



## The Second-Chance Self: Transformation as the Gift of Life for Maternal Caregivers of Transplant Children

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### Abstract

*This paper examines the phenomenon of transformational growth in maternal caregivers of children who have undergone a kidney transplant. Semi-structured interviews were conducted with seven mothers of transplant children who shared narrative accounts of their lived experience. Through a phenomenological analysis of the interview data, the fundamental structure of positive growth in caregivers of transplant children was illuminated, revealing both themes of unresolved suffering and trauma and themes of posttraumatic growth and transformation.*

While being a parent is one of the most rewarding challenges a person can experience – what happens when that role requires that a mother also become an informal medical caregiver and, perhaps, even an organ donor for a child diagnosed with end-stage renal disease (ESRD)? ESRD is defined as permanent kidney failure necessitating dialysis treatment or an organ transplant in order to remain alive. A review of the literature reveals that caring for a child with ESRD is a complex and challenging task, and that, as a result, parents often suffer anxiety, depression, and even posttraumatic stress disorder (PTSD) (Young et al., 2003). Parents who are faced with the need for a child to undergo a kidney transplant are most often highly stressed at every stage of the transplant journey.

Prior to transplantation, for example, children with ESRD experience declining kidney function or even complete kidney failure, with nearly one-third of them undergoing dialysis, a treatment modality that utilizes peripheral equipment to remove harmful wastes that build up in the body. Whether dialysis takes place at home or in a clinical setting, it is a time-consuming, exhausting, and often risk-laden procedure, especially with paediatric patients (Tong, Lowe, Sainsbury, &

Craig, 2008). A child with ESRD also needs to be confined to a special diet and take medications to help keep the electrolyte system balanced. Suffice it to say that the list of challenges parents encounter seems endless. One of the most noteworthy issues in this regard is the shortage of donor organs, resulting in 50% of parents waiting for an uncertain period of time for a deceased donor organ while another 50% are hoping for a living donation, or are themselves being evaluated as potential organ donors (Zelikovsky, Schast, & Jean- Francois, 2007).

The transplant and posttransplant stages of the three-stage journey present parents with another set of challenges no less daunting than those encountered in the pretransplant stage. Indeed, parents express similar emotions throughout their journey; however, at this juncture they have the added worry of rejection of the kidney graft. Additionally, parents manage a complex regimen of anti-rejection medications and the need to keep the transplanted kidney adequately hydrated (Tong et al., 2008). Mismanagement of these tasks, or a simple mistake, can result in loss of the transplanted kidney and even the death of one's child. In this regard, as the findings of Young et al.'s (2003) study

indicate, a parent's appraisal of, firstly, the threat to the life of the child and, secondly, the intensity of the treatment are significant predictors of PTSD and severity of symptoms. It has in fact been shown that a parent's perception of these variables significantly outweighs the objective reality of the child's actual health status. It is thus crucial for medical personnel to support the parents by helping them understand the degree of threat to the child and details regarding the treatment regime, accurate and timely information in which regards can serve as vital to the formulation of accurate parental appraisal of a child's health status.

In sum, even though research reveals that high levels of stress in a caregiver can compromise his or her physical health and quality of life, the severity of the stress experienced by parents of children diagnosed with ESRD who are awaiting a kidney transplant is largely undetermined (Zelikovsky et al., 2007). What is certain is that both mothers and fathers experience stress and depression related to their child's ESRD, with mothers reporting higher rates of each as a result of carrying the greater share of the caregiver burden. If the mother also served as her child's organ donor, her level of personal strain was further compounded. All of the foregoing have a negative influence on a caregiver's ability to adjust psychologically, which in turn is known to have a negative impact on the health and psychosocial outcomes of the child (Zelikovsky et al., 2007).

### Positive Growth and Self-Transformation

The power of traumatic events to fuel psychological distress cannot be underestimated. A review of the literature established the existence of trauma, stress and PTSD in some parents of transplant children (Williams & Yule, 1997). Despite this disheartening evidence, there is an increasing body of evidence that positive psychological changes can also evolve from stressful events. Over the past decade, research on adjustment following trauma has expanded to include a perspective on the phenomena of personal growth and transformation in the aftermath of adversity. Positive growth is not focused on emotional states and subjective well-being by, for example, reducing the experience of posttraumatic stress with its symptomatic avoidance, hyperarousal, and re-experiencing, but is instead more attentive to fundamental positive changes in schema, world view, and psychological well-being (Joseph & Williams, 2005). Psychological well-being, in this sense, is concerned with the existential challenges in life that include acceptance of self, mastery of environmental influences, personal growth, autonomy, relationships with others, and purpose in life (Ryff & Singer, 1996). At the same time, the growth approach does not preclude the acknowledgement that suffering is inherent in stress, as it incorporates the process of suffering into its

spectrum by assuming that suffering is a part of the process.

There have even been some limited but promising studies specifically aimed at exploring the incidence of positive transformational growth in parents of children with acquired disabilities, chronic illness, or acute illness (Barakat, Alderfer, & Kazak, 2005; Konrad, 2006). The findings of these preliminary studies to date appear to accord with the findings of a larger body of research on the phenomenon as it applies to chronic illness populations of adult patients and their caregivers, and adult victims of other types of trauma.

### Theories of Transformative Growth

In adult populations, four noteworthy theories on transformative growth stand out as prominent, with each providing a diagrammatic model for depicting the phenomenon and explaining the process underlying its occurrence. While all four of the models have common threads of explanation, each is unique and valuable in its own right. The phenomenon of transformative growth is labelled and described as *posttraumatic growth* by Tedeschi and Calhoun (1995), *self-transcendence* by Reed (2008), *transformation* by Dubouloz et al. (2010), and *worldview transformation and social consciousness* by Schlitz, Vieten, and Miller (2010). A brief overview of these theoretical approaches provides a foundational framework for understanding the value of conducting the phenomenological study being reported here: a study designed to illuminate the process of transformational growth in caregivers of transplant children.

Tedeschi and Calhoun (1995, 1996) addressed the possibility of assimilating trauma in such a manner that a person might ultimately derive positive benefit. To conceptualize this outcome and process, they used the term *posttraumatic growth* – an outcome noted by the present researcher as one of the three phenomena present in the experience of particular maternal caregivers of transplant children. Tedeschi and Calhoun's schematic model of post-traumatic growth provides a concise overview of this process, which they view as part of a self-regulatory system of feedback loops that operate on both intrapersonal and interpersonal levels. The schematic of their model is segmented into sequential events or processes. Tedeschi and Calhoun (1996) also provide an empirical instrument designed to measure the phenomenon.

In brief, personality characteristics are expected to influence the initial and ongoing responses to trauma, with the underlying assumption being that people are predisposed to order in the face of chaos. Growth occurs, however, only if there is change to the integral structure of one's basic schema. Essentially, after the initial shock and denial dissipate, resulting in the failure

of primary control strategies, a serious challenge to higher-order schemas evolves. Behaviours that had previously been effective in halting or reversing the impact of the trauma no longer work. The situation is assessed to be unmanageable, incomprehensible, and devoid of meaning, eliciting a secondary response of rumination. A person who engages in rumination for a period of time, without staying stuck in an endless cycle, essentially gains a semblance of psychological control. A perceived ability to have possibly altered the situation in a positive way renders one more powerful than seeing oneself as having been completely vulnerable or powerless. Provided that the person does not get stuck in guilt, engaging in rumination can thus be viewed as an emotion-focused coping approach that relieves distress.

The influence of environmental factors, such as help from other people, also aids the traumatized person in gaining insight. In this phase of the process, new and unique ways to handle the circumstances are realized. Facilitated by active support from others, positive personality characteristics in the affected party, and the ultimate alteration of his or her schema structure, acceptance, effective coping, and a sense of personal strength are able to be realized.

While posttraumatic growth uniquely emphasizes trauma as a precursor to growth, thereby providing a model which incorporates the issue of complex trauma into its framework, two additional concepts help to describe and account for personal growth from a different but equally important perspective: *self-transcendence* and *transformation*. Aspects of each of these concepts are also potentially applicable to the experience of positive change in maternal caregivers of children who are organ transplant recipients.

Reed's (2008) theory of self-transcendence, which is an empirically validated theory of nursing, is unique when compared with psychological definitions of the concept. Reed's conceptual model of the process of self-transcendence diagrams three fundamental sets of relationships: vulnerability, self-transcendence, and well-being. Firstly, increased levels of vulnerability such as those caused by a health crisis can effect an increase in levels of self-transcendence. Events that heighten one's sense of mortality, insufficiency and vulnerability can promote developmental progress toward a new sense of identity and expanded self-boundaries. The relationship between vulnerability and self-transcendence is nonlinear, in that the degree of vulnerability does not directly relate to the level of self-transcendence. Secondly, self-transcendence and well-being directly relate to one another, with a sense of one correlating positively with a sense of the other. Well-being is also regarded as a consequence of self-transcendence. Thirdly, a wide array of personal and contextual factors may mediate and moderate these

central relationships involving self-transcendence.

Self-transcendence theory addresses intrapersonal and interpersonal change, and expands comprehensively to include contextual, environmental and transpersonal shifts. It also uniquely includes the underpinnings of lifespan development theory, which is often regarded as an integral framework from which to conceptualize personal growth. Whatever change may occur, however, may not be a pervasive or lasting change. Both posttraumatic growth and self-transcendence include meaning-making as an integral element of change; but, if additional trauma is incurred and meaning is lost, one might well ask if the potential for personal growth is also lost. This raises yet another interesting question, namely, whether positive growth as a transformative phenomenon can include a lasting change.

Transformation is a concept that helps to complete the picture of positive change in the world of chronic illness. A preliminary understanding of its potential application to transplantation can be gleaned from a meta-synthesis project proposed by Dubouloz et al. (2010) that situated transformation in a chronic-illness context in a primary-care medical environment. Dubouloz et al.'s (2010) model diagrams the process of transformation as beginning with a medical illness diagnosis that initiates a reaction period of up to five years wherein the interplay of personal responses and the responses of significant others contributes to triggering a catalytic experience as a turning point in the process of transformation for the patient. This turning point is the stepping-stone to the next phase, referred to as "embracing the challenge", where the reality of the illness is acknowledged and embraced. Critical reflection is engaged, the context is assessed, and adjustments are made in perception, activities, relationships, and the differentiation of body and self.

The final phase of the transformation process is identified as "integration of new ways of being" and entails the person's both identifying and experiencing personal transformation. This includes a heightened sensitivity to life, understanding and acceptance of the new self, and greater appreciation of significant others. A penetrable boundary – including a social and personal context, interactions with peers and healthcare professionals, social support, the healthcare system, and the person's willingness and ability – comprises a context for the model as a whole. The model furthermore captures other important elements of change common to living with chronic illness, such as acknowledgement of the condition as being life-long, acceptance of the necessity of having seemingly never-ending interactions with medical professionals, and recognition of the trajectory of the illness as being nonlinear, cyclical, and sometimes regressive.

Lastly, researchers at the Institute of Noetic Sciences

(Vieten, Amorok, & Schlitz, 2011) engaged, for over a decade, in both qualitative and quantitative studies of the phenomenon of transformation and found evidence of individual growth serving as a catalyst for the transformation of society as a whole. Their work included the investigation of individual narratives of personal transformation, including three focus groups of teachers of transformative processes, in-depth interviews with 60 recognized sages of ancient and modern wisdom traditions, surveys of over 2,000 people who reported experience(s) of transformation, and longitudinal studies of people who engage in ongoing regular transformative practices. Generally, their findings revealed that lasting change springs from a profound shift of perspective and fundamental change in world view.

The most fundamental change leading to deeper meaning and a clearer purpose in life occurs internally as one's reality is redefined (Schlitz, Vieten, & Amorok, 2008). The benefits of this transformation may, however, not be limited only to the persons who are experiencing a shift in their world view. Schlitz, Vieten, and Miller (2010) proposed that, when a change of internal structure does occur, a transformation of world view is primed to develop into a new social consciousness that over time translates into a conversion process that might be described as evolving from a "me to we" perspective. What is implied is that one becomes aware of being part of a greater whole in an interrelated community of others.

Schlitz et al. (2010) identified five developmental levels of social consciousness that essentially describe how consciousness transformation can be conducive to an experience of having more meaning and purpose in life, which in turn leads to the person becoming more empathetic, compassionate, and service-oriented, as well as an active agent of change in his or her community.

One of the circumstances shown to impact deeply on a person's world view is being diagnosed with a serious illness, especially one that poses the very real possibility of death. A diagnosis of ESRD and the need for transplantation is no exception. As Schlitz et al. (2010) noted after initial interviews with their focus groups:

Transformation is a process that can be stimulated by even the most shattering of circumstances. In fact, some transformations seem to require the kind of vulnerability that accompanies extreme loss or grief. This is what separates transformation from more linear processes of psychological development as typically understood. Transformation often asks for something to die so that something new can be born. (p. 30)

In sum, posttraumatic growth, self-transcendence, and transformation are phenomena that reveal overlapping processes and a desirable positive outcome that often involves an expansion of self-boundaries so as to encompass a new world view or orientation that may have a lasting effect. Whether growth occurs as a post-traumatic shift in cognitive schema, manifests as an unprovoked noetic event, or evolves out of a catalytic turning point, understanding what contributes to the phenomenon and how it might be encouraged in the lives of those managing chronic illness is a valuable endeavour.

### Trauma, Personal Growth, and the Transplantation Process

As a maternal caregiver of a transplant child, it is my first-hand experience that, in spite of the trauma associated with a child's transplantation, growth and transformation are possible. As the literature reveals, however, maternal caregivers of transplant children are largely understudied, and the limited research that does exist lacks exploratory consistency. As Schlitz (2005) pointed out, health, healing and wholeness are woven together in a multidimensional tapestry that demands a consistent and integral approach built on a sound structure of understanding. Proceeding from this perspective, a qualitative phenomenological study of posttraumatic growth, self-transcendence and transformation in maternal caregivers of transplant children emerged as the focus of the research reported here. Essentially, through a rigorous phenomenological analysis of the content of caregiver interview data, a fundamental structure of the phenomenon of transformational growth in this context became illuminated, leading to a better understanding of its makeup and of how it might become more intentionally cultivated.

As presented in the following sections, the present research points to the possibility that a traumatized caregiver can overcome the negative impact of her trauma, making a pivotal turn toward personal growth and transformation that results in a rippling effect of positive outcomes for her herself, the patient, family members, medical providers, and communities at large. Indeed, given that transplantation is a worldwide treatment modality that continues to grow, the occurrence of transformative change in a caregiver on an intrapersonal, interpersonal, and spiritual level might have a far-reaching influence on all who are directly or indirectly affected by this experience.

In this inquiry, the phenomenon of transformational change unfolded in the stories that caregivers shared. But, just as Tedeschi and Calhoun (1995), Reed (2008), Dubouloz et al. (2010) and Schlitz et al. (2010) noted, the caregiver's path to transformation is not a linear one, with the stories shared here revealing that the fundamental structure of the phenomenon

includes a process of evolving through many layers of suffering. Following an overview of the research methodology and design, and the process whereby the data was analyzed, the themes extracted from the caregivers' accounts, along with excerpts from their interviews, are presented.

### Research Methodology and Design

Heidegger (1927/1962) proposed that phenomenology uncover concealed meanings through the interpretation of narratives of the lived. The experience of living through a situation or event in time (lived experience) is only known reflectively and is expressed through speech and language. For the present study, seven mothers who each had a child who had received a kidney transplant were recruited to participate in face-to-face, semi-structured, audio-recorded interviews where the reflective content of their experience could be captured in a narrative format. The end result of this phenomenological inquiry tells a story that provides insights into the phenomenon of positive growth and its associated meanings in maternal caregivers of transplant children (Kleiman, 2004).

For the present study, an existential-phenomenological approach was selected in order to allow for any experiences of trauma and transformative growth to surface in the narrative accounts of the transplant caregivers. This orientation takes into account that the caregiver is inextricably intertwined with her environment, and that she thus makes choices within an external situation with its own unique characteristics (Braud & Anderson, 1998). Consequently, context is key to how the individual experiences a phenomenon. In this study, a phenomenological approach allowed the caregiver's experience of positive growth to emerge within the unique context of the paediatric transplant environment, thus providing an in-depth look at *what* the phenomenon is and *how* it unfolds (Giorgi, 2009). This resulted in a diagrammatic representation of the fundamental structure of positive growth in the transplant caregiver.

### Data Analysis

The analysis of the descriptive data incorporated the phenomenological approaches of Giorgi (2006, 2009), Colaizzi (1978), and Hoskins and Mariano (2004). Primarily reflecting the suggestions of Giorgi and Colaizzi as presented by von Eckartsberg (1998), the process of handling, transforming and reporting the data unfolded in the following sequence: (a) firstly, the audio-recorded interviews of the seven caregiver participants were transcribed verbatim by a third party, (b) the transcripts were then read and reread several times in order to gain a clear sense of the whole, organized into demarcated meaning units, and transformed to highlight the dimensions of psycholo-

gical meaning within the phenomenological reduction, and (c) the general meaning units were transformed into first explicit, and then implicit, units of meaning within a psychological perspective, with particular sensitivity to the phenomenon of transformative growth. This approach to the data helped to prevent interpretation being coloured by any pre-existing bias of assumption, hypothesis, imaginative construction, theory, causal speculation or explanation in reference to what the participants presented (Giorgi, 2009, pp. 88–89), and allowed for formulation of the most accurate description possible of the psychological aspects of the participants' experiences.

At this juncture, analysis of the data as outlined above is usually considered to be complete, with the fundamental structure of the phenomenon being delineated and reported. I was, however, also curious about how the experiences of transplant caregivers fit with the four established models of growth referenced earlier.

Traditionally, a mixed-methods study might have provided a viable avenue of exploration. However, I was interested in obtaining a more in-depth picture of how the growth process occurs, and more specifically in understanding how the general meaning units generated in this study related to the central themes presented in each of the four existing models. In addition, I compared each of the four models with one another and identified a component unique to each of them. From this, the following four questions were generated:

- 1) Posttraumatic Growth: What is the maternal caregiver's experience of stress and trauma?
- 2) Posttraumatic Growth: What is the maternal caregiver's experience of beneficial change?
- 3) Self-transcendence: What is the maternal caregiver's experience of connection with self, others, and the environment?
- 4) Transformation and Worldview Transformation: What are the specific events or experiences that create a turning point or catalyst for positive change in the experience of the maternal caregiver?

Details of this analysis can be found in Grace (2014).

### Results

Participants revealed that being a caregiver for a transplant child is an endless quest that entails layers of loss, and with each loss there is the need to start anew. The experience of loss and renewal is recurrent and at times seemingly endless. The overarching theme describing this process was labelled a "journey of

endless beginnings". In the context of this description, three main themes were identified:

- (1) encountering loss,
- (2) transitioning through loss,
- (3) reconciling loss.

Six sub-themes comprised the first part of the journey, a time laden with trauma. Months before and after the child's transplant, a second or transitional period unfolded, with three sub-themes characterizing this pivotal time. It was at this juncture that profound connections with others were made, leading to the possibility for caregivers to transcend their trauma and have the opportunity to experience positive growth. The third phase of the journey, comprising six sub-themes, entailed additional losses, and yet also presented a time of renewal. These three parts of the transplant journey are presented below in terms of the three main themes, each with its underlying sub-theme clusters. Excerpts from caregiver interviews are provided to substantiate the themes identified.

### Main Theme 1: Encountering Loss

The first part of the journey, "encountering loss", comprised six sub-themes: (a) intangible losses and emotional scars, (b) becoming an informal medical caregiver, (c) disconnection and isolation, (d) looking for connection with medical providers, (e) environmental impact and learned hopelessness, and, finally, (f) endurance, suffering, and survival. This first part of the journey comprised the timeframe prior to the child's organ transplant and is referred to in the study as the pretransplant phase.

#### Sub-theme 1: *Intangible losses and emotional scars.*

Receiving the news that one's child has been diagnosed with ESRD can be devastating, but caregiver accounts reveal that the way in which the message is delivered can be even more traumatic.

*Well, the most challenging thing, and the thing that has always stuck out in my mind was the many times that I was told during all these – to take my – well ... I was told ... to take my four-and-a-half month old organism home and let it die. And explaining to that particular doctor ... that she was not an "organism", she was a living, breathing immortal soul – going to live with me as long as I had breath.*

*Then I went to a perinatologist – this one that had done the amnio, and said – he identified it: "Oh, this is polycystic kidney disease." He goes, "I'm sorry, this – these children don't live – I don't know if it's ... if it's autosomal recessive polycystic kidney*

*disease [ARPK] or con-genital hepatic fibrosis [CHF]." So it's ARPK, slash, CHF. And he goes, "These – these kids don't live. He said we can either cut her out now and have her pass away, or she – she'll die inside you and then we'll have her cut out, but that's riskier. So – and I went back home to just cry.*

#### Sub-theme 2: *Becoming an informal medical care-giver.*

The transition from being a mother to becoming an informal medical caregiver is abrupt and brutal. The wonder attached to mothering is all at once obliterated by the unnatural prospect of the child's death and the caregiver's shift from nurturing mother to being both mother and medical provider. The merging of these roles runs contrary to nature or reason, forcing the caregiver to become a condoning witness and participant in her child's invasive medical treatment. As the caregiver proceeds in her journey, the tasks of caregiving prove to be both countless and never-ceasing, merely changing form over time.

Six of the seven mothers who were interviewed dealt with pretransplant dialysis and feeding tubes. All seven had encountered challenges associated with management of their child's nutrition, hydration, and medication pre- and posttransplant. All seven had to advocate on the child's behalf in the school system and with health insurance. Four of the seven had also had to deal with special needs that were not related to the transplant, including cognitive delay, blindness, seizure disorder, and orthopaedic issues.

*I stayed up all night long watching A's blood pressures. I had the machine on this table over here with the – with the bags up here, and the cyclor here that A was on, and I would watch her blood pressures all night long. And I would stop the machine and add another bag to keep A's blood pressure exactly steady, really low. I kept it low – in fact, maybe a little too low. I kept her in the 70s and 80s because – because she'd been on four blood pressure meds for hypertension, when she was under-dialyzed, when she was – when it wasn't working well.*

*The bottom line is the moms, you know, typically are the ones that end up with the lion's load of the – the caregiver duties, going from doctor's appointments to lab visits ... to overnight hospital stays ... everything really kind of falls on the mom. It's the constant management of the fluids, pills, medical centre visits ... . It's ... the bulk of it falls onto the mom 99% of the time.*

**Sub-theme 3: Disconnection and isolation.** Being a caregiver demands a great deal of self-sacrifice. As layers of the caregiver's prior identity were peeled away by the demands associated with becoming an informal medical provider, one mother revealed the greater need than ever before for support from her spouse, family, friends, and social networks. This, however, required her to have both the capacity and the willingness to reach out for help and to receive help that was offered. Sometimes others wanted to help, but they did not know how to help. Sometimes others abandoned the caregiver. A lack of support, for whatever reason, contributed to the many layers of loss experienced by the caregiver, especially early on in the journey.

*Marital issues, I think, come into play quite a bit. Not so much now, but in the early years ... . And not that – you know, my husband works full-time and it's logical that it does fall on me, but I think in some – you know, there have been times definitely that there was resentment that I had to carry that load, because it's a big load. We're fine now, but I mean there have been for sure issues because of that.*

**Sub-theme 4: Looking for connection with medical providers.** A key step to functioning effectively as an informal medical caregiver includes forging a viable working relationship with the transplant team and other medical providers both pre- and posttransplant, and learning how to survive in the hospital and other medical environments. It is a foreign territory for the vast majority of caregivers. It is not an even playing field, and the caregiver is on a steep learning curve, all while her child's life hangs in the balance. The caregiver is dependent on the connection she forms with the medical providers. They are the experts she looks to for instruction, guidance, and moral support. Some of the biggest complaints heard from caregivers were the medical system's emphasis on protocol, lack of personable and respectful interchange with medical providers, and feeling demoralized in their efforts to be an adequate caregiver.

*Yes, they are on call and they see it, but they don't live that – this life 24/7. They do not live this life 24/7. One of the providers right now, actually, I see her name or I see the number come up [on caller ID] and I cringe. I have anxiety attacks because she has been mean to me ... . And just – the coordinator treated me like I was the stupidest thing, really rude to me.*

*It's just been a nightmare. I refuse to work with her now. They (the transplant team) – they don't really understand. Yes ... they*

*deal with it every day ... they are while they're at work and ... they are on call, but they get to go home! They get to go home and live their lives. They don't understand that it goes on.*

**Sub-theme 5: Environmental impact and learned hopelessness.** As each caregiver revealed, she had to be an active advocate for her child in medical settings, especially in the hospital environment, which is not designed to take individual needs into account. Many protocols and regimens seemed as though they were universally applied whether warranted or not. Some were even felt to be inadequate. One mother went so far as to write a protocol herself.

*And I find that nurses and doctors don't necessarily always look at one patient, as this is an individual patient. It's not the other 20 that they're seeing right now. For them it's not ... "This is E and this is his situation. These are his parents ... these are their likes and dislikes." They don't – they just kind of look at you, like, "Oh, well, he has this, so we're going to do X, Y, and Z. That's what we do. That's protocol."*

**Sub-theme 6: Endurance, suffering, and survival.** Caregivers suffer through a seemingly endless stretch of uncertainty prior to their child's transplantation. Caregiving tasks are countless and exhausting. Some deal with the trauma of dialysis and feeding tubes, while all of them manage medications, appointments with doctors, and endless blood draws, in addition to dealing with the demands of everyday life. However, just as the winter solstice is a turning point towards the season of spring and rebirth, so is transplantation a turning point for another new beginning. Although the pretransplant period is a time of suffering, marked by endurance and survival for every caregiver, there is the trust that eventually the day of transplantation will arrive. However, as the following account so poignantly revealed, the road leading up to that event is difficult.

*When I brought her home on peritoneal dialysis, I, you know, I didn't know if I could take care of a child, you know, here is this child ... . [As her daughter was finally released from the hospital for the first time, a nurse said to her] "Here's all the tubing and things and oh, oh, now you be very careful because you've got to put heparin – inject heparin in the bag" [the peritoneal dialysis solution bag]. And here's little vials, and you've got to get the little needle right in the little – the little hold and put ... " – and I had really strong glasses and strong lights and if I saw a little piece of lint over*

*there, I'd throw everything away and start over. Because I – because I didn't know just how easily they could get peritonitis because I left her at the hospital; they did it one night, gave her methicillin-resistant staphylococcus aureus ... almost killed her.*

## Main Theme 2: Transitioning Through Loss

At some point in the journey, each caregiver seemed to enter a transitional phase where she was found to experience renewed strength and hope. This period of time included the three to four months immediately preceding and then directly following the transplant procedure. Prior to the transplant, each caregiver anticipated the day when her child would finally get a second chance, a new beginning if you will. There was significant suffering during this interval, and the ups and downs came in shorter bursts of time and with greater intensity. In other words, the stakes were higher and the impact of the gains and losses were proportionate, predisposing the caregiver to increased incidences of stress, trauma and loss, exacerbating her vulnerability.

After the transplant took place, caregivers expressed relief, but within weeks they discovered that the relief was only temporary. There was loss experienced post-transplant as well. Thus, the main theme identifying the middle phase of the journey is described as “transitioning through loss”, and contains three sub-themes, identified as: (a) the second-chance search, (b) transplantation as the gift of life, and (c) facing posttransplant loss. This phase proved to be critical in the sense that a caregiver could get “stuck” or unable to come to terms with past, current and anticipated future losses. In essence, during the transitional phase leading up to and following the transplant, caregivers were scourged in a relentless fashion by their circumstances, adding to an already overwhelming load of stress, and causing the pain and suffering to deepen. The increased vulnerability that caregivers experienced at this juncture, even though catalytic with regard to their experiencing traumatic stress, paradoxically increased the opportunity for positive change as well.

*And we had a couple of false alarms. My niece was the first person that was supposed to be C's donor ... and then – the surgery was scheduled for a Monday and she flew up on Friday, and Friday afternoon, they discovered that we lost our match ... he had an antibody, C developed an antibody. So, literally, she was on the airplane on her way out. So we lost that match ... and then we had a second one and the person didn't want to be identified ... and they wanted to do it – their goal was*

*for C to transplant before he failed ... but they had a second donor lined up and as he was going through his screening they found something wrong with him. So he couldn't be a donor.*

**Sub-theme 1: The second-chance search.** Exhausted by endless duties, caregivers endured days and nights hoping the time for transplant would finally arrive. For some of the caregivers, the pretransplant period included a frantic search for a donor organ, while for others this period involved identification, testing and preparation of the living donor candidate, who may have been the caregiver herself. For caregivers with infants, there was a need for the infant to grow to an acceptable size and weight in order to be a recipient. All child recipients also had to be healthy enough to receive an organ.

During this preparatory timeframe, the caregivers experienced hope, shattered hope, and finally some level of relief when a donor organ was found or a living donor candidate was selected. During the search and preparation for transplantation, the caregiver and her child simultaneously continued to endure the demands of pretransplant treatment and to weather the associated trauma and crisis. For some caregivers, the pretransplant journey included the child receiving dialysis, which was, in and of itself, highly stressful. Since the hope of being relieved of dialysis treatment was vested in the prospect of receiving a kidney transplant, the search for a living or deceased donor organ became the primary concern. Unfortunately, organ donors and donor organs are in short supply. Even when a deceased-donor organ was found or a living donor volunteered to donate, there were delays, often with reasons why the transplant could not be done.

*While R was on dialysis, we got a call ... “Oh, we might have a match for you.” So we took him. They prepped him up and he was – the surgeon came the next morning and said, “Sorry, it wasn't a good match, so we're going to give it to the next candidate.” Oh, that was very – that was very hurtful, very.*

**Sub-theme 2: Transplantation as the gift of life.** When the long awaited day arrived that the transplantation finally took place, caregivers were grateful. Even the stress of being a donor herself and going through the angst of the child's surgical process was an improvement over the pretransplant experience of dialysis and the darkness of constant unknowns. The time of transplantation was a time to celebrate life, but paradoxically also a time to grieve a death.

*We had a donor transplant organ, so I think*

*that we've – with that happiness that knowing that D was going to be saved, the guilt of knowing that another family paid the ultimate price by their giving their daughter's organ, the kidney came from a 7-year-old girl who was hit by a car. I know what the cost was to that family. So that was very difficult.*

**Sub-theme 3: Facing posttransplant loss.** The post-transplant period proved to mark a pivotal time of adjustment for the caregiver, who came face-to-face with the harsh reality that transplantation was a treatment modality and not a cure. Now the caregiver had two deaths to worry about: the possible death of the transplanted organ and the possible death of the child. In retrospect, the caregiver came to the realization that the early part of her journey was just the beginning of a never-ending story.

*Oh, it's insane. It's like every time we're in lab and then get a phone call, "Oh, they need to make adjustments", this and that. It was a constant thing. Even now, R has quite a few labs, but it was not like right after transplant. That was like labs every day.*

### Main Theme 3: Reconciling Loss

One can become accustomed to the dark and, upon emerging into the light, find it quite uncomfortable. In time, however, one's vision gradually adjusts and even looking toward the sun can become somewhat tolerable. The healing of the caregiver's grief and loss might be likened to an emergence or awakening from the darkness into the light. It is a painful experience, but, in time, she adapts and her vision becomes clearer. However, time itself is not what eased her pain or fostered her healing. Exposure over time to the harshness of the light and connection with others is what gave her sight and healed her heart. In due course, she awakened to a dawn, no longer lost in her vulnerability and blinded by the intensity of her pain. Through her experience, she gained wisdom. Through her suffering, she gained resilience. And, through her connection with others, she ultimately experienced transformative growth.

**Sub-theme 1: Making peace with posttransplant loss.** The prospect of the child's early death is a brutal and harsh reality. Things are not "fixed" because the child finally received a kidney transplant. Indeed, life has permanently changed and so has the caregiver. The idealized hope that dominated the pretransplant phase has been replaced by a more realistic set of posttransplant expectations. With the passage of time, caregivers learned that many of the losses they had incurred early on in the journey were not temporary, and, worse yet, there were new ones to face. What

inevitably moved the caregiver from the twilight of posttransplant trauma to the dawn of personal growth was acceptance of loss, as well as acceptance of the inevitability of impermanence. The gift of life was a gift of time, not a cure or a guarantee of life.

*He was – he was diagnosed with epilepsy. He had viral meningitis and, as a result of that, had learning disabilities and epilepsy from that. So that's a whole ... another issue ... but all manageable over time.*

*Yes, knowing that at any time our son could pass away is tough, but I can't dwell on that ... I know – there's so many families that I've met that, they just – they live on the what-ifs. They live on, you know, well they could go at any time. They could die. They could go at any time.*

### Sub-theme 2: Embracing the caregiver burden.

Embracing the role of being a caregiver means permanently integrating the role into one's identity. This reality presented itself clearly upon the child's posttransplant release from the hospital, when the mother was faced with a new set of informal medical caregiving duties. The child required vigilant post-transplant attention lest the organ be rejected. The focus of the regimen became the administration of medications, proper hydration, and frequent lab draws of blood. The endless cycle of caregiving thus did not go away; it just took on a different form. The caregiver now faced the threat of the child's possible organ rejection and frequent secondary illness due to immunosuppression.

At this juncture, the caregiver's ability or inability to recover from the pretransplant and transplant phases of trauma became palpable. The moments of toil and suffering were no longer ameliorated by anticipation of a life-saving transplant. It became another kind of survival. Many of the same obstacles were once again encountered, but new ones also arose and, in contrast to the adult world of transplantation, the paediatric world presented unique challenges. The caregiver not only had to administer informal medical care, but she was tasked with the challenge of parenting a transplant child through all the critical stages of development with little guidance. Two examples of what caregivers encountered follow:

*Then her taste buds developed and we started having fights. And that's when I taught her how to take capsules ... I lost a little boy in 1977 to the same thing that P has. And so P and I had had this big argument one day, which ... by the way, medicine is not an argument the mom can afford to lose.*

*The school thing was big for me and us ... . Elementary, high school, and now college! D did need lots of extra help in the beginning. Although she looked normal, she was really "in between". She had frequent absences. It wasn't unusual for her to miss 40 days of school at a time.*

**Sub-theme 3: Finding relationship with medical providers.** Having a good relationship with medical providers on the transplant team was revealed to be vital to the mother's positive adjustment, particularly in terms of fulfilling her role as an informal medical caregiver. The partnership established with members of the team was also revealed to contribute to the caregiver's personal growth. This was most evident in the accounts of those caregivers who referred to the medical providers as "being like family members". When the patient is a child, the child goes through critical stages of development, essentially growing up under the care of not only the parents, but the medical providers on the transplant team as well. Although the medical provider's role was aimed at the physical health of the patient, it could not be reasonably confined as such in the eye of the maternal caregiver. Whether it was consciously recognized or not by either, the medical providers made a significant contribution to the emotional welfare of both the patient and the maternal caregiver, as was revealed in the caregiver interviews, fostering, in some cases, post-traumatic growth, self-transcendence, and transformation in the caregiver.

*So, I think, even now, almost three years later, I still have a great relationship with all of his doctors and his nurses, and you know, I'm the mom that, when some other crazy hippy mom wants to do purees instead of canned formula, they have them call me. And they're like, "Hey, how did you do purees?"*

*And it got to the point where doctors were like, "We want to do this. Here's the form. Here's what this drug is." They knew, that's who we were and we questioned everything.*

The most outstanding aspect of positive change at any phase in the transplant journey included making a meaningful connection. The significance of this is, perhaps, best exemplified by Sub-theme 4.

**Sub-theme 4: Receiving, giving, and growing.** Reciprocity is important when it involves supporting human relationship and contributing to human growth. A world that supports interaction is a world that creates hopefulness and removes isolation. Specifically, it was found that human connection fostered positive adjustment in a caregiver, helping to sustain her over

the course of her journey and, when inclusive of receiving, giving, and reciprocating, was ultimately what fostered positive growth.

While the caregiver's connection with her child, partner, extended family, friends and community was imperative, her connection with the medical providers was also critical. The quality and design of these connections were also revealed to be of importance. Caregivers needed relationships of mutuality in terms of equality, respect and commitment. Unique to this study was the further finding that the caregiver's ability to receive and her opportunity to give back were even more crucial, as they related to fostering her positive growth.

It was well-established in the posttraumatic growth, self-transcendence and transformation models that support from others was a key component of growth. Nowhere, however, was it pointed out that the caregiver needed to be an active and grateful recipient of the offerings. In others words, this study revealed that receiving support from others was neither automatic nor comfortable for some caregivers; it was a learned skill, or an acquired art if you will. The findings also revealed that accepting help "from the inside out" was common. It was easiest first to accept assistance from the inner circle of immediate and extended family members. The caregiver was eventually better able also to accept help not only from friends, but also from community acquaintances, and even compassionate strangers.

*My husband and I support each other, especially in times of personal weaknesses. And that is the biggest thing. My husband and I ... when I can't go any further, he picks me up and he carries me. And when he can't go any further, I do the same.*

*We leaned on each other, on our family, our friends, our church ... . It's – sometimes it's hard to ask for help, but we've got to do it. And we're lucky that we have people around that are willing to help us.*

**Sub-theme 5: Enfolding dying into living.** Death is not the end, but a transition into the mysterious and the unknown. No matter what one's belief, there is little dispute that the human spirit or soul needs nourishment to survive and thrive. This is especially true for those who undergo extraordinary experiences of suffering. Such is the world of a transplant caregiver, who lives in a conscious state of awareness that her child's fragile health is a daily invitation to an early death. However, there is a kind of deep understanding, strength and growth that comes with her acknowledgment of vulnerability. The caregiver of a transplant child becomes practised at surrendering

control, learning to accept and even embrace many small losses or small deaths that paradoxically give her strength to make peace with her journey.

*Yes, that is one of my favourite Bible verses. Isaiah 41:13; it says, "For I the Lord, your God, take hold of your hand, saying unto you, fear not. For I will help you." And I know that – God's been good. I know that I trust Him. I know that whatever He has in store, there's a reason for it. If it is that B's only with us for a little bit, there's a reason for it. B is needed elsewhere. You know it's – it's hard to think that one of these days B might not be here, but just knowing that God has a plan and that God's there, that I can pray, that I can, you know, read scriptures. I can do what I need to. I can go to church. You know that – that helps.*

**Sub-theme 6: The second-chance self.** Nothing can bring back the dreams a mother had before the diagnosis of her child's kidney failure. It is a life-changing event that unfolds into a never-ending story of loss and renewal. The mother of a transplant child loses parts of herself on the journey; however, there are gifts that come with the experience that help her to find a "second-chance self" and uncover what Mary referred to in her story as "silver linings". In the final analysis, the phenomena of posttraumatic growth, self-transcendence and transformation in the maternal caregivers of transplant children could not have been captured more succinctly than in the accounts that were shared by mothers in their interviews. Excerpts from those interviews provide a peek into what the phenomenon looks like. Even more revealing are the "silver lining" stories, a term borrowed from one of the participants, that described the phenomenon of positive growth in the words of the caregivers as they were spoken. An example follows.

#### ***A Silver Lining Story – The Search for a Second Beginning***

*Going through the second transplant is when we really realized we had to be reliant on other people, whereas before we could shelter ourselves and isolate ourselves and insulate ourselves and just handle it. And people didn't know how to help. And because we really didn't need the help, so we didn't ask for it; but when the second transplant came around, I couldn't do it alone. And the community just was incredible in embracing us. And we went out to our family first and we said "Listen, we need another kidney and*

*R is not a match ... and we need another kidney", and so our families were wonderful. Everybody stepped up and we went through probably almost all family members on both sides and couldn't come up with anybody, because we were all related and blood-related and so it just didn't make for a good match for C.*

*And so we finally went out to the public and it was hard going public. You know, we had been so private for so long. It was really hard to go public. But it was the most rewarding thing we ever did; to see the power of prayer and of people's compassion and willingness to help was incredible. So we had probably over 200 people call and get tested.*

*It was unbelievable. I mean our email went around the world. We had people in London emailing us and people really sent it on. You know, we'd send it to one person and they send it to 10 more, so it touched around the world. It was incredible – incredible. And the irony of all of it is that we ended finding a donor here and he was an altruistic donor – his wife had been in her book club one night and the girls were talking about it and they hadn't even received the email. They were acquaintances of ours, but not super close friends.*

*And they had heard about it and she went home and she talked to her husband and said, we need to do this. We need to get tested. And so the friend that she had heard about it from forwarded on the email. And that's how it went.*

#### **The Fundamental Structure of Positive Growth**

Just as other researchers created conceptual process or outcome models to help describe posttraumatic growth (Tedeschi & Calhoun, 1995), self-transcendence (Reed, 2008), transformation (Dubouloz et al., 2010), and worldview transformation and social consciousness (Schlitz et al., 2010), the findings of this study lent themselves to the creation of a model (Grace, 2014) depicting the fundamental structure of positive, self-transformative growth in caregivers of transplant children. This model, presented in Figure 1, provides the reader with a visual illustration of the process of transformational growth as illuminated by the research findings reported above and further elucidated by the discussion that follows below.

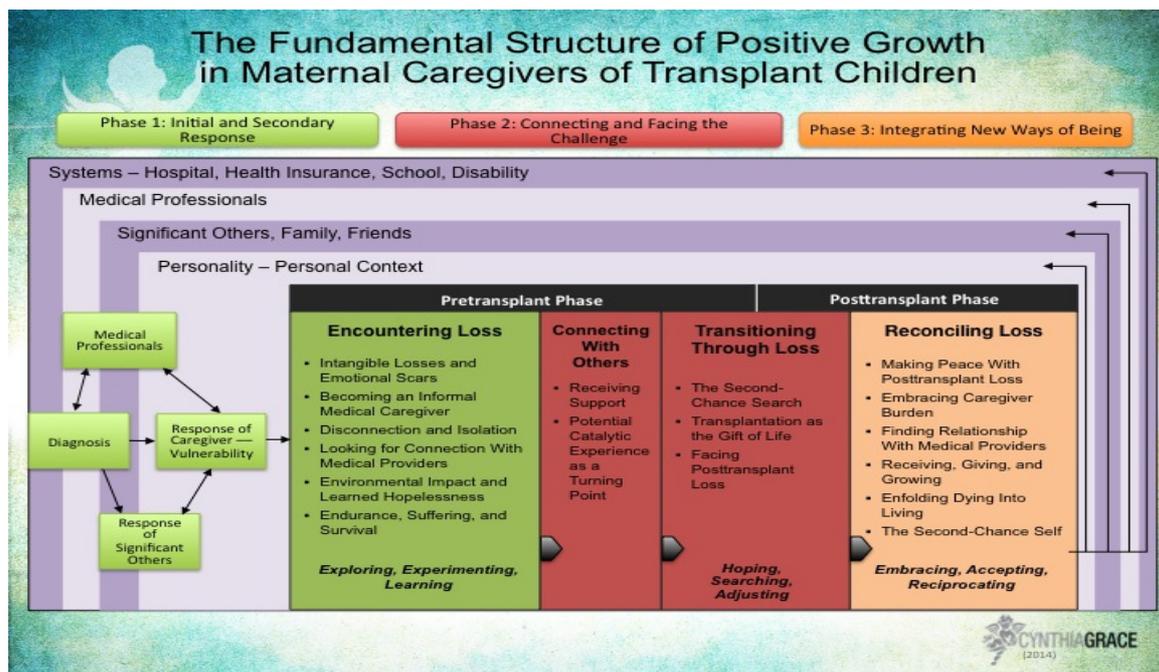


Figure 1. Grace's Structure of Positive Growth

## Discussion

It is notable that the analysis of accounts of the experience of being a transplant caregiver revealed that the fundamental structure of positive growth in this population had much in common with the models reviewed in the literature – posttraumatic growth (Tedeschi & Calhoun, 1995), self-transcendence (Reed, 2008), transformation (Dubouloz et al., 2010), and worldview transformation and social consciousness (Schlitz et al., 2010). In other words, if one were to ask what exactly the phenomenon of positive growth is, one would find that the models reviewed in the literature and the one that unfolded in this study share common themes. If one were to ask how the phenomenon of positive growth unfolds, one would find that the process of growth in the existing models is once again consistent in a number of regards with the findings of the current study. A quick visual reference comparing the current study's diagrammatic model with the first three models of growth can be found in Grace (2014, pp. 339-341), and the fourth comparative model, worldview transformation, can be viewed in Schlitz et al. (2010, p. 23). Although a comprehensive commentary on the parallels between these models and the current study's model is beyond the scope of this paper, the discussion that follows will briefly address the unique questions raised within each of the four models.

The first question derives from the model of post-traumatic growth wherein Tedeschi and Calhoun (1995) propose that a traumatic experience is pivotal to growth. Asking about the maternal caregiver's

experience of stress and trauma associated with the transplant journey, it was found in the current study that all seven mothers experienced a significant amount of each associated with her experience of being a caregiver for her transplant child, and as such often managing complex situations both pre- and post-transplant – a journey of endless beginnings. All caregivers at some point in their journey experienced posttraumatic stress, while two caregivers revealed unresolved symptoms of PTSD. While many factors were identified as contributing to caregiver stress and trauma, all of which entailed experiences of loss that transpired in various ways and to different degrees, the time of diagnosis emerged as being especially significant. In fact, all seven caregivers saw the initial diagnosis as one of the most stressful times in the journey. This supports the findings of studies that reported that 70% of parents in any chronic illness context are traumatized by news of their child's medical diagnosis (Clements, Copeland, & Loftus, 1990). It is therefore not surprising that the pre-transplant phase, which includes encountering loss (Main Theme 1) and transitioning through loss (Main Theme 2), proves to be especially traumatizing in the case of transplant caregivers.

The second question also comes from the model of posttraumatic growth, and asks about the maternal caregiver's experience of beneficial change associated with the transplant journey. Beneficial change did occur in seeming shifts in the way a caregiver viewed her circumstances over the course of the journey. The positive shifts, however, were most pronounced in the third or posttransplant part of the journey described as

reconciling loss (Main Theme 3). This phase of the journey found the caregiver resolving, accepting, and making peace with the many layers of loss she had experienced and the new ones she continued to face. She not only fulfilled her role as a caregiver, but she embraced it fully, integrating it into her identity and being.

This did not mean that she found the posttransplant tasks easier to handle; she simply learned how to do them with greater efficiency and less damage to her self-regard. She had mastered parts of a previously unpredictable environment, and now she knew that she could do it again. Like the Hiroto (1974) and the Hiroto and Seligman (1975) studies in which subjects were exposed to inescapable noise conditions and their belief in their own ability to control the noise predicted their behavioural responses, caregivers had learned how to prevent or avoid being severely traumatized by psychologically “jumping over” the mental barriers that had previously rendered them helpless. Through their experience, they had learned to modulate their responses and developed a belief in their ability to do so, transforming the likelihood of learned helplessness into the potential for “learned helpfulness”. Caregivers’ experiences of facing and transitioning through loss in phases 1 and 2, leading to their ability in phase 3 to accept that these losses had caused a permanent change in their lives and identities, were powered by increasing belief in themselves and their own ability to affect their external environment and modulate their internal one as they moved forward. They not only embraced their role as a caregiver, but they accepted the layers of loss that they knew would continue to occur. This internal shift did not happen, however, without external support.

The third question comes from the model of self-transcendence (Reed, 2008) and asks how a caregiver changes in connection with self, others and the environment. Shifts in this regard were revealed as a gradually occurring process that started in the pre-transplant phase and extended throughout the transitional phase of transplantation and into the post-transplant period. The caregiver experienced a self-perception of changed intrapersonal identity, interpersonal relations and environmental relations leading to learned helpfulness and, eventually, growth and wisdom. This study revealed that learned helpfulness did not occur in a vacuum, as the formation of caregiver belief leading to learned helpfulness came from having a connection with others. However, connection and offers of support are not enough alone to inspire caregiver growth. As this study found, the real catalyst and crucial factor necessary for the experience of positive growth in these caregivers rested on their ability to actively receive what others had to offer them. Ultimately, reciprocal connections with supportive others expanded to include relating

differently to the environment as a whole, as can be seen markedly throughout Main Theme 3, reconciling loss.

The fourth question comes from the models of transformation (Dubouloz et al., 2008; Schlitz et al., 2010) and asks about events that are pivotal to positive change which leads to individual worldview transformation and broadened social consciousness. It was revealed that, while each caregiver experienced a turning point that was catalytic to positive change, some caregivers experienced more than one turning point. The events that led to a turning point or catalyst for change varied with each caregiver, but all of them had at least one thing in common – each caregiver experienced a profound connection with others. As pointed out earlier, her transition was not made in isolation. The two key elements of that connection consisted of a gift of support (giving on the part of one individual), and the willingness/ability of the caregiver to accept the gift (receiving on the part of the other). This may seem like a logical exchange, but receiving is not easy for many people, especially during times when they feel vulnerable and the risk of being given inappropriate or innocently harmful gifts of help can have a damaging impact.

No matter how dire the caregiver’s personal situation or how frustrating the limitations imposed by complex and rigid systems, at the end of the day it is human connection and support from others that help the caregiver to survive and thrive, creating circumstances conducive to experiencing posttraumatic growth, self-transcendence and transformation (Dubouloz et al., 2010; Reed, 2008; Tedeschi & Calhoun, 1995). The current study revealed, however, that supportive help from others is only able to contribute to the well-being of the caregiver if she has the willingness and capacity to receive it. Unfortunately, there has been very little research on the art of teaching a vulnerable person how actively to receive quality help when it is offered. This study revealed that vulnerable caregivers were more apt to accept help from those in their inner circle, and that those who experienced growth eventually accepted help not only from family members and friends, but also from medical providers and even complete strangers. Caregivers who grew as a result of their connection with others were caregivers who were able to participate as active receivers regardless of who initiated the transaction. Essentially, when a caregiver felt empowered to take the support others offered, she experienced less isolation. Her hope was renewed and she found meaning in her suffering, especially when the time came for her to reciprocate by giving back in some way.

## Conclusion

The crux of what the findings of this study revealed is

that, while caregivers of transplant children experience trauma, they also experience positive growth. The findings furthermore suggest that interventions aimed at discouraging trauma and promoting growth can encourage healthy human connection between caregivers and those who support them, especially family members and the medical providers who tend to become like family members over time. The acts of receiving, giving, validating, and giving back – and the reciprocity implied – are integral components of a functional human connection. They were found to be necessary elements in terms of caregiver positive growth. A caregiver's experience of positive growth is a beneficial outcome not only for her but also for everyone who is part of her journey. The population of children needing organ transplants continues to increase, translating into increased numbers of caregivers, patients and families who are searching for a second chance. If and when that opportunity appears, those involved in the journey will already have experienced

a significant amount of trauma and loss. Those who make peace with the suffering and find meaning in their losses stand the chance of realizing much more than survival as a result of the journey.

In spite of the challenges that the caregivers of transplant children face, there is a silver lining of hope. That hope does not simply rest in the promise of what is delivered through transplantation, but resides in the heart of what is offered through human connection, nurturing the possibility for growth to occur and for everyone involved in the connection to flourish as a result. As this study revealed, through the unique animation of human connection, reciprocal interaction in the form of receiving, giving, validating, and giving back becomes a catalyst for post-traumatic growth, self-transcendence and transformation, thereby serving as a conduit for finding the second-chance self that might very well be the real gift of life.

### Referencing Format

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Prior to receiving her doctorate in clinical psychology, Dr Grace was employed as a full-time business professional in management and marketing for several major corporations. During that time she also served as a liaison and ambassador for a number of organizations, including the Family-Centred Care Team at the Stanford Medical Centre, the California Transplant Donor Network, and the National Kidney Foundation.

A mother, organ donor and caregiver with 22 years of ongoing experience in the world of organ transplantation and physical and developmental disability, Dr Grace is also the co-director and acting vice-president of the *Awakening Retreat Centre* in Brentwood, CA. Under the umbrella of the centre, she focuses substantial energy on *Angels of Grace* (<http://angels-of-grace.com>), a subsidiary organization aimed at raising awareness of the need for organ donation, patient and caregiver advocacy, and compassionate medical care.

An advocate, caregiver, public speaker, and therapist, Dr Grace is devoted to creating communities where those on the journey of chronic medical illness or disability might connect with one another, discovering, as she did, that there is hope for meaning, renewal, growth and transformation in spite of the many challenges that are encountered.

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