

Frail elderly and palliative care

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This paper deals with the assessment of suffering in frail elderly end-of-life patients. Our main goal was to determine the factors that cause suffering and the resources the patients may have to cope with such suffering. In addition, we tested a method of assessing the subjective global well-being in this population by asking about the patient's perception of time passing. The study also includes the assessment of the need for information in these elderly patients. Forty patients were assessed using the ESYF form, applied individually. A descriptive analysis of all variables was made and Spearman's correlation coefficient was used to determine whether there was any relation between patients' perception of time passing and their feelings of well-being. Results showed that no single symptom was common to all patients and those symptoms that did appear caused varying degrees of concern to each person. A moderate correlation was found between well-being and the perception of time passing. We observed a discrepancy between the patients' and their families' expressed desire for information about the illness.

Anciano frágil y cuidados paliativos. Este trabajo pretende ser una aproximación al sufrimiento del anciano frágil que se encuentra en situación de final de vida: descubrir qué factores le ocasionan sufrimiento y cuáles son los recursos que poseen para hacerle frente. También hemos querido comprobar la relación existente entre la sensación de bienestar global y la percepción del paso del tiempo, así como las necesidades de información que tienen estos pacientes de edad avanzada. Se ha evaluado a 40 pacientes usando el ESYF, aplicado de forma individual. Hemos realizado un análisis descriptivo de todas las variables y hemos usado el coeficiente de correlación de Spearman para determinar la relación entre la percepción del paso temporal de los pacientes y su sensación de bienestar. Los resultados muestran que no existe ningún síntoma que aparezca en todos los pacientes y que los que lo hacen provocan diferentes grados de preocupación en cada persona. Encontramos una correlación moderada entre la sensación de bienestar global y la percepción del paso temporal. Observamos una discrepancia entre el deseo de información relativa a la enfermedad expresada por los pacientes y por sus familiares.

Palliative care has essentially been developed within the framework of oncologic end-stage illness, even though the WHO does not mention any specific pathology in its definition (Bayés, Arranz, Barbero, & Barreto, 1996). In fact, as indicated by Botella et al. (Botella, Errando, & Martínez, 1998), elderly patients who suffer from a non-oncologic, end-stage illness are rarely admitted to units where this kind of care is provided. With the exception of the U.S.A., where other conditions in addition to the oncological are attended to; and South Africa, with a high prevalence of A.I.D.S., in the remaining developed and developing countries, palliative care has not spread to other circumstances such as those that form the subject of this paper (Doyle, 2003).

Several approaches to terminal illness arise in geriatrics. It has been highlighted that health care for terminally ill elderly patients should not merely be a withdrawal of curative treatments, but

requires the expert management of their condition; and that this management demands fundamental changes in both professional training and health care (Americans Geriatrics Society, 1995).

Moreover, it is important to highlight two issues with respect to non-oncologic frail elderly and palliative care (Roy, 2003). On the one hand, there is the need for a definition of the palliative condition based on sufficient objective data (Botella et al., 1998); such a definition would avoid distressing futile interventions as well as premature withdrawal, both sometimes suffered by our old people. On the other hand, the peculiarities of elderly conditions have to be taken into consideration (Barreto & Martínez, 2000): the higher probability of nihilism regarding therapeutics, the higher risk of underestimating pain, a lower prevalence of certain symptoms with a higher frequency of others, better overall coping with the illness and its collateral effects, better acceptance of one's own death, reduced social support, less involvement in decision-making, a more irregular evolution of illness and a lower perception of seriousness even when facing a worse prognosis. Therefore, the authors of this paper consider it essential to individualize assessment of the non-oncologic frail elderly end-stage conditions.

Our first objective is to assess those factors that cause suffering in the patient. Regarding this assessment we start from the premise

Fecha recepción: 18-6-07 • Fecha aceptación: 30-4-08

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that the degree of threat perceived by patients from the symptoms is more important than the symptoms themselves (Arranz & Bayes, 1997). On this point we agree with the definition of suffering given by Chapman and Gravin (1993): an 'emotional, cognitive, complex and negative condition characterized by the person's feelings on finding his or her integrity threatened, by a feeling of powerlessness to face this threat, and by the exhaustion of those individual and psychosocial resources that would allow him or her to cope with the threat'.

According to this definition, a person suffers when two elements combine simultaneously (Bayes, 2001; Arranz, Barbero, Barreto, & Bayes, 2003; González, Lacasta, & Ordóñez, 2003):

- An experience, or a fear, of physical or psychosocial damage judged as a threat to life or to psychosocial and/or physical integrity.
- A feeling of having a lack of resources to cope successfully with that threat.

Both the threat experience and the feeling of being overwhelmed are subjective factors, as is suffering itself. A specific symptom of a given intensity would not necessarily cause the same degree of threat and burden in two different individuals, even if they had some characteristics in common. This makes it essential in our professional practice to fully understand the physical and emotional symptoms experienced by each patient, and the degree of worry expressed by the patient. In other words, the identification and understanding, at all times, of those symptoms and conditions perceived as threatening by patients, and how those symptoms and conditions are classified by the patient, is fundamental (Bayes, 2001).

Similarly, it is equally important to discover the patient's own resources in order to develop and complement them with others, and so help to reduce, eliminate or prevent their feeling of helplessness, and increase their sense of control over the situation (Arranz et al., 2003). For this reason, those elements that provide a sensation of well-being in the patient are included in our assessment.

Time passing perceptions have previously been used to establish a method of assessing subjective global well-being (Cassell, 1982; Merskey, 1979), based on the proposal of W. James, who considers that time is perceived to pass more quickly when patients feel better, compared to when they are suffering. In this paper, we consider both issues (well-being and time passing perception) in order to determine if there is any connection between the two among non-oncologic frail elderly patients.

Lastly, and given its importance in having a good relationship between patients, health caregivers and their families, this study also includes the assessment of the elderly patient's need for information. In order to prepare a personalized evaluation which will assist the provision of adequate emotional support, it is considered essential to know how much the patient understands about his or her clinical condition, what they want to know and how much they can assimilate (American Geriatrics Society, 1995; Arranz et al., 2003; Bayes, Limonero, Barreto, & Comas, 1995). In this study, our aim was to find out what patients say about both the fulfillment of their current need for information and their suggestions for the future, as well as the perception of these issues as expressed by the primary caregiver.

Thereby, the aims of our work are: to assess how the frail elderly perceive their physical and emotional symptoms,

determining any additional concerns, exploring the protective factors that are perceived by the frail elderly as providing well-being; also assessing the degree of worry about the symptoms, and how these concerns are prioritized; moreover to assess the time passing perception and its connection with a feeling of well-being.

Finally, To assess the patient's need for clinical information: if they consider that they currently receive all the information they want about their condition, and if they would like to know how their condition may develop in the future; and to assess the primary caregiver's perception of these same issues. In addition, to explore any connection between the patient's and caregiver's opinions.

Methods

Participants

Forty patients were assessed, 29 male and 11 female, in-patients aged between 75 and 93 years; most of the patients (70%) were younger than 85 (mean age= 82).

Inclusion criteria were:

- Admission to the Palet Unit of La Magdalena Hospital (Castellón).
- To correspond with the definition of frail elderly proposed by Botella and others (1998): being an elderly person (over 75 years of age), with the presence of numerous chronic diseases (multiple pathology) or geriatric syndrome (incontinence, falls, cognitive impairment, immobility, etc.).
- Absence of any oncologic diagnosis at the time of assessment.
- No awareness impairment that would prevent patients from understanding the questions. According to Bayés et al. guidelines (2001), when in doubt a «reduced Mini-Mental State Exam» was applied. Patients must answer the following five questions exactly: current year, current month, name of this town, name of this hospital, and name of the parents.

Each primary caregiver was also assessed in order to achieve objective F, which refers to the caregiver's perception of the patient's need for information. We consider the 'primary caregiver' to be a relation (either a blood relative or someone having a personal commitment with the patient) who looks after the ill person for the majority of the time, and who is often the one most involved in decision-making.

Variables and instruments

Were categorized into demographic, clinical and research variables.

Demographic variables

The assessment form collects two personal characteristics that help to superficially describe our sample, namely sex and age.

Clinical variables

Patient diagnoses were included. All patients showed multiple pathology, so the three most important diagnoses were considered in patient.

Research variables

- Subjective perception of both physical and emotional symptoms.
- Other sources of concern.
- Factors relating to well-being.
- Method of prioritizing concerns.
- Time passing perception.
- Patient's subjective well-being.
- Patient's need for current information.
- Patient's thinking about future needs for information.
- Patient's need for current information as perceived by the primary caregiver.
- Patient's future need for information as perceived by the primary caregiver.

An ESY (Evaluation of Symptoms and Preoccupations) was used to achieve the first four aims. This is an evaluation form previously used by Bayés, Limonero, Barreto and Comas within the framework of a multicenter study with terminally ill oncologic and AIDS patients (1995). It is not a graded questionnaire as it does not intend to extract conclusions with respect to a population, but is used to help the patient describe their symptoms and the worry they create.

Instructions for application of the ESY are as follows (Bayes et al., 2001):

- Throughout the completion of the form, the patient must be alone, except for the assessor.
- The assessor, in our case the hospital psychologist, introduces herself as such, in the event that the patient does not know her.
- The patient's collaboration is requested, explaining that we would like to ask a few questions to know and better understand those problems that are affecting them at that time. It is also explained that our aim is to help them to solve those problems as far as possible. Patients are told that many of the problems listed may not affect them. Finally, they are instructed how to complete the form.

The questionnaire lists a series of physical and emotional symptoms. Patients must answer the questions about the presence of each symptom based on a 5-point Lickert scale consisting of 1-none, 2-a little, 3-normal, 4-quite a lot, and 5-a lot. Following the list of symptoms there is an open question that asks the patient about other concerns they may have, as well as about those things that help him or her feel better.

Once all the questions are answered, the four symptoms perceived by the patient as the most intense are chosen and written on cards. The four cards are shown to the patient, who must order them in decreasing degree of worry posed by each symptom. Responses are coded as follows: that which causes the highest degree of worry is assigned a 6; the second in importance 7, the third 8, and finally 9 to the fourth and least worrying symptom.

In order to assess the time passing perception and its relationship with the feeling of well-being, patients are asked about how long the previous day had seemed. Again, there are five possible responses to this item: 1-really dragged, 2-dragged, 3-as usual, 4-short, 5-really short. The next question asks how well he or she felt that day; the response range is from 1-very bad to 5-very well.

With regard to the patient's need for information, four dichotomous items were included, two answered by the patient and two by the primary caregiver. These items refer to the current needs of the patient (fulfilled or not) and his or her possible future needs (if they think they will or will not want more information in the future); and similarly, to the primary caregiver's perception of the current and future patient's needs for information.

Procedures

Assessment was made by individualized applications and with previous agreement of each patient.

Data analysis

A descriptive analysis of all variables was made. The Spearman correlation coefficient was used to determine if any relationship existed between patient's perception of the passing time and their feeling of well-being.

The percentages obtained from patients and caregivers responses about information needs were compared through contingency-table association measures.

Results

Regarding patient pathology, the most frequent diagnosis, was chronic respiratory failure (present in 87.5% of patients), followed by cardiac failure (77.5%), arterial hypertension (37.5%) and diabetes mellitus (35%). Table 1 shows the presence of each symptom.

As shown in table 1, three of the problems included in the ESY do not appear within our sample (paralysis, odor and spiritual concerns) and others appear with a low frequency (diarrhea in two cases, and hemorrhage and concerns about appearance in one case each).

Most of the individuals (70%) experienced breathing difficulty and weakness. Forty-five percent of patients reported having had quite a lot or a lot of difficulty in breathing; 37.5% reported quite a lot or a lot of loss of appetite; and 30% reported quite a lot or a lot of sleep and hearing problems (27.5% and 25% respectively).

Table 2 shows the frequency of symptoms that may be more closely related to emotional and behavioral issues.

The emotional and behavioral related symptoms most frequently reported by patients are sleeplessness (67.5%), loss of appetite (60%) and nervousness and sadness (57.5% each). The first two (sleeplessness and loss of appetite) are the ones most indicated by patients as quite a lot and a lot (15 and 11 patients, respectively).

Regarding the questions about other concerns, it is notable that only 17 patients indicated having any other preoccupation, apart from those listed in the ESY, and only 5 of those indicated a second additional concern.

Six patients (15%) expressed worry about their relatives or loved ones; 3 patients (7.5%) were worried about their prognosis; 2 worried about dependence on other people and two more worried about proximity of discharge from hospital. The remainder reported concerns related to specific aspects of the illness (limb amputation, catheter), closeness of death and suffering from nightmares.

Table 1
Frequency of appearance of symptoms within the sample

Symptoms	None	A little	Normal	Quite a lot	A lot	Total
Sight problems	14	7	15	4	0	40
Hearing problems	19	7	4	5	5	40
Difficulty in breathing	12	4	6	10	8	40
Speech problems	30	6	2	2	0	40
Thinking difficulties	28	4	8	0	0	40
Cough	19	8	8	3	2	40
Nausea	29	8	2	1	0	40
Itchiness	34	6	0	0	0	40
Paralysis	40	0	0	0	0	40
Loss of appetite	16	4	5	9	6	40
Discomfort in mouth	34	1	3	1	1	40
Pain while swallowing	33	2	3	2	0	40
Feeling smelly	40	0	0	0	0	40
Diarrhea	38	0	2	0	0	40
Constipation	21	4	10	5	0	40
Hemorrhage	39	1	0	0	0	40
Urinary incontinence	27	5	7	0	1	40
Rectal incontinence	35	2	2	0	1	40
Pain	21	7	3	6	3	40
Weakness	12	9	7	12	0	40
Loss of weight	17	8	7	5	3	40
Sleeplessness/insomnia	13	5	11	9	2	40
Nervousness	17	8	8	4	3	40
Sleepiness	13	11	12	3	1	40
Sadness	17	3	12	8	0	40
Discomfort with cures	36	2	1	1	0	40
Noncompliance*	35	3	1	1	0	40
Lack of concentration	32	5	2	1	0	40
Fear	33	2	3	2	0	40
Irritability	37	3	0	0	0	40
Loneliness	30	2	3	4	1	40
Concern about appearance	39	1	0	0	0	40
Spiritual concerns	40	0	0	0	0	40

* Problems in taking medication as indicated

Table 2
Frequency of symptoms most likely to be related to emotional issues

Symptoms	1	2	3	4	5	Total
	None	A little	Normal	Quite a lot	A lot	
Loss of appetite	16	4	5	9	6	40
Sleeplessness/insomnia	13	5	11	9	2	40
Nervousness	17	8	8	4	3	40
Sadness	17	3	12	8	0	40
Noncompliance*	35	3	1	1	0	40
Fear	33	2	3	2	0	40
Irritability	37	3	0	0	0	40
Loneliness	30	2	3	4	1	40
Appearance concerns	39	1	0	0	0	40

* Problems in taking medication as indicated

Of the 5 patients who expressed a second additional concern, 2 worried about dependence on others, 2 patients about relatives and one patient expressed a sense of uselessness.

Twenty-five patients (62.5%) answered the question about what activities or events bring them a sense of well-being. The main sources of well-being for 13 patients (32.5%) were the company of loved ones; the proximity of discharge, the availability of enjoyable activities, the relief of pain and feeling physically better were expressed by 2 patients each. Sleep, rest, the optimism of people in the immediate environment, and medical treatment, were other elements highlighted by one patient.

Just 2 patients referred to a second source of well-being; one of which was related to improvement in physical symptoms and the other one to being in hospital.

With respect to placing worries in order of importance, there was a great variety, since no one symptom was marked by more than 15% of patients. Table 3 shows the order of the symptoms established by patients.

Three symptoms (breathing difficulty, loss of appetite and sleep problems) were the most frequent principal preoccupation, each one being indicated by 5 patients (12.5%). Pain and weakness were the main preoccupation for 4 patients (10%).

Loss of appetite is the symptom more often reported by patients (n= 4) as second in importance. Sight problems, hearing problems, breathing difficulty, weakness and loss of weight were reported as second in importance by 3 participants for each symptom.

Table 3
Order of symptoms according to degree of worry indicated by patients.
Frequencies

Symptom / Disorder	1st	2nd	3rd	4th
Sight problems		3		1
Hearing problems	1	3	2	2
Difficulty in breathing	5	3	5	5
Speech problems		1	1	1
Thinking difficulties				1
Cough	2		2	
Nausea			1	
Loss of appetite	5	4	2	3
Discomfort in mouth		1		
Constipation		2	1	1
Urinary incontinence		2	1	1
Rectal incontinence		1	1	
Pain	4	2	3	2
Weakness	4	3	4	3
Loss of weight	1	3	3	4
Sleeplessness/insomnia	5	2	4	6
Nervousness	3	2	4	2
Sleepiness	2		1	2
Sadness	1	2	2	3
Discomfort with cures		1		
Noncompliance*	1			
Fear	1	1	1	
Loneliness	2	2	2	1

* Problems in taking medication as indicated

The third cause of worry was breathing difficulty for 5 patients (12.5%) and weakness, sleep problems and nervousness for 4 patients (10%) each.

Six patients (15%) placed sleep problems in the fourth position, while 5 patients (12.5%) indicated breathing difficulty, and 4 (10%) put loss of weight.

In answer to the question about the perception of time passing and the feeling of well-being, the answer was 'dragged' in 47.5% of patients and 'as usual' in 45%. More than a half (52.5%) labeled the day before as 'really dragged' or as 'dragged', while no patient labeled it as 'really short'.

Nearly a half of participants (42.5%) felt bad the day before the evaluation, 32.5% felt well and 25% felt as usual. No one marked the edge points, that is, nobody referred to having felt very bad or very well.

In order to detect any statistically significant relationship between the time passing perception and the feeling of well-being the Spearman coefficient was applied; finding a correlation of 0.35 ($p < 0.05$).

As regards questions related to the need for information perceived by both patients and caregivers, results are:

Most patients (90%) considered that the need for current information about their illness and related issues is fulfilled. The caregiver's perception was similar: 97.5% of caregivers stated that patients had suitable information.

With respect to future needs, a greater discrepancy appears. 77.5% of patients would like to be informed about illness-related issues, both positive and negative, that could arise. Nevertheless, only 22.5% of caregivers agree with patients on this point.

There is no significant relation between patients' and caregivers' opinions ($\chi^2 = 0.736$ need for current information and $\chi^2 = 0.353$ future information needs).

Discussion

The results show that no one symptom occurred in all patients and those that did appear brought different degrees of worry to each person. This fact leads us to emphasize the need for individual evaluation and attention for each person, since the end stage of life is different for each person, as is the whole of one's life.

Difficulty in breathing and weakness were the most frequently presented symptoms, not surprisingly since respiratory insufficiency was the most prevalent diagnosis in our sample.

Most patients (82.5%) stated having no fear. Although no grounds for fear were specified in the question, closeness of death was frequently indicated in the answer. Absence of fear of death thanks to the sense of having lived for quite some time was also a very usual response. This better acceptance of one's own death among the elderly has been noted as a distinctive characteristic of terminally-ill elderly patients (Bayes, 2001).

Percentages relating to other emotional and behavioral issues, such as irritability and noncompliance, were similarly low.

Nervousness and sadness were present in more than a half our sample (57.5% in each case). It is important to remember that these two symptoms can modulate the appearance and the perception of the others, thus their approach is especially relevant (Arranz et al., 2003).

A half of our sample (57.5%) did not refer any other preoccupation different from those dealt with in our questionnaire.

A great diversity is observed among those patients who did express other new concerns, the highest percentage (15%) relating to worries about relatives.

As regards factors of well-being, a question aimed at assessing the resources of our patients, 37.5% did not answer. It must be said that a lot of these non-respondent patients did express some ways of diminishing discomfort related to specific problems when asked within the context of the clinical interview.

This question also induced a wide variety of responses, all them from areas that characterize a good death in a diverse range of individuals (Tong, McGraw, Dobihal, Baggish, Cherlin, & Bradley, 2003). 32.5% of patients reported the company of loved ones as a source of well-being. The remaining items were indicated by just one or two patients for each item.

The following data support the hypothesis that suffering does not come from one's own situation itself, but from the interpretation of that situation: proximity of discharge from hospital was a factor of well-being for two patients, at the same time it was an additional concern for another two. Presumably discharge had diametrically opposite implications for these patients.

With respect to the priority of concerns, we found once again a wide range of responses. Sleepiness in the daytime, sight problems and sadness, in spite of appearing as symptoms in more than half our patients (67.5%, 65% and 57.5% respectively), they only appear as primary concerns in quite low percentages (12.5%, 10% and 20% respectively).

The most worrying symptoms were difficulty in breathing (45%) and sleep problems (42.5%), weakness (35%) and loss of appetite (35%). Pain and nervousness also cause much suffering (27.5%). The importance given to loss of appetite is probably a reflection of a socially deep-rooted belief on a strong connection between health and appetite.

In agreement with results from previous studies among A.I.D.S. and cancer patients (Bayes et al. 1995), a statistically significant correlation was found in our sample between the time passing perception and the feeling of well-being. The question about time passing perception could serve as a first, simple, non-invasive, indicator of feelings of well-being; later, a more in-depth assessment can be made if necessary (Bayes, 2001).

High percentages were found both in patients who reported being satisfied with the information received (90%) and in caregivers who felt that patients had all the information they needed (97.5%). Obviously, the fact that a large majority are satisfied with the information can not lead us to underestimate in our clinical practice the 10% of patients who have doubts. In such cases it would be necessary to go into more detail during our assessment, and the team should be prepared to fulfil these kinds of needs.

With respect to the lack of agreement found between the wishes expressed by patients for future information and the caregivers' feelings on this point, the relatives' desire to reduce the patients' suffering could lead them to be reluctant to give him or her all the clinical information that he or she wants. It would be advisable (Arranz et al. 2003) to let relatives know the importance of clear, realistic patient-need centered information, highlighting the repercussions of both the presence of communication (improvement in the sense of control) and its absence (isolation). Counselling relatives and training them to detect the patients'

needs for information could improve their relationship and decrease anxiety levels.

The assessment form used in this study has allowed us to find out more about the concerns and needs of the non-oncologic frail elderly, and thus guide interventions according to the specific needs of each individual.

The presence of multiple, intense, multi-causal and changeable symptoms have frequently been indicated as being one of the defining elements of the terminal condition (Sanz et al., 1993). Several authors (Chochinov, Tataryn, Clinch, & Dudgeon, 1999), also indicate that the rapid changes in dying patients may not only occur with physical symptoms, but also take place in the cognitive and emotional arena. Our assessment form allows us to repeat the evaluation in such a way that the current needs and concerns of our patients can be known at all times.

The authors consider that in the future it would be interesting to study in greater depth the following topics that have arisen from this study:

- Inquire as to why none of our patients expressed spiritual concerns, while the literature and studies with patients suffering from other end-stage conditions produce opposite results.
- Similar actions with respect to the low percentage of patients who expressed being worried about their appearance.
- Deepen knowledge of the probable relationship between the worry about loss of appetite and the cultural beliefs that associate not being hungry with poor health.
- Longitudinal studies to show if patient's wishes for future information remain constant with the passing of time.

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