Press Portrayals of the Psychological Experiences of People Involved in Organ Transplantation

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Abstract

The media represents an important source of information on organ donation and transplantation for the general public, affecting people's relevant attitudes and behaviors. These topics are frequently represented in a narrative manner in the media, through stories of people personally involved in such situations. Consequently, the audience's mental transportation through emotional involvement in these narratives contributes to the media influences. In turn, the transportation effects stem, in part, from the explicit depictions of the protagonists' psychological states experienced during the events narrated. This study is focused on the Romanian press portrayals of the psychological experiences of people who had been involved in organ transplant cases, either as recipient, donor or as one of their family members. The sample includes 319 articles published from 2010-2011 in 8 newspapers. The thematic analysis reveals 11 types of psychological experiences depicted, mainly organized according to the moment in the transplant story (pre- or post-transplant) and to the main character to whom they pertain (recipient or donor). Overall, psychological states are represented as multilayered and frequently polarized across the narration and the protagonists, focusing on the organ recipient as the main protagonist of the psychological journey that the transplant entails.

Keywords: organ donation, organ transplantation, mass media, press portrayals

Given the worldwide discrepancy between the demand and the supply of organs for transplantation, the identification of the factors that could be put to use in order to increase organ donation rates represents an important task for social scientists. One such factor is the mass media, which has an important role in the creation of a positive social atmosphere regarding organ transplantation, some authors arguing that it should be actively involved in the public education on this topic (Rady et al., 2011).

Previous research has investigated the manners in which mass media communicates on the topic of organ donation and transplantation, focusing on its positive or negative portrayals (Kalra & Bhugra, 2011), frames (Maloney & Walker, 2000; Morgan et al., 2007), narratives (Morgan, Movius & Cody, 2008), patterns of representation O'Neill, 2006), etc. In addition, past investigations have revealed the relationship between the mass-media representations of these issues and organ donation attitudes in various cultures: USA (O'Neill, 2006; Morgan et. al., 2010), Australia (Maloney &

Walker, 2001), Spain (Rios et al., 2010), Poland (Misterska et al., 2010), Holland (Coppen at al., 2010), etc.

Among other psychological phenomena mediating these influences of media messages, studies have revealed the importance of transportation (Green & Brock, 2000), conceived as the emotional involvement in a narrative. First, organ transplantation is a topic which easily lends itself to dramatization, given the succession of events with strong emotional charge that it usually encompasses. Hence, organ transplantation tends to be represented in a narrative manner not only in the entertainment media (Morgan et al., 2007), but also in the news (Harrison et al., 2008). Since the purpose of the latter is not merely to inform, but to generate controversies through stories (Lupton, 1994), news reports on transplantation frequently focus on human-interest narratives.

Second, previous research has documented the significant effects of narrative communication on the receivers' acceptance of the story-based arguments (Green & Brock, 2000; Green, 2004) and on the subsequent changes in behavioral intentions. The audience becomes "transported" into the storyline, mentally absorbed and focused on the plot; consequently, their abilities of critical processing and counterargument are partially suspended. The degree of transportation generated by a narrative depends on the emotional involvement it can instigate, as a catalyst of the cognitive processes which the narrative absorption relies on. In the area of organ donation, Morgan et al. (2009) show that the emotional involvement in TV dramas narratives on this topic predicts the likelihood of becoming an organ donor. Furthermore, emotional responses to media stories can be differentiated into sympathy and empathy (Escalas & Stern, 2003); with the former denoting a lesser degree of internalization of the target's affective state. Empathy refers to the experiencing of another's feelings, the recipient's empathic responses to the story protagonist's emotional experiences having a significant role in persuasion (Shen, 2010). Sympathy denotes the awareness of another's affective reactions to the situation and the emotional state stemming from this awareness; previous results (Bae, 2008) show that both emotional phenomena predict one's issue involvement and, consequently, one's intention to register as organ donor.

The present study

One of the sources of emotional involvement in the media stories in general, and in particular in the organ transplantation – related narratives may be the portrayals of the psychological experiences of the people involved in such events. The transplant involves a series of separate events with distinct psychological charge, such as the illness of the future organ recipient's, the actual transplant, his recovery, as well as the death of the donor and his family consent – in the cases of deceased donors. The explicit descriptions of the psychological reactions of the various protagonists (organ recipient and donor and their families) to these events could stimulate the audience's sympathetic and empathic responses, which, in turn, facilitate their narrative absorption. Both types of responses to the media stories are conceived as primarily stemming from the explicit depictions of the

characters' psychological experiences; for instance, in the case of empathy, "the affective responses from the recipients are going to be the same as, or similar to, what is portrayed in the message" (Shen, 2010, p. 401). Thus, the "psychological explicitness" of the media portrayals could affect the overall impact of the media reports on organ transplantation. Our study focuses on these descriptions of the psychological experiences of the people involved in organ transplantation cases reported by the Romanian press. Given the dramatic nature of the organ transplant issue, we expect the media discourse to be concentrated on certain focal psychological elements, anchored in the various situations that the protagonists of these events go through. Furthermore, although we expect the emotional array to be the one most frequently depicted, the complexity of the organ transplant situation suggests that other types of psychological experiences are also likely to be represented.

Data collection

The newspapers sample includes eight daily publications of three types: three national broadsheets – *Gandul*, *Evenimentul Zilei* (*EVZ*) and *Adevarul*, tree tabloids (*Click*, *Cancan* and *Libertatea*) and two regional newspapers - *Ziarul de Iasi* (ZI) and *Foaia Transilvană* (FT), selected in order to investigate the effects of proximity to a large regional medical center on the relevant content. The period under study covers the twelve months between 1 March 2010 and 28 February 2011. We scanned the online archives of these newspapers with the keywords "organ transplant", "organ donation" or "organ donor", retrieving all articles containing one of these expressions. The sample consists of 319 articles: 143 from the three tabloids, 131 from the three broadsheets and 45 from the two regional newspapers.

Data analysis

In our thematic analysis, the selected articles were first distributed across the two coders, who identified all depictions of psychological experiences of the people involved in transplant – related events in each article. Each coder elaborated a coding scheme to subdivide these experiences into distinct categories. These two sets of codes were then discussed and synthesized into an initial coding scheme through which all the articles were re-analyzed by both coders, who proposed, discussed and agreed upon its further modifications through this process. Each coder used this final scheme – summarized in table 1 – to recode each article on its 11 dimensions of interest, noting the psychological experiences depicted in it. Each article was paired with a category only once. The Kappa inter-rater reliability statistic was computed for each dimension, ranging from a low of .75 to a high of .98, with a mean kappa of .88, indicating high levels of agreement.

Results

Most of the articles (167, representing 52.35%) report cases of performed transplant surgery, while 127 (39.81%) concern potential transplants, that were not already done either because of the

lack of an compatible organ or of the necessary financial resources – as in the case of bone marrow transplants -, focusing solely on their prospective recipients. Another type of article in this category is that reporting cases of organs retrieved from deceased donors that are to be found a recipient in the near future. The remaining 7.84% of the articles report either on general issues regarding the Romanian organ transplantation system (13, representing 4.08%), without any reference to particular cases of either past or potential transplant surgery, or on criminal investigations of suspected organ trafficking networks (12, representing 3.76%). Thus, the vast majority of the press reports concern actual people directly involved in this issue at least on one of the transplantation sides, as recipient or donor. Their focus is on certain events relevant for the organ transplantation issue involving these protagonists, the number of these events varying from one – as in the articles focusing only on deceased people whose organs were retrieved – to the whole series of events making up the performed transplantations: the illness of the recipient, the organ donation event (either from a deceased or a living donor), the actual transplant surgery, his recovery process. Consequently, the same narrative manner identified in the depictions of organ transplantation in other types of media (Morgan et al., 2007; Harrison et al., 2008) is also prevalent in the Romanian press reports on this topic.

This "transplant plot" employs a temporal frame centered on the main event in its course, the transplant surgery. In the cases of performed transplant surgeries, it splits the narration in two parts, distinct not only in the actual events encompassed, but also in the overall psychological dynamics that are represented. As the transplant brings a dramatic change in one's objective (medical) state, it also generates an evident shift in the reported psychological experiences of those involved. Hence, our coding scheme, accommodating this temporal frame centered on the organ transplant event, splits the psychological categories coded in two parts: pre-transplant and post-transplant experiences. The reports of potential transplants differ only in their narrative breadth (encompassing more events in the "transplant plot") from those on performed transplants. Otherwise, the psychological experiences depicted in the two types of reports and generated by the events in their common timeframe are similar. Also, there are some differences in the coding scheme pertaining to the two types of reports defined by the donor's status (living or deceased). The scheme relevant for the articles on organ transplants from living donors includes a supplementary psychological category (the ease of donation consent), while two such categories are specific to the reports on transplants from deceased donors (the difficulty of donation consent and the family's suffering). Except these variations, segmenting the sample of articles into distinct categories, most of the coding scheme is applicable to all articles focused on people involved in some way in the organ transplantation issue, representing the vast majority (92.16%) of the selected sample.

The frequencies of each of the psychological categories in the coding scheme, organized according to the part of the transplant narrative and to the protagonist which they are relevant to are presented in table 1. The comparisons between the three types of publications revealed no significant differences in the frequency of the various psychological categories under scrutiny.

Table 1. Psychological experiences in the coding scheme and their frequency

Part of transplant narrative	Protagonist	Category	Frequency
Pre-transplant	Recipient	Suffering	65 (20.38%)
		Hope	58 (18.18%)
		Willpower	32 (10.03%)
		Organ availability happiness	22 (6.90%)
		Pre-surgery anxiety	18 (5.64%)
		Living: ease of donation consent	20 (6.27%)
	Donor	Deceased: difficulty of donation consent	21 (6.58%)
Post-transplant	Recipient	Gratefulness	50 (15.67%)
		Subjective well-being	42 (13.12%)
		Quality of life enhancement	35 (10.97%)
	Donor	Deceased: family's suffering	32 (10.03%)

a. Pre-transplant psychological experiences

Together with the physical suffering, the psychological one is mostly common in the articles focused on patients in need of an organ, many of which represent humanitarian calls. The two compose a multidimensional picture of the misery of patients on the transplant waiting list; on one hand, the depictions of such experiences provide information concerning the implications of terminal organic insufficiencies, while on the other they may sensitize the public, inducing sympathetic and empathic responses. Moreover, the depictions of psychological suffering could be interpreted as a "price paid" by the patient, legitimizing his potential organ recipient status. Thus, in the journalists' ethical frame on organ transplantation, it counterbalances the sudden and acute suffering of the deceased donor's family.

Apart from its association to the physical illness, the dramatic character of the patient's psychological state is accentuated in certain distinctive manners. One such manner is the emphasis on the chronicity of the protagonist's intense negative feelings, suggesting the affective magnifying effect of waiting, for example: "The agony is not the pain, but the wait for the miracle, which for this patient came after 12 years of torture"(). In other articles, the suffering is aggravated by multiplying its sources, apart from the actual physical state, such as the autonomy impairments it generates (for example: "It's hard to sit and wait for somebody to bring you a cup of water"), or the current medical treatments ("The 4-years patient is a soul tormented by transfusions, perfusions and files"). Also,

a.i. The prospective recipient's experiences

a.i.1. The psychological suffering

sometimes the psychological suffering is displayed at its maximum height, the article focusing on the shock of being diagnosed with the respective illness ("the drama began when she was diagnosed with acute lymphoblastic leukemia. From that moment, her whole universe was shattered"). As illustrated here, this psychological shock restructures one's relationship to the world; it also provides a counterpoint for the other essential moment in the narration, opposite as valence, namely the transplant.

a.i.2. The hope of finding a compatible donor

A compatible graft represents, for the people portrayed, the only way to reestablish their quality of life, if not to save their life; hence, hope is part of the universal psychological experiences of those in such situations. Nevertheless, since most of the times it can only be fulfilled by retrieving the necessary organ from a deceased donor, it becomes a somewhat uncomfortable issue for the journalists. Consequently, its occurrence in the articles is not ubiquitous; also, when depicted, its object is either covert, all references to the actual organ being eliminated (for example: "His wife trusted that her man will live a normal life after the transplant"), or disguised in some manner, such as the divine intervention ("We have prayed to God to find him the bone tissue"). In the perspective of the recipient and his family, the organ hoped for is, thus, an independent object, separated from the donor's body, which conceals the direct link between saving the recipient's life and the death of another person ("I wish for a kidney to fall out of the sky so that my husband would stop suffering"), leaving the former as the single character of the transplant psychological drama.

The patient's optimistic outlook on the future is sometimes accompanied by positive post-transplant projections, concerning behaviors that will become possible after the transplant and that are part of a scheme of existential normality, intrinsically attractive but currently censored: "I can't wait to go out, take a walk [...] go fishing". In other articles, the positive projections are less specific; they may concern the regaining of "normality", comprising the array of behaviors available before the occurrence of illness ("I want to have a normal life again"), or as a return to one's natural life course ("After the kidney transplant I will live my life"). In any case, the present appears as temporarily suspended, as a hiatus in one's existential journey, the only escape from this psychological captivity being the transplant.

a.i.3. The potential recipient's willpower

Willpower represents, in the media discourse, the personal trait that explains one's resistance to physical and psychological sufferings, a valuable weapon in the long-term "passive war" that waiting for an organ entails ("She is small but strong. She fights illness as an adult"). Sometimes will is accompanied by the anticipation of its rewards, by positive post-transplant projections ("Then, he decided to go through no matter how any hardships just to be able to kiss the little girl again"). Willpower is an important quality in this context because one's medical evolution doesn't depend

only on the physical corporeal phenomena, but also on the psychological ones. The main battle is the wait for the organ, making one's self-control abilities and resistance essential: "All I want now is to be healthy and to have the power to get over this").

When the medical issues are understood, and the role of patient on the transplant waiting list is adequately assumed, this resistance earns the nuance of dignity: "She glues to your soul not because she's a suffering child, but due to the dignity with which she accepts an anguish hard to endure even by an adult").

a.i.4. The happiness generated by finding about the availability of a compatible organ

Psychologically, the key moment of the pre-transplant interval is when the patient and his family receive the news about a compatible organ being available for him. It reverses the characters' emotional polarity, being contrasted with the distress accumulated so far ("You can't imagine the happiness of the family now, after they were told that the older son was found a compatible donor"). As in the case of the other psychological experiences, the media portrays an intricate relationship between this positive state and the long wait that the organ recipient had endured, which potentiates its affective intensity: "She waited for her husband to come home to tell him the news; he was so shocked that he had to lie down".

The recipient's happiness in these moments, as depicted in the press, is complete and self-centered, with no concern for its objective source – the donor's decease –, in sharp contrast with the portrayals of the similar experiences of those receiving an organ from living donors. The source of the positive emotions in this latter case is the organ compatibility diagnostic, which is explicitly mentioned in the text units describing them ("An aunt offered to be a donor. The analyses were ok. When I found out, I jumped for joy.") Conversely, such references to the donor are missing in the portrayals of happiness when the organ is to be retrieved from a deceased donor. Similar to the other pre-transplant psychological experiences, the depictions of happiness are also focused on the recipient's person; it's only after the transplant that the psychological dynamics open towards the donor and his family.

Moreover, this self-absorption implies, as in the case of hope, analyzed above, the objectification of the organ to be transplanted. The press discourse represents it as an independent object which the recipient's emotions are focused on and, consequently, as detached from the donor's body, imposing a mechanical perspective which depicts organs as spare parts that the recipient can "benefit" from: "I was just provided with a kidney. I received the news with great joy, and now I'm waiting to see the results".

a.i.5. The pre-surgical anxiety

Following the positive shock of organ availability news, the pre-transplant recipient's psychological evolution ends with his anxiety about the surgery ("I'm very nervous. I have waited for

this moment for so long, but now I'm afraid"), shared with his family members ("The mother recalls that during the three-hours surgery she climbed up and down the stairs so that time would go faster"). Frequently, the recipient is depicted during these moments as experiencing opposite states: on one hand, the long-term desire for the transplant to occur, and on the other, his anxiety ("I've been waiting for this for five months. But I'm also dreadful scared"). This pairing implies that the latter is not limited to the universal anxiety about surgery, in general, but it also concerns the recipient's personal investment (in terms of suffering and hardships endured) that he had made so far.

a.ii. The donor's / his family's experiences

a.ii.1. The living donors' ease of donation consent

This psychological category is prevalent in the articles reporting cases of organs transplanted from living donors. Since the donor and the recipient are close relatives, the main motivation of donation is emotional ("I would had also given him my heart!"). The personal relationship between the two "transplant partners" puts forth the significance of donation as a "help in need", with a lower dramatic charge compared to the "life-saving" frame assigned to organ transplantation from deceased donors ("I didn't need to think about it, I just made the decision. I knew that was what I had to do [...]. We're there for each other in hard times.").

a.ii.2. The difficulty of donation consent experienced by the deceased donor's family

The intense pain generated by the death of a family member hinders on the donation consent, a fact acknowledged – after the actual transplant – by the recipient ("It was probably a difficult decision for the family, and I respect them for what they've done"), and by the medical actors involved. In their perspective, beyond the emotional reasons, the Romanians are not yet prepared for this decision, mainly due to their lack of understanding of brain death ("The first step of the discussion with the family is trying to make them understand that although the heart is still beating, the loved one is, in fact, dead") and of the general lack of information on this topic ("It's very hard to consent if you've never heard about this issue before").

b. Post-transplant psychological experiences

b.i. The organ recipient's experiences

b.i.1.Gratefulness

The post-transplant period is generally characterized by a psychological opening, the most frequent manner of which is the expression of gratefulness to the deceased donor's family. The fact that if not for their consent, the transplant would not had been possible is fully acknowledged. This awareness is accompanied by the empathic concern for their suffering: "I know it's a great pain for them, but I promise I will never forget that I live thanks to him"). The deceased donor appears as the savior of the recipient's life and, through their consent, his family not only ends his suffering, but also

makes him the gift of life. Thus, the value of medical change that the transplant brings is amplified from the pre-transplant period (where the focus is on the health recovery) to the post-transplant moments (where it is portrayed as a "re-birth"). This shift in press discourse probably aims at balancing the two sides, fully legitimizing the donor's death, which becomes more than a source of health for the recipient, even a source of life ("My child lives because of them and their son, and we're extremely grateful"). Sometimes the transplantation consent is also depicted as indicating the superior moral qualities of the deceased donor's family ("You must be a very wise man to think about others when your child is dead").

Although less frequently, the recipient's gratefulness is also directed towards the medical team who performed the transplant surgery. Together with the donor's family, they are acknowledged the key status in the existential shift that the transplant entails: "I want to thank the medical staff and the family who consented to donate their child's heart so that my girl would have a chance for life".

b.i.2. Subjective well-being

The depiction of positive post-transplant affective states represents an almost ubiquitous ingredient in the composition of press reports ("I'm extremely happy right now, when I learned that the surgery was a success"). The dramatic tension previously accumulate received its expected counterpoint. As the pre-transplant emotions, it also a socially shared emotion, the transplant success becoming a reason to celebrate the familial unity: "We are all very happy. Yesterday, little S. had his birthday, celebrating together with the whole family". Sometimes, the post-transplant positive emotions are depicted as a marker of the recipient's regaining of his "true personality", by abandoning the patient role he had been playing so far. Thus, the transplant appears as the end of a negative temporal loop that affected not only the recipient's body, but also his soul: "They hadn't lost their cheerfulness and joy of life, on the contrary."

b.i.3. Quality of life enhancement

The recipient's positive psychological state stems from his positive assessments of the important areas of his life, such as his physical functioning ("Six months after surgery, the patient completely recovered his physical abilities") or his social functioning ("After one month of hospitalization, the girl feels good and she is ready to play with her brother again"). Again, such media contents suggest the idea of the transplant as a re-opening of the patient towards the world. On the other hand, the references to the quality of life consequences are generally vaguely formulated, lacking any operational definition, similar to many portrayals of "normality" hoped for by the patient before his transplant.

b.ii. The suffering of the deceased donor's family

Given the nature of most deaths following which transplantable organs are retrieved – sudden, accidental deaths – the donor's family is going through an emotional shock, frequently labeled as "drama" ("One family's drama saves four children from certain death"). Yet, even in these circumstances of sudden and intense circumstances, the psychological openness to donation consent is still possible. Some articles frame this consent in a manner going beyond a mere helping hand, lent to a stranger and, consequently, difficult to offer; it is also conceived as a way to diminish the suffering: "They convince the relatives of brain death patients that in all the drama they go through they can still find some comfort by saving others' lives".

As illustrated above, the suffering of the donor's family is sometimes reflected through the recipient's family expressions of gratitude. In some other cases, the press discourse explicitly contrasts it from the opposite state experienced by the recipient and his family ("Agony in the V. family, overwhelming joy in the C. family").

Discussion

The depictions of psychological experiences represent a substantial part of the Romanian media reports of organ transplantation cases. The area receiving most coverage is the emotional one, with a composition that reflects the epic deployment of the transplant scenario. The psychological states of the protagonists change dramatically from the pre-transplant period to the post-transplant moments. In both these time intervals, the experiences depicted are mixed in valence: before the transplant, the conflict is intra-psychic, the press discourse opposing the recipient's suffering and anxiety to his hope and resilience. After the transplant, the contrast is interpersonal, between the suffering of the deceased donor's relatives and the positive affective states of the recipient and his family. Across the whole narration, these psychological oppositions increase its dramatic charge, and subsequently enhance the appeal of the articles for the general public, an important quality of the media output dealing with organ donation (Kalra & Bhugra, 2011).

The psychological dimension enriches the press narratives on organ donation and transplantation, adding a universally human dimension to the strictly medical – scientific issues reported. It transforms the medical cases presented into "human spectacles", with complex and frequently contradictory psychological dynamics, raising organ transplantation from the strictly corporeal and mechanical level, of body parts moved from one body to the other, to the spiritual one. Moreover, this psychological layer diminishes the perceived distance between the characters and the reader, enhancing the relatedness of the media reports. While the objective events that the protagonists go through (being an organ recipient or donor, or having a family member experiencing such events) are statistically rare, the psychological underpinnings of these events (suffering, hope, happiness) are universal. Hence, the press depictions of these psychological states and their dramatic arrangement, in terms of oppositions and transitions along the narrative line, call for sympathy and

empathy for the protagonists' hardships and contribute to potential transportation effects (Green & Brock, 2000).

The organ recipient is the main character of the transplant narrative; the story deployment follows his medical and mental journey from the pre- to the post-transplant period. Although some psychological depictions also concern the experiences (of opposite emotional valence) of the donor's family, the spotlight is still mainly on the recipient. As the transplant represents, in his psychological evolution, the end of self-focalization, the negative emotions and consent difficulties experienced by the donor's relatives frequently occur as reflected in his own words or concerns. Moreover, the recipient's states are frequently represented as shared with similar intensities by those close to him, conveying a systemic outlook on the illness and the transplant as fundamental events not only in the individual's life, but also in the collective history of one's family. This focus on the recipient's psychological experiences across the narrative could amplify the influence of the press reports on people's attitudes toward organ donation, as previous research (McIntyre, 1990) indicate that the organ recipient represents the most efficient source of persuasive messages on this topic.

The articles analyzed are relevant not only for the media choices in portraying organ donation and transplantation, but also for the psychology on the actual people involved in these events, especially as they provide access to their testimonials through the interview excerpts they include. Nevertheless, their validity in this regard is disputable, since they are selected by the journalists in accordance to their own frames (Hornig, 1993), which impose a certain order of priorities on the reported issues. Consequently, our results inform less on the psychology of those involved in transplant-related events than on the ways the press represents this issue.

The degree in which these patterns of media representation of the psychological experiences affect people's attitudes and intentions concerning organ donation is an issue that remains to be investigated. Future research could also further explore certain frames suggested by our results as structuring the press discourse on organ donation and transplantation, going beyond the layer of the protagonists' mental states, such as the objectification of the organs to be transplanted or the legitimization of organ reception through physical and mental suffering.

Acknowledgement: Work supported from the program POSDRU/89/1.5/S/61879.

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