

LIFE ON HOLD: THE EXPERIENCE OF THE SUPPORT PERSON INVOLVED IN A LUNG TRANSPLANT PROGRAM

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Lung transplantation, which includes heart-lung, single lung and double lung, has been available as a therapeutic option for some patients afflicted with end stage irreversible pulmonary disease for only a short period of time (Griffith & Zenati, 1990; Morrison, Maurer & Grossman, 1990).

One centre which offers lung transplantation has developed an intensive pre-operative assessment that applies stringent patient selection criteria. One of these requirements is the identification of a support person who is willing to accompany and commit him- or herself to the potential transplant candidate 24 hours per day for an indeterminate period. Because the transplant candidates are often disabled to a significant degree, this support person is mandatory. In most cases, the support person is a family member, but, any individual who has the trust of the patient and is prepared to fulfil the necessary commitment is eligible. The identification and selection of such a support person is unique and not known to be mandatory in other health care programs.

The investigators explored the family and transplantation literature to see what previous investigations had been carried out vis-à-vis the role of the support person in transplantation. While there is considerable evidence in the literature regarding the social and psychological impact of cardiac and cardiopulmonary transplantation on the recipients themselves (Cardin & Clark, 1985; Covner & Shinn, 1983; Hyler, Corley & McMahan, 1985; Lahde, 1981; Lough, Lindsey, Shinn & Stotts, 1985; McAleer, Copeland, Fuller & Copeland, 1985; O'Brien, 1985; Santamaria & Smith, 1985; Shinn, 1984), if the family members of these recipients are mentioned, it is only in passing (Covner & Shinn, 1983; Hyler et al., 1985; Lough et al., 1985; McAleer et al., 1985; O'Brien, 1985; Santamaria & Smith, 1985; Shinn, 1984). The one exception is the study by Mishel and Murdaugh (1987) study of family adjustment to heart transplantation. This study explored the processes used

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by the family members to manage the unpredictability elicited by the need for and receipt of a heart transplant. "Redesigning the dream" was the main theme that described how family members gradually modified their beliefs about organ transplantation, and developed attitudes and beliefs to live with the continual unpredictability that they encountered.

The existing literature on lung transplantation describes mostly the surgical technique, patient selection criteria, pulmonary donors, and postoperative complications (Bonser & Jamieson, 1990; Boychuk & Patterson, 1988; Cooper, 1986; deLeval et al., 1991; Egan & Cooper, 1990; Emery et al., 1991; Gluckman & Cooper, 1987; Griffith & Zenati, 1990; Mauer, 1990; Morrison et al., 1990; Nelems et al., 1980; Novick et al., 1991; Patterson, 1990; Patterson et al., 1991; SerVaas, 1985; The Toronto Lung Transplant Group 1985, 1986, 1987; Todd, 1990; Veith, 1978; Williams, Grossman & Maurer, 1990).

The literature alluded to the importance of a supportive network in other populations such as with cardiac and liver transplant recipients (Craven, Bright & Loughheed-Dear, 1990) but no research has examined the effect of the transplant process on a support person in a lung transplant program. Because of this gap in the literature, we addressed the following question:

"What is the experience of the support person involved in a lung transplant program?"

Method

Design

The grounded theory method which involves simultaneous collection, coding, and analysis of data (Glaser & Strauss, 1967; Strauss, 1987; Strauss & Corbin, 1990) was selected for this study. Grounded theory allowed the study of complex areas of behaviour where salient variables had not been identified (Stern, 1980) and discover basic social processes as the subjects experience them, rather than have the investigators assume what is occurring. Therefore the subject is the expert and the theory is inductively derived from the interview data.

Sample

During the time of data collection there were ten possible candidates awaiting a lung transplant. Only five of the ten subjects approached by the clinical nurse specialist of the transplant team, who assisted in subject procurement, met the selection criteria; i.e., they spoke and understood English, were available to be interviewed weekly and bimonthly, and were interested in participating in a research study. Of the five subjects who did not meet the

selection criteria, two were unavailable for weekly or bimonthly interviews, one did not speak English very well, one was a paid homemaker obliged to accompany her employer to the transplant program and the last support person did not wish to be involved in a research study. Of the five subjects who did agree to participate, all were provided with an explanation of the study and signed a consent form. No one withdrew from the study. In the group of five, there was one mother, one son, one husband and two wives. Their ages ranged from 22-73. Prior to accepting the commitment to be a support person each subject had a life of his or her own. Three were employed full time and had to leave their jobs. Once was a university student who requested an extended leave of absence. The last was a full time mother since giving birth to a high-risk infant. Among the five subjects, three had permanent homes in another city and had to relocate. During the four-month period of data collection, two of the transplant candidates received lung transplants; one a single lung, the other a double lung transplant. Therefore their support persons' data contained both prospective and retrospective perspectives. However, one limitation of this study was that the sample was able to be interviewed only as long as the patient was hospitalized or undergoing the rehabilitative phase of the program because the majority lived in other cities. Another limitation of this study is that the ideas generated from this small sample can only be restricted to support persons in this transplant program.

The Grounded Theory method

In keeping with the grounded theory method, empirical data were collected by one of the two investigators, through unstructured informal interviews and participant observation. This involved one investigator's daily on-site interactions with the subjects as well as attendance at the weekly support group meetings for patients and their support persons.

Over a four-month period of data collection, 34 private interviews were held, with each support person being interviewed a minimum of six and a maximum of nine times. The interviews were conducted weekly or every other week, depending on the support person's schedule. Duration of the tape recorded interviews was usually 30-45 minutes.

In keeping with the process of constant comparative analysis (Glaser 1978, Glaser & Strauss, 1967; Strauss, 1987) data from each interview, observation and interaction were transcribed verbatim analyzed line by line, coded (usually by each word or phrase), and compared to excerpts from previous interviews, observations and interactions. From the transcribed interviews and field notes, substantive codes were derived and analyzed prior to the investigator re-entering the field. Next, the initial substantive codes were clustered to create categories. Data were collected until categories were saturated, i.e. no new conceptual information was being added (Chenitz &

Swanson, 1986; Glaser & Strauss, 1987; Hutchinson, 1986, p. 125). From the major categories, theoretical codes were derived that contributed theoretical meaning and scope to the substantive theory (Glaser, 1978, p. 70).

Credibility of the data

The criteria of truth value, applicability, neutrality and consistency for ascertaining credibility in qualitative research suggested by Woods and Catanzano (1988) were applied in this study. Truth value refers to "adequate representation of multiple constructions of reality". Some of the ways truth value was established was through prolonged engagement with the subjects in the field setting to ensure sufficient time to build a trusting relationship with them and through persistent observation to provide depth to the findings.

Applicability refers to "fittingness", which means describing the data in detail and generating working hypotheses to enable someone to consider the possibility of verifying the hypotheses in another context (Woods & Catanzano, 1988). The analytic scheme generated was submitted to an expert whose research concerns families with chronic illness. She confirmed the suitability of the fit of the analytic framework generated for this study for other chronic populations in other contexts.

Neutrality depends on the existence of truth value and applicability (Woods & Cantanzo, 1988).

Consistency is the process by which other researchers can follow the method used in this study and are able to find similar concepts, not contradictory ones, if they were to have access to the investigator's data (Woods & Cantanzo, 1988). This criterion is similar to reliability in quantitative research. In this study, 28 of the 34 interviews (82%) were independently coded by the two investigators. Consensus on substantive codes, categories and theoretical codes was achieved.

Findings

The core variable which best explained the experience of the support persons was *Life on Hold*. Life on Hold begins when the support person and the patient make the initial decision to apply to a lung transplant program and continues to an unknown period post transplantation. This is a process with five phases.

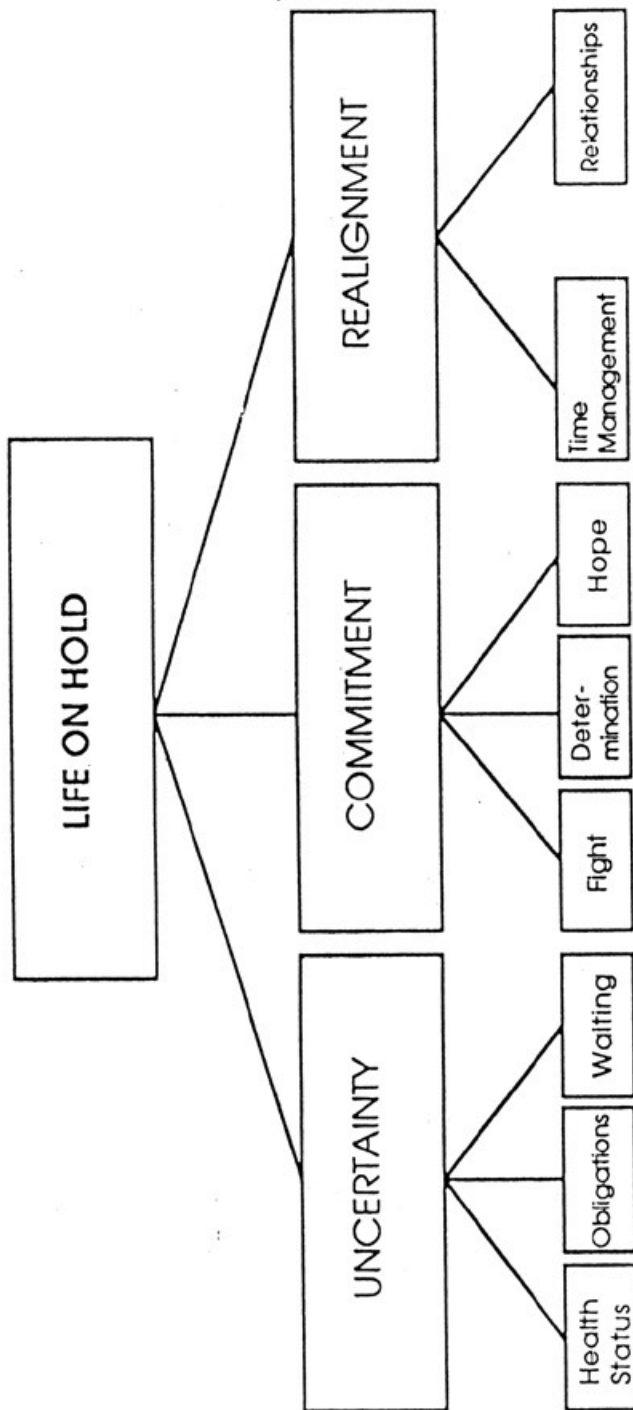


Figure 1
 The analytic scheme for the life experiences
 of the support person of a lung transplant recipient

In this study, the phases paralleled the five stages of the lung transplant program, i.e., Pre-acceptance, Assessment, Pre-Transplant, Transplant and Convalescence. The process of Life on Hold is composed of three interrelated concepts -- *Uncertainty*, *Commitment* and *Realignment*. (See Figure 1). Each concept is evident during all phases of the transplant process, but changes in its intensity and character depending upon the demands and issues confronting the support person, as well as on the circumstances arising from each particular phase of the transplant process.

Uncertainty

Uncertainty prevails through all of the support person's experiences, but in varying degrees. Initially there is uncertainty about whether or not one should become the "designated support person" and how long one would have to maintain that role. The support person is also uncertain whether their family member will be considered an eligible candidate and hence allowed to undergo the initial assessment. Once the support person becomes involved with the lung transplant program, there is uncertainty with respect to the patient's *health status*, their own *obligations* and the *continual waiting*.

Initially, the patient's *health status* is stable enough to meet the criteria for eligibility into the program but, as time passes, a physical and mental deterioration often takes place. As explained by two of the support persons: "Her quality of life isn't very good. She never feels wells. Her quality of life is not worth not doing the transplant," and, "We are going the expected route, we obviously are not getting any better."

It is at this time that the support persons become uncertain as to their *obligations* towards the patient. What does the transplant program expect from them? What are their roles? For many, they will take on new roles, unthought of prior to being accepted into the transplant program. Others will carry on with their normal roles, but with more dedication now as they await "a chance" at a transplant. As the support persons become more involved with the patients, their obligations become more complex. Prior to transplant they become the primary caretaker of the patient: they are responsible for assisting the patient with their health maintenance needs, carrying out the domestic chores and chauffeuring or accompanying the patient to and from the hospital for pre-transplant physiotherapy. One support person commented, "One thing I had to quickly get over was the fact that I had to bathe my father. My God, my father. I had to help him get from the bed to the wheelchair, I had to help him get dressed. I made him breakfast, filled his oxygen tanks and took him for walks in his wheelchair". At all times, the support persons were obligated to manifest strength for the pair. "You need a bit of time away to recoup your own strength every once in a while."

The support person's obligations change remarkably during the transplant and convalescent stages. During these phases the health care professionals abruptly take over most of the care of the patient. No longer are the support persons the primary caretakers or considered knowledgeable consultants, as they were in the earlier three phases. They are treated just like a relative of any surgical patient in the fifth phase (convalescence) until the transplant recipient is discharged from the hospital. Once home, there is less strain imposed upon the support persons and more opportunity to spend quality time with the family member. They start to feel relief and great pleasure at watching the convalescing patient's progress.

In addition to being uncertain with respect to the patient's health status and the support persons' obligations, there is much uncertainty with regard to the *waiting* that goes on. There is always waiting to be done. Initially, in the pre-acceptance phase the support person and patient wait to hear from the program about whether they are eligible for assessment, a wait that can vary from three to nine months. Next they wait for the assessment, and then for a decision to be made about whether or not they are accepted into the program. Typical comments expressed by the support persons were: "The assessment is very trying on your relationship. Your life is in an uproar. You don't know where you are headed and what direction you are going in. You need to demonstrate some tough love." Another subject stated that: "We had no idea what we were in for at all, not at all."

Once accepted into the program the waiting for a donor organ is potentially one of the longest phases of the entire transplant process. There is little that the support persons or the patients can do to increase organ availability. As they wait for "the call" for a transplant, the patient's health status starts to deteriorate further. During the waiting, the support persons are faced with the reality that the patient may not live long enough to be given "the chance" at the transplant surgery.

At the time of the transplant surgery, the support persons encounter a different kind of waiting. There is more uncertainty as they wait to hear whether or not the patient survived the transplant surgery: "I was thinking how relieved I was that it was over and he had survived." After hearing whether the patient has survived or not the support persons encounter another kind of waiting, one of restricted visiting hours in the intensive care unit. Family members could only visit the patient for ten minutes on the hour, every hour, provided that the health care professionals were not too busy with the patient. Even though the support persons are less uncertain about the patient's health status, for many it is difficult to visit on such a restricted schedule. "I found myself doing a lot of waiting and walking." After all, the support persons have been with the patient 24 hours a day for months and now must abide by a designated visiting schedule. This waiting

for infrequent visiting carries on into the hospital convalescence phase in which almost all of the patient's waking hours can be accounted for by a rehabilitation program. As expressed by one support person, "It was stressful dealing with his schedule which restricted you to an hour here or there to visit." The transition of family members visiting the patient for a total of two to three hours per day from previous 24 hours per day took some time to adjust to.

Commitment

The second major concept evident in the process of placing one's Life on Hold is the *commitment* made by the support persons. This commitment to the patient's welfare begins when the support persons make the decision to become the "designated support person" and accompany the patient to the transplant program. At this time, they free themselves from all prior commitments. This commitment is very encompassing. As one support person stated, "I gave up everything to come here with my husband." The support person will be responsible for the patient, and confined with the him or her 24 hours a day. The support person's commitment to the patient is demonstrated through their ability to *fight*, their *determination* and their *hope*.

Once the decision is made to apply to the transplant program, the support persons *fight with and for* the patients to get into the program for "a chance" at an assessment. Then the pair fights to keep the patients alive and stable long enough to be able to undergo the transplant surgery. Underlying the support persons' commitment to the patient is their ability to fight at all phases for the patient's survival. "Once he made the decision, I just supported what he wanted to do....It was a fairly heavy duty commitment and once I made it there was no backing out."

As other support persons commented: "The people you are supporting are physically sick and mentally tired, they are tired of waiting and as their support person you have to fight for them. It would be nice to know the ground rules before you got in there and put up your dukes with the transplant team."

As the support persons fight for the patients, they also become *determined* to attain their major goal -- a transplant for their family member. The fight is more patient-oriented, whereas the determination is more support person oriented. Once committed to being in the support person's role, the support persons are determined to carry on as expected and help the patients in any way that they are capable of, in order to have the transplant surgery. As one support person explained, "You have to be determined. If you are not determined and not dedicated, you are not going to make it through the transplant program at all."

At all times, from the initial decision to apply to the program until after the transplant, an element of *hope* prevails. The transplant is viewed as the last source of hope at improving the patient's quality of life. Hope keeps the support persons going. Without hope, they would not be as committed and without the accompanying determination they would not fight as hard to keep the patient going, to achieve their goal of a transplant.

Realignment

In addition to uncertainty and commitment, there is also a *realignment* of the support person's *time management* and *relationships*. To accompany the eligible transplant candidate means realigning the support person's personal life. The support persons realign their lives with the hope that the situation is only temporary.

The support persons now learn to *manage time* differently. Some spend the majority of their time caring for the patient. Some spend their free time (what little there is of it) by continuing with familiar activities and hobbies. Others manage the waiting by taking up new interests. But most become involved in some way with the activities offered by the transplant program.

All of these support persons were limited in their *relationships* with other people outside of the lung transplant program. It is as if they are on the inside of "a shell" and have minimal relationships outside their shells. Their relationships with others are based on their common interest -- receiving a lung transplant. The support persons neither have the time nor the energy to invest or carry on with relationships with other family and friends who are far away. Restricted visiting can disrupt the previous continuity in the support persons' relationship with the patients. During all phases of the process of placing one's Life on Hold there is a continual realignment of the support persons' time management and relationships.

Questions Arising from the Study

The identification of the theoretical analytic scheme of Life on Hold is a beginning step to realizing the psycho-social needs of the support persons involved in a lung transplant program. The ease, enthusiasm and eagerness with which the support persons responded to participation in the present study indicated that the support persons must be provided with regular opportunities where they can be encouraged to discuss their experiences, thoughts and feelings with a receptive listener.

Why is it that the program requires each candidate to be accompanied by a support person, but does not provide reinforcement of that role as they do for the patient's role? Why does it appear that the role of the support person is

not valued as much in the transplant and convalescent phases as in the earlier phases?

The support persons may need just as much caring and support as does the transplant candidate but in a different mode. What would happen if the lung transplant program did not require each candidate to be accompanied by a support person? Would the natural supportive network of each patient unfold? Would more than one family member or friend volunteer to be the so called "designated support person"? Would they be as committed throughout the entire transplant process? Could the program offer a support group solely for the support persons themselves? Health care professionals should be cognizant of the commitment of the support person on the patient's behalf. If not for the support persons, where would the patients be? Each support persons has placed their Life on Hold for their family members to be provided with the chance to have a lung transplant as the last viable option for extending their life expectancy and their lives together.

Recommendations

The findings from this study should be expanded upon in future studies within the lung transplant population and among other transplant groups. We also advocate the use of qualitative research designs with more extensive theoretical sampling. Theoretical sampling using this framework also could be used to explore the long term trajectory after successful transplantation. Such studies could assist in increasing the health care professional's knowledge of the demands and expectations placed upon those who provide support to transplant recipients.

In this study we have taken the first step towards increasing the health care professional's insight into the experience of the support persons involved in a lung transplant program. With the use of grounded theory methods, the emergent substantive theory of *Life On Hold* accounted for most of the support person's behaviour in the social scene under study. During each of the five phases of the transplant process, the support persons experience uncertainty, commitment and a realignment of their lives.

The findings from this study have some similarities to Mishel and Murdaugh's (1987) study of family adjustment to heart transplantation. In both studies there is much uncertainty with respect to whether or not the patient will live to receive a transplant and, if they do, whether they will survive the surgery. If they survive, both the patient and family presumably undergo a number of role changes and assume a new lifestyle. As yet data are unavailable to track this process over time.

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RÉSUMÉ

La vie en suspens : l'expérience des personnes-ressources participant à un programme de greffe pulmonaire

On décrit dans la présente étude qualitative l'expérience des personnes-ressources participant à un programme de greffe pulmonaire. Nous servant d'une théorie à base empirique, nous avons recueilli des données auprès de cinq personnes-ressources (tous des membres d'une famille). Les données font ressortir un processus social de base dans lequel les personnes-ressources doivent mettre leur vie en suspens pour une période indéfinie allant souvent jusqu'à deux ans. Ce processus est dicté par les cinq étapes du programme de transplantation : présélection, évaluation, prétransplantation, transplantation et convalescence. À chacune des cinq étapes, la personne-ressource fait l'expérience a) de l'incertitude liée à l'état de santé du malade, à ses responsabilités en tant que personne-ressource et à l'attente prolongée; b) d'un engagement envers le malade, exprimé par une aptitude à se battre pour obtenir une greffe du poumon, par une détermination à voir le malade s'en sortir et par l'espoir; et c) du rajustement de sa vie sur le plan de la gestion de son temps et de ses relations interpersonnelles.