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HEALTH PSYCHOLOGY | RESEARCH ARTICLE

Post-donation evaluation of life of donors of liver transplantation

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Abstract: *Aim:* Liver transplantation from living donors affects not only recipients' but also donors' lives. The aim of this study was to explore living donors' experience of life. *Methods:* The sample consisted of 16 living donors who donated a part of their liver to a patient who had end-stage liver failure. Anonymised interview transcripts were analyzed following established conventions. *Results:* The analysis showed that participants evaluated their life in terms of limitations brought by organ donation surgery, awareness of the need for lifestyle changes, emotional changes, changes in character, and mixed relationships. Emotional changes involved the experience of both negative and positive emotions (feeling reputable, feeling like being born again). Changes in character included both worsening of character (becoming half human, turning into an aggressive person) and positive changes in character (becoming more of a believer and a humanist). Mixed relationships included feeling supported by loved ones and doctors, reduction of burden of care, formation of a special bond, not feeling supported by potential supporters like mothers, or spouses and worsening of close relationships. *Conclusions:* Some findings (experience of negative emotions, lack of support from others) could be interpreted in terms of existing psychological theory. Other findings (worsening aspects of character, experience of positive emotions, improvement in aspects of character, formation of a special bond, worsening of close relationships) extended the literature and could be viewed as targets for educational programs for donors.

ABOUT THE AUTHOR

Dr Margorit Rita Krespi is an associate professor at Kadir Has University, Turkey. Krespi received her bachelor degree from Bosphorus University, Turkey in 1990. She completed her master's degree in clinical psychology at the same university (1990-1993). She studied patients' perceptions of their chronic physical illness, its treatment and its effects during her PhD at University of Liverpool, UK (2001). Her clinical and research interests are psychosocial aspects of chronic physical illness, organ donation and transplantation, coping with stress, obesity, illness prevention and health promotion. The research presented in this paper aims to understand the ways in which living donors of liver transplantation experience life following their surgery for organ donation and identify targets for psychoeducational program or clinical consultations in order to improve their wellbeing.

PUBLIC INTEREST STATEMENT

This paper stresses the value of providing support for donors of liver transplantation in addition to support that is needed for recipients of liver transplant. We were interested in understanding the experiences of donors and whether these experiences could actually make sense on the basis of what we already knew as professionals. This paper showed that donors not only experienced negative and positive emotions but also felt that their character had changed. Being a donor involved also changes in relationships with closed ones. Some donors felt that they formed a special bond with other people whereas other donors reported their relationships with other people have changed for the worse. These findings highlighted the value of consulting donors' for designing psycho-educational programs and shaping the content of meetings with their surgeons in order to improve how they feel.

Subjects: Death and Dying; Research Methods; Health Conditions

Keywords: organ donation; liver failure; qualitative research; living donors; evaluation of life

1. Introduction

The main treatment of end-stage liver disease (ESLD) consists of liver transplantation either from a cadaver or from a living donor. Transplantation aims to ensure good quality of life (Keeffe, 2001). The donors' experience of life should not be understood in terms of only physical symptoms. Studies aiming at understanding the effects of organ donation have focused on the construct of adjustment. Adjustment has been usually examined on the basis of the presence of psychological problems including depression and anxiety, and quality of life.

There is limited evidence on the psychological effects of donation of a part of one's liver on one's life. A small number of studies have shown that donors experience depressive symptoms (Fukunishi et al., 2001; Walter et al., 2002). Research has also shown that liver transplantation has a negative impact on primary caregivers who may or may not be donors. In terms of quality of life, the findings have been mixed (Bolkhir, Loiselle, Evon, & Hayashi, 2007). Studies (Walter et al., 2003) have shown that before organ donation, donors' quality of life is low and that quality of life after liver donation is high among donors (Chen & Yan, 2001; Feltrin, Pegoraro, & Rago, 2008; Zhang et al., 2005). However, other studies have shown that although before organ donation donors' quality of life is high, after organ donation significant reduction in quality of life occurs in physical health, and living conditions (Walter et al., 2003). More specifically, a study found that health-related quality of life was significantly worse during the second year after organ donation than during the fifth year (De Bona, Ponton, & Ermani, 2000).

Qualitative methods offer an alternative approach to the understanding of living donors' experience of life. However, a small number of qualitative studies have investigated this aspect of donors' experience. In these qualitative studies, donors recounted a number of feelings in relation to being a donor. These included negative emotions including feeling stressed, sad, anxious, frustrated, angry, ambivalent and frightened, and positive emotions including feeling motivated, certain, and frightened (Papachristou, Marc, Frommer, & Klapp, 2010; Walter, Papachristou, Danzer, Klapp, & Frommer, 2004). Qualitative studies have also shown that donors idealize the relationship with the recipient (Walter et al., 2004) and experience difficulties in accepting ESLD (Papachristou et al., 2010). These qualitative findings can help to identify key targets for clinical consultations and/or psycho-educational interventions to improve outcomes among living donors following organ donation. However, there are only a small number of studies and in turn there is limited evidence to base these interventions on. Therefore, more qualitative studies are needed among donors of liver transplantation. Among patients with other chronic illnesses including end-stage renal disease (ESRD), previous qualitative work identified themes of evaluation of life that vary from the findings of quantitative work. For example, patients evaluated their life in terms of mixed feelings about caregivers and changes in their own character (Krespi, Bone, Ahmad, Worthington, & Salmon, 2008). Patients perceived caregivers not only as supportive but also as sources of distress and difficulty. Patients felt that ESRD and its treatment have worsened not only their emotional state, but also aspects of their character. However, the effect of ESRD also involved the experience of positive changes in character. Donors can perhaps experience life in similar ways. Therefore, due to limited evidence further in-depth qualitative research is necessary to understand donors' experience of life in detail. Therefore, this study explored donors' experience of life following surgery for organ donation.

2. Method

2.1. Participants

Among different purposeful sampling procedures that could be used in qualitative research, typical sampling procedure was used. This not only ensured that the sample consisted of participants who guaranteed the provision of detailed information in relation to the aims of the study (Patton, 1990)

but also the transferability of the findings to other living liver donors (Henwood & Pidgeon, 1992). During the present study, the coordinator of the Liver Transplant Unit identified and referred to the second author the typical living donors who provided a part of their liver as a transplant to somebody who needed it because of a common cause of ESLD. The pool from which the sample was selected consisted of living donors who had organ donation surgery in one of the private hospitals in Istanbul. The participants consisted of 16 living donors of liver transplantation. There were 6 males and 10 females. The age ranged from 23 to 41 (mean age = 30 years). The duration of time from surgery for organ donation ranged from 3 days to 7 months (mean age = 4.47 months). Donors were first degree relatives ($n = 10$), second degree relatives ($n = 3$), and those approved by the ethical committee ($n = 3$) (see Table 1).

Table 1. Demographic characteristics of the participants

No.	Age	Gender	Marital status	Education	Occupational status	Relationship of donor to recipient	Duration after transplantation
1	30	Male	Single	High school	Had medical report for 6 months	Son	2 months
2	40	Female	Married	Primary school	Housewife	Mother	2 years
3	23	Female	Single	University	Housewife	Daughter	8 months
4	26	Female	Married	Primary school	Housewife	Mother	1.5 years
5	27	Male	Single	University	Employed	Son	1 month
6	24	Female	Engaged	Primary school	Housewife	Niece/uncle	3 weeks
7	23	Female	Married	Secondary school	Housewife	Mother	2.5 months
8	30	Male	Single	High school	Gave up work until recovery	Patient's colleague (Accepted by the ethical committee)	2.5 months
9	35	Male	Married	High school	Gave up work for organ donation surgery	Nephew/uncle	12 days
10	40	Female	Married	Primary school	Housewife	Wife	3 days
11	29	Male	Married	Primary school	Employed	Son	1.5 months
12	27	Female	Widowed	Primary school	Housewife	Third degree relative (Accepted by the ethical committee)	1.5 months
13	28	Female	Married	Primary school	Housewife	Mother	1.5 months
14	25	Female	Married	Secondary school	Employed	Mother	1 week
15	30	Female	Married	High school	Housewife	Third degree relative (Accepted by the ethical committee)	15 days
16	41	Male	Married	Secondary school	Employed	Brother	7 months

2.2. Procedure

Following ethical approval and informed consent, the interviews were held in a private room and continued for 60–90 min. An interview guide approach was taken during the interviews. Participants were prompted about their experience of life based on the interview guide that consisted of a list of topics prepared before the interviews. This flexible approach helped to probe for topics that were not thought of before the interviews commenced and to adjust the flow of the interviews to the individual participants (Henwood & Pidgeon, 1992; Patton, 1990). Donors were also questioned about recipients' illness and surgery for receiving a transplant, the process whereby an individual becomes a donor, the effects of these for donors themselves and the recipients, their understanding of the development of these effects and the nature of the difficulties experienced by themselves and the recipients, and to describe their views on recipients' experience of life following the diagnosis of ESLD and transplantation surgery. Part of these findings was published elsewhere (Tankurt et al., 2016). The interviewer (AT) audio-tape-recorded the interviews and transcribed them anonymously.

2.3. Data analysis

The present study was based on the Grounded Theory (Glaser & Strauss, 1967) which aimed not only to develop a theory about the topic in hand based on the views of the sample but also formulated specific data analyses strategies (Henwood & Pidgeon, 1992; Miller & Crabtree, 1992; Patton, 1990). In the present study, the aim was not to develop a theory as such but to use these strategies in a pragmatic way. These strategies necessitate a repeated cycle of data collection, data coding, and a comparative analysis (Glaser & Strauss, 1967; Strauss & Corbin, 1990; Yardley, 1997). This pragmatic approach has been used in other studies by the first author (Krespi, Bone, Ahmad, Worthington, & Salmon, 2004; Krespi Boothby, 2011; Krespi et al., 2008).

Established procedures for qualitative analysis were used to analyze the data and to base the analysis on the data rather than pre-existing theoretical knowledge (Glaser & Strauss, 1967; Patton, 1990; Stiles, 1993, 1999). The process of thematic analysis went in parallel with interviews. The first 10 transcripts formed the basis of a preliminary analysis by the second author (AT). This analysis was developed by other authors who also analyzed the data. Themes were changed on the basis of new data and subsequent data analysis. Procedures may not be sufficient to get to relevant findings (Barbour, 2001). Three methodological aspects were considered important. These included consensus, trustworthiness of data, and trustworthiness of the analysis. Established procedures of qualitative analysis helped toward achieving consensus (Elliott, Fischer, & Rennie, 1999; Guba & Lincoln, 1989). Sufficient transcript material was provided to ensure that the themes identified in the analysis were illustrated. This helped to ensure the trustworthiness of data. Attention was given to coherence, theoretical validity, and catalytic validity to assess the trustworthiness of the analysis (Stiles, 1993, 1999). The notion that the analysis incorporates comprehensive interpretations and the degree to which the themes identified during the analysis fit the data are referred to as coherence (Henwood & Pidgeon, 1992; Stiles, 1993, 1999). The extent to which the themes identified and the interpretations and conclusions made are related to theoretical constructs is referred to as theoretical validity (Henwood & Pidgeon, 1992; Stiles, 1993, 1999). The potential of the qualitative analysis to improve future clinical consultations and research is referred to as catalytic validity (Guba & Lincoln, 1989). The findings given below include illustrative transcripts. Each participant of the study is given a number to ensure anonymity.

3. Findings

Donors were aware of physical limitations, disruption in plans, and social life brought by recipients' ESLD. These were linked to the feeling that one dedicated his/her life to the recipient at the expense of neglecting other children ²*We have one more, you know, 12 years old, I think we neglected her while dealing with this one.*, which was also felt by the neighbors as well as the doctors ²*There is this pediatrician, to whom we take both kids together. He said, "I will make a complaint about you. You don't spend the money, time for (name: patient's sister) you spent for this one".* Donors felt the need to make lifestyle changes. Some donors changed their lifestyles including giving up smoking ¹*I was*

*a drinker and smoker, ... I was a social drinker. I stayed away from these., and putting on weight after surgery*¹*I am trying to eat well ... If you don't put on weight, then it means that there is something wrong.* However, others did not change their lifestyles.

Donors recounted that recipients' ESDL made them feel angry, sleepless, unhappy, hopeless, shocked, down, helpless, uncertain, distressed, but also confused¹*we were confused when we heard. The cirrhosis we knew occurs because of smoking and drinking, how could it be for God's sake?, and unable to accept the illness.* Fear was the predominant aspect of the donors' experience before surgery and worry was the predominant aspect of the donors' experience following recipients' transplantation. There was fear of losing the recipients and/or themselves during surgery for organ donation²*It is terrifying, while you are healthy then all of a sudden, I mean something will happen to you., and fear of hurting their dependents.* In fact, donors felt that they needed their loved ones' blessing before they went into surgery. However, other donors asserted that they did not experience fear⁴*While I was going to have surgery, I was not frightened at all or anything.* Some donors found a way to comfort themselves by focusing on destiny¹*I thought of my child. ... I said "If the Allah ... it's destiny, then it would happen somewhere out there if not here. ... So I considered this as a self-comfort.* Sources of worry involved the recipients' need to use prescribed medications regularly, side effects of the recipients' medication⁷*I mean side effects to the extent of causing cancer.",* recurrence of recipients' illness²*When his enzyme levels goes up that fear, you know, that something will happen? "are we going to go through all of this suffering again",* rejection of the recipients' transplant³*It is an uncertain process, if it is rejected or not.,* risk of infertility for the recipients²*I mean, will the girl be able to get pregnant? can she have a baby?,* and the occurrence of ESDL in the offspring of the recipients and the donors.

Donors felt⁶*irritable* during the convalescence period, and before organ donation, stressed, tired and angry, ugly, inadequate²*I will get ugly, I won't be able to handle all the chores I used to do at home, will I fall short in taking care of my children?,* down⁷*I lost a lot of children in the hospital environment. Seeing children, my head was full of children's cries.,* and disappointed²*you know he (the uncle) said "I will donate it and save you" and when he gave up afterwards, I was disappointed.,* and lost confidence and courage. According to donors, before organ donation, relatives other than donors, such as fathers also felt down and upset and siblings wetted themselves¹³*The kid, who never wet his clothes, started to do so.,* vomited and had fever and headache¹⁵*I was hospitalized and next day they hospitalized my daughter, I had psychological vomiting, fever and all.*

In addition to negative emotions, following organ donation, donors recounted not only feeling happy, relieved, comfortable, strong, proud of themselves, excited, joyful, and confident but also feeling appreciated⁴*Nobody knows organ transplantation in my village for example. The elders who heard this said "We appreciate, no mother would do what she did.",* reputable¹⁶*It reflects on our family, relatives and even neighbors'. ... They say "Well done, a sibling donated his liver to his sibling.",* and¹¹*conscientiously comfortable.* Donors also felt like being born again⁴*It is like a new world for both her and me, we are like newborns.,* saving the world¹⁶*It felt as if saving the world.,* rewarded in afterlife¹⁶*I can say that I have guaranteed half of the heaven.,* and paying off the debt of conscience⁵*I guess this is the greatest duty you would fulfill for your mother, ... after all you ensure your mother's life to continue.*

Donors recounted both worsening of character and positive changes in character. Worsening of character included becoming half human³*I guess I became half human in his eyes.,* turning into an aggressive person¹*Sometimes I can get angry for no reason. I can get angry about trivial things, which didn't happen before.,* and facing up to the bitterness of life¹*I learned how bitter life could be.* Similarly, donors also reported worsening of character in the siblings of the recipients. In particular, these also included becoming jealous, aggressive, and disobedient¹³*He is disobedient, after all he is not grown up, and he is a 5 year-old kid.* Positive changes included becoming²*more of a believer.,* being grateful²*I say "thank you God for granting me such thing so that I can do something good for my child. You gave me such a good liver that it also did good to her.",* becoming¹¹*stronger,* becoming a

humanist ¹⁶*you start to think in a more humanistic way*, and having a better outlook on life ¹⁶*The way I looked at the world changed after the surgery. ... It offered me additional benefits.*

In addition to improvement in social life following organ donation, donors remarked that they were supported especially financially by family and non-family members and the government. However, support from doctors and their trust were also important ²*I trusted the doctors so much ... I mean, Mr. (doctor's name) consoled us very much.* On the other hand, some donors felt not supported by potential supporters like mothers, or spouses ¹³*My father and mother are very old, they are in the village. When I had this operation, they weren't here.* However, for some donors this reduced the burden that was felt ⁷*It was better for me that my mother didn't come, because she would fall, faint and cry. ... I was kind of relieved when she didn't come.* On the contrary, particularly mother donors felt that they were the sole caregiver throughout the whole process and found this burdening ⁴*Nobody supported me. I didn't have anyone with me. I was worn out too much.* During this process a special bond was formed between some donors and recipients ⁵*It creates a different bond between you, I mean, you donating your organ, your liver to your mother is an entirely different thing, it creates a completely different bond I mean.* Other donors, on the other hand, mentioned that close relationships got worsened ³*there was a person who I had been seeing for 5–6 years ... His attitude changed right after the surgery.*

4. Discussion

Consistent with literature suggesting low levels of quality of life among donors (Walter et al., 2003) in the present study donors were aware of limitations brought by recipients' ESLD including physical limitations, disruption in plans and social life. There was also dedication of one's life to the ill person even to the point of neglecting the other family members which reflected the burden of caregiving (Dillehay & Sandys, 1990) brought by ESLD. Although all donors were aware of the need to make lifestyle changes, some changed their lifestyles whereas others did not, consistent with previous studies (Fujita et al., 2005). In the present study, donors regarded lifestyle changes as restrictions imposed by doctors to which they reacted with obedience or disobedience rather than perceiving them as beneficial and internalizing them. Viewing lifestyle changes in this way may lead to reactance (Brehm, 1966) and consequent non-adherence.

Donors recounted emotional changes including the experience of both negative and positive emotions, worsening aspects of character and positive changes in character. Consistent with previous work (Papachristou et al., 2010; Walter et al., 2004), fear and worry were the predominant aspects of the donors' experience. However, the experience of negative feelings or symptoms by other relatives such as wetting oneself, vomiting, and having fever has not been reported before within the context of organ donation for ESLD so as worsening aspects of character including becoming half human, turning into an aggressive person and facing up to the bitterness of life. Donors could also experience positive feelings and positive changes in character. Of particular importance, these included feeling appreciated, reputable, feeling like being born again, saving the world and rewarded in afterlife as well as becoming more of a believer and a humanist. Apart from feeling motivated for an operation, feeling certain (Walter et al., 2004) and feeling free (Papachristou et al., 2010), these have not been reported before. These findings suggest that donors' experience of life does not only involve experiencing loss but also finding benefits as reported before in other chronic illnesses (Krespi et al., 2008).

Perception of support from loved ones was not universal. Although some donors felt supported by other people especially by their surgeons which is consistent with previous quantitative and qualitative findings (Fujita et al., 2005; Papachristou et al., 2010; Tong, Morton, Howard, & Craig, 2009), others did not. The view of not feeling supported by other people reduced the burden of caregiving for some donors whereas the view of being the sole caregiver throughout the whole process as a mother was too burdening. These findings extended the literature by providing specific mechanisms whereby burden of caregiving is felt by donors. Consistent with previous qualitative findings showing the strengthening of relationships and donors idealizing their relationship with the recipients (Tong et al., 2009; Walter et al., 2004), there was the formation of a special bond between some donors

and recipients. This finding indicates the specific way in which social support can be beneficial within the context of organ donation. On the other hand, there was also worsening of close relationships. This finding has not been reported among donors of liver transplant.

Religion was an important aspect of donors' experience. There was the view that organ donation might be a sin. Moreover, following surgery for organ donation, some positive feelings (including feeling like being born again, saving the world, feeling like rewarded in afterlife) could be interpreted within the construct of finding meaning following a traumatic event like organ donation in a religious context. These findings extend the literature by suggesting mechanisms whereby religion provides the basis for finding meaning.

5. Conclusion

Existing psychological theory about adjustment can help to understand a number of findings of the present study including physical and social limitations brought by recipients' ESLD and surgery for organ donation, awareness of the need for lifestyle changes, experience of negative emotions and the lack of support from others. Some ways of adjusting (worsening aspects of character and close relationships, positive emotional changes and reduction of burden of caregiving because of lack of support) which have not been reported before within the context of organ donation for ESLD may represent targets for individual consultations or psycho-educational programs for promoting adjustment and fostering emotional well-being among donors of liver transplant.

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