

# Organ and tissue donor parents' positive psychological adjustment to grief and bereavement: practical and ethical implications



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**Abstract:** Organ transplantation from the deceased typically involves requesting close family members' consent to procure the deceased's organs. This raises ethical and clinical concerns whether this difficult decision, taken while they are grieving, might have a long-term impact on their adjustment to bereavement. The study employed five measures of bereavement, adjustment and meaning of life (three developed for this study), administered to 216 bereaved Israeli donor and non-donor parents, mainly of deceased adults. The analysis distinguished between organ/tissue donors and donor/non-donors and determination of death (brain/cardiac). No differences were found according to grief measures or method of diagnosing death but donor parents scored higher on 'life development', 'meaning of life after loss' and 'personal growth'. Findings suggest the donation process is not associated with a more negative adjustment to bereavement and might have benefited some donor parents in terms of adjustment to loss or meaning of life and growth, in particular those with higher levels of grief. Methodological and practical implications are discussed.

**Keywords:** bereavement adjustment, meaning of life, organ donation, organ transplantation, ethical issues, bereavement measures, complicated grief

## Background

Organ transplantation from the deceased presents a special case of bereavement because when close family members are officially informed of their loved one's death, they are also approached by medical professionals to make a difficult organ donation decision.<sup>1</sup> This decision inevitably takes place under extreme emotional conditions, in which family members suffer from acute and profound grief. Further, they might be struggling with conflicting feelings regarding organ transplantation (Anker & Feeley, 2011; Eckenrod, 2008; Walker, Broderick & Sque, 2013) and might not know the deceased's explicit preferences (Siminoff

& Lawrence, 2002). Adding to this complexity, the death may have been determined according to loss of brain functions, which might not be congruent with their religious or cultural conceptions of death (Siminoff, Burant & Youngner, 2004; Sque, 2006).

This study was conducted in Israel, in which about three quarters of the population is Jewish. The Jewish religion upholds saving lives and there is strong support among orthodox religious leaders for donation of kidneys from living donors. However there are ultraorthodox groups that do not recognise 'brain death' as death and some groups oppose organ transplantation because of beliefs that the body should be intact for resurrection (Ashkenazi, Lavee, & Mor, 2015).

Some researchers raise concerns whether introducing organ procurement at the time of death might interfere with the

<sup>1</sup> Family consent to organ transplantation is requested regardless whether it is mandated by official organ procurement policies (Rithalia *et al*, 2009).

grieving process and add emotional stress (Stouder *et al*, 2009). Some describe donor families' experience as involving suffering or sacrifice (Sque, Payne, & McLeod, 2006). These concerns raise an ethical question as to whether family members' consent to donate organs from the deceased might have an enduring adverse impact on their future psychological adjustment to the loss (Shaw, 2010). Studies aiming to answer this question differ in their findings. Some found no differences between donor and non-donor family members according to measurements of adjustment to loss (Bellali & Papadatou 2006; Cleiren & Van Zoelen, 2002). Others found positive aspects associated with the donation decision and that donor family members were satisfied with their decision. Some reported negative aspects (Kesselring, Kainz & Kiss, 2007; Manuel, Solberg, MacDonald, 2010; Merchant *et al*, 2008). However, these studies were mainly conducted within a relatively short time period after the donation or with a relatively small number of participants, and most utilised limited bereavement measures (Hogan, Coolica, Schmidt, 2013). Therefore, it is important to study adjustment to bereavement over time and with measures specifically adapted to organ donation (OD).

### Conceptual perspectives on grieving and OD

Previous approaches in the bereavement literature focused on the need to resolve the bereavement process through several stages, or on 'letting go' of the deceased. These have been replaced with alternative conceptions, including recognising the positive role of maintaining 'continuous bonds' of emotional attachment with the deceased (Boelen *et al*, 2006; Hall, 2014) and evidence of resilience (Bonanno, 2004). Some scholars maintain that the reconstruction of meaning is critically important in grieving. Some add that crisis and trauma could provide an impetus for personal growth in terms of enhancing personal and social abilities, by attributing meaning or 'making sense' of the traumatic loss (Davis & Nolen-Hoeksema, 2001; Kasher, 2000; Neimeyer & Sands, 2011; Schaefer & Moos, 2003). In some OD studies meaning of life themes were found when bereaved parents expressed a need for the meaning of the suffering caused by the death of their child and their role as bereaved parents. Researchers concluded that for some donor parents OD was associated with adjustment to loss by attributing a positive meaning to their child's death, or by feeling there is some continuity by having his or her organs 'living' in another person (Bellali & Papadatou, 2006).

OD bereavement studies also draw on conceptual approaches that make distinctions between 'acute' grief associated with intense longing for the deceased, typically for a particular period, and 'complicated' or prolonged grief related to lesser ability to adjust to life after the loss. The latter is associated with a long-term negative impact on psychological and physical wellbeing (Merchant *et al*, 2008). Some propose that not finding meaning following the loss could be associated with higher levels of complicated grief symptoms (Hall, 2014). In the case of losing a child (of any age), researchers concur that parental

bereavement might be particularly prolonged and even lifelong (Holtkamp, 2002). This study aimed to investigate whether the adjustment of donor parents differed from non-donors in their adjustment to loss and whether it differed according to method of determination of death and whether they were organ or tissue donors.

### Methods and measures

This study employed several types of measures, including measures specifically for OD. Adjustment to loss was measured according to five types of measures concerning grief, personal growth after loss, 'meaning of life after loss' and 'meaning of organ/tissue donation'. Three measures, including meaning of life, were developed for this study. Two measures on 'complicated grief' and 'personal growth after loss' were adapted from the adjustment to loss literature. These are elaborated below and in the Appendix. Participants were asked to respond to thoughts or feelings they had in the past week or month, depending on the items.

### Measures of adjustment to loss

*Inventory of 'Complicated Grief' (ICG)* (Prigerson & Jacobs, 2001): This measure is intended to assess the level of parental grief, which is one of the elements of adaptation to loss. Symptoms of emotional distress are distinguished from symptoms of depression and anxiety, as components of personal adaptation to loss. An overall score was derived by computing the items' mean. Higher scores were considered less positive adjustment.

*Personal growth and change after the loss*: This measure utilised two types of items: (a) *The Post-Traumatic Growth Inventory (PTGI)* scale: This measure is intended to assess the level of growth after loss, as one of the components of adaptation to loss. It measures the intensity of several types of changes reported by people who had experienced traumatic events (Tedeschi & Calhoun, 1996). (b) *Change after loss-direction and intensity* scale: in order to learn about the direction of the change the response scale was modified to include the direction of the respondent's experience. Responses were used to indicate both the intensity of the change and its direction. A final score was derived by calculating the mean of the items for 'intensity of change' and 'overall change'.

*Life development*: This measure is intended to assess the internal resources, activities and growth according to parental conceptions of their lives after the loss. This is a complementary tool for the PTG. It uses a series of 12 items measuring people's utilisation of internal resources following loss based on a content analysis of narratives from support groups for donor bereaved families (Ashkenazi, 2009). This contributed to face validity of the measures (Machin, Bartlam & Bartlam, 2015).

*Meaning of life after loss*: This measure is intended to assess the meaning of life according to parental conceptions in terms of the extent to which certain things are important to them in order

for them to make an effort to realise them. A 16 item measure was developed for this study, based on bereaved parents' responses to open-ended questions about issues concerning them after the loss and important goals they strive to realise.

*Meaning of donating organs/tissue:* This measure is intended to assess the meaning of OD per source (eg. comfort, saving a life) and the intensity of the meaning of each source. This measure was intended for donor parents, asking them to rate the meaning of various issues concerning OD. Higher mean scores were assumed to indicate a more meaningful donation.

## Participants

Participants were 531 bereaved parents approached by healthcare professionals in 22 Israeli hospitals to donate their deceased child's organs or tissue. Parents who declined to participate mainly explained they did not want to reopen wounds, it was too painful to talk about their child, or they did not want to share their feelings with a stranger. Most (93%) bereaved parents were Jews and the rest were Muslims and Christians. The time elapsed from the death of the child ranged from six months to 27 years ( $M = 3.77$  years,  $SD = 3.48$ ). No differences according to these variables were found among the four groups of respondents. Regarding religiosity, 12% of donor parents defined themselves as religious compared to 51% among non-

donor parents. This difference was statistically significant ( $Z = 5.04$ ,  $p < .001$ ) and represents the actual higher frequencies of non-religious people as organ/tissue donors in Israel.

## Procedures

Ethical approval to conduct the research among the bereaved parents was obtained from the Institutional Review Board of Tel Aviv University and participating major medical centers. The research committee of the National Transplant Center gave approval to use the database of donors and parents for the purpose of contacting respondents. Parents were contacted by telephone. Those who consented were sent a letter about the study and contacted with a follow-up telephone call to confirm their participation in the study and schedule a meeting. Interviewers arrived at participants' home and explained how to respond to the questionnaire and returned two weeks later to collect the completed questionnaires or to help those who had difficulty reading or writing. Confidentiality was obtained by assigning a code to each participant.

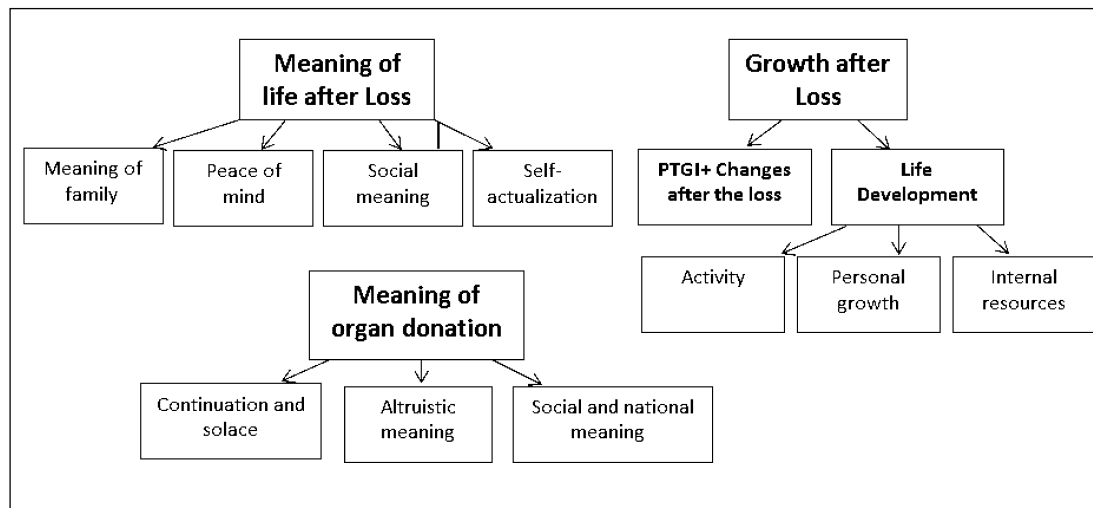
## Analysis

The analysis distinguished between organ and tissue donors and the method of determination of death (brain/cardiac).

**Table 1:** Participants in the study

	Organ donors	Tissue donors	Non organ donors	Non tissue donors	Total
Death determination	Brain activity	Cardiac	Brain activity	Cardiac	
Participants	100	46	37	33	216
Fathers	39	17	11	15	82
Mothers	61	29	26	18	134
Couples	31	16	9	11	67
Single parents	38	14	19	11	82
Years of Education (average/SD)	14 (4.12)	14 (3.20)	13 (4.33)	12 (3.08)	13 (3.86)
Age (average/SD)	54 (9.98)	55 (9.94)	51 (9.27)	53 (10.27)	54 (9.93)
Number of children at time to donation (average/SD)	3.36 (1.16)	3.50 (1.21)	4.58 (2.06)	4.56 (1.63)	3.80 (1.54)
Identified for the study	211	92	115	113	531*
Declined to participate	111	46	78	80	315
Agreed to participate	100	46	37	33	216
Response rate	47%	50%	32%	29%	40.6%

\* 100 were not located



**Figure 1:** Factors in the analysis of the 'meaning of life' and of 'organ donation' and 'growth after loss' measures

Donor parents' measures of adjustment to loss over time were compared to non-donors'. The analysis was conducted also according to method of determination of death (cardiac or brain) and whether organs or tissues were donated. The analysis included a factor analysis for the 'life development', 'meaning of life after loss', and the 'meaning of donation' items and internal consistencies were examined for all scales (Figure 1). This was followed by a multivariate and univariate two-way analyses of covariance (MANCOVAs and ANCOVAs) by donation and method of diagnosing death (brain death versus cardiac death), controlled for by parent's gender, education, religiosity, and time elapsed since the loss and Pearson for donors and non-donors. Differences between groups in the dimensions of 'life development' and 'meaning of life' were examined by multivariate analyses of covariance (MANCOVAs).

## Findings

There were no statistically significant differences between donor and non-donor parents according to grief measures or method of diagnosing death. Specifically, no significant differences were found between donors and non-donors in grief and personal growth (PTGI), by the method of diagnosing death (brain/cardiac death), or interactions between donation and the method of diagnosing death. Significant differences were found between donor and non-donor parents regarding 'life development' and the factors of this variable ('activity' and 'internal resources', and 'growth'), as well as in 'meaning of life after loss' and its factors ('social meaning' and 'self-fulfillment') for which donor parents had higher scores. The differences indicate all aspects of 'life development' were higher among the donor parents. Overall scores on 'activity' and 'internal resources' and 'growth' were higher than among non-donor parents ( $F(2,169)=5.01$ ,  $p<.01$ ,  $\eta^2=.06$ ), as were the overall scores on 'meaning of life after loss' and on 'social meaning' and 'self-fulfillment' ( $F(2,185)=2.95$ ,  $p=.06$ ,  $\eta^2=.03$ ). An examination of the means, while controlling for background variables and in light of the standard errors, also revealed 'life development' was higher

for donors than for non-donors ( $M = 3.19$ ,  $SE = .06$ , and  $M = 2.84$ ,  $SE = .08$ , respectively). Similarly, several 'life development' scores were higher for donors than for non-donors: 'activity' and 'internal resources' ( $M=3.89$ ,  $SE=.08$ , and  $M=3.54$ ,  $SE = .11$ , respectively); 'growth' ( $M=2.32$ ,  $SE = .09$ , and  $M=1.88$ ,  $S = .12$ , respectively); 'meaning of life' ( $M=4.55$ ,  $SE = .07$ , and  $M=4.30$ ,  $SE=.09$  respectively); 'social meaning' and 'self-fulfillment' ( $M=3.85$ ,  $SE = .10$ , and  $M=3.43$ ,  $SE=.14$ , respectively).

'Meaning of donation' was examined among organ and tissue donor parents, including a total score, and factor scores for 'continuity' and 'comfort' social and 'national meaning', and 'altruistic meaning'. Differences in the total score between organ and tissue donors were examined through ANCOVAs. Differences in factor scores were similarly examined through MANCOVAs. 'Meaning of donation' was greater for organ donors than for tissue donors ( $M=3.45$ ,  $SE=.12$ , and  $M=2.98$ ,  $SE=.08$ , respectively—adjusted means). The total meaning of donation score was not significantly different for organ/ tissue donors. Similarly, the MANCOVA for the three factors of 'meaning of donation' was not significant ( $F(3,119)=2.59$ , n.s.,  $\eta^2=.06$ , Wilks Lambda=.94, Hotellings Trace=.07). The difference for 'continuity and comfort' was significant with a low effect size. Figure 2 illustrates differences between organ and non-organ donors and Figure 3 between tissue and organ donors.

Correlations between the study variables were examined for donors and non-donors (Table 2), and a similar pattern of correlations was found. The higher the participants' levels of grief (the less adaptive), the lower their scores on 'personal growth', change after the loss, 'life development' and 'meaning of life after the loss'. Further, positive correlations were found between 'personal growth' (and change after the loss), 'life development', and 'meaning of life after the loss' in both groups. Among donor parents, whereas a greater meaning of donation was associated with higher levels of grief and lower life development, it was also associated with greater meaning of life after the loss. It should be noted the correlations with 'meaning of donation' were relatively weak, thus implications should be interpreted with caution.

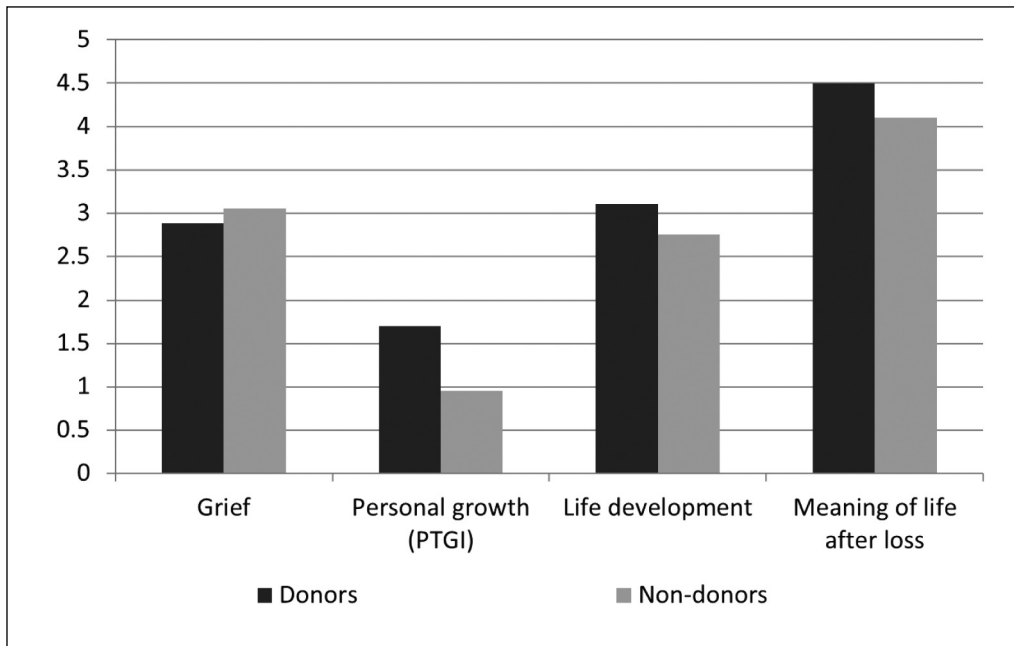


Figure 2: Adjustment, growth and meaning of life variables according to donor and non-donor families

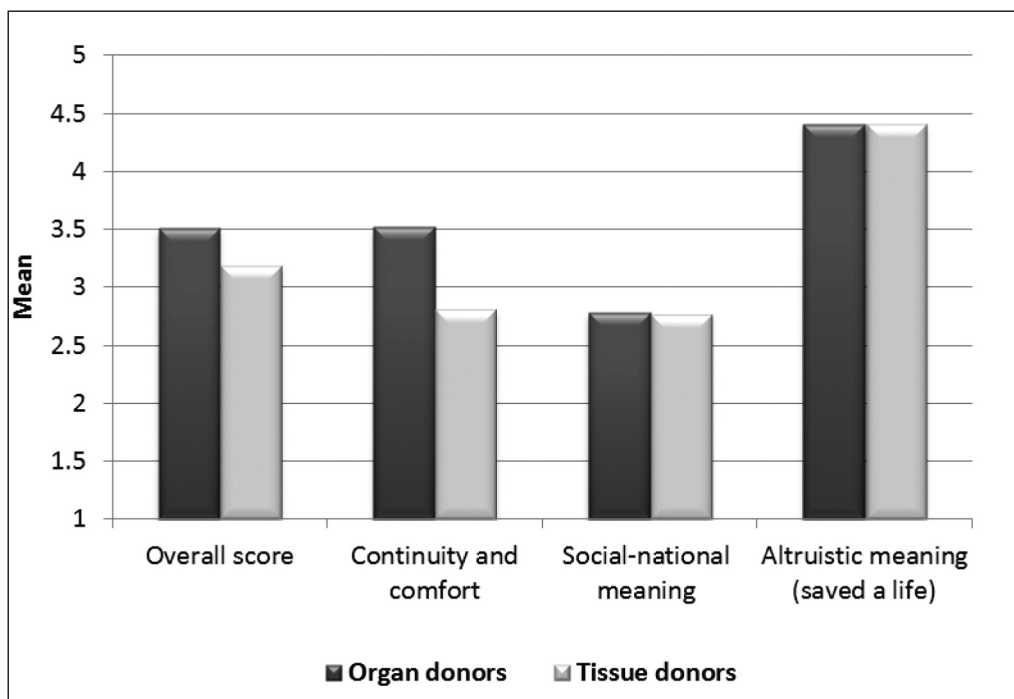


Figure 3: Meaning of donation according to organ or tissue donors

### Discussion

Organ donation requires close family members to make a difficult decision in an acute situation of grief under dire emotional circumstances (Walker, Broderick, Sque, 2013). Consequently ethical concerns are that OD may adversely affect donor family members’ adjustment to their loss. This study aimed to investigate whether donor family members’ adjustment to their loss differs from non-donors’. Participants were parents,

of mainly adult children. An important feature of this study was that in order to answer this question it employed both measures of adjustment to loss previously used in bereavement studies as well as measures specifically related to OD meaning (Hogan, Coolica & Schmidt, 2013). This enabled comparing the adjustment of donor parents to non-donor parents on multiple measures regarding personal growth after loss; meaning of life after loss, and meaning of donation. Overall, findings indicate

**Table 2:** Comparison between donor and non-donor parents

	Meaning of donation	Meaning of life after loss	Life development	Personal change after loss– overall change	Personal growth after loss, intensity of change after
<b>Donor parents (n = 140)</b>					
Grief	.28**	-.42***	-.62***	-.41***	.11
Personal growth after loss – intensity of change	.06	-.09	.17*	.46***	
Personal growth after loss – overall change	.06	.36***	.44***		
Life development	-.21*	.38***			.19*
Meaning of life after loss	.19*				
<b>Non-donor parents (n = 64)</b>					
Grief		-.28*	-.60***	-.33*	.21
Personal growth after loss – intensity of change		-.04	.02	.24	
Personal growth after loss – overall change		.45***	.55***		
Life development		.54***			

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

participating parents across groups, tended to report 'high' to 'moderate' grief levels, but also relatively positive adjustment to the loss according to the measures used. This suggests that the OD decision did not have a notable adverse impact on their reported adjustment, even when brain function criteria were used for the determination of death. The similar level of grief found across groups could be explained, as noted by researchers, that losing a child, in particular in a shocking and unexpected manner, is so devastating it is similar among parents over time, regardless of other factors involved (Hun & Greeff, 2012). Since levels of grief were found to be similar across groups, it does not appear that religious belief is associated with the relationship between meaning and level of grief regarding the loss of a child.

### Personal growth after loss and the meaning of life

Donor parents tended to report a relatively higher meaning of life compared to non-donors, including reporting being more involved in social activities, helping others, taking an interest in new activities, or doing things they never thought they could. Similarly, in the life development items, donor parents tended to score higher on dimensions of 'activity' and 'internal resources' and

'growth' than non-donor parents. One possible explanation for this difference is that before the tragedy, donor parents may have had relatively higher levels of emotional resources as defined by the study's measures, which could have helped them be more resilient and thus help them focus on moving forward rather than mainly on surviving the loss (Hun & Greeff, 2012). Resiliency was found to help bereaved persons experience positive emotions to improve their lives in unanticipated ways (Corr & Coolican, 2010). Although these findings cannot be used to indicate a causal relationship between organ/tissue donation and higher positive growth measures, a positive association between growth after loss and organ/tissue donation was found. Perhaps donor parents might have had stronger internal resources before the loss of their child associated both with giving their consent to the donation and with parental adjustment to loss (Hun & Greeff, 2012). This might also be explained by the supposition that donor families' value system might enable them to live with the loss in a more adaptive way (Corr & Coolican, 2010).

Perhaps the most interesting finding regarding the meaning of life concerns parents who reported a relatively higher level of grief and lower level of growth (ie. they were overall less adaptive). Within this group, those who attributed greater meaning to the OD were associated with an overall greater meaning of life after

loss measure. This finding might indicate donor parents with higher levels of grief experienced the loss in a more adaptive way than non-donor parents with similar high levels of grief, in terms of components of growth and meaning of life. One possible explanation is people who suffer intensely might have a greater need to construct a meaning for their loss (Neimeyer *et al*, 2008) and OD might help provide this meaning.

### Meaning of organ/tissue donation

The main difference found between organ and tissue donor parents was that organ donor parents rated the importance of 'continuity and comfort' higher in the meaning of donation than tissue donors. This might be attributed to conceptions of the physical and symbolic continuity organ transplantation of the deceased child might provide (Bellali & Papadatou, 2006). Further, consistent with other studies, life-saving contribution of organ and tissue donation was found to be the most meaningful aspect for the donor parents (Stouder *et al*, 2009). The high importance accorded by donor parents to saving a life might explain their conception of the overall positive contribution of OD.

### Differences among donor parents according to the determination of death

This study also aimed to examine whether there might be differences in the adjustment of bereaved donor parents according to the determination of death (brain/cardiac). This is important because in many cases organ procurement from the deceased is from people whose death was determined according to brain functions, which might not be congruent with cultural conceptions of death. Also, the finding that no statistically significant differences regarding adjustment measures were found according to determination of death criteria is important because there are concerns regarding parental acceptance of death when it is determined according to brain activity (Siminoff, Burant & Youngner, 2004).

### Limitations

This study has several limitations, including absence of data about the psychological state of parents before the loss of their child. Another limitation is about half of the bereaved parents approached chose not to participate. Although this response rate is considered appropriate, it cannot be determined if they had a higher or lower level of distress compared to participants in the study. They mainly explained this by not wanting to 're-open their wounds'. Yet, since participants included parents with medium and high levels scores of grief it can be assumed non-participants' scores would not have changed the overall main findings. Another limitation is the three instruments developed for this study were based on statements of Israeli bereaved families. Therefore, these instruments need to be further tested and adapted to other cultural contexts. Yet, the items are likely to be useful in other contexts because the Israeli population is multicultural and the items were based on the meaning of life literature.

## Conclusions

The findings of this study present theoretical and practical implications for researchers and practitioners. From an ethical perspective, the findings suggest that intervening in donor families' grieving process with an OD request not only did not cause them harm in terms of adjustment to loss, but it may have benefited them in terms of attributing meaning of life and personal growth, in particular among donor parents with higher levels of grief. From a theoretical perspective the findings point to the association between meaning of life and positive adjustment among certain grieving parents. This has implications for clinical practice in the development of grief counseling for organ donor families and addressing their needs. Specifically, one of the issues discussed by organ donation coordinators refers to the meaning of the donation (Ankler & Feeley, 2011; Ashkenazi, 2010), which is justified by this study. It could also have implications for communication about organ donation to potential donors, who are considering registering as organ donors, who might find comfort in the positive aspect of OD for their families. It could help family members make the difficult decision and could help in the grieving process. From a methodological perspective, these findings indicate it is important to include meaning of life and growth measures when studying donor family members' adjustment to loss, and this can contribute to more recent types of scales in bereavement (eg. Machin, Bartlam, Bartlam, 2015). ■

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## Appendix 1

Instrument items developed for the study (translated from Hebrew)

### Life development instrument items (items were mixed)

After the loss I find myself:

- Feeling ill
- Feeling lonely
- Feeling depressed
- Able to invest energies in things that are important to me
- Find abilities I didn't know I had within me
- Busy in social activities not involved with previously
- Able to return to activities I stopped right after the tragedy
- Doing things that show I chose to live
- Busy in activities to commemorate the deceased (eg, memorial days, anniversary)
- Busy in personal activities to preserve the image of the deceased (eg, collecting photos, memorial book)
- Finding interest in new things
- Busy with volunteer work
- Paying attention to family
- Doing things I never thought I would do

Content validation was conducted with five bereaved parents. Items were rated on a 5-point Likert scale ranging from 1 ('not at all') to 5 ('to a great extent'). Factor analysis with Varimax rotation revealed two main factors: (1) 'activity and internal resources' - items on respondents' ability to invest in important things and cope with illness and loneliness (Eigenvalue = 4.15, 34.57% of the explained variance,  $\alpha=.79$ ). (2) 'growth': items relating to new areas of interest and discovery of new competencies (Eigenvalue=2.01, 16.76% of the explained variance,  $\alpha=.78$ ). Two measures of development were defined: 'activity and resources' and 'growth'. The correlation between them was significant ( $r=.37, p<.001$ ). Higher mean scores were assumed to indicate a more positive life development. Internal consistency was .83.

### Meaning of life after the loss instrument items

- Investing in being in contact with the close family
- Investing in being in contact with the extended family
- Achieving accomplishments at work
- Achieving accomplishments in studies
- Investing in contact with friends
- Investing in 'passive' consumption of culture and leisure activities
- Investing in being 'active' in cultural and leisure activities
- Taking care of own health
- Taking care of my family's health



Investing in maintaining my child's memories  
 Providing help to others  
 Investing in actions to change things in the country  
 Achieving personal fulfillment  
 Investing in activities related to religion  
 Reaching personal tranquility; achieving personal happiness.  
 Responses were on a 6-point Likert scale ranging from 1 ('to a very great extent') to 6 ('not at all'). Content validation was conducted with seven bereaved parents. Factor analysis with Varimax rotation revealed two main factors: (1) 'social meaning and self-fulfillment' (Eigenvalue = 4.05, 31.13% of the explained variance,  $\alpha = .78$ ); (2) 'family meaning and peace of mind' (Eigenvalue = 1.85, 14.25% of the explained variance,  $\alpha = .65$ ). The first focused on the meaning of life in relation to the outside world and development beyond the existing situation. The second on family, health, remembering the deceased person and peace of mind. Overall internal consistency was .80. Higher mean scores were assumed to indicate a more positive attitude to the meaning of life.

#### Meaning of organ/tissue donation instrument items

What is the meaning of organ/tissue donation to you?:  
 Fulfilling the wish of the deceased (adult) child  
 Giving life to others  
 The feeling of doing something good  
 The appreciation and esteem of others  
 Continuation of life  
 Consolation that something good came out of the tragedy  
 Knowing people who receive the transplanted organs/tissue  
 Increased social status  
 Legitimises telling the donation story in social gatherings  
 Legitimises talking proudly about the child in family gatherings in terms of saving lives  
 Belonging to the 'family' of organ donors and the support system it provides  
 Advancing a social cause

The donation improved negative aspects of the child  
 The decision to donate created closeness within the family  
 The items were based on focus group findings conducted with organ donor families (Ashkenazi, 2010) and were rated on a 5-point Likert scale ranging from 1 ('gives no meaning at all') to 5 ('gives considerable meaning'). Content validation was conducted with 10 donor parents. Internal consistency of the items was  $\alpha = .80$ . Factor analysis with Varimax rotation revealed three main factors: (1) 'continuity and comfort' (Eigenvalue = 3.56, 35.60% of the explained variance,  $\alpha = .79$ ); (2) 'social-national meaning' (Eigenvalue = 1.76, 17.61% of the explained variance,  $\alpha = .74$ ); (3) 'altruistic meaning', which included two items (Eigenvalue 1.76, 17.61% of the explained variance,  $r = .45$   $p < .001$  between the two items). The items were pretested among fifteen parents (tissue donors, organ donors, non-donors).

#### Personal growth and change after the loss

This measure utilised two types of items: *The Post-Traumatic Growth Inventory* [PTGI]: Developed to measure the intensity of several types of changes reported by people who had experienced traumatic events (Tedeschi & Calhoun, 1996). A scale to measure change after loss-direction and intensity. In order to learn about the direction of the change the response scale was modified to include the direction of respondents' experiences ranging from -3 (negative) to +3 (positive) and to indicate two dimensions: The intensity of the change and its direction. Two scores were derived: 'intensity of change', on the basis of the original scale (Cronbach's Alpha internal consistency = .92), and 'overall change', calculated by multiplying the intensity by the direction of the change (Cronbach's Alpha internal consistency = .89). The higher the score, the greater the 'intensity of change' (scale 0-5) and the more positive the 'overall change' (on a scale from -15 to +15). A final score was derived by calculating the mean of the items for 'intensity of change' and 'overall change' (ranging -15 to +15).