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Courage and representations of death in patients who are waiting for a liver transplantation

Ines Testoni^{1*}, Valentina Milo¹, Lucia Ronconi¹, Alessandra Feltrin², Adriano Zamperini¹, Maddalena Rodelli¹, Giacomo Germani³ and Umberto Cillo⁴

Abstract: *Context:* In the last decade, a wide literature has highlighted the importance of religiosity as support of severe illnesses, especially the oncological ones, and in the end of life. In the field of the liver transplant, there is a lack of similar research. This article aims to bridge this gap and presents an exploratory study on the relationships between fear of death, courage and religiosity among patients who wait for liver transplant. *Method:* Sixty-two participants awaiting a liver transplant were interviewed with regard to their quality of life, religiosity, ontological representations and fear of death, courage and fear of intervention and donor-related thoughts. The following instruments were utilized: a specific interview; the Short Form Health Survey (SF-36); the Testoni Death Representation Scale (TDRS); and the Courage Measure. *Results:* Patients reporting higher levels of fear for intervention showed less courage and were more likely to avoid the surgery. They also tended to be non-believers, to have a lower quality of life and to represent death as an absolute annihilation. *Conclusions:* Less death was represented as a passage, the stronger the avoidance behaviour and the fear of transplant were. Since it is possible to develop a positive thought about death, the study underlined how spiritual support could be useful to manage fear of transplantation.



Ines Testoni

ABOUT THE AUTHORS

The group is composed by psychologists (Ines Testoni, Valentina Milo, Alessandra Feltrin, Adriano Zamperini and Maddalena Rodelli), methodologists (Lucia Ronconi) and physicians expert in liver transplant (Umberto Cillo, Giacomo Germani). These specialists are interested in improving the quality of life of patients suffering from liver failure and destined to the transplant. In particular, this research unified the competence of all the components through the analysis of patients' existential suffering in order to better understand how to improve their courage and hope before the surgery, reducing the anxiety. The next step of the collaboration regards the relationships between fear of death, anxiety, spirituality and compliance after the transplant. Further issues involving the group are inherent to the psychological implications in the bioethics problems related to the liver transplant in alcoholics.

PUBLIC INTEREST STATEMENT

Many studies has highlighted the importance of the religious experience for the management of fear of death and the following anxiety which breaks into life after the bad news of severe illnesses. Religiosity seems to be a factor able to support sick persons to face their anguish. Despite the condition of transplant patients being defined as a "dance with death", there are few studies about the relationship between the representation of death and religiosity. The article focuses on this gap. The results show how religiosity and representations of death as a passage may help cope with anxiety, while non-believer patients representing death as annihilation are more likely avoidant and threatened with respect to the intervention, while believers, representing death as a passage, show more courage and coping skills. Since these patients need to find ways to better address the challenges they have to overcome, we affirm that the reanimation of the existential sense of life and transcendence help them, reinforcing resilient resources. This theme is important because the need to prepare patients and their families for death while maintaining hope is widely asked by the health services.

Subjects: Religion & Psychology; Health & Society; Health Conditions

Keywords: awaiting a liver transplant; representation of death; courage; religiosity

1. Introduction

Khun and colleagues defined the condition of transplant patients as a “dance with death” because they are facing terminal illness, despite this circumstance being often overshadowed by the focus on continued medical care and the pursuit of a donor organ with related thoughts or concerns (Kuhn, Davis, & Lippmann, 1988). Notwithstanding that the rate for post-liver transplant survival is considerably increasing and information that quality of life (QoL) in the postoperative state is better than in the preoperative is widely diffused (Schulz, 2015), people waiting for a lifesaving organ transplant are overwhelmed by fear of death (Annema, Roodbol, Stewart, Porte, & Ranchor, 2015). Indeed, this is one of the most stressful surgeries for patients (Annema et al., 2015; Gruttadauria, 2009; López-Navas et al., 2010; McCaughan et al., 2016; Ordin, Dicle, & Wellard, 2011), and those who suffer from liver diseases undergo both the typical problems of transplant (Goetzmann et al., 2006; Schulz, 2015; Stewart, Hart, Gibson, & Fisher, 2014; Telles-Correia, Barbosa, Mega, & Monteiro, 2009) and the impairment in the QoL due to liver failure (Bajaj et al., 2011; Bjørk & Näden, 2008).

Since the discomfort is severe and strongly characterized by mortality salience, research explored the stressful variables (Dew et al., 2007; Díaz-Domínguez, Pérez-Bernal, Pérez-San-Gregorio, & Martín-Rodríguez, 2006; Sainz-Barriga et al., 2005; Stewart et al., 2014). Most of the studies especially analysed the conditions of ill patients with alcoholic liver disease (Addolorato et al., 2013; Doane, 2014; Hasanin, Dubai, McGuire, Schiano, & Singal, 2015; Neuman et al., 2015; Pegum, Connor, Young, & Feeney, 2015). In particular, the literature underlined the difficulties related to the management of medication compliance and the following ethical implications. In fact, in the context of organ shortage, which imposes a need for strict selection of transplant candidates, patients with severe alcoholic hepatitis raise major ethical questions because of their relapse caused by the non-compliance and the following high risk of death (Addolorato et al., 2013; Doane, 2014; Donckier, Lucidi, Gustot, & Moreno, 2014; Karim et al., 2010; Pegum et al., 2015). However, independently from the cause of their pathology, the fear of death may assume a special role since a high anxiety contributes to patients’ lower levels of recall, and increases the risk of non-adherence (Martin, Williams, Haskard, & DiMatteo, 2005).

As Furer and Walker (2008) review, pain and sufferance in severe illnesses raise the level of anxiety, which in turn worsen the health conditions, while anxiety is hugely increased by fear of death triggered by mortality salience. This emotional effect has been analysed by the Terror Management Theory (TMT), which shows how health and bodily conditions continuously evoke the inevitability of death, resulting in a paralysing terror (Burke, Martens, & Faucher, 2010; Goldenberg, 2012). TMT shows how fear of death creates such a profound anguish that people spend their lives attempting to make sense of it, and developing specific form of defence mechanisms. In particular, believing in a transcendent existence curbs abysmal fear, religiosity, promoting the faith in a literal afterlife, being the most important cultural effect of this process (Kesebir & Pyszczynski, 2012).

Running in a parallel direction, psychology of religion and positive psychology have emphasized the importance of spirituality in reducing existential anxiety, in the improvement of QoL and resilience (Peterson, Ruch, Beermann, Park, & Seligman, 2007; Seligman & Csikszentmihalyi, 2014; Testoni, Falletti, Visintin, Ronconi, & Zamperini, 2016; Testoni, Visintin, Capozza, Carlucci, & Shams, 2016). Despite several meta-analyses confirming the positive influence of religiosity on the well-being (Hackney & Sanders, 2003; Ronconi, Testoni, & Zamperini, 2009), in the liver transplant field, there is a significant shortage of similar studies. Exceptions are the analyses of Bonaguidi, Michelassi, Filippini, and Rovai (2010) and Vocht (2011). The former suggested that religiosity and an active seeking God are associated with improved survival in liver transplant recipients, while the latter pointed out the difficulty to identify religiosity as the causative factor of this relationship because other elements may mediate such an association, among which one is the cultural role of religion in

social support. Research already examined how religiosity buffers stress towards enhanced life satisfaction since it improves social supports and life meaning, which are the concrete factors which help (Laudet, Morgen, & White, 2006). Indeed, a large body of studies have described the mechanisms through which social support promotes physical and mental health and buffers psychological stresses (for a review, see Uchino, Bowen, Carlisle, & Birmingham, 2012). However, in the field of organ transplant, this question has not yet been considered as an important issue; the positive relationships between religion and health management are widely detected, showing how this dimension plays a protective role in the management of anxiety deriving from sicknesses (Koenig, King, & Carlson, 2012). Indeed, spirituality and religiosity strengthen the representations of death as a passage rather than an absolute annihilation, boosting courage to face difficulties and pain (Fereshteh, 2006; Frost, Johnson, & Atherton, 2012; Norton & Weiss, 2009).

The present research pointed towards this controversy, investigating some variables, which may facilitate the recognition of the role of religiosity in the management of liver transplant. The key concept was the ontological representation of death (Testoni, 2016; Testoni, Ancona, & Ronconi, 2015), which explains the fundamental differences between the representation of death as the passage of the human identity essence (soul), generally assumed by religious perspectives, and the opposite one, which indicates the absolute annihilation of the dying person, sustained by materialistic views. In particular, it was considered the resilient force of religion as related to the courage derived from considering death as a passage (Dahlsgaard, Peterson, & Seligman, 2005; Maddi, 2006).

2. Aims and hypotheses

The study was aimed at analysing the courage to face liver transplant in candidates of waiting list. The first hypothesis stated that the representation of death as annihilation decreases their ability to cope with the disease, and in particular with the transplantation, facilitating an elusive attitude caused by excessive anxiety. On the contrary, the second hypothesis assumed that the representation of death as a passage, in particular when reinforced by religious beliefs, increases courage as well as the ability to cope with the illness and surgery. In order to verify such suppositions, firstly, ontological representations of death, religious beliefs and their relationships with courage and health status were assumed as fundamental constructs to be analysed. Secondly, the relationships among these dimensions and the QoL were measured. Since the area of the religious studies has already shown that people may experience spirituality in a variety of ways, including a sense of closeness, oneness or connection with a theistic or transcendent being (Davis et al., 2015) and patients express interest in discussion of religion and spirituality in medical consultations (Best, Butow, & Olver, 2015), meanwhile disease can lead to religious conversion as well (Gubo, Zhenhua, & Xiaoyun, 2014), we want to confirm that this variable should be more valorised in the setting of supportive intervention among people awaiting liver transplant as well.

The research followed APA Ethical Principles of Psychologists and Code of Conduct and the principles of the Declaration of Helsinki, obtaining the approval of the Padova Hospital Ethics Committee for Experimentation.

3. Participants

Sixty-two patients (45 male, 17 female, average age 56) with liver failure awaiting a transplant at the Padua Liver Transplant Centre were involved in the research. The inclusion criteria were: that they were first of all interested in participating in the research; that the severity of their pathology was low; and the cognitive abilities sufficient to understand the questions. In order to assess the severity of the disease, the Model for End-Stage Liver Disease score (MELD) was calculated in the last visit before the research. Usually, the MELD is used to predict the risk of mortality, one year after the transplant (Onaca et al., 2003; Saab et al., 2003). The average MELD score of our participants was 13, indicating a low level of severity.

Most of them stated to believe in God (87%), and among them, 48% claimed to participate in religious practices. Hepatitis C virus (HCV) or Hepatitis B virus (HBV) and related cirrhosis (31%) were the

most frequent diseases. The sample was divided into two groups: patients with Hepatocellular Carcinoma (HCC: 29%) and patients without HCC (71%). For these patients, the average period of being on the waiting list was 14 months. The main participants' characteristics are described in Table 1.

The interview was administered face to face by a psychologist of the research group in a specific setting disposed in the hospital ward.

Table 1. CM avoidance and TDRS interaction on interview Factor 1

| Variable | N | % | Mean (SD) |
|--------------------------------------|----|------|-------------|
| Gender | | | |
| Male | 45 | 76.6 | |
| Female | 17 | 27.4 | |
| Age (years) | | | |
| Range 24–71 | | | 56.2 (11.1) |
| Education | | | |
| Low | 26 | 41.9 | |
| Middle-high | 36 | 58.1 | |
| Marital status | | | |
| Married | 46 | 74.2 | |
| Other | 16 | 25.8 | |
| Presence of children | | | |
| No | 14 | 22.6 | |
| Yes | 48 | 77.4 | |
| Believe in god | | | |
| No | 8 | 12.9 | |
| Yes | 54 | 87.1 | |
| Participation in religious practices | | | |
| No | 32 | 51.6 | |
| Yes | 30 | 48.4 | |
| Pathology | | | |
| Cirrhosis HCV/HBV | 19 | 30.6 | |
| Cirrhosis HCV/HBV and HCC | 12 | 19.3 | |
| Cirrhosis esotossica | 13 | 21.0 | |
| Cirrhosis esotossica and HCC | 6 | 9.7 | |
| Recidiva | 3 | 4.8 | |
| Other | 9 | 14.5 | |
| Pathology recoded | | | |
| Cancer | 18 | 29.0 | |
| Other | 44 | 71.0 | |
| Time in waiting list (months) | | | |
| Range 0–120 | | | 13.7 (20.3) |
| MELD | | | |
| Range 4–30 | | | 13.1 (5.4) |

4. Measures

The protocol composed four instruments, and was conducted in a face-to-face clinical interview.

- (1) The Short Form Health Survey (SF-36) is a health-related QoL measure, which assesses the self-perception of health across eight domains: physical functioning (PF), role functioning–physical (RP), role functioning–emotional (RE), vitality (VT), pain (PA), general health (GH), social functioning (SF) and mental health (MH) (Hays, Sherbourne, & Mazel, 1993). Italian versions were utilized, validated by Apolone, Mosconi, and Ware (1997).
- (2) A structured interview was specially crafted to investigate biographical data, the history of the disease, the personal attitude towards the disease, the thoughts about the transplant, the perceived sources of social support and religiosity. It consisted of 19 items, among which 13 were dichotomous (presence/absence) and 6 ordinal (3 or 4 levels).
- (3) The Testoni Death Representation Scale is a five-level Likert scale constituting six items, measuring the ontological representations of death, as an annihilation or as a passage (Testoni et al., 2015).
- (4) The Courage Measure is a seven-level Likert scale, constituting 12 items and investigating the perception of courage (defined as persistence and perseverance in facing terrifying stimuli). Its structure is bi-factorial: courage and coping vs. avoidance of unpleasant situations (Norton & Weiss, 2009).

5. Data analysis

The internal consistency of all the scales was estimated using the Cronbach's α value. Thereafter, the total scores of the scales were compared to the standard values. A principal component factor analysis with Varimax rotation (Kaiser, 1958) was conducted on the data of the interview, whose structure resulted in a three factorial design. The total scores of the factors, their correlation with other constructs and with the socio-demographic variables (gender, age, education, marital status, children, believe in god, participation, pathology, waiting time and MELD) were measured. Lastly, for each interview factor, a hierarchical multiple linear regression was computed, including all the predictive dimensions. This statistical analysis was utilized because linear regression is an approach for modelling the relationship between scalar dependent variables and one or more further explanatory variables (or independent variables). It is particularly useful to quantify the strength of the relationships among dependent and independent variables, through which it is possible to identify which of them have no relationship with others at all, ascertaining which subsets of such dimensions contain redundant information. In the first step, the variables related to the QoL and in the second step, the variables related to the representations of death and courage were entered. In the third step, the interaction between the representations of death and courage was included. The statistical analyses were done with the SPSS 21 software. The level of significance was set at .05.

6. Results

6.1. Comparing sample with normative data

All the instruments demonstrated high levels of reliability, except for the SF-36 General health (GH) factor, which consequently was eliminated. Table 2 shows that the group of participants reported a higher impairment than the normative sample in some areas investigated by SF-36, such as: PF, RP, VT and SF (Apolone et al., 1997). Conversely, concerning TDRS and CM avoidance, the sample did not differ significantly from the normative sample.

6.2. Factor analysis on the structured interview

As shown in Table 3, the factor analysis of the structured interview highlighted three main factors, together explaining the 51% of variance (25, 13 and 13%, respectively). The matrix of factor loadings after the Varimax rotation showed loadings .40 higher in absolute value. The first factor, fear of intervention, constituted eight items, with a good reliability ($\alpha = .75$); it indicated the relationships between the fear of death with courage. The second factor desire to avoid the surgery was

Table 2. Descriptive statistics for study variables of current study compared with the respective normative study

| Variable | Range | Cronbach's α | Current study | | Normative study | |
|---------------------------------|-------|---------------------|---------------|-------|-----------------|-------|
| | | | Mean | SD | Mean | SD |
| SF-36 Questionnaire | | | | | | |
| Physical functioning (PF) | 0–100 | .94 | 59.03 | 31.07 | 79.10 | 22.34 |
| Role functioning–physical (RP) | 0–100 | .94 | 25.40 | 40.11 | 72.53 | 34.59 |
| Role functioning–emotional (RE) | 0–100 | .98 | 66.13 | 46.55 | 69.66 | 36.98 |
| Vitality (VT) | 0–100 | .79 | 50.89 | 25.92 | 58.71 | 20.2 |
| Pain (PA) | 0–100 | .95 | 65.48 | 40.11 | 68.31 | 25.89 |
| Social functioning (SF) | 0–100 | .88 | 69.15 | 32.54 | 76.33 | 22.39 |
| Mental health (MH) | 0–100 | .84 | 62.84 | 24.74 | 63.18 | 20.22 |
| TDRS Questionnaire | | | | | | |
| TDRS Total score | 6–30 | .92 | 18.27 | 7.75 | 17.98 | 6.05 |
| CM Questionnaire | | | | | | |
| CM Coping | 8–56 | .76 | 46.65 | 7.45 | 38.58 | 7.87 |
| CM Avoidance | 4–28 | .62 | 11.11 | 5.87 | 11.0 | 4.21 |

Notes: SF-36 Questionnaire: Apolone et al. (1997); TDRS Questionnaire: Testoni et al. (2015); CM Questionnaire: Norton and Weiss (2009) adapted by Nota et al.

composed of five items and retraced the representations of the transplantations. Item 9 of the second factor was excluded in order to increase the reliability of the factor, so that it resulted in sufficient reliability ($\alpha = .63$). The third factor donor-related thoughts constituted five items, with a sufficient reliability ($\alpha = .67$) as well, and pinpointed concerns towards the donor.

6.3. Correlation analysis

Within SF-36 scales, several internal correlations were highlighted, showing how the various aspects of physical and mental health and QoL were interrelated. A negative significant correlation appeared between CM avoidance and two SF-36 scales: role functioning–physical (RP) ($r = -.30, p < .05$) and vitality (VT) ($r = -.36, p < .01$). Besides, CM avoidance also negatively correlated with CM coping ($r = -.36, p < .05$). The first factor of the structured interview (fear of intervention) was negatively correlated with vitality (VT) ($r = -.35, p < .01$) and role functioning–physical (RP) ($r = -.33, p < .01$) of the SF-36, and with CM coping ($r = -.40, p < .01$). On the contrary, the first factor was positively correlated with TDRS ($r = .31, p < .05$) and CM avoidance ($r = .37, p < .01$). The second factor (desire to avoid the surgery) was positively correlated with the physical functioning scale of SF-36 (PF) ($r = .320, p = .011$), while the third factor (donor-related thoughts) had a significant negative correlation with the physical functioning scale of SF-36 (PF) ($r = -.40, p < .01$). Lastly, there were some internal correlations within the structured interview, showing that the first factor was positively related with the second ($r = .39, p < .01$), which in turn had a significant negative correlation with the third one ($r = -.30, p < .05$).

Gender had a significant positive correlation with several SF-36 scales: physical functioning (PF) ($r = .26, p < .05$), role functioning–emotional (RE) ($r = .36, p < .01$), vitality (VT) ($r = .38, p < .01$) and mental health (MH) ($r = .34, p < .01$). In particular, males were less compromised than females in these constructs. Age had a significant negative correlation with the physical functioning (PF) ($r = .31, p < .05$) of the SF-36 scale, indicating that the more the age increased, the more the physical activity decreased. Pathology had a positive significant correlation with several SF-36 scales: physical functioning (PF) ($r = .26, p < .05$), role functioning–physical (RP) ($r = .22, p < .05$), vitality (VT) ($r = .28, p < .05$), pain (PA) ($r = .26, p < .05$) and social functioning (SF) ($r = .26, p < .05$). HCC patients had less impairment in these areas. A positive significant correlation between MELD and CM coping and between MELD and the third factor of the interview (donor-related thoughts) also emerged. It is

Table 3. Results of factor analysis for interview items

| Item | Factor 1 | Factor 2 | Factor 3 |
|---|----------|----------|----------|
| What did you think at that time? I did not believe it (No = 0; Yes = 1) [Q2b] | .73 | | |
| What did you think at that time? I was afraid of intervention (No = 0; Yes = 1) [Q3b] | .68 | | |
| Do you have enough courage to face this experience? (Almost always = 1; Sometimes = 2; No = 3) [Q7] | .67 | | |
| Now what do you think of transplant? I'm afraid of not succeeding (No = 0; Yes = 1) [Q3c] | .66 | | |
| What did you think at that time? That they were wrong (No = 0; Yes = 1) [Q2a] | .64 | | |
| What did you think at that time? I was afraid (No = 0; Yes = 1) [Q2c] | .60 | | |
| What did you think at that time? I realized that the situation was serious, but that there was a possible solution (No = 0; Yes = 1) [Q2d] | -.57 | .55 | |
| Does faith help you? (No = 1; Not a lot = 2; A lot = 3) [Q10] | -.55 | | |
| Now what do you think of transplant? I am not yet convinced that it is the right thing for me (No = 0; Yes = 1) [Q3d] | | .70 | |
| What do you expect after the transplant? (Go on as before = 1; Improve a little = 2; Nothing = 3) [Q11] | | .69 | |
| As is the transplant waiting? (Difficult and painful = 1; I do not think about it = 2; With confidence and hope = 3) [Q4] | | -.58 | |
| Now what do you think of transplant? I look forward to be called for the intervention (No = 0; Yes = 1) [Q3a] | -.45 | -.51 | |
| In your opinion, where does the courage come from? External factors (No = 0; Yes = 1) [Q8b] | | -.44 | |
| Do your beloved ones help you face this experience? (A lot = 1; Partially = 2; A little = 3) [Q9] | | | |
| If you happen to think of the donor, how do you feel? I cannot define, I think about it without emotional involvement (No = 0; Yes = 1) [Q6c] | | | -.79 |
| If you happen to think of the donor, how do you feel? Gratitude, thankfulness, in general positive emotions (No = 0; Yes = 1) [Q6a] | | | .73 |
| In your opinion, where does the courage come from? Faith (No = 0; Yes = 1) [Q8c] | -.53 | | .60 |
| Do you ever think of the donor and his/her biography? (Often = 1; Sometimes = 2; Never = 3) [Q5] | | | -.55 |
| If you happen to think of the donor, how do you feel? Guilt, regret, sadness (No = 0; Yes = 1) [Q6b] | | | .49 |
| Cronbach's α | .75 | .63 | .67 |
| Range | 2-12 | 2-9 | 1-7 |
| Mean | 5.42 | 4.18 | 3.19 |
| SD | 2.60 | 1.89 | 2.18 |
| Skewness | .61 | .68 | .16 |
| Kurtosis | -.21 | -.56 | -1.50 |

Notes: Factor loadings over .45 are shown in the upper part of the table (retained items for each factor have respective factor loadings in bold); descriptive statistics of three factor scores are shown in the lower part of the table.

important to note that religious faith had a negative significant correlation with TDRS ($r = -.41, p < .01$), and with the first factor (fear of intervention) ($r = -.29, p < .05$). Participation in religious practices had a negative significant correlation with TDRS ($r = -.46, p < .01$) and with the first factor (fear of intervention) ($r = -.31, p < .05$). Participation in religious practices also had a significant positive correlation with CM coping ($r = .30, p < .05$).

Correlations among all constructs are illustrated in Table 4, while correlations among all constructs and participants' characteristics are shown in Table 5.

6.4. Hierarchical regression

In the hierarchical regression models, the percentage of variance explained by QoL and the variable entered in the first step was significant for each factor of the interview (R^2 between .22 and .26). The variables courage and representations of death, entered in the second step, significantly increased the percentage of the explained variance only for the first factor ($\Delta R^2 = .17$). Moreover, for this factor, the variable interaction between courage and representation of death, entered in the third step,

Table 4. Correlations among all constructs (N = 62)

| Constructs | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 |
|---|--------|--------|-------|--------|--------|-------|------|------|--------|-------|-------|-------|----|
| <i>SF-36 Questionnaire</i> | | | | | | | | | | | | | |
| 1 Physical functioning (PF) | – | | | | | | | | | | | | |
| 2 Role functioning–physical (RP) | .45*** | – | | | | | | | | | | | |
| 3 Role functioning–emotional (RE) | .31* | .45*** | – | | | | | | | | | | |
| 4 Vitality (VT) | .38** | .48*** | .37** | – | | | | | | | | | |
| 5 Pain (PA) | .36** | .39** | .30* | .53*** | – | | | | | | | | |
| 6 Social functioning (SF) | .21 | .375** | .26* | .45*** | .49*** | – | | | | | | | |
| 7 Mental health (MH) | .20 | .41** | .51** | .64*** | .28* | .35** | – | | | | | | |
| <i>TDRS Questionnaire</i> | | | | | | | | | | | | | |
| 8 TDRS Total score | .11 | .00 | .17 | –.08 | .05 | .03 | –.04 | – | | | | | |
| <i>CM Questionnaire</i> | | | | | | | | | | | | | |
| 9 CM Fronteggiamento | –.15 | –.02 | .06 | .13 | –.15 | –.12 | .11 | –.01 | – | | | | |
| 10 CM Evitamento | –.22 | –.30* | –.21 | –.36** | –.15 | –.13 | –.20 | .06 | –.36* | – | | | |
| <i>Intervista</i> | | | | | | | | | | | | | |
| 11 Factor 1–Fear of the intervention | .03 | –.33** | –.12 | –.35** | –.07 | –.04 | –.24 | .31* | –.40** | .37** | – | | |
| 12 Factor 2–Desire to avoid the surgery | .32 | .06 | –.05 | –.19 | –.11 | –.06 | –.07 | .21 | –.19 | .11 | .39** | – | |
| 13 Factor 3–Donor-related thoughts | –.40** | –.14 | –.09 | –.19 | .01 | –.07 | –.02 | –.23 | .05 | .15 | –.07 | –.30* | – |

*Significance level at $p < .05$.

**Significance level at $p < .01$.

***Significance level at $p < .001$.

Table 5. Correlations between constructs and participants' characteristics (N = 62)

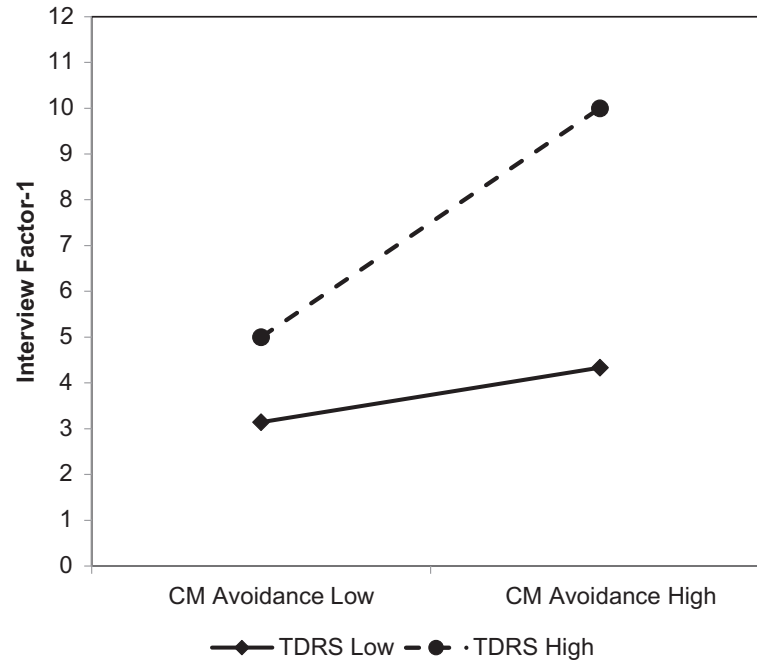
| Constructs | Participants' characteristics | | | | | | | | | |
|---|-------------------------------|-------|-----------|----------------|----------|----------------|---------------|-----------|--------------|-------|
| | Gender | Age | Education | Marital status | Children | Believe in god | Partecipation | Pathology | Waiting time | MELD |
| Physical functioning (PF) | .26* | –.31* | .07 | –.12 | –.12 | –.16 | –.09 | .26* | –.18 | –.20 |
| Role functioning–physical (RP) | .19 | .01 | .01 | .01 | .13 | .03 | .13 | .22* | –.13 | –.32 |
| Role functioning–emotional (RE) | .36** | .03 | .01 | –.01 | .16 | –.18 | .01 | .21 | –.07 | –.18 |
| Vitality (VT) | .38** | –.03 | .12 | –.04 | .17 | –.01 | .17 | .28* | –.22 | –.15 |
| Pain (PA) | .12 | .03 | –.07 | .07 | .06 | –.14 | –.08 | .26* | –.22 | –.24 |
| Social functioning (SF) | .03 | .01 | –.05 | .01 | .07 | .01 | –.01 | .30* | –.25 | –.23 |
| Mental health (MH) | .34** | –.05 | .15 | –.02 | .01 | .04 | .13 | .09 | –.22 | .04 |
| TDRS Total score | .08 | .08 | –.18 | –.06 | –.06 | –.41** | –.46** | .06 | .14 | –.15 |
| CM Fronteggiamento | .02 | –.09 | .02 | –.09 | .04 | .19 | .30* | –.23 | .21 | .39** |
| CM Evitamento | –.06 | .10 | –.24 | .15 | .08 | –.08 | –.17 | .01 | .02 | .00 |
| Factor 1–Paura dell'Intervento | .10 | –.15 | –.20 | .01 | –.15 | –.29* | –.31* | –.04 | –.16 | .01 |
| Factor 2–Desiderio di non sottoporsi all'Intervento | .06 | –.16 | .08 | –.12 | –.15 | –.12 | –.09 | –.25 | .01 | –.01 |
| Factor 3–Pensieri Riguardo il Donatore | –.09 | .12 | –.16 | .17 | –.01 | .20 | .10 | –.15 | –.12 | .31* |

Notes: For Gender 0 = female, 1 = male; Age (years); Education 0 = Low, 1 = Middle-high; Marital status 0 = Other, 1 = Married; Children (Presence of children) 0 = No, 1 = Yes; Believe in god 0 = No, 1 = Yes; Participation in religious practices 0 = No, 1 = Yes; Pathology 0 = Other, 1 = Cancer; waiting time for intervention (months).

*Significance level at $p < .05$.

**Significance level at $p < .01$.

Graph 1. CM avoidance and TDRS interaction on interview Factor 1.



significantly increased the percentage of the explained variance ($\Delta R^2 = .10$). With regard to the variables of QoL, a significant effect of the physical functioning scale (PF) was pointed out on all the three factors of the structured interview ($\beta = .28, .50$ and $-.43$, respectively), and a significant effect of the vitality scale (VT) on the first and second factors of the structured interview ($\beta = -.44$ and $-.42$, respectively) was pointed out as well. Likewise, the representation of death as annihilation corresponded to a higher score on the first factor of the interview ($\beta = .26$), while a higher score on CM coping corresponded to a lower score on the first factor of the interview ($\beta = .29$). Lastly, for the first factor

Table 6. Results of hierarchical regression analyses predicting three interview factors

| Variable | Factor 1 | | | Factor 2 | | | Factor 3 | | |
|---------------------------------|----------|--------------|--------|----------|--------------|-------|----------|--------------|-------|
| | β | ΔR^2 | R^2 | β | ΔR^2 | R^2 | β | ΔR^2 | R^2 |
| Step1: Quality of life | | .26* | .26* | | .25* | .25* | | .22* | .22* |
| Physical functioning (PF) | .28* | | | .50** | | | -.43** | | |
| Role functioning-physical (RP) | -.37* | | | .06 | | | .04 | | |
| Role functioning-emotional (RE) | .11 | | | -.12 | | | .28 | | |
| Vitality (VT) | -.44* | | | -.42* | | | -.27 | | |
| Pain (PA) | .17 | | | .04 | | | -.07 | | |
| Social functioning (SF) | .03 | | | -.13 | | | -.03 | | |
| Mental health (MH) | .05 | | | .16 | | | .18 | | |
| Step2: Spirituality and courage | | .17** | .42** | | .04 | .28* | | .05 | .28* |
| TDRS Total score | .26* | | | -.09 | | | .09 | | |
| CM Fronteggiamento | -.29* | | | .05 | | | .09 | | |
| CM Evitamento | .13 | | | | | | | | |
| Sep3: Interaction | | .10* | .52*** | | .08 | .36* | | .05 | .33* |
| Fronteggiamento_x_TDRS | .08 | | | -.14 | | | .25 | | |
| Evitamento_x_TDRS | .37* | | | .23 | | | .02 | | |

*Significance level at $p < .05$.
 **Significance level at $p < .01$.
 ***Significance level at $p < .001$.

of the interview, only the interaction between CM avoidance and TDRS was significant. As shown in Graphic 1, for those representing death as annihilation (high score at TDRS), the impact of CM avoidance on the first factor was stronger than for those representing death as a passage (low score at TDRS). More specifically, participants having both high score at TDRS (representation of death as annihilation) and high score at CM avoidance also had a high score on the fear of intervention (first interview factor). The results of the hierarchical regression analyses predicting interview factors are shown in Table 6.

7. Discussion

In agreement with the literature, the results of this study suggested that severe liver diseases compromise the quality of life, which in our group of participants is lower than in the general population (Gutteling, De Man, Busschbach, & Darlington, 2007). Furthermore, a specific gender impact was obtained since men reported a better QoL than women. Bianco et al. (2013) already underlined this effect. They found that the gender of the patients may be an important variable in the way severity of the disease is perceived. In particular, their observation highlighted that male subjects had significantly higher scores on physical role functioning, bodily pain and physical activity compared with females, while females have a better QoL compared to males, with regard to the emotional state and mental health. As discussed by Sarkar, Watt, Terrault, and Berenguer (2014), despite clear differences in waitlist outcomes, the reasons for this particular disparity still remain partially unexplained. We agree with the authors that further data are clearly needed to narrow the gender gap in transplant-related events.

Moreover, our outcomes presented a further effect: QoL of HCC subjects was higher than non-HCC ones. With respect to this specific difference, it is important to remind that in oncological field, a particular importance is given to early palliative care (Howie & Peppercorn, 2013). Indeed, as supported by literature (Gandhi, Khubchandani, & Iyer, 2014), despite HCC being a rapidly fatal cancer, liver-directed therapy and oral-targeted therapies are used in these patients to prolong life and palliate symptoms of the cancer. It means that the QoL levels of liver transplant patients are different, depending on the pathology causing the liver failure and the need to extend palliative care in all forms of transplantation has already been highlighted by the literature (Larson & Curtis, 2006).

With respect to our research, the results confirmed that the fear of intervention was positively correlated with death-related thoughts and avoidance, as already underlined by Santos et al. (2012) and Woodard (2004). Furthermore, we confirmed that avoidance was negatively correlated with CM coping. Patients representing death as annihilation are more likely avoidant and threatened with respect to the intervention, while people who desire to avoid the surgery also have less donor-related thoughts, confirming that all transplantation-related aspects are avoided. Conversely, donor-related thoughts are more prevalent in patients with a higher physical impairment.

The literature has considered donor-related thoughts of recipients after the surgery, especially in heart transplant (Inspector, Kutz, & David, 2004; Kaba, Thompson, Burnard, Edwards, & Theodosopoulou, 2005), and in the case of living donors (Fukunishi et al., 2002; Pradel, Mullins, & Bartlett, 2003). Surprisingly, despite the view of the importance that the donors take for recipients, there are very few studies on the psychological emotions, representations and thoughts of patients about them before the surgery. In our research, the positive association between donor-related thoughts and the MELD score betrays the presence of a high severity of the disease and the need for a transplantation increases donor- and transplant-related thoughts. However, wider analyses are needed to offer an exhaustive explanation of this effect.

All these results validated the research hypotheses. On the one hand, the representation of death as annihilation, which is typical of non-believers, was related to the avoidance of transplant, even when the health conditions were quite critical. On the other hand, believers (especially the observant ones) represented death as a passage, showing more courage and coping skills. Then, these results

endorse the entire literature, which demonstrated that spirituality and religiosity improve resilience in the management of stressful situations and chronic illness (Koenig & Larson, 2001; Lindqvist, Carlsson, & Sjoden, 2004; Pargament, 2001; Ragsdale, Hegner, Mueller, & Davies, 2014; Thuné-Boyle, Stygall, Keshtgar, & Newman, 2006). As already the positive psychology stated (Lopez & Snyder, 2011; Snyder & Lopez, 2002), both courage, as coping skill, and spirituality, as representation of death as a passage, in our research had a positive influence on patients.

Since nowadays topics related to death and human existential conditions are strongly censured both in the social and in health care communication (Capozza, Falvo, Testoni, & Visintin, 2015; Codato, Shaver, Testoni, & Ronconi, 2011; Testoni, Di Lucia Sposito, De Cataldo, & Ronconi, 2014; Testoni, Simioni, & Sposito, 2013; Zamperini, Paoloni, & Testoni, 2015), it is important to implement the possibilities to reflect on such themes with patients. The importance of spiritual aspects in severe illnesses and in the end of life cares has been widely discussed by the literature; however, a broad view of spirituality is needed, enabling to involve traditional religious beliefs and also to include personal perspectives on what is sacred (Churchill, 2015). In fact, the psychological distinction among mysticism, orthodoxy, religiosity and secularism has been recognized by scholars; however, it does not exclude the spiritual dimension of each position (Saucier & Skrzypińska, 2006). This perspective has been definitively adopted by the World Health Organization Executive Board (1998), after about 15 years of discussion on the relationships between spirituality and health, when, during the Fifty-second World Health Assembly, the Article 73 of the Constitution was modified, deleting the previous definition of health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” and inserting the following: “Health is a dynamic state of complete physical, mental, spiritual and social well-being and not merely the absence of disease or infirmity” (World Health Organization, 1997). From this standpoint, the research on the improvement of well-being also in sick conditions until the end of life has been developing and constantly confirming the importance of spirituality, also in not so religious people. Many studies have already widely considered the spirituality of this last kind of persons, showing how their understanding needs are wide and complex (Ammerman, 2013; Fuller, 2001; Wong & Vinsky, 2009).

Since these patients need to find ways to better address the challenges they have to overcome, it is possible to affirm that the reanimation of the existing sense of life and transcendence may help them in this task, reinforcing resilient resources (Fonseca & Testoni, 2011). This theme is particularly important because the need to prepare patients and their families for death while maintaining hope has been already underlined by research (DiMartini, Crone, Fireman, & Dew, 2008). Indeed, patients listed for transplantation are also facing terminal illness despite families and health care providers delaying discussions on issues relating to end of life care such as palliative care and dignity therapy (Chochinov et al., 2006). Instead, professional caregivers’ work is often directed at the preparation of patients for transplant surgery and post-operative care. In this way, patients and families avoid addressing end of life issues and deny its drawing near because of a sense of hopelessness. These concerns can be addressed with respect to balancing a hopeful outlook with appropriate issues, among which are fear of death, spirituality and transcendence.

Addressing the promotion of the consciousness raising about their fear of death could be a good way to promote their resilience. Since this strategy requires existential competences, that is the ability to acknowledge, absorb and interpret anguishing narrations of these sick persons, spiritual counselling could be a great help.

8. Limits of the research

The most important limit of the research is the scarcity of the group of patients caused by the difficulty to reach people who were willing to participate in the survey. In particular, it is to underline the disproportions on the one hand between believers and atheists, and on the other between people who represent death as a passage and those who represent it as a total annihilation. Despite from a statistical point of view, this problem did not impede to notice the significant differences discussed in the article; such an exiguity does not permit to generalize the results. This difficulty may be solved

with further surveys, which would amplify the number of subjects, in order to reinforce or confute these early results, and to investigate if other variables influence death-related thoughts, positive coping strategies and compliance.

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