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Quality of life of primary caregivers of patients in a vegetative state receiving home enteral nutrition

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Quality of life of primary caregivers of patients in a vegetative state receiving home enteral nutrition.

^a, *Metabolism and Nutrition Unit, Treviso Hospital, Treviso, Italy.*

^b*Department of Psychology, University of Turin, Italy.*

^c *Department of Psychology, University of Padua, Italy.*

^d*Hospital Direction ULSS 9 Treviso, Italy.*

Home enteral nutrition and caregivers' wellbeing

1. Introduction

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2

4-9

10,11

5

12,13

5

perceived stress, and (v) conditioning variables such as the caregivers' individual

ivers'

2. Methods

.1. Research background: organisation of HEN in Italy

Nutritional Team (NT), which evaluates the patient's clinical condition, plans the nutritional

2.2. Participants and procedures

aregivers of patients in a vegetative state (Karnofski performance status 40) were

2.3. *Measurements*

categories: 6 categories for the advantages (patient's survival, easy management of HEN, time/work load, nutritional aspects, patient's health/wellbeing, no advantage), and 5 disadvantages (time/work load, technical problems with HEN, patient's

¹⁸ to assess the caregivers'

The caregivers' psychological wellbeing was assessed with a subset

t score 63, 90

2.4. Statistical Analysis

ssociations between the caregivers' sociodemographic characteristics and the

—

Furthermore, the caregivers' scores on the 8 SF

Student's *t*

(conditioning variables, objective stressors, perceived stress) on the caregivers' HRQoL.

3. Results

3.1. Descriptive results

patients' primary caregivers, 12 (7.8%) were the caregivers of patient

±

nson's or Alzheimer's.

sionally active, and were either the patient's

-square test revealed that the caregivers' sociodemographic characteristics and the

			X^2	N	
p		X^2	N		p

ANOVA analysis revealed the effects of the caregivers' sociodemographic characteristics on

<i>F</i>	<i>p</i>	<i>F</i>	<i>p</i>	
		<i>M</i>	<i>SD</i>	
		<i>M</i>	<i>SD</i>	
			<i>M</i>	<i>SD</i>

ient's room had to be relocated; in others, furniture had to be moved or removed or the rooms' assigned to family members had to be changed. The reported costs of modifications exceeded €500 in 24 cases.

(e.g. “Handy”, “Comfortable”, “Excellent and punctual delivery service by very efficient staff”), 22.1% referred to the patient’s health/wellbeing (i.e., “the patient is calmer”, “the patient had no more complications”), 17.5% to a reduction in the time and work load (i.e., “No more need to prepare, or whip special food”), 14.8% to nutritional aspects (i.e., “Adequate calorie intake”), and 14.8% to the patient’s survival (i.e., “ the patient is still alive”). Finally, 4 answers (2.7%) could not be categorized.

“Problems with the feeding tube”), followed by problems related to the patient’s health/wellbeing (30.7%; i.e. “Increase in weight”) and the time and work load involved in the management of HEN (23.9%; i.e. “the patient needs more time”). Nine disadvantages (10.2%) referred to the negative emotional impact of HEN (i.e., “Suffering when seeing the patient in this condition”) and, f

t *p*

F *p* *F* *p*
F *p* *F* *p*

estimated parameters showed that the higher the caregivers' discomfort

B *p* *B* *p* *B*
p *B* *p* *B* *p*
 B *p* *B*
p

X^2 *N* *p*

B *p*

B *p*

4. Discussion

egivers' HQRoL and subjective well

6-8, 22, 23

level of stress, there is a strong relationship between the patient's physical and cognitive
of their daily needs, and their caregivers' well

Alzheimer's disease²² 23 24 25

social support, the poor functional status of patients and the patient's cognitive impairment
to an increase in the caregivers' burden.

^{11,26}, analysing caregivers' needs, found that assisting the patient in activities of daily living

HEN. They indicated the ease of its management and its necessity for the patients' health as

^{10,27} can lead to a reduction in the caregivers' burden and could

10

28

17,29

d of support is needed in order to reduce the caregivers' stress.

5. Conclusions

from the hospital to the patients' homes, the

that can be activated. Since we did not find a negative impact on the caregivers' HRQoL, we

References

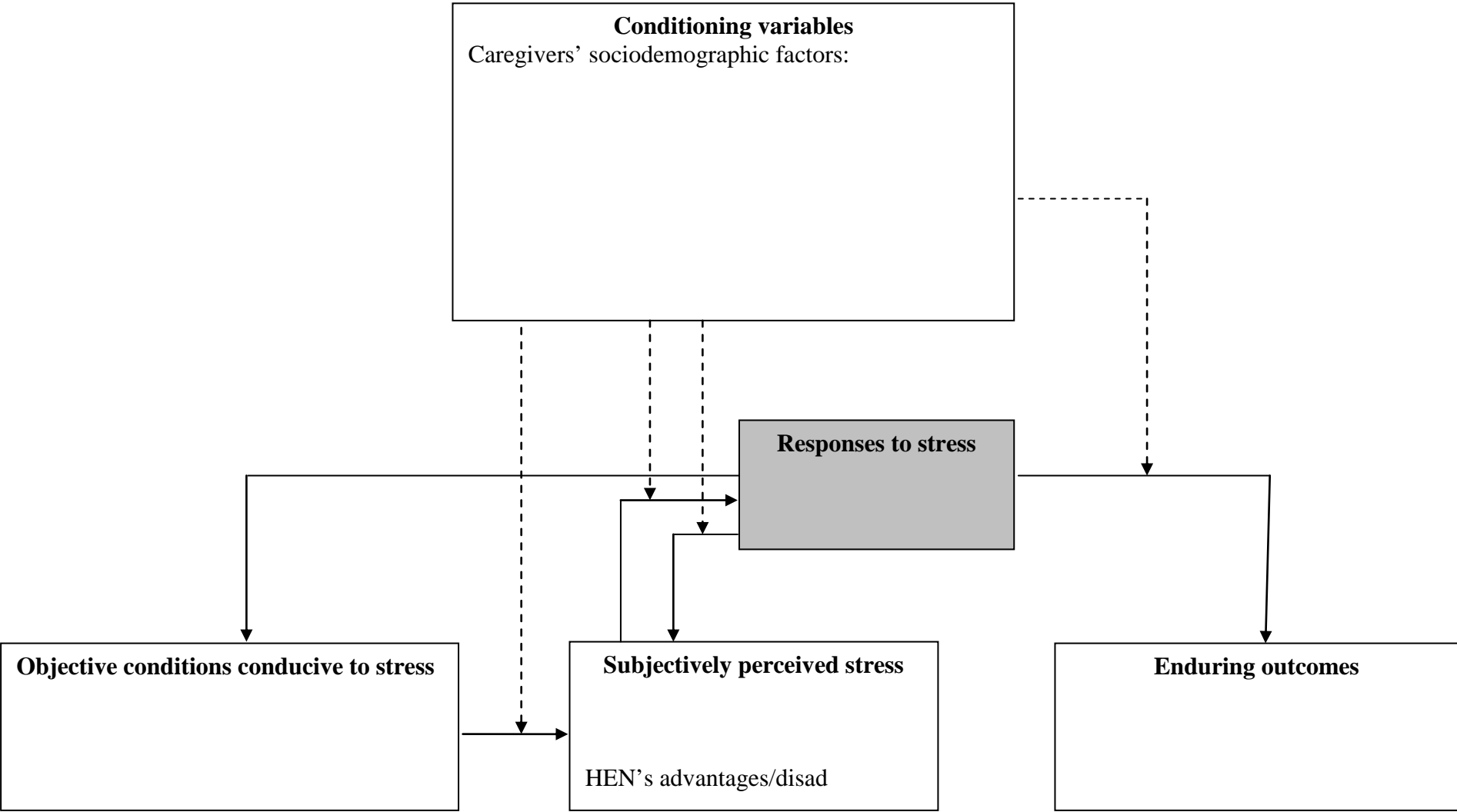
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Descriptive statistics of independent variables

n

M SD

Caregivers' sociodemographic factors

Caregiving contextual variables

Environmental impact of HEN

< 500 €

> 500 €

Perceived stress

HEN's advantages

SF-36: Comparison between caregivers and the Italian norm data

				<i>p</i>
<i>N</i>		<i>N</i>		
<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	

Multivariate effects of independent variables on the 8 SF-36 scales

	<i>F</i>	<i>p</i>
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Caregivers' sociodemographic factors

Caregiving variables

Environmental impact of HEN

Perceived stress

HEN's advantages

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