

The instrument ‘Sense of Security in Care – Patients’ Evaluation’: its development and presentation

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Abstract

Objective: The aim of this paper is to report the development, construction, and psychometric properties of the new instrument Sense of Security in Care – Patients’ Evaluation (SEC-P) in palliative home care.

Methods: The preliminary instrument was based on a review of the literature and an analysis of qualitative interviews with patients about their sense of security. To test the instrument, 161 patients (58% women) in palliative home care were recruited and participated in a structured interview based on a comprehensive questionnaire (response rate 73%). We used principal component analysis to identify subscales and tested the construction in correlation with other scales and questions representing concepts that we expected to be related to sense of security in care.

Results: The principal component analysis resulted in three subscales: Care Interaction, Identity, and Mastery, built on a total of 15 items. The component solution had an explained variance of 55%. Internal consistency of the subscales ranged from 0.84 to 0.69. Inter-scale correlations varied between 0.40 and 0.59. The scales were associated to varying degrees with the quality of the care process, perceived health, quality of life, stress, and general sense of security.

Conclusions: The developed SEC-P provides a three-component assessment of palliative home care settings using valid and reliable scales. The scales were associated with other concepts in ways that were expected. The SEC-P is a manageable means of assessment that can be used to improve quality of care and in research focusing on patients’ sense of security in care.

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Introduction

Research has shown that a sense of security in care is greatly important to dying patients and that palliative care teams can promote this sense [1–4]. In fact, patients’ sense of security has recently been suggested as a potential new endpoint of cancer care [5], and patients’ higher sense of security in cancer care has been reported to be significantly associated with both lower pain intensity and higher patient-reported quality of palliative care [2,6]. Despite increasing interest in the significance of patients’ sense of security in care [7], there is a dearth of validated instruments to measure this sense of security in palliative care.

To enhance the validity of the instrument, its development should be based on profound knowledge of the topic to be measured. Qualitative interview studies of patients in palliative care have described aspects that may facilitate a sense of security, for example, feeling informed, being recognised as individuals [4], having trust that staff are available and competent to provide symptom relief, and being able to remain at home and continue everyday life, despite severe illness [4,8]. To our knowledge, there is so far only one published instrument to measure patients’ sense of security in care, a five-item scale for measuring

feelings of support and security in cancer care [5]. Although it has been used to collect sense of security data from advanced cancer patients about their received care [6], the scale was originally developed for use in the general population regarding a hypothetical diagnosis of cancer; at present, the instrument has unclear construct validity. It seems important for the further development of palliative care that individual palliative care units and larger stakeholders have a proper instrument to assess patients’ sense of security, which is a vital measurement of the quality of palliative care. Therefore, we set out to develop the instrument ‘Sense of Security in Care – Patients’ Evaluation’ (SEC-P).

Assumptions about the validity and reliability of the instrument

We assumed that the SEC-P would possess a valid underlying component structure demonstrable through principal component analysis and that the instrument would show good internal reliability (internal consistency) and content and construct validity. To demonstrate construct validity, sense of security was expected to correlate positively with general health, quality of life, perceived support from

others, and perceived quality of the care process, and to correlate negatively with stress. These assumptions were based on empirical findings showing that patients' sense of security in palliative care are associated with comfort and symptom relief [2,4,6], perceived support from the palliative care unit (e.g. provision of information, trust in staff members' competence, and staff availability when needed), support provided to family members [1–4,6], and perceived quality of the palliative care received [3,4,6].

The aim of this paper is to report the development, construction, and psychometric properties of the new instrument, SEC-P, for assessing patients' sense of security in palliative home care.

Methods

Study population

Participants were recruited from six palliative home care units in two counties southeast of Sweden over 10 months. Three of the units were advanced multi-professional palliative home care teams including a physician, specialist nurses, a physiotherapist, 24-h services, and access to a backup ward. The other three teams were based in primary care, with a palliative care consultant and a specialist nurse available during the daytime.

The patients were all in the palliative stage of their illness, diagnosed with incurable disease such as disseminated cancer or other non-malignant severe or lethal disease with expected short survival, over 18 years of age, and able to speak and understand Swedish. During data collection, 391 patients were admitted to the participating palliative care units. One hundred thirty-five patients were excluded according to the following criteria assessed by members of the palliative care team: cognitive failure/confusion ($n=46$), patient too weak to participate ($n=47$), speaking and/or hearing problems ($n=22$), not able to speak and understand Swedish ($n=11$), or other reasons ($n=9$).

Eligible participants ($N=256$) received written information about the study and were asked by a member of the palliative care team whether they wanted to participate. They were assured confidentiality and their right to withdraw at any time without giving any reason. Those who wished could answer via a printed form and a pre-paid envelope.

One hundred and eighty-six patients (73%; 111 women [60%] and 75 men [40%]) agreed to participate in the study, and 161 of the original 256 were interviewed (63%; 94 women [58%] and 67 men [42%]). The mean age in years was 68 ($SD=13$) for women and 72 ($SD=12$) for men (Table 1). Most dropouts from the interviews were patients who died after giving consent or those who withdrew or were excluded because of their deteriorating health.

Measurements

The structured questionnaire used in the study included background questions about patients' sex, age, educational level, family members, housing, and duration of care. To test its psychometric properties, the questionnaire contained the following questions, instruments, and scales (the response scales are presented in Table 3):

- Security in care for patients: SEC-P preliminary version (described in detail in the next section)
- Perceived general security: one general question developed by the authors
- Health: a general question from Short Form-36 [9]
- Quality of life: a general question from the WHOQOL [10]
- Health-related quality of life: EQ-5D index [11]
- Stress: two questions, one on feeling nervous and stressed and one on the perception of having too many problems to manage, drawn from the Perceived Stress Scale [12]
- Perceived support from others: four questions on support received from friends and neighbours, from family, and from health and social services, and perceived overall support from the Quality of Support Scale from COPE index [13]
- Perceived quality of the care process: the fulfilment scale on the Patient Perspective on Care and Rehabilitation Process instrument [14]. In order to fit the actual care process and the care context, some questions were modified, and a few questions were deleted. The measured dimensions were adequate care, orientation within the care context, knowledge and control, support and autonomy, medical and interactional needs, preparedness, and the general situation.

Table 1. Characteristics of the participants ($n=161$)

Characteristics	%	<i>n</i>
Female	58.4	94
≥70 years of age	49.1	79
Cohabiting	67.7	109
Single	31.1	50
Supported by a relative	99.4	160
Born in Sweden	90.6	145
Having a higher education (college level)	26.7	43
Receiving social care (personal care at home and/or domestic service)	23.9	38
Having (some or extreme) problems with health-related quality of life ¹ :		
Mobility (walking)	69.8	104
Personal care	28.0	42
Daily activities	66.7	100
Pain	81.3	122
Worry or depression	58.0	87

¹EuroQoL-5 dimensions [11].

In the selection of questions and instruments, we had to consider the patients' deteriorating health and energy; consequently, short scales or single questions were preferred whenever possible.

Procedure

The development of the SEC-P proceeded in five steps:

1. *Decisions about questions, scale, data collection method and presentation of results*

The questions were constructed on the basis mainly of the results of a qualitative study of patients' and relatives' perceptions of security in palliative home care [4] and also through reviewing other studies on the subject [2,3,15]. Other literature guided the choice of response scales and our decision to administer the questionnaire via telephone interview to achieve a high response rate and high quality data [16,17].

The constructed questions concerned aspects that seemed to facilitate a sense of security in care and those that reflected the consequences of being secure. To allow variance and to avoid neutral answers, we decided to use a six-point Likert response scale: Never=1, Seldom=2, Sometimes=3, Often=4, Very often=5, and Always=6.

We also took decisions about additional questions and instruments to be used in analysing the construct validity of the instrument.

2. *Testing the content and face validity*

An expert panel of three researchers and six practitioners discussed the correspondence between the preliminary instrument and what it theoretically was expected to measure (i.e. its content validity). They found the instrument and the complete questionnaire valid for its purpose. One of the authors conducted a pilot study (two home visits and five telephone interviews) with seven patients, who were also asked about the instrument and the method of collecting data. This led to appropriate corrections to the instructions and minor revisions to the wording of the questions.

3. *Data collection*

The five interviewers were well trained before the interviews. They were experienced in palliative home care but were not involved in the care of the patients they interviewed. The researchers and the interviewers were in regular close contact throughout the data collection process.

The interviewers contacted the participants via telephone and asked whether they would rather be interviewed

in a personal meeting or via telephone. Most patients (92%) preferred to have a telephone interview.

The items on the questionnaire were read aloud by an interviewer to the participants, who chose their responses from a list of alternatives included in the information letter, which they had been asked to keep if they wished to participate. The interviewer could also read the alternatives aloud if necessary. The SEC-P interviews took an average of 10 min.

4. *Statistical tests of validity and reliability*

We first conducted a univariate analysis of the questions to examine the quality of the data. At this stage, we excluded one question about what patients thought and felt about their relatives' situation in relation to their care. This question was not distinctive enough, because 24% of the participants considered it inapplicable; for example, they did not have any relatives closely involved in their care.

Principal component analysis was used to scrutinise the underlying dimensions covered by the instrument and to examine its internal (factorial) construct validity. We tested reliability in terms of internal consistency by calculating the Cronbach's alpha coefficient for the different components and for the total scale. At this stage, one question about continuity of care staff was excluded because although it increased internal consistency, it had low communality with other items, and the continuity aspect was sufficiently represented by another question.

We tested the construct validity (convergent and discriminant) by analysing the three components of the instrument in relation to the aspects that we expected to be associated to security in care: general security, general security in care, health, stress, quality of life, health-related quality of life, quality of support, and quality of the care process.

5. *User acceptance*

We asked the interviewers how they experienced the data collection, the preliminary instrument, and the methodology. The interviewers found the instructions and the preliminary instrument satisfactory and useful. Most participants had no difficulties understanding or answering the questions using the printed response scales received in the information letter. Some, however, could not answer the entire questionnaire because of their weak health.

Statistics

We next conducted descriptive analyses and carried out the requirements for multivariate analysis. The content

validity analysis of the SEC-P was tested using a principal components and transformation method: orthotran/varimax rotation, oblique solution, and eigenvalue ≥ 1 . In the case of internal missing values (missing and not applicable), the component analysis was based on pairwise deletion. The component cut-off was set to 0.40. The internal consistency of the components of the SEC-P instrument was assessed with Cronbach's alpha test for reliability. The construct validity analysis was based on a two-tailed non-parametric correlation using Spearman's rank correlation coefficient, with significance set at $p < 0.05$. SPSS 18.0 was used for the statistical analyses.

Ethics

The study was approved by the Research Ethics Committee at Linköping University (Dnr: 144-06).

Results

The SEC-P is presented in full length in Appendix A.

Sample

More than half of the sample consisted of women and participants younger than 70 years. The majority had

malignant diagnoses (95%) as the most frequent diagnoses concerning gastrointestinal (33%), urological (17%), breast (12%), and respiration (9%) diseases; further participant characteristics are shown in Table 1.

Descriptive analysis of the response scale

The mean values of the 15 security questions ranged from 4.06 to 5.48 (SD 0.82–1.36). The response rate varied between 156 and 161 per item. The whole range of response alternatives, 1–6, was used in about half of the questions; the lowest response alternative was not used in the other half, and the second lowest alternative was not used in two of the questions. The 'not applicable' response alternative was used by only a few participants in five questions (numbers 1, 5, 7, 8, 9).

Construct validity and reliability – internal consistency

The principal component analysis of the internal construct was based on the ratings of 15 questions about security in care and resulted in a three-component solution. The three components were labelled (a) *care interaction*, (b) *identity*, and (c) *mastery*. The labels were based on qualitative conclusions about the questions that constituted each component. The component solution had an explained variance of 55%, and the

Table 2. Principal component analysis of the security in care questions¹ and internal consistency of the components

How often have you found ...	Rotated component matrix			Communality	Cronbach's alpha if item is deleted	Cronbach's alpha	Component solution
	1	2	3				
1 h-care ² is available when you need it	0.57	−0.10	0.27	0.40	0.83	0.84	1: Care Interaction
2 h-care personnel keep their promises	0.61	0.00	0.02	0.37	0.84		
3 h-care personnel provide health care in a competent manner	0.70	0.24	−0.02	0.55	0.82		
4 h-care personnel provide health care in an empathic manner	0.71	0.16	−0.02	0.53	0.82		
5 h-care personnel know you, your situation, and your h-care	0.63	0.19	0.03	0.43	0.83		
6 h-care personnel welcome your questions and listen	0.78	0.08	0.17	0.65	0.81	0.77	2: Identity
7 you have enough say over your h-care	0.69	0.04	0.33	0.59	0.82		
8 your h-care works smoothly	0.62	0.28	0.06	0.47	0.83		
12 you receive h-care in the location you prefer	0.25	0.56	0.29	0.46	0.65		
13 your home feels secure given your health condition	0.16	0.78	0.05	0.63	0.60	0.69	3: Mastery
14 you can be yourself when interacting with h-care personnel	0.06	0.75	0.19	0.61	0.61		
15 you can do what is most important to you	0.05	0.60	0.29	0.44	0.65		
9 you felt confident that you can handle your daily life	0.26	0.37	0.68	0.67	0.70	0.63	
10 you felt in control of your situation	0.02	0.32	0.79	0.73	0.63		
11 h-care personnel have adequately informed you	0.10	0.14	0.79	0.65	0.73		
Percentage of explained variance (%)	24.96	15.41	14.23				
Cumulative percentage of explained variance (%)	24.96	40.37	54.60				
Mean value (SD)	5.11 (0.65)	4.92 (0.85)	4.25 (1.07)				

Numbers in bold print indicate the factor set.

¹Shortened for table text; for full form length, see Appendix A.

²h-care = healthcare.

three components contributed from 14% to 25% each. Reliability in terms of the internal consistency of each component varied from 0.84 to 0.69 and was 0.85 for the total instrument (Table 2).

The results for concurrent construct validity (convergent and discriminant) showed that the three components were correlated. All three components correlated significantly to perceived general security, stress (difficulty managing problems), and quality of support, one care process dimension (medical and interactional needs) and general sense of security in care, although the relationship to the different components varied in strength. The *care interaction* component had the strongest correlations to quality of support, quality of the care process dimensions, and general sense of security in care. This component did not correlate to aspects of general health and quality of life. The *identity* component, on the other hand, was most related to general health, quality of life, health-related quality of life, stress, and general situation. After general security, the *mastery* component related most to stress, especially to difficulty managing problems. The *mastery* component was also correlated, but more weakly, to aspects of general health and quality of life (Table 3).

A high score on any of the three components indicated high scores on the two other components, as well as high scores on both general sense of security in care and general security. A high score on the *care interaction* component denoted both perceived good quality of support from others and good quality of care. A high score on the *identity* component indicated perceived

good general health, good aspects of quality of life, and a good general situation. A high score on the *mastery* component mainly indicated low perceived stress (Table 3).

Discussion

Main findings

Patients' sense of security in care is a fundamental quality issue and thus important to measure in order to maintain and improve quality. Until now, there has been a dearth of valid and reliable instruments available for such a purpose, irrespective of care setting. Our SEC-P is a novel instrument that can contribute to filling this gap. It is built on knowledge about patient perspectives on security in relation to care [1–4,6], and the present results show that it is a valid and reliable measure of security in care for patients in palliative home care.

A three-component assessment

The component analysis showed that the 15-item SEC-P possesses a three-component structure: *care interaction* (eight items), *identity* (four items), and *mastery* (three items). Each of the components can be used individually with satisfactory internal reliability and construct validity. The internal consistency of the *care interaction* and *identity* components were satisfactory, and the *mastery* component had an internal consistency very close to that regarded as satisfactory for scales ($\alpha = <0.90$ to >0.70) [18]. All scales can be used on a group level as they exceed

Table 3. Bivariate association between the three components and criterion validity measures (non-parametric correlation, two-tailed)

Scales and questions	1. Care Interaction		2. Identity		3. Mastery	
	r_s	<i>n</i>	r_s	<i>n</i>	r_s	<i>n</i>
1. Care Interaction (1–6 = always)						
2. Identity (1–6 = always)	0.40**	158				
3. Mastery (1–6 = always)	0.36**	158	0.56**	159		
General security (1–6 = always)	0.26**	155	0.41**	156	0.59**	156
General health (1–5 = poor)	–0.01	146	–0.31**	147	–0.21*	147
Quality of life (1–5 = very good)	–0.003	146	0.24**	147	0.19*	147
Health-related quality of life (–0.594–1 = full health)	0.03	148	0.35**	149	0.18*	149
Stress: felt nervous and stressed (1–5 = very often)	–0.11	146	–0.25**	147	–0.21*	147
Stress: too many problems to handle (1–5 = very often)	–0.19*	145	–0.26**	146	–0.32**	146
Quality of support from others (4–16 = highest quality of support)	0.31**	142	0.21*	143	0.18*	143
Quality of care process: fulfillment of (1–4 = yes, definitely)						
Need for adequate care	0.20*	122	0.09	122	–0.01	122
Need for orientation within care context	0.22*	102	0.11	102	0.16	102
Need for knowledge and control	0.40**	82	0.13	82	0.21	82
Need for support and autonomy	0.33**	86	0.10	86	0.08	86
Medical and interactional needs	0.36**	89	0.29**	89	0.32**	89
Need for preparedness	0.15	131	–0.04	131	–0.04	131
General situation	0.24**	136	0.33**	137	0.16	137
General sense of security in care	0.50**	156	0.41**	157	0.28**	157

* $p < 0.05$; ** $p < 0.01$.

$\alpha = >0.60$ [19]; if used on an individual level, >0.70 is recommended [18].

The construct validity analyses verified our assumptions and confirm to a large degree the theoretical dimensions upon which we based the instrument by demonstrating several strong associations in the expected directions [1–4,6]. It showed that patients' sense of security correlated positively with general health, quality of life, perceived support from others, and perceived quality of the care process, and correlated negatively with stress. Each of the three scales of SEC-P measures an important aspect of security in care for patients.

The *care interaction* scale was most positively linked to support from others and to the care process quality. Thus, good interaction between patients and care staff, including a high quality care process, ought to improve patients' sense of security in care. This is also indicated in other studies [1,3]. There were no associations with health and quality of life, which suggests that patients' sense of security in the care interaction is not affected by their health and quality of life.

The *identity* scale was mainly associated with aspects of health, quality of life, and general situation, and it was negatively associated with stress. This scale was also associated with medical and interactional needs in the care process, which seems logical as the *identity* scale emphasises aspects of health and quality of life. This association was supported by the qualitative study, in which the patients' sense of security was connected to their identity and their ability to do what they found important [4]. Poor health can restrict people's abilities to do things they consider important and can thereby reduce their quality of life. Feeling sick and being in pain can undermine patients' sense of security [3,6]. To strengthen patients' sense of security, it is important that health care staff provide good medical and interactional support, for example, symptom relief [2,4,6]. It is also important that they help patients to keep their identity, for example, by encouraging and supporting them in setting meaningful goals in activities important to them.

The *mastery* scale was primarily linked to stress, which also makes sense. A large body of research focus on stress and the ability to manage stressful situations [20]. It has been shown that people who feel secure are less stressed in stressful situations [21]. Medical and interactional needs were also associated with the *mastery* scale, pointing to the importance of care professionals' competence and ability to support patients' coping and reduce their stress.

The three scales are associated with each other and also with the general sense of security, showing that they all concern the same general issue even though they are separate scales. The single question about general security may be used as a substitute for more detailed measures if needed; although the correlations

are high, this question does not provide the same information as any of the three subscales. The internal consistency of the total instrument is also high, which suggests that it can be used as one scale. However, the subscales are differently associated with other concepts, which indicates that they measure different aspects of the sense of security in care. Thus, we recommend using the SEC-P as a three-component assessment as that will provide more detailed measure of sense of security and information for quality improvement.

Limitations

Bearing in mind the vulnerability of this group, the participation rate of about three out of four should be the expected rate in further studies. The ceiling effect, with high mean values and small variances, may be a limitation of our statistical analyses, even though we have achieved good results. Because the instrument has been developed for and in a special setting – palliative home care – it should therefore be tested in other settings and with other groups of patients to ensure its validity and reliability for broader use. In the construct validity analyses, we used short scales and single questions as much as possible in consideration of the patients' deteriorating health and energy. This might have provided less nuanced data, but we felt this possible lack of nuance was a reasonable trade-off against the risks of having too many missing values or dropouts. Nevertheless, we found the construct validity results logical and in line with other research findings. The explained variance for the total instrument was comparable with many other instruments; however, the measurement does not explain all aspects of security in care. In particular, we excluded a question about patient's thoughts and feelings about their relatives' situation in relation to their own, because several patients had no relatives involved and we wished to avoid having too many missing values in the analysis. Future studies may ask about relatives' situations as a complementary question.

Conclusion

The SEC-P instrument provides a three-component assessment using the valid and reliable scales of care interaction, identity, and mastery. The instrument has been developed in and for palliative home care settings, and its 15 items make it very manageable. Our study shows that patients' sense of security in care is strongly associated with the quality of the care process, their perceived health, their quality of life, their stress, and their general sense of security. The value of this instrument is that it can be implemented and used not only as a measure for quality improvement in care but also in research focusing on patients' sense of security.

Appendix A: The instrument “Sense of Security in Care – Patients’ Evaluation”

No.	How often ...	Never 1	Seldom 2	Sometimes 3	Often 4	Very often 5	Always 6
1 ¹	is healthcare available when you need it?						
2 ¹	do the healthcare personnel keep their promises? E.g. about appointments, information, treatments						
3 ¹	do the healthcare personnel provide care in a competent manner? E.g. they provide relief of pain and distress						
4 ¹	do the healthcare personnel provide care in an empathic manner?						
5 ¹	do the healthcare personnel know you, your situation and your care requirements?						
6 ¹	do you feel welcomed by the healthcare personnel? E.g. they welcome your questions, they listen						
7 ¹	do you have enough say over your healthcare?						
8 ¹	does your healthcare works smoothly? E.g. without unnecessary delays, without too many healthcare units or personnel						
9 ³	do you feel confident that you can handle your daily life?						
10 ³	do you feel you have control over your situation?						
11 ³	do you feel healthcare personnel have adequately informed you about what to expect in your care? E.g. appointments, treatments, health progress						
12 ²	do you receive healthcare in the location you prefer?						
13 ²	does your home feel secure given your health condition?						
14 ²	can you be yourself when interacting with healthcare personnel?						
15 ²	can you do what is most important to you in your daily life?						

Item belonging: 1, the Care Interaction scale (eight items); 2, the Identity scale (4 items); 3, the Mastery scale (3 items).

Total score of each scale is based on mean values, that is, the sum of the item values divided by the total number of items of the scale.

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References

- Friedrichsen MJ, Strang PM, Carlsson ME. Cancer patients’ perceptions of their participation and own resources after receiving information about discontinuation of active tumour treatment. *Acta Oncol* 2000;**39**(8):919–925.
- Boström B, Sandh M, Lundberg D *et al.* Cancer patients’ experiences of care related to pain management before and after palliative care referral. *Eur J Cancer Care* 2004;**13**(3):238–245.
- Goldschmidt D, Schmidt L, Krasnik A *et al.* Expectations to and evaluation of a palliative home-care team as seen by patients and carers. *Support Care Cancer* 2006;**14**(12):1232–1240.
- Milberg A, Wählberg R, Jakobsson M *et al.* What is a “secure base” when death is approaching? A study applying attachment theory to adult patients’ and family members’ experiences of palliative home care. *Psycho-Oncology* 2012;**21**(8):886–895.
- Igarashi A, Miyashita M, Morita T *et al.* A scale for measuring feelings of support and security regarding cancer care in a region of Japan: a potential new endpoint of cancer care. *J Pain Symptom Manage* 2012;**43**(2):218–225.
- Akiyama M, Takebayashi T, Morita T *et al.* Knowledge, beliefs, and concerns about opioids, palliative care, and homecare of advanced cancer patients: a nationwide survey in Japan. *Support Care Cancer* 2012;**20**(5):923–931.
- Epner DE, Ravi V, Baile WF. When patients and families feel abandoned. *Support Care Cancer* 2011;**19**(11):1713–1717.
- Goldschmidt D, Groenvold M, Johnsen AT *et al.* Cooperating with a palliative home-care team: expectations and evaluations of GPs and district nurses. *Palliat Med* 2005;**19**(3):241–250.
- Brazier JE, Harper R, Jones NM *et al.* Validating the SF-36 health survey questionnaire: new outcome measure for primary care. *Br Med J* 1992;**305**(6846):160–164.
- The WHOQOL Group. The World Health Organization Quality of Life Assessment (WHOQOL): development and general psychometric properties. *Soc Sci Med* 1998;**46**:1569–1585.
- Brooks R. EuroQol: the current state of play. *Health Policy* 1996;**37**(1):53–72.
- Cohen S, Kamarck T, Mermelstein R. A global measure of perceived stress. *J Health Soc Behav* 1983;**24**(4):385–396.
- Balducci C, Mnich E, McKee KJ *et al.* Negative impact and positive value in caregiving: validation of the COPE Index in a six-country sample of carers. *Gerontologist* 2008;**48**(3):276–286.
- Krevers B, Oberg B. Development of the “Patient Perspective on Care and Rehabilitation Process” instrument (POCR). *Aging Clin Exp Res* 2002;**14**(5):402–411.
- Milberg A, Strang P. Met and unmet needs in hospital-based home care: qualitative evaluation through open-ended questions. *Palliat Med* 2000;**14**(6):533–534.
- Streiner DL, Norman GR. Health Measurement Scales: a Practical Guide to their Development and Use. (2nd edn), Oxford University Press: Oxford, 1995.
- Harris LE, Weinberger M, Tierney WM. Assessing inner-city patients’ hospital experiences. A controlled trial of telephone interviews versus mailed surveys. *Med Care* 1997;**35**(1):70–76.
- Nunally J. Psychometric Theory. McGraw-Hill: New York, 1978.
- Polit DF, Hungler BP. Nursing Research: Principles and Methods (5th edn), Lippincott: Philadelphia, 1995.
- Folkman S, Moskowitz JT. Coping: pitfalls and promise. *Annu Rev Psychol* 2004;**55**:745–774.
- Mikulincer M, Shaver PR. Boosting attachment security to promote mental health, prosocial values, and inter-group tolerance. *Psychol Inq* 2007;**18**(3):139–156.