillment subscale only for items that receive the two highest possible ratings on FIN–Importance (Friethriksdottir et al., 2011). This suggests there may have been issues with missing responses that could be adequately dealt with by reducing the overall number of included items.

In our study, missing responses increased toward the end of the questionnaire. Hence, the reasons for missing responses may not necessarily be due to a lack of comprehensibility but to the overall length of the questionnaire and similarities between questions. This may make the scale appear overly repetitive to participants and lead to noncompliance. One solution may be to shorten the scale. Six questions (item 9 and 16–20) showed particularly high rates of missing responses on both subscales. The same items also received rather low importance scores when rated. Together, this suggests their exclusion

may improve the scale's acceptability without losing potentially clinically relevant information.

The internal consistency of both subscales was very high:  $\alpha = 0.94$  (FIN–Importance) and 0.96 (FIN–Fulfillment). This means that the items within each subscale had a high degree of concordance, measuring the same latent construct. The very high value of alpha is also consistent with an assumption that the questionnaire may be repetitive and that it may be possible to shorten it without any major loss of information.

Retest reliability for FIN–Importance was excellent. The fact that it was not possible to calculate retest reliability for FIN–Fulfillment reinforces conclusions about a potential lack of acceptability due to the scale's lengthiness or repetitiveness. Caregivers may simply not find it meaningful to rate the fulfillment of a large number of similar and partly overlapping or interdependent needs.

The discriminative power of items showed an equal spread of values between 0.4 and 0.7. However, there were no items with very low or very high indices, suggesting that the scale is not highly discriminative at the extreme ends of the spectrum. This may simply be due to the nature of the scale, which assesses a range of needs in a population that may consider most or all needs to be at least somewhat important.

Concurrent and discriminant validity of the FIN–Fulfillment subscale were confirmed by the moderate but significant correlations with hope, distress, depression, and anxiety in the expected directions. For FIN–Importance, a lack of correlation was confirmed with hope, distress, and depression, but we found a small but significant positive correlation with anxiety. So far, a relationship has been described between anxiety and need fulfillment (Sharpe et al., 2005; Molassiotis et al., 2011) but not between anxiety and the perceived importance of support needs. One possible interpretation of this finding is that caregivers with higher levels of anxiety may assume more support needs to be important due to increased safety seeking.

### Research Implications

Our results suggest that the FIN cannot be recommended for use in research in its current version. Given the high number of missing responses and participants' erratic answering style, including items in the FIN–Fulfillment analysis only if the corresponding FIN–Importance rating is above a certain value effectively results in the loss of a significant amount of data.

We can identify four suggestions to increase the scale's acceptability and usefulness. First, when

using the scale in its current version, supported assessment may be used to reduce the number of missing items. Second, it may be advisable to calculate FIN–Fulfillment means irrespective of the ratings on the FIN–Importance subscale to avoid loss of available data. Third, the FIN–Fulfillment subscale may be replaced by a single question, rated in VAS or Likert-type style, that assesses the overall fulfillment of all important support needs. This strategy would be justified by the hypothesis that people automatically take into account everything that is important to them personally when answering broad questions (Cummins, 2003). Hence, completion of each fulfillment item may not be necessary. Fourth, our results suggest that excluding questions 9 and 16–20 may increase the scale's overall acceptability. However, qualitative research with the client group may help to further inform adaptations of the questionnaire, including response options and the choice of questions to retain, and also support in rephrasing of items to make them more meaningful and potentially also more discriminative.

### CLINICAL IMPLICATIONS

As opposed to its application in research, the FIN appears valuable for clinical practice. It is important for support planning to know exactly which of many needs are most important to caregivers and to what degree they are perceived to be met (Hannon et al., 2012). The usefulness of the scale may be further increased if completed collaboratively with clinical staff, helping to identify the most pressing needs while at the same time attenuating the emotional burden of answering difficult questions that many caregivers come across in practice.

Need fulfillment showed both a statistically and clinically relevant relationship with hope, as did (to a lesser degree) distress, anxiety, and depression. Our results also suggest that there may be a link between anxiety and needs considered important for caregivers of terminally ill cancer patients. While these associations and their power to predict potential mental health problems in caregivers will need to be confirmed in future research, it appears prudent for health professionals to be mindful of caregivers' psychological state when assessing their support needs, including their hopes, distress, and anxiety, as well as their depressive symptoms.

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