

# Cultural adaptation and linguistic validation of the Family Decision Making Self Efficacy Scale (FDMSES)

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*Parole chiave: Autoefficacia, validazione di strumenti, scale, caregiver, cure palliative*

## Abstract

**Introduction:** Nurses, following their ethical mandate, collaborate with other health and social professionals or people involved in caring activities. Caregivers in this context are becoming more and more significant for the family or the cared person, who for their stable presence and emotional proximity play a pivotal caring role. To maximize the contribution of caregivers, objective tools that emphasize their skill sets are necessary. The cross-cultural adaptation and validation of the Family Decision Making Self-Efficacy Scale is part of a larger project aimed at understanding the resilience of caregivers in the field of palliative care. Self-efficacy is one of the aspects of personality most closely associated with resilience. Self-efficacy is shown in a specific context, therefore, its study and evaluation of its level, require capabilities that enable individuals perceive themselves as effective in a particular circumstance. The Family Decision Making Self-Efficacy Scale assesses the behavior of caregivers of patients at the end of their life.

**Methods:** The Family Decision Making Self-Efficacy Scale was translated (forward and back translation) and was adapted to the Italian clinical cultural setting by a research team that included experts in palliative care, native translators with experience in nursing and experts in nursing. A consensus on the wording of each item in relation to semantic, idiomatic, experiential and conceptual equivalence was sought. The clarity of the wording and the pertinence of the items of the scenario with the conscious patient and with the unconscious patient were evaluated by a group of caregivers who tested the instrument.

**Results:** The Italian version of the instrument included 12 items for the scenario with the conscious patient and 12 for the scenario with the unconscious patient. The working group expressed consensus on the pre-testing version of the instrument. The pre-testing version of the scale was tested on 60 caregivers, 47 taking care of conscious patients and 13 taking care of unconscious patients. In both cases the content of the items was judged relevant and understandable.

**Conclusions:** The results for the cross-cultural validation were satisfactory and allowed the application of the instrument in the Italian context.

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## Introduction

The involvement of caregivers in the team is becoming more frequent, and in particular circumstances their psychological and behavioral characteristics have a considerable importance on the outcome of care (1).

This is more evident when the intensity of their relationship with the patient is crucial to the quality of care, or when the caregiver is helping or replacing the patients in their choices of care. Every care intervention involving caregivers, in the presence of emotional stress that can alter their attitudes, requires the knowledge of their possible reactions (2, 3). Caregiver responses to environmental stimuli are influenced by several variables including self-efficacy, which influences either their behavior or ability (4, 5). Bandura defines self-efficacy as: the conviction of a person about his/her ability to organize and implement one line to handle a given situation (6). The variability in the ability of caregiving can be explained, at least in part, by the theory of self-efficacy (5), which supports that the perception of its effectiveness has effects on psychosocial functioning: on the control of the activation of coping behaviors, on the extent of the effort required to overcome the difficulties and on the duration of the effort needed to overcome obstacles and adverse experiences. The theory also states that self-efficacy influences the vulnerability to emotional stress and depression (6). Although, sometimes it is confused with self-esteem, with the locus of control, or with self-confidence, self-efficacy is a specific conceptual framework related to the evaluation of being able to cope with competence and skill with particular situation (5). Therefore, self-efficacy is a context-specific construct that depends on specific circumstances with which a person compares himself/herself (7).

The perception of self-efficacy is accompanied by well-being and increases

security in uncertain situations by reducing stress and the tendency to depression (8).

Self-efficacy perceived by caregivers of cancer patients in relation to pain management is inversely proportional to stress (9). Self-efficacy is also expressed with the ability of decision-making (6), and the ability of decision-making is pivotal for the outcomes of care especially for severe diseases (10). Since self-efficacy is related to the context, the instruments that measure it must be constructed on its characteristics (7).

Palliative care differs from any other type of care because the goal of care is not total or partial recovery but the increase or maintenance of quality of life in the awareness of an adverse outcome (11, 12). The main actors in this care setting are subject to particular stress and the decision making skills of caregivers is one of the aspects that mostly influence care (13, 14). Also the relationship between the caregiver and the team assumes an important value. The assessment of the ability of caregivers to take decisions about the aspects that characterize the setting fosters a proper attribution of their responsibilities with clinical and organizational advantages.

Hence, the aim of this work was: the cross-cultural adaptation of the Family Decision-Making Self-Efficacy Scale (FDMSES) to the Italian cultural setting to improve the process of reintegration resilience of caregivers and their decision-making.

A review of the literature was conducted from March to April 2013, on the databases: Pubmed, Ovid, CINAHL and Google Scholar where two articles were found that addressed instruments of self-efficacy for caregivers of patients with a poor prognosis; the first one was the Caregiver Self Efficacy Scale (CaSES) (15), the second one was the Family Decision Making Self-Efficacy Scale (FDMSES) (16). After analyzing the scales we preferred FDMSES to CaSES because it considers both the care of conscious

and unconscious patients, and because the former also examines situations and specific activities of caring in palliative care. CaSES does not take into account the centrality of the decision making process in the evaluation of self-efficacy, while, the process of decision making in FDMSES is pivotal (6). In addition to this, by comparing the values for the internal consistency of the two tools, those of FDMSES were more significant. FDMSES is the only instrument for assessing the ability of caregivers in taking decisions when the patient is at the “*End of Life*” (EoL).

## Materials and Methods

### *Description of the Family Decision-Making Self-Efficacy Scale (FDMSES)*

FDMSES, developed by Nolan (16), is divided into two parts: a) the scenario with the conscious patient where the caregiver is involved in the patient's decision making, b) the scenario with the unconscious patient where the caregiver replaces the patient in his/her decision making. Each scenario consists of 13 items that are structured using a 5-point self-anchoring scale. The instrument is completed by an overlapping table which brings together the same items of the two scenarios to facilitate comparisons between the two situations. The instrument was originally tested with good results for reliability (Cronbach's  $\alpha = 0.91$  for the scenario with the conscious patient and Cronbach's  $\alpha = 0.95$  for the scenario with the unconscious patient) (16).

### *Italian Language and Cultural Adaptation of the Family Decision-Making Self-Efficacy Scale*

The need for a cross-cultural adaptation along with the translation of the Family Decision Making Self Efficacy Scale was supported by the guidelines of Guillemin (17) that indicate that this approach is valid

if an instrument has to be used in different cultural and linguistic contexts. The main aim of a validation process is to look for cultural, linguistic, semantic, idiomatic, experiential and conceptual equivalence between the original tool and the translated version that has to be obtained through 5 steps (18):

STEP 1. The Family Decision Making Self Efficacy Scale was translated by two Italians experts in palliative care (forward translation). These experts produced two independent translations, T1 and T2, noting:

a) semantic, idiomatic, conceptual doubts or relating to the use of words and expressions;

b) the solutions adopted to overcome the difficulties encountered and the reasons for the choices made.

STEP 2. The two translators compared T1 and T2 and agreed on a common version called T12. This stage was documented by a report that described the process of synthesis, the doubts that arose and the solutions adopted.

STEP 3. T12 was re-translated from Italian into English (*back translation*) by two native translators who worked independently and without knowledge of the original version of the instrument. The translators did not know the topic of translation. The main researcher discussed with the translators about the problems encountered and the solutions chosen for the back translation BT1 and BT2. BT1 and BT2 were compared with the original scale to highlight the differences due to conceptual errors, inconsistencies or unclear formulations. The main researcher subsequently prepared a report on the findings from the meetings with the translators and the comparison between BT1 and BT2.

STEP 4. A committee was set up including 11 people who were the experts of palliative care who produced T1 and T2, native translators who produced BT1 and BT2, a methodologist, an experienced English researcher, the head of training of a non-profit organization that operates in palliative

care, the head nurse of a hospice, a hospice psychologist, two doctoral candidates in nursing experts in this field.

The working group met several times and discussed the documents producing a synthesis based on T12. At this stage, the committee was in contact with the developers of the original instrument to whom a provisional draft was submitted, and the issues raised by the debate among experts were presented. The comparison between experts had the aim of ensuring the adequacy of the contents of the translation with those of the original instrument.

We tested:

- *semantic equivalence*: the use of more words with the same meaning or words that had multiple meanings was avoided and the solution of grammatical problems was sought;

- *idiomatic equivalence*: was reformulated, in the culture of final users, colloquialisms or slang idioms used where the instrument was developed;

- *experiential equivalence*: situations and typical activities of the original context in similar conditions in the culture of the users were transformed;

- *conceptual equivalence*: the adaptation of concepts that could have had different meanings in the culture of origin with respect to the target was made.

The experts finished the work with the production of a pre-testing version of the instrument.

**STEP 5: Face validity.** The scale was submitted by trained health care professionals to caregivers of patients in palliative care in the centers participating in the study. The health professionals were instructed to carry out the submission of the questionnaire. The education of professionals was addressed to uniform the collection of data. Proposals for participation to fill in the tested instrument were made in 33 cases by physicians and in 31 cases by nurses. Data collection took place between October 2013 and February 2014.

The evaluation of the linguistic pre-testing version of the tool was administered to a convenience sample of 64 caregivers. The inclusion criteria for caregivers were: 1) to be the main caregiver, (i.e. be the point of reference of the family, of friends or health personnel) and 2) to be in this role for at least 15 days prior to the compilation of the instrument. The sample was recruited from 3 hospices (2 in Turin and 1 in its Province) and from 3 home palliative care services (1 in Turin, 1 in its Province and 1 in Rome). The caregivers interviewed filled in a pre-testing version of the scale on the basis of the health conditions of the patient they took care of (scenario with the conscious patient or scenario with the unconscious patient) and, besides, they filled in a form on demographics. The health professionals who administered the tool, after the caregivers had completed the pre-testing version of the scale, asked verbally if: "The contents of the questions reflected the experience that they were living" and "How clear the different items were" to assess the relevance and the clarity of the questions.

Out of 64 caregivers who responded to the pre-testing version (52 at home and 12 in hospice), 60 of them (93.7 %) returned the pre-testing and the demographics data (Table 1). Two caregivers did not participate, and two returned incomplete documentation.

The internal consistency of the pre-testing version was calculated with Cronbach's  $\alpha$  using the software SPSS 19.0 (SPSS, Chicago, IL, USA). The calculation was performed for the conscious and the unconscious patients in different scenarios.

## Results

To build the Italian version of the scale we addressed issues related to its translation and cultural adaptation. The problems encountered and the solutions adopted are listed below.

Table 1 - Demographic data of caregivers.

Caregiver demographic data	Overall data n (%)	Conscious patient scenario n (%)	Unconscious patient scenario n (%)
N	60	47 (78,3 %)	13 (21,6)
Gender			
males	12 (20)	10 (16,6)	2 (3,3 )
females	48 (80)	37 (61,6 )	11 ( 18,3 )
mean age	53,1 (21 - 74)		
Relationship with the assisted person			
wife / husband	19 (31,6)		
father / mother	1 (1,6)		
other	39 (65)		
not responding	1 (1,6)		
Level of education of the caregiver			
elementary school	3 (5)		
middle school	19 (31,6 )		
secondary school/high school	26 (43,3 )		
degree	12 (20 )		
Previous caring experiences of the caregiver			
none	33 (55%)		
one or more of a	27 (45 %)		
Previous bereavement experiences of the caregiver			
none	6 (10 )		
one or more of a one	51 (85 )		
not responding	3 (5)		

a) In the original version, both scenarios, with the conscious patient and with the unconscious patient were introduced by a phrase that precedes the item: “I am confident that I will be able to ...”. This expression is idiomatic and literally could be translated as: “I am sure that ...” or “I am confident that ...”, in the Italian version it was preferred “I think I can ...” because more commonly used in Italian and more responsive, in our context, towards attitudes experienced by caregivers of people with severe diseases. This sentence ends, in the scenario with the conscious patient, with “help” (translated in full from: I think I’m able to help...).

b) The modal auxiliary “will” that indicates the future was only used in items 8, 9 and 10 of the scenario with the conscious patient and in items 10 and 11 of the scenario with the unconscious patient. For this reason,

if translated literally, most of the scale would have had verbs inflected in the present tense and only a few items would have had verbs in the future. After an internal debate among the group of experts it was decided to use verbs in the present tense for all items. In fact, the prognosis of these patients places the activities evaluated by the scale in a very limited period of time, therefore, in the present tense.

In addition, we feared that conjugated verbs with different tenses could confuse caregivers.

c) Item number 5 of the scenario with the conscious patient and item number 7 of the scenario with the unconscious patient of the original version, concerning resuscitation, were eliminated. These deletions were decided by the group of experts who considered that this topic could

not be applied to the philosophy of palliative care that characterizes the Italian setting. According to this panel, the palliative care approach, does not alter the natural course of the disease and care is aimed exclusively at reducing pain and symptoms. In the United States, palliation activities are implemented in end of life (EoL) circumstances, regardless of the setting (intensive care, hospice care, home care, etc.), therefore, clinical care does not always strictly adhere to the philosophy of palliation. In addition, when Nolan (16) designed the instrument, he had envisaged that the healthcare choices previously made could always be modified. These motivations were reported to the panel of experts who decided, however, to remove the items.

d) Each item includes a 5-point self anchoring scale placed between two statements “cannot do at all” and “certain people can do it”, which could literally be translated, “not everyone can do it” and “sure I can do it”. These expressions have been replaced with “impossible to do” and “sure to be able to do”.

It was thought that, in the original scale, the impersonal formulation of the first period (impossible to do) intended to avoid blaming caregivers in case they did not feel capable of accomplishing the task. This choice seemed appropriate and, hence, to avoid uncertainties and misunderstandings the panel also adopted an impersonal form for the second period (sure to be able to do).

Table 2 - Same items in the original version between the two scenarios: “conscious patient” and “unconscious patient” and their adaptation to the Italian version.

Original version		Italian version			
Original text	Scenario with the conscious patient	Scenario with the unconscious patient	Text culturally adapted and translated into Italian	Scenario with the conscious patient	Scenario with the unconscious patient
make decisions about his/her health care.	Item 1	Item 1	prendere decisioni sulla sua assistenza	Item 1	Item 1
make decisions about how he/she will receive food and fluid	Item 3	Item 4	prendere decisioni su come assumerà alimenti e liquidi	Item 3	Item 4
make decisions about where he/she will be cared for at the end of life.	Item 6	Item 8	prendere decisioni in merito al luogo di cura nel fine vita	Item 5	Item 7
make decisions about continuing to fight his/her disease	Item 7	Item 9	prendere decisioni su come continuare a trattare i sintomi della malattia	Item 6	Item 8
make decisions that will help him/her avoid suffering	Item 8	Item 10	prendere decisioni che aiuteranno ad evitare la sua sofferenza	Item 7	Item 9
make decisions that promote his/her comfort	Item 9	Item 11	prendere decisioni che favoriscano il suo benessere	Item 8	Item 10
make decisions that will respect his/her dignity	Item 11	Item 12	prendere decisioni che rispettino la sua dignità	Item 10	Item 11

Table 3 - Different items in the original version between the two scenarios: “conscious patient” and “unconscious patient” and their adaptation to the Italian version.

Original version	Italian version				
	Scenario with the conscious patient	Scenario with the unconscious patient	Text culturally adapted and translated into Italian	Scenario with the conscious patient	Scenario with the unconscious patient
Original text					
make decisions that are in his/her best interest	item 2	NC	prendere decisioni nel suo interesse	item 2	NC
make decisions about whether to stop trying to eat if he/she wants to stop	item 4	NC	decidere se interrompere gli sforzi per mangiare, se non vuole	item 4	NC
make decisions that are consistent with his/her faith beliefs or ultimate concerns	item 10	NC	prendere decisioni che siano coerenti con la sua fede o con i suoi valori spirituali o con le sue attuali preoccupazioni	item 9	NC
make decisions that will avoid burdening our family	item 12	NC	prendere decisioni che non pesino sulla famiglia	item 11	NC
handle the news if the doctor says that his/her death is near	item 13	NC	gestire le informazioni sulla vicinanza della morte se il medico la comunica	item 12	NC
make decisions that he/she would make for himself/herself	NC	item 2	prendere le decisioni che lui / lei avrebbe preso	NC	item 2
make decisions that are in keeping with his/her values	NC	item 3	prendere decisioni che rispettino i suoi valori	NC	item 3
make decisions about whether to stop urging him/her to eat	NC	item 5	decidere se interrompere le sollecitazioni a fargli / le assumere alimenti	NC	item 5
make decisions about treatments to manage his/her pain	NC	item 6	prendere decisioni sui trattamenti per la gestione del dolore	NC	item 6
talk to other family members about his/her health care	NC	item 13	parlare con persone significative della sua assistenza	NC	item 12
NC has no match in this scenario					

### *Similarities and differences between the original instrument and the Italian adaptation*

In the original version of the scale some items were the same in the scenario with the conscious patient and with the unconscious patient. Table 2 shows the correspondence

between these items and those of the Italian version, while Table 3 shows the items that differ between the two scenarios. In the following analysis, each item is examined for the first time it is presented in the scale. The items of the scenario with the conscious

patient that repeat the items of the scenario with the unconscious patient are only considered for the first scenario.

*Item analysis of the instrument: "Scenario with the conscious patient"*

Because of the cross-cultural adaptation, a full correspondence between the numbering of the items of the original scale and those of the Italian version has not been maintained. As detailed below we refer to the numbering of the original scale.

Item 1: "healthcare" was translated with "care" instead of "healthcare itself" or "cure" deemed too generic.

Item 2: "To make decisions that are in his/her best interest" has been translated as "to make decisions in his/her interest". It was felt that "best interest" was not usual in the context and potentially confusing.

Item 3: "Will receive" was translated as "will take in" that is a verb frequently used to describe the consumption of food or drink.

Item 4: The literal translation of "take decisions about whether to stop trying to eat if he/she wants to stop" would be "make decisions about stop trying to eat if he/she wants to stop" which is unusual and unpleasant in Italian. It was preferred, to translate the sentence as follows: "to decide whether to stop the efforts to let him/her eat, if he/she does not want to".

Item 5: The panel did not detect any linguistic and cultural differences in the translation of the item.

Item 6: This item was changed. Its literal translation would have been: "continue to fight to make decisions about his/her disease" but the palliative care relates to a symptomatic treatment and the management of pain and other ailments that cannot be suspended. Therefore, the item was translated as follows: "to take decisions about how to go on treating the symptoms of the disease".

Item 7: The panel did not detect any linguistic and cultural differences in the translation of the item.

Item 8: The panel did not detect any linguistic and cultural differences in the translation of the item.

Item 9: The term "comfort" could be translated as: consolation, comfort, reassurance or welfare. "Welfare" was preferred because more suitable in Italian to describe a condition either physical or relational.

Item 10: "Faith beliefs" was translated as "faith" because "religious beliefs" seemed too vague to define a framework within which to take decisions. To translate "ultimate concerns" the alternatives were: doubts, problems and worries. "Concerns" was preferred because it seemed that this term would have described the difficulty of the topic and the situation more effectively in the Italian culture.

Item 11: "burdening our family" was interpreted as "weighing on the family" because it seemed that the expression "make the family feel guilty" would have a sense of blaming.

Item 12: The panel did not detect any linguistic and cultural differences in the translation of the item.

Item 13: "Handle the news if the doctor says that his/her death is near" has been translated as "managing the information in proximity of death if the doctor communicates it". The panel decided to use "to manage" because this expression could have conveyed the comprehension of both the inner aspects determined by the communication that the practical aspects evoked also by the term "the news"; a plural noun that refers to many different aspects of an imminent event.

*Item analysis of the instrument: "Scenario with the unconscious patient"*

Five items of the scenario with the conscious patient were different compared to the scenario with the unconscious patient. The translation of these items, and in particular, the choice of the verbs aimed to highlight the condition of passivity of unconsciousness.



Item 2: The formulation of the most common sentence in the Italian language was chosen.

Item 3: This item was correlated with item 10 of the scenario “conscious patient”. The item regards the values of the patient that have to be respected by the caregivers when they make decisions for the patient himself/herself, when the same patient is no longer able to interact. In item 9 of the “conscious” scenario, instead, spiritual values, faith and ultimate concerns were described analytically because the patient could still express his/her needs and decide about their importance.

Item 5: The literal translation of “... whether to stop urging him/her to eat” would have not been suitable for the Italian context and the expression “to interrupt the strain to ingest food” was preferred because eating involves an active participation that is not a stable activity in the unconscious patient.

Item 6: It was believed that to take decisions about the different treatments for pain management did not imply the possibility of suspending such treatments but they just regarded the side effects they could entail.

Item 12: “Talk to other family members about his/her health care” was translated as follows: “to speak with significant people in his/her care” because it is increasingly common that besides the family there are, close to the patient, significant people with affective ties.

The panel produced a pre-testing version of the Italian Family Decision-Making Self-Efficacy Scale that consisted of two scenarios, each one with 12 items.

#### *Assessment of the relevance, linguistic clarity and internal consistency of the items*

The evaluation of the relevance and clarity of the items was carried out verbally on 60 caregivers in palliative care. All caregivers reported that the content of the items was relevant to the experience they

were living and the linguistic formulation clear. In particular, the caregivers expressed a favorable opinion about the choice of the topic of the items and recognized that the arguments were part of their own experience. Internal consistency was measured by calculating Cronbach’s  $\alpha$  on tests returned by 60 caregivers. The Cronbach  $\alpha$  values were 0.925 for the scenario with the conscious patient and 0.946 for the scenario with the unconscious patient.

## **Discussion and conclusions**

The adaptation of the Italian FDMSES version was influenced by cultural factors that acted on two levels:

a) the practice of palliative care is strongly influenced by the cultural context and by the connected ethical values, that determine its orientation;

b) the construct of self-efficacy is specific to the context in which it is presented (7) and it is, therefore, characterized by the singularity and the emotional implications of the experience of carers towards the dying person (19, 20, 21).

This makes the experience of the caregivers in palliative care hardly comparable with other caring experiences and also the perception of its self-efficacy very special.

The work of translation and of cultural adaptation took into account these experiences and it attempted to satisfy them looking for solutions that would guarantee: a wide applicability of the instrument to caregivers and its adaptability to the individual experience of the caregiver himself/herself.

The original version of the scale and the Italian adaptation differ in the number of items. While in the original version of the scale (16) there are 13 items for the scenario with the conscious patient and the same for the scenario with the unconscious patient,

in the Italian version the items were reduced to 12 in both scenarios. The reason for this was linked to the consistency of patient resuscitation practice in palliative care in the two countries. While in the United States (22) palliative care is given according to the staging of the disease and regardless of the setting where the patient is cared for, in Italy the prevailing criterion in the application of palliative care is the placement of the patient in a dedicated care environment (23, 24). In the first case, palliative care is provided regardless of the clinical setting, therefore, you have both principles of palliation and those typical of that particular clinical environment. In the second case, in Italy, caregivers in palliative care, working in hospices and domiciliary care, can fully comply with the principles of palliation. Therefore, it could be that in the United States, if requested by the family, a patient is resuscitated, while in Italy, the same request may not be deemed suitable to comply with ethical values stated by nurses ethical code such as: "Nurses defend the patients' will to limit interventions that are not proportional to their clinical conditions and consistent with their declared conception of the quality of life" (25, 26).

This is reflected in the structure of the instrument that, in the Italian version, is intended to be applied exclusively in palliative care, whereas, in the original version, is used in conditions of EoL care regardless of the context of care.

In fact, both the group of experts and caregivers who took part in the test, judged the topics of the items sufficiently specific and inclusive of all care activities normally assigned to family members. Particularly, according to the answers of the caregivers, the questions that investigated the clarity and pertinence of the items, aspects difficult to define but of remarkable importance for the experience of caring, were identified. For instance, this was the case of the items that appraised the ability to replace the patient in

the inherent decisions about respect of their spiritual values.

In the comparison the Italian adaptation of FDMSES and the original version (16) we had to take into account the different cultural approaches to the "death" event by the caregivers in the United States compared to the Italian ones. This factor emerged during the analysis conducted by the group of experts who underlined, for instance, the inopportunity to include in the Italian contextualization some strong expressions for our cultural approach towards death.

Lastly, the comparison of the values of Cronbach's  $\alpha$  between the FDMSES scale and the CaSES scale confirms the impression of major specificity of the first instrument, which prompted the initial choice of the tool to be adapted. In fact, the high value of the FDMSES Cronbach's  $\alpha$  in both scenarios is reflected in only one of the four subscales of the CaSES (15).

#### *Limitations and future developments*

The evaluation of the work was conditioned by the limited comparability with other equally specific instruments. It should be remembered, in fact, that there are no other translations and adaptations of the FDMSES scale and currently the only comparable one is the CaSES scale. Moreover, the specificity of the setting makes it impossible to compare, albeit from the linguistic point of view, the Italian version of the FDMSES with instruments that assess the caregiver's self-efficacy in other contexts. A better evaluation of the instrument can be made through its implementation on a larger scale to measure more specific psychometric characteristics (27, 28, 29).

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## Riassunto

### *Adattamento culturale e validazione linguistica della Family Decision Making Self Efficacy Scale (FDMSES)*

**Premesse:** L'infermiere, seguendo il suo mandato etico deontologico, collabora con altre figure socio-sanitarie: professionisti o persone che partecipano alle attività di cura. Tra questi ultimi assume una rilevanza crescente il familiare o la persona vicina all'assistito (*caregiver*) che per la costante presenza e la prossimità emotiva svolge un ruolo fondamentale nell'assistenza. Affinché l'integrazione avvenga utilizzando al meglio il contributo del *caregiver* occorrono strumenti che ne rendano oggettive le abilità.

L'adattamento culturale e la validazione linguistica della Family Decision Making Self Efficacy Scale fanno parte di un progetto più ampio finalizzato alla conoscenza della resilienza del caregiver in cure palliative. L'autoefficacia è uno degli aspetti della personalità più strettamente connessi con la resilienza. L'autoefficacia si manifesta in un contesto specifico, quindi, il suo studio e la verifica del suo livello, presuppongono la conoscenza delle capacità che permettono all'individuo di sentirsi efficace in quella particolare circostanza. La Family Decision Making Self Efficacy Scale valuta i comportamenti dei *caregiver* di pazienti alla fine della vita.

**Metodi:** La Family Decision Making Self-Efficacy Scale è stata tradotta (*forward e backward translation*) ed è stata adattata al contesto clinico – culturale italiano, da un gruppo di ricerca di cui facevano parte esperti in cure palliative, traduttori madrelingua ed esperti in scienze infermieristiche. È stato ricercato il consenso del gruppo sulla formulazione di ciascun item relativamente a: equivalenza concettuale, semantica, idiomatica ed esperienziale. La chiarezza della formulazione e la pertinenza degli item dello scenario con paziente cosciente e di quello con paziente incosciente sono state valutate da un gruppo di caregiver ai quali è stato proposto il test dello strumento.

**Risultati:** La versione italiana della scala comprende 12 item per lo scenario con paziente cosciente e 12 per quello con paziente incosciente. Il gruppo di lavoro ha espresso il consenso sulla versione *pre-testing* dello strumento. La versione *pre-testing* della scala è stata testata su 60 caregiver dei quali 47 assistevano un paziente cosciente e 13 un paziente incosciente. In entrambi i casi il contenuto degli item è stato giudicato pertinente e comprensibile.

**Conclusioni:** I risultati relativi alla validazione linguistico-culturale sono soddisfacenti e ammettono l'applicazione dello strumento stesso nella realtà italiana.

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