Tools for the Measurement of Psychological Aspects of Organ Donation among the Families of Brain-dead People

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ABSTRACT

Background: According to the basic ethical principle of non-maleficence, organ procurement systems need to be accountable to donor families. As organ donation can be potentially traumatic, donor families are at risk of developing psychological damage. Appropriate measurement tools are needed to diagnose such disorders and develop appropriate treatment measures.

Objective: To examine the appropriateness of measurement tools and approaches used in previous studies for assessing donor families' psychological well-being.

Methods: A structured online search was conducted in electronic databases namely *ScienceDirect, PubMed, ProQuest, Scopus, Ovid,* and *Web of Science*. The main inclusion criterion was the use of psychological assessment tools for data collection.

Results: 10 studies were included in which different tools had been used for measuring donor families' psychological well-being in the following 5 dimensions: stress, depression, grief, general health, and positive legacy of trauma. The major pitfalls of the reviewed studies were failure to specifically assess complicated grief and differentiating it from other psychological disorders, diversity of the tools used for psychological well-being assessment, and lack of clear definitions of donor families' psychological well-being and its dimensions.

Conclusion: Donor families' psychological well-being is a complex and multidimensional concept and the existing measurement tools cannot accurately assess it. Therefore, the concept needs to be clearly explored and defined. Developing a comprehensive measurement tool or a set of scales is necessary for the early diagnosis of any impairment in donor families' psychological well-being.

KEYWORDS: Organ donation; Donor families; Psychological well-being; Measurement tools; Systematic review

INTRODUCTION

In most countries, families play the pivotal role in deciding whether to donate their brain-dead members' organs or not [1-5]. Such a decision is made in a difficult and traumatic condition [6]. In this process, the brain-dead relatives experience extreme emotions, psychological dynamics, and anticipatory grief [7]. The unexpected death of a family member, itself, is among the most stressful life events [8-11]. In such a stressful condition, family members also need to go through the difficult and damaging phases of experiencing and perceiving a family member's brain death [12] because they usually have difficulties in differentiating brain death from coma [13]. Meanwhile, they are confronted with the problem of decision making about organ donation [12, 14]. Organ donation request is made while the family members are consumed with great grief and thus, thinking and concentrating are excessively difficult for them [15]. Furthermore, limited time for making

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such a critical decision makes their conditions more complex and difficult [1]. Consequently, donor families are extremely vulnerable [14].

Studies show that donor families are at risk for developing different types of psychological problems such as depression [16]. Moreover, they usually use the avoidance defense mechanism, which has been identified by Boelen, et. al., to have a significant role in causing post-grief emotional problems [17]. Moreover, organ donation, in turn, may induce them to think that their dead family member is still alive in the body of somebody else. Therefore, they may become confused about the source of grief and suffer added psychological pain. Such donation-related confusion and added psychological pain can complicate their grief [18]. Also, traumatic memories related to the simultaneity of a family member's unexpected death and decision making about organ donation may result in post-traumatic stress disorder [7, 19]. Such memories can last for long periods depending on the type of the final donation-related decision, which can be either a clear or an ambivalent decision [19]. Ambivalent feelings about organ donation have been reported by many donor families [14]. Some studies even reported a feeling of post-decision regret among donor families [6, 20]. Such a regret at donation-related decision can potentially complicate the process of grief [21].

The grief experienced by donor families is due to their decision to donate [14]. Yet, the results of previous studies into the effects of organ donation on families' grief are conflicting. Some studies report that organ donation positively affect the process of grief [22, 23], while another study shows that donor families' decision to donate does not protect them against the psychological consequences of grief [24]. Another study indicates that the consent to donate is not per se a barrier or a facilitator to the process of grief; rather, other factors such as satisfaction with hospital care affect donation-related outcomes [25]. Moreover, donation-related outcomes are attributed in another study to the immediate religious, legal, and socio-cultural context as well as the quality of families' grief [24]. Considering the potentially traumatic nature of organ donation, evaluating the outcomes of this process for donor families seems obviously crucial. According to the basic ethical principle of non-maleficence [26], organ procurement systems need to be accountable to donor families and their health.

Huppert noted that psychological well-being (PWB) "is about lives going well." This definition is a combination of good feelings and effective functioning. Huppert also believes that sustainable well-being does not necessarily mean having good feelings all times; rather, painful feelings such as despair, failure, and grief are normal parts of life. An important point here is that the ability to manage such feelings is essential for long-term well-being. In other words, prolonged negative feelings can threaten PWB and negatively affect daily practice [27]. According to this definition, donor families are expected to manage all loss-related negative emotions, successfully pass the bereavement period, and finally cope with the loss and return back to their normal lives. Considering the severe trauma of a sudden death of a beloved person as well as the potentially traumatic pre- and post-donation phases, some donor families may be unable to cope and thus, may be at risk for PWB problems.

All professions who are involved in the process of organ donation are responsible for providing care to donor families and continuously supporting them in order to promote their psychological stability [5]. These families need adequate counseling and psychological services [14]. Moreover, psychiatric therapies may be needed if they develop psychological disturbances [28].

In order to diagnose psychological problems of donor families, appropriate measurement tools are necessary. In psychological screening programs, measurement tools are usually used to diagnose psychological problems and make clinical decisions [29]. Because of their simplicity and cost-effectiveness, psychological screening tools can also help diagnose and manage psychological disorders in non-psychiatric settings. Health care providers can

also design and execute their care plans based on the results of such psychological measurement tools [30].

Psychological measurement tools have been widely used in previous studies to assess PWB of donor families. Nonetheless, there are limited data on the appropriateness and the efficiency of the available psychological tools as well as the necessity to develop new tools for measuring donor families' PWB. In other words, despite the long history of organ donation in many countries [31, 32], no comprehensive study has yet been conducted in this area. Consequently, the present study was undertaken to systematically examine the appropriateness of the measurement tools used in previous studies to assess donor families' PWB. Through reviewing previous studies respecting the measured PWB components and the used PWB-related instruments, this study sought to answer these questions: "Whether measurement tools used in previous studies to diagnose PWB have been appropriate?" and "Whether PWB assessment approaches used in previous studies have been appropriate?"

MATERIALS AND METHODS

A systematic review was conducted based on the University of York Center for Reviewers and Dissemination Guidance [33] in order to review previous studies in the area of assessing and measuring the psychological aspects of decision making among the donor families of brain-dead people. Accordingly, we initially performed an online search in PubMed and Cochrane Database of Systematic Reviews to ensure that the study had not been previously done elsewhere. The review team consisted of two experts in psychometric evaluation (the third and fifth authors), an expert in systematic review methods (the second author), an organ donation specialist (the fourth author), and an expert in information retrieval (the first author). The first and fifth authors were independently engaged in all phases of the review in order to minimize probable biases and errors.

Study Question

"Whether measurement tools used in previous studies to diagnose PWB have been appropriate?" and for response to secondary objective of the study "Whether PWB assessment approaches used in previous studies have been appropriate?"

In order to answer these questions, the search strategy designed so as to retrieve studies that had been conducted to assess and measure psychological aspects among the donor families of brain-dead people.

Search Strategy

A structured online search was conducted in electronic databases namely ScienceDirect, PubMed, ProQuest, Scopus, Ovid, and Web of Science. The search key terms were "organ donation," "brain death," "family," "relatives," "next of kin," "emotion," "stress," "depression," "anxiety," "psychological effect," "psychological outcome," "psychological consequence," "psychological aspect," and "psychological well-being." These search key terms were combined by using the "OR" and "AND" operators. Following the definition of "brain death" by Harvard ad hoc Committee on Brain Death in 1986, organ procurement activities were initiated in early 1970s [34]. Consequently, we searched studies which had been published from 1970 to July 11, 2016. As the Web of Science database was founded in 1983, the data limit for searching this database was set to be between 1983 and July 11, 2016. Based on this search strategy, potentially relevant studies were identified by the first author.

Selection of Studies

The EndNote X1 reference manager software was employed to import and sort the retrieved studies. Duplicated studies were excluded and then, two observers independently started to select the studies. Based on the inclusion and exclusion criteria, potentially relevant studies were identified in the following two steps: (1) Initial screening of all studies that had been retrieved in the primary search; and (2) appraising the full text of those studies that we could not firmly decide on their inclusion/exclusion based on their abstracts.

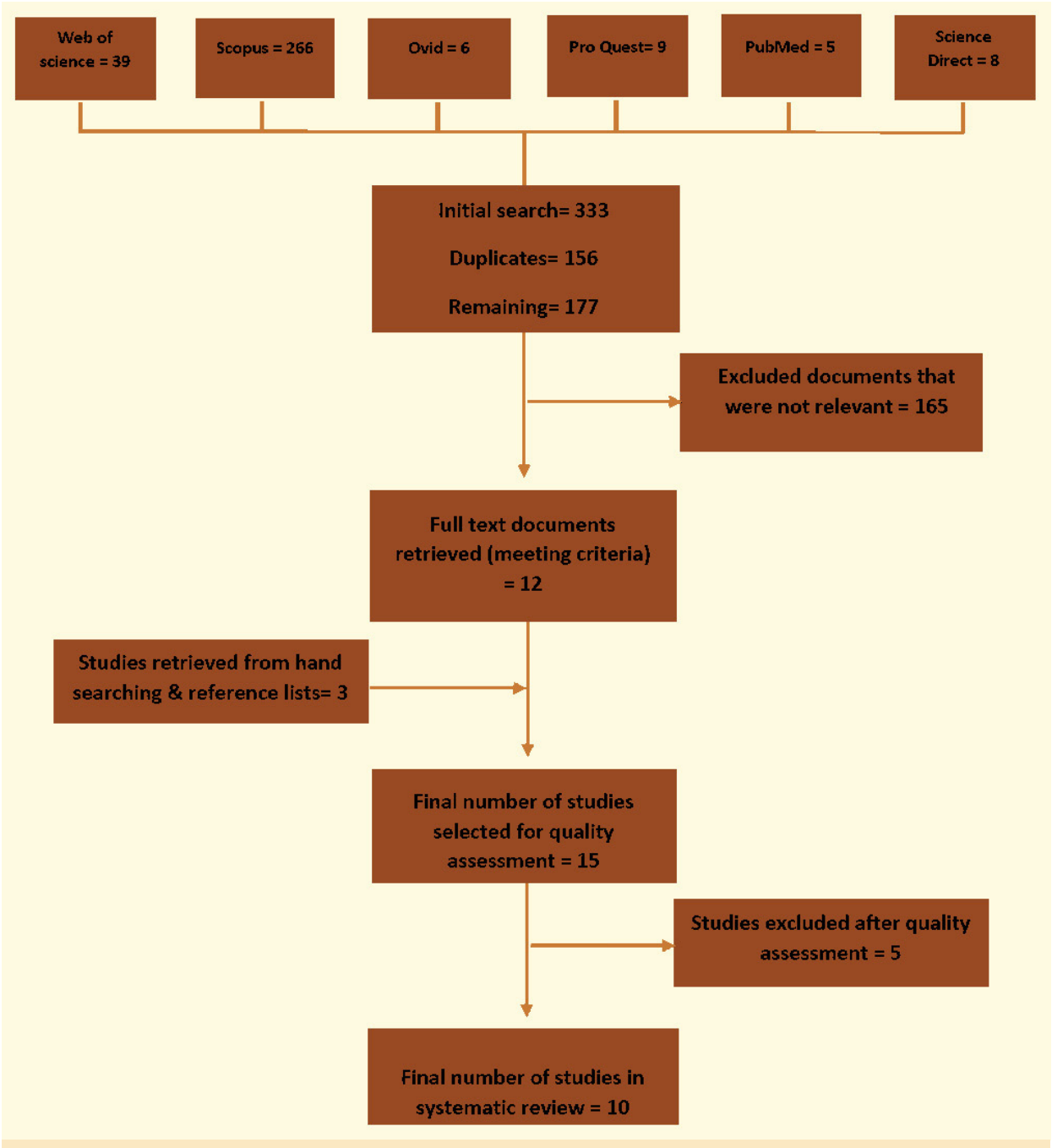

Figure 1: The flowchart of retrieving and selecting the studies

Inclusion criteria were having been published in English, having been performed by using quantitative designs or mixed methods, having been performed on the donor families of brain-dead people, and having used at least one psychological assessment tool for data collection.

Studies that had been conducted on health care providers, organ transplant recipients, and living donors were excluded. Any disagreements between the observers with regard to including or excluding studies were resolved by a third reviewer. In addition to the online search, a hand search was performed on the reference list of the retrieved studies as well as the table of contents of several key journals namely American Journal of Transplantation, Clinical Transplantation, Transplantation Proceeding, and Progress in Transplantation.

Eligible studies were then subjected to quality assessment.

Quality Assessment

The specific criterion for assessing the quality of the included studies was "data collection by using a standard tool for measuring psychological problems." By "standard tool" we meant all tools the psychometric properties of which had been evaluated and confirmed elsewhere or in the retrieved studies. Considering the objective of the study, we did not intend to evaluate the methodological aspects of the retrieved studies. Consequently, we did not use routinely-used tools for appraising the quality of the studies.

Data Extraction

The data that were extracted from the retrieved studies were related to the objectives, designs, samples, loss-measurement time interval, measured components of PWB, data collection tools, and the results of using the tools in the studies.

Data Synthesis

The measurement tools that had been used in the retrieved studies were categorized according to the measured psychological aspects. The criterion for judging the appropriateness of the used measurement tools was the degree to which a given tool assessed the components of PWB among donor families.

RESULTS

In total, 333 abstracts were retrieved from six electronic databases. Based on the inclusion criteria, 15 studies were assessed from which 10 were included in the review. These studies had used standard tools for measuring PWB (Fig 1).

Characteristics of Studies

The studies had been published from 1989 to 2015. The first study was a dissertation; others were journal articles (Table 1). Eight studies had used common standard tools; two studies had developed new tools for measuring donor families' stress [35] and donor parents' adjustment to the loss of their children [36]. It is worthy to note that data on the demographic questionnaires, interviews, and construct validity assessment tools were not included in Table 1.

The Objectives of the Studies of Using the Tools

PWB measurement in the retrieved studies had been performed for different objectives and thus, by using different methodologies. Generally, the objectives of the studies could be grouped in the following three categories: (1) Assessing the effects of the experience of organ donation on PWB: studies with this objective dealt with the potentially traumatic nature of organ donation and thus, evaluated one or more psychological factors among donor families; (2) assessing the effects of care provision to donor families during the process of donation on their PWB: studies in this category tested the effects of professional care as well as families' communication with health care providers on the potential damages of organ donation; (3) assessing the effects of families' participation in the process of diagnosing brain death on the PWB of brain-dead people's relatives: the hypothesis of the studies in this category was that families' participation in the process of diagnosing brain death can help them better understand brain death. Thereby, these studies assessed the effects of this added potentially traumatic experience on families' PWB.

It is noteworthy that each of the studies in these three categories dealt with different aspects of PWB. As an example, the objective of one of the studies in the third category had been the measurement of grief reaction while the aim of another study in this category had been PWB assessment; yet, both of these two studies had used the same tool for measuring these two variables. The categorization of the objectives of these studies, the diversity of the measured PWB components, and the used measurement tools are summarized in Table 2.

The Samples of the Studies

Two studies had assessed the "system of fam-

Table 1: Characteristics of reviewed studies

Code	Objective of the study	Authors & Year	Study design	Samples	Time of data collection	Data collection tools
1	To measure the relationship of six selected situational variables to the stressful experience that families perceive at the time of organ donation	Soukup 1989	Correlational	Donor families: n=46	6–64 weeks after the loss	Organ Donation Family Stress (ODFS)
2	To examine the differences in levels of well-being between respondents in the three conditions (ODC[1], ODR[2], NDR[3])	Cleiren & Van Zoelen 2002	Quasi-experimental	ODC: n=36 ODR: n=23 NDR: n=36	Within the first half year after the loss	Impact of Event Scale (IES) Beck Depression Inventory (BDI) Leiden Detachment Scale
3	To identify the grief reaction after observation of brain stem death testing	Ormrod, *et. al.* 2005	Exploratory observational	Brain-dead families: n=27	Mean of 12.6 months after the loss (SD 4.1)	Impact of Event Scale (IES) General Health Questionnaire-12 (GHQ-12)
4	To identify the impact of hospital care offered to relatives in terms of decision-making about donation and subsequent grief	Sque, *et. al.* 2005	3-year longitudinal design	Donor families On 3 TP[4], respectively: n=45, 38, 25	TP_1=3–5 TP_2=13–15 TP_3=18–26 months after the loss	Grief Experience Inventory (GEI) Beck Depression Inventory (BDI-II)
5	To investigate effecting of donation process on the bereavement process for organ donor families	Merchant, *et. al.* 2008	Cross-sectional	Donor families: n=73	within the last 5 years; but not within the last 3 months after the loss	Core Bereavement Items (CBI) Beck Depression Inventory (BDI-II) Impact of Event Scale-Revised (IES-R)
6	To study the relationship between depression and organ donation among families of brain-dead cases	Tavakoli et al. 2008	Descriptive, Cross-sectional	Donor families: n=54 Non-donor families: n=104	At least 3 months after the loss	Beck depression Inventory (BDI)

Continued

Table 1: Characteristics of reviewed studies

Code	Objective of the study	Authors & Year	Study design	Samples	Time of data collection	Data collection tools
7	To explore how communication in the ICU[5] about brain death and consent to donation affected family members' psychological Condition	Smudla et al. 2012	Prospective Cohort Study	Donor families: n=29	3–6 months after the loss	Revised Grief Experience Inventory (RGEI) Shortened Version of the Beck Depression Inventory (s BDI)
8	To evaluate impact of family presence during BDE[6] on psychological well-being	Tawil et al. 2014	Randomized controlled trial	Present for BDE: n=38 Absent for BDE: n=20	1 month after loss	Impact of Event Scale (IES) General Health Questionnaire (GHQ-12)
9	Assess the interactions with health care personnel on adjustment to loss	Ashkenazi et al. 2015	Descriptive, Cross-sectional	Donor families: n=216	6 months to 27 years after the loss	Inventory of Complicated Grief Posttraumatic Growth Inventory Life Development Questionnaire Meaning of Life after Loss Questionnaire Meaning of Donating Organ Questionnaire

1. Organ donation consent 2. Organ donation refusal 3. No donation request 4. Time point 5. Intensive care unit 6. Brain death evaluation

Table 2: Diversity of evaluated psychological components and used measurement tools in the reviewed studies

Objective of Studies	Code of studies	Measurement	Considered components	Used measurement tools
Assessing the effects of decision to donate on PWB	1	Stress	Stress	Organ Donation Family Stress (ODFS)
	2	Bereavement process	Bereavement intensity	Texas Bereavement Questionnaire
	3	Levels of well-being	Depression	Beck Depression Inventory (BDI)
			Typical loss-related reactions	Impact of Event Scale (IES) Leiden Detachment Scale
	6	Bereavement process	Depression	Beck Depression Inventory (BDI-II)
			Post-traumatic stress	Impact of Event Scale-Revised (IES-R)
			Grief	Core Bereavement Items (CBI)
	7	Depression	Depression	Beck Depression Inventory (BDI)
Assessing the effects of care provision to donor families during the process of donation on their PWB	5	Grief	Depression	Beck Depression Inventory (BDI-II)
			Multidimensional nature of bereavement	Grief Experience Inventory (GEI)
	8	Psychological condition	Depression	Shortened Version of the Beck Depression Inventory (sBDI)
			Grief reaction	Revised Grief Experience Inventory (GEI-R)
			Grief	Inventory of Complicated Grief
	10	Adjustment to loss	Personal growth after loss	Post-traumatic Growth Inventory Life Development Questionnaire
			Meaning of life after loss	Meaning of Life after Loss Questionnaire
			Meaning of organ donation	Meaning of Donating Organ Questionnaire
Assessing the effects of families' participation in the process of diagnosing brain death on the PWB of brain-dead people's relatives	4	Grief Reaction	Specific responses to psychological trauma	Impact of Event Scale IES
			Psychological distress	General Health Questionnaire-12 (GHQ-12)
	9	Psychological Well-being	Emotional and psychological impact	Impact of Event Scale (IES)
			Psychiatric state	General Health Questionnaire (GHQ-12)

ily" to examine the level of families' stress [35], coherence of families, and family members' grief [37]. The samples of the other studies had been individual family members. Some studies had recruited family members before their decision to donate and then, had used measurement tools among both families who had consented and refused to donate [38, 39]. Two studies had also compared families who had consented to donate with those who had refused to donate [25, 40] and those who had never received an organ donation request [25].

The Time of Using the Tools

The time interval between families' decision to donate and the administration of the tools to them varied a lot (Table 1). For instance, one prospective study had assessed PWB one month after the experience [39] while a retrospective one had assessed PWB six months to 27 years after the experience [36].

The Results of Using the Tools

Due to the differences among the studies with respect to their objectives and methodologies, their results also varied a lot. Yet, the main focus of studies had been donor families' psychological problems. Several studies reported the significant effects of some factors on donor families' psychological problems. These factors included preference unknown to the family that the brain-dead family member wanted to donate an organ [35], having no one to communicate with about grief-related emotions [41], discomfort, negative experiences, and health problems during the process of donation [22], lack of confidence in the diagnosis of brain death [42], and the quality of communication with health care providers [36]. Although one study reported no significant difference among families who consented, refused, or not requested to donate [25], two other studies on donor families indicated that 46% of families had the criteria of complicated grief [37] and 72.4% of them suffered from depression [42]. Studies into the effects of families' participation in the process of brain death diagnosis also reported no significant difference between participating and non-participating families respecting their general health and post-traumatic stress [38, 39].

Measured Psychological Components

Study findings revealed that to evaluate PWB, the reviewed studies had dealt mainly with the five components of stress, depression, grief, general health (i.e., the risk of developing psychiatric disorders), and positive legacy of trauma. Table 3 shows the categorization of the tools used for measuring these five components. This categorization was solely done based on the main constructs measured by the used measurement tools. The most commonly used tools in the studies were for measuring symptoms of depression and diagnosing post-traumatic stress. Although these studies had been made over time, some of them did not use the revised versions of the measurement tools.

Measurement of Stress

The reviewed studies had used two approaches for measuring donor families' stress. One study had measured stress at organ donation situation by using the Organ Donation Family Stress scale [35]. On the other hand, four studies had measured post-traumatic stress by using the Impact of Event Scale [25, 38, 39] and its revised version [22].

Measurement of Depression

Five studies had measured donor families' depression by employing Beck Depression Inventory [25, 40], its revised version [22, 41], and its shortened version [42].

Measurement of Grief

The studies had assessed grief by using the Grief Experience Inventory [41], its revised version [42], the Inventory of Complicated Grief [36], Texas Bereavement Inventory [37], and Leiden Detachment Scale [25].

Measurement of General Health

In order to assess the risk of developing psychiatric disorders, two studies had used the General Health Questionnaire [38, 39]. This questionnaire is a screening tool for diagnosing actual or potential psychiatric disorders. This questionnaire measures common mental health problems such as depression, anxiety, somatic symptoms, and social withdrawal

Table 3: Categorization of the tools used for measuring psychological components in donor families

Components	Used Tools
Stress	Organ Donation Family Stress (ODFS)
	Impact of Event Scale (IES)
	Impact of Event Scale-Revised (IES-R)
Depression	Beck Depression Inventory (BDI)
	Beck Depression Inventory (BDI-II)
	Shortened version of the Beck Depression Inventory (sBDI)
Grief	Grief Experience Inventory (GEI)
	Revised Grief Experience Inventory (RGEI)
	Inventory of Complicated Grief
	Leiden Detachment Scale
Psychiatric disorder	General Health Questionnaire (GHQ-12)
Positive legacy of trauma	Post-traumatic Growth Inventory
	Life Development Questionnaire
	Meaning of Life after Loss Questionnaire
	Meaning of Donating Organ Questionnaire

[43].

Measurement of Positive Legacy of Trauma

Among the reviewed studies, just one study [36] had dealt with the positive effects of trauma including personal growth after loss (i.e., improvement of personal and social abilities), the meaning of life after loss (i.e., whatever a person attempts to achieve), and the meaning of organ donation. These components had been assessed by using the Post-traumatic Growth Inventory, the Life Development Questionnaire, the Meaning of Life after Loss Questionnaire, and the Meaning of Donating Organ Questionnaire. Except for the Post-traumatic Growth Inventory, which measures personal growth and the intensity of changes after loss, the other three questionnaires had been developed in that study [36] and specifically for donor families.

DISCUSSION

This systematic review examined the evidence regarding the use of PWB measurement tools among donor families in order to provide comprehensive information about the appropriateness of these tools for the assessment of donor families' PWB. Due to the wide diversity of measurement tools used in previous studies, this study did not focus on evaluating and comparing the psychometric properties of PWB measurement tools; rather, the main focus of the study was to systematically examine the appropriateness of the measurement tools used in previous studies to assess donor families' PWB. Beside the PWB component assessed in previous studies, the study also focused on approached used in previous studies for assessing donor families' PWB.

PWB Components Measured in Previous Studies

None of the reviewed studies had used a comprehensive and specific tool for PWB measurement. Measurement tools used in previous studies mainly assessed the five psychological components of stress, depression, grief, general health (i.e., the risk of developing psychiatric disorders), and positive legacy of trauma. The most commonly-used tools were post-traumatic stress and depression-related tools. Although some studies had clearly stated that

they aimed at evaluating PWB, they had dealt with different components other than PWB, without providing clear reasons for such deviation. An important point was that these components did not pertain to the definitions of PWB. Moreover, none of the reviewed studies had provided a clear definition of the concept of PWB even though accurate assessment of PWB necessitates a clear definition of the concept and its components. Well-being is described as "intangible, difficult to define, and even harder to measure" [44]. Nonetheless, some scholars have made attempts to define and measure the concept [45].

Approaches Used in Previous Studies for Assessing Donor Families' PWB

This study recognized the Huppert's definition of PWB, i.e., feeling good and functioning effectively, as the best available definition. She emphasized the need to differentiate the three approaches to PWB promotion that include "prevention of a disorder," "treatment of an existing disorder," and "enhancement of PWB" (i.e., increasing flourishing) [27].

A researcher developed and evaluated the psychometric properties of a specific tool for measuring donor families' stress in different situations of organ donation [35]. Consequently, her study is consistent with the first approach proposed by Huppert, i.e., "prevention of a disorder." Another study also reported that greater discomfort and stronger negative feelings during the donation process are associated with greater risk of developing depression and post-traumatic stress [22]. Moreover, some scholars showed that in order to minimize the negative psychological effects of organ donation, donor families should be provided with adequate support and care services as early as the time of their loss [42]. Using stress measurement tools for controlling the stressors of the organ donation process can help minimize negative psychological effects of the process and prevent the occurrence of psychological distress.

The third approach of Huppert is "well-being enhancement," which deals with the positive aspects of PWB. She noted that well-being is far beyond the absence of ill-being [27]. One study also found that PWB is not exactly the opposite point of psychological distress on a same spectrum [46]. Moreover, A researcher focused on the positive aspects of PWB and provided a different model of this concept [47]. The researchers developed a scale the six dimensions including autonomy, environmental mastery, personal growth, positive relations with others, purpose in life, and self-acceptance [48]. Some scholars in a study, referred to this scale as a multidimensional tool that had been developed based on a more detailed conceptualization of PWB compared with other PWB measurement tools [46]. It is noteworthy that except for one study that dealt with assessing personal growth after loss as a positive outcome of a traumatic accident [36], none of the reviewed studies had assessed the mentioned six dimensions.

The findings of the present study also indicated that most reviewed studies had assessed donor families' PWB through assessing their psychological disorders or distress. In other words, most studies were consistent with Huppert's second approach, i.e., "treatment of existing disorders." This finding denotes that the tacit assumption of previous studies for monitoring donor families' PWB had been the diagnosis of psychological distress. Nonetheless, no evidence was found in these studies about using the results of psychological measurement tools for developing and providing treatments. In a concept analysis study, Ridner defined psychological distress as "the unique discomforting emotional state experienced by an individual in response to a specific stressor or demand that results in harm, either temporary or permanent, to the person" [49]. As the most striking experience of donor families is a terrible sudden loss in a traumatic situation, the particular focus of most reviewed studies on grief-related psychological problems is justifiable and consistent with the definition of psychological distress.

Individuals' ability to cope with grief ranges widely from an almost complete acceptance of loss to serious consequences [50]. The process of grief among some individuals may be ab-

normal and thus, they may suffer from grief-related symptoms and behavioral disorders for longer period and need serious psychiatric interventions [51]. Donor families' grief is a unique experience, the bereavement process of which can be complicated by a variety of factors [52]. Although psychological distress (manifested as disorders such as depression and post-traumatic stress) may be a clue to a complicated bereavement process [22], only one of the reviewed studies had assessed donor families' PWB by using the Inventory of Complicated Grief [36]. Some other studies had also measured the symptoms of depression and post-traumatic stress either independently or in conjunction with grief measurement tools. Although recent versions of the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders recommend the diagnosis of grief-related problems through diagnosing major depression, empirical studies show considerable difference between complicated grief and major depression. Therefore, considering and treating complicated grief as a subset of major depression can cause it to remain undiagnosed and untreated [53, 54]. Another study also indicated that a large number of individuals who suffered from complicated grief had wrongly received the diagnosis and treatments of other psychological problems such as depression or anxiety due to using wrong diagnostic criteria for evaluating their conditions [55]. There is increasing evidence showing that complicated grief is different from other pathological disorders such as loss-related depression, anxiety, and post-traumatic stress disorder [56, 57]. Some scholars also highlighted the importance of differentiating and diagnosing complicated grief as a major risk to sustainable well-being [58].

Complicated grief is a bereavement-related syndrome which is characterized by the symptoms of separation distress (including yearning and searching) and traumatic stress (including disbelief, trouble in accepting the death, and bitterness) as well as some degrees of functional disorder for at least six months [59, 60]. Contrary to normal grief, complicated grief is not a self-limiting process. Therefore, grieved individuals are unable to return to their previous level of functioning and emotional well-being. Apparently, time (i.e., the first months after loss) is a vital aspect of complicated grief assessment because untreated grief puts afflicted persons at great risk for long-term altered functioning and persistent social, psychological, and medical impairments [61]. Because of experiencing unique traumatic conditions, donor families are very likely to develop other psychological disorders such as depression, anxiety, and post-traumatic stress. Therefore, none of these disorders should be neglected when assessing donor families' PWB. Previous studies have also highlighted that grieved individuals may suffer from disorders such as depression or anxiety either as the consequences of complicated grief or comorbid disorders [55, 61].

One of the major limitations of the reviewed studies in using PWB measurement tools to differentiate healthy and unhealthy people had been the wide time interval between the time of decision to donate and PWB measurement. This period in one study was six months to 27 years [36]; in another study it was three months to five years [22]. Another study reported that during the first six months after donation, the level of distress among families who consented to donate was the same as the families who refused to donate [25]. This finding is not surprising in a short period of time after loss, because it may be due to the fact that both groups of families had experienced the loss of one loved person. Besides, an important point here is not simple comparison of donor families with non-donor families; rather, due to the traumatic nature of organ donation and its profound effects on donor families and the importance of providing respect and care for them, early diagnosis of any psychological problems should be taken into account in order to prevent serious and chronic complications and problems. Based on the recognized definition of PWB, it is important to diagnose a continuing grief, which can negatively affect normal functioning over time.

One of the studies that had reported a wide gap in providing necessary support to donor

families had suggested an ideal follow-up program consisting of frequent planned support services in different post-loss time points [62]. Our findings also showed that PWB measurement tools should be used systematically at different time points in order to diagnose all types of common post-loss psychological problems. Not only can this strategy protect donor families' dignity, but it can also ensure non-maleficence.

In conclusion, the findings emerged from this review study highlighted that there is a wide gap in the assessment of donor families' PWB. In other words, donor families PWB has not been assessed comprehensively and based on clear definitions of PWB and its components. Moreover, the studies had mainly focused on the diagnosis of psychological distress, denoting their insufficient attention to other two approaches to PWB promotion, i.e., "prevention of disorders" and "PWB enhancement." The two neglected aspects of PWB assessment in the reviewed studies were failure to early PWB assessment at the time of donor families' extreme vulnerability and failure to differentiate complicated grief from other post-loss psychological disorders. Furthermore, there is no evidence about the use of the results of psychological measurement tools in clinical settings and for treatment purposes. It seems that these handful studies have been performed merely for developing knowledge about donor families' psychological disorders.

Given the complexity and multidimensionality of donor families' PWB and the inefficiency of the existing measurement tools to accurately assess it, we suggest that the concept of PWB be clearly explored and defined. Moreover, development of a comprehensive measurement tool or a set of measurement tools is recommended for the early diagnosis of any impairments in donor families' PWB. Besides, in order to prevent psychological disorders and minimize their effects on donor families, development of specific measurement tools to identify the stressors of donation process is recommended.

ACKNOWLEDGMENTS

This article was extracted from a PhD thesis.

CONFLICTS OF INTEREST: None declared.

FINANCIAL SUPPORT: This study was supported by grant #476/2/6/14/340/S from Baqiyatallah University of Medical Sciences.

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