

行政院國家科學委員會專題研究計畫成果報告

肺臟移植病人術後的恢復經驗及對醫療人員的期望：長期性追蹤(2/2)

Taiwanese Patients' Experiences of Recovery from Lung Transplantation
and Expectations for Health Care Providers: A Longitudinal Approach (2/2)

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International Conference on Transplantation in Nagoya 2001

July 22-27, 2001, Nagoya, Japan



The 6th Congress of the International Society for Organ Sharing (ISOS)
including The 4th Workshop on Non-Heart-Beating Donors
The 3rd Congress of the International Transplant Coordinators Society (ITCS)
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Title: The Context Framing the Changes in Health-Related Quality of Life and Working Competence Before and After Lung Transplantation: Taiwanese Experiences

Abstract Receipt No.: 6179

We are very pleased to inform you that, because of its high scientific quality, the above paper has been selected for presentation in front of the poster panel during the poster discussion period scheduled for Friday, July 27, from 12:00 to 13:30. Your presentation will consist of a four-minute presentation and a two-minute discussion period.

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**THE CONTEXT FRAMING THE CHANGES IN
HEALTH-RELATED QUALITY OF LIFE AND WORKING COMPETENCE
BEFORE AND AFTER LUNG TRANSPLANTATION:
ONE YEAR FOLLOW-UP IN TAIWAN**

by

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**THE CONTEXT FRAMING THE CHANGES IN
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Lung cancer has been ranked as the second leading cause of cancer death in the past three years (19.47% in 1995 and 19.65% in 1998) in Taiwan.^{1,2} It currently accounts for 21.52% and 13.14% of all deaths among Taiwanese male and female cancer patients, respectively.² Meanwhile, in Taiwan, in terms of leading causes of death, pneumonia increased from 8th (14.44%), in 1995, to 7th (20.37%), in 1998.^{1,2} Other respiratory system diseases, such as emphysema, bronchitis, and asthma, were ranked 10th among leading causes of death in Taiwan in 1995.¹ Although requests to the Society of Pulmonary and Critical Care Medicine, Republic of China, to provide care for the respirator-dependent patients and to establish work models have been made, only six hospitals have enrolled in this pilot project in Taiwan.¹

Western literature regarding transplants report that lung transplantation (LT) is effective as a modality for increasing life expectancy and improving health-related quality of life (HRQoL) in patients with end-stage lung disease. LT recipients enjoy bolstered physical and social functional capacities, as well as a stronger sense of psychological well-being due to both, a decrease in disease and treatment-related disabilities and an increase in positive psychological perceptions.³⁻⁸ The first successful Taiwanese LT was performed at the National Taiwan University Hospital (NTUH) in 1995. As proof of its expanding application, LT surgery has since been conducted on 22 separate patients at NTHU.

With its growing popularity, the previously evaluated post-operative patient HRQoL has become of interest. In particular, the resumption of patient working competence (WC) post-operatively has drawn the attention of recipients and researchers alike, since most past transplant recipients were young to middle-age adults. WC was cited as an important indicator of self-addressed quality of life in Taiwanese kidney (KT) and orthotopic liver transplant (OLT) recipients.⁹⁻¹¹ Since recovery time for patients spans a considerable length, from the preoperative stage to the postoperative long-term follow-up,^{12,13} LT recipients' perceptions of HRQoL and WC are highly subject to change. During the first critical post-transplant year, similar trends of changes in WC and HRQoL were reported between Taiwanese KT and OLT recipients; however, due to a small size, no significant correlation between the continuous changes in these two parameters was detected.^{10,11} Even now, thorough investigation into the impact of LT on the HRQoL and WC of recipients, the relationship between HRQoL and WC, and the stress on Taiwanese LT recipients has yet to be conducted. The purpose of this study was fourfold: (a) to examine the changes in the

HRQoL and WC; (b) to assess the relationships between the changes in the HRQoL and WC before and after LT; (c) to explore the major difficulties and stress perceived by Taiwanese LT recipients; and (d) to explore the background context which frame the changes in HRQoL and WC in the first post-transplant year.

PATIENTS AND METHODOLOGY

Adult LT candidates were recruited on the day before transplantation from NTUH throughout the years of 1995-2000. The inclusion criterion were as follows: (a) at least 18 years old; (b) clear consciousness; (c) no transplant surgeries other than LT; and (d) be willing to participate in the study for one year. A prospective triangulation design encompassing quantitative and qualitative data was used. The LT recipient's profile and perceived HRQoL and WC before and after surgery were all recorded quantitatively. Patient profiles were used extensively to collect the demographic information, medical history, current medications, postoperative complications, and length of floor unit or ICU stay. The recipient's perceptions of HRQoL and WC; however, were obtained by using the visual analog scale (VAS).

Each subject was interviewed seven times: once preoperatively, and six times post-operatively (the last day in the ICU, the day before discharge from the hospital, and the 1st, 3rd, 6th, and 12th months after discharge). Each times the subjects were asked to rate their perceptions of HRQoL and WC on separate VASs. Then, a semi-structured interview with audio-tape recording was conducted to obtain qualitative data. During the first interview, the participants were also asked to rate their perceptions of HRQoL and WC on VASs based on the entire 24 hours preoperative period.

The VAS is a generic global index that gives researchers the opportunity to access the global impact of disease on patient well-being, and to compare different programs with disparate endpoints.¹⁴ The VAS has been successfully introduced in investigations and comparisons involving the HRQoL and WC of transplant recipients.^{6,10,11} The VAS used in this study was a 100-millimeter (mm) vertical line, anchored at the bottom with the words "Worst quality of life" or "Unable to work," and at the top by "Optimal quality of life" or "Optimal working competence." In this study, data was obtained by asking the subjects to rate their self-perceived degree of HRQoL and WC on separate VAS's at each of the seven time points. The quantitative data was then analyzed by descriptive and inferential statistics. Meanwhile, qualitative data regarding the background context framing the recipients' perceptions of HRQoL and WC, as well as the patients' subjective perceptions of the difficulties and major stress encountered during their recovery process, which were collected by use of semi-structured interviews,

and were analyzed by qualitative content analysis.

RESULTS

Patients' Demographic Data

Eight LT recipients from various counties in Taiwan who survived in the first post-transplant year were recruited. They were all female with ages ranging from 31 to 46 (mean 35.4 ± 4.4) years old. 63% of the subjects ($n = 5$) were married. 13%, 25%, 38%, and 25% were graduates of college, senior high school, junior high school and elementary school, respectively. 88% of them ($n = 7$) adhered to a religious belief (5 Buddhists and 2 Protestants). At the 12th month postdischarge stage, all of them were unemployed. Half were housewives, 38% ($n = 3$) quitted their jobs in order to help foster their recovery, and one was retired. At the preoperative stage, all of them were incapable of work and self-care, and required constant comprehensive care. During the seven interviews, none of the subjects reported their monthly family income.

Changes in the Perceived HRQoL

The mean scores (with range) of perceived HRQoL at each of the seven stages were $37 \pm 16\%$ (20-60%) at the preoperative stage, $67 \pm 13\%$ (53-90%) at the ICU stage, $67 \pm 13\%$ (53-90%) at the predischage stage, $71 \pm 16\%$ (53-90%) at the postdischarge-1st month stage, $71 \pm 16\%$ (53-90%) at the 3rd month, $63 \pm 14\%$ (40-80%) at the 6th month stage, and $63 \pm 10\%$ (50-80%) at 12th month stage (Table 1). Significant changes in the perceived HRQoL were identified, using paired t-tests, between the preop stage and postop ICU, one-day predischage, and 6th and 12th month postdischarge stages. In addition, significant continuous improvement in the perceived HRQoL was found from the pre-op stage to the 12th month-postdischarge stages using one-way ANOVA ($p < .01$) (Table 2). However, 50% of the recipients experienced fatigue and shortness of breath during the 6-12 months after discharge from the hospital. As a result, the HRQoL during this period was poorer than during other postoperative stages. Meanwhile, the mean scores of perceived HRQoL in the six postoperative stages ranged from 1.7 to 1.9 times those of the preoperative stage: 1.8 (67/37%), 1.8 (67/37%), 1.9 (71/37%), 1.9 (71/37%), 1.7 (63/37%), and 1.7 (63/37%) accordingly (Table 1).

Changes in the Perceived WC

The mean WC scores (with range) were $18 \pm 12\%$ (0-30%) at the preoperative stage, $56 \pm 9\%$ (48-70%) at the ICU stage, $59 \pm 10\%$ (48-70%) at the predischage stage, $61 \pm 13\%$ (48-80%) at the postdischarge-1st month stage, $64 \pm 16\%$ (48-90%) at the 3rd month stage, $57 \pm 15\%$ (30-70%) at 6th month stage, and $58 \pm 17\%$ (40-90%)

at 12th month stage (Table 1). Significant changes in the perceived WC were noted, using pair t-tests, between the preop and each of the postoperative stages. Nevertheless, no significant continuous improvement from the first to the seventh stage was detected by using one-way ANOVA (Table 2). Meanwhile, mean scores of perceived HRQoL in the six postoperative stages were found ranging from 3.1 to 3.6 times those of the preoperative stage: 3.1 (56/18%), 3.2 (59/18%), 3.4 (61/18%), 3.6 (64/18%), 3.2 (57/18%), and 3.2 (58/18%) accordingly (Table 1).

Correlation between Changes in the Perceived HRQoL and WC

The aforementioned mean scores of perceived HRQoL were consistently higher than those of perceived WC across pre- and post-operative stages. While examining the mean scores of perceived WC/HRQoL in the single pre- and six post-operative stages, the ratio ranged from 0.49 to 0.92: 0.49 (18/37%), 0.84 (56/67%), 0.88 (59/67%), 0.86 (61/71%), 0.90 (64/71%), 0.91 (57/63%), and 0.92 (58/63%). In other words, HRQoL was appraised to be 1.1 to 2.0 times that of WC (Table 1). Significant correlations between the changes in the perceived HRQoL and WC were detected in the preop, postop ICU, predischARGE, and postdischarge-3rd month stages. Nevertheless, no significant correlation between the continuous changes in HRQoL and WC from the first to the seventh stage was identified (Table 1).

Major Difficulties and Stress Encountered during the Recovery Process

The pressure of intense post-operative pain, discomfort, and sense of insecurity. As with any major surgery, the pressure of intense post-operative pain, discomfort, and feelings of insecurity serve only to exacerbate the diminishment of patient confidence in a situation likely already perceive as hostile and beyond personal control. As such, it becomes obvious that post-operative stress plays a critical role in promoting regression of self-appraised HRQoL in patients. All of the subjects complained of post-op pain from the surgical wounds, periodic tracheal sputum suction, as well as sore shoulders and lower back pain caused by bed-rest in the hardly bearable ICU and floor unit. Meanwhile, the unfamiliar and unfriendly environment augmented by noise, high-tech machinery, lack of recreation, such as television, and an unstable health status further contributed to their sense of pain with additional psychological insecurity. For example, patients mentioned, "After I was conscious I started to feel pain and the pain went through the hospitalization period. My pain was worsened by sputum suctioning. Noise of those cold-look machine in the ICU made my pain even more intolerable;" "I used to watch TV before the surgery, and it's so boring in the ICU after 9:00 p.m. My family members were not with me, and I had a sense of emptiness and insecurity... This made me pay more attention to my pain from surgical wounds and sore shoulders and lower

back due to bed-rest;" and "I started to breathe with exertion around the 6th month after I went home due to the graft rejection. I started to suffer from this sense of insecurity about the future from that time on."

Feeling frustrated from physical incompetence in reality testing. 88% of the subjects reported that they were in their 30s and under the assumption that following LT, they would be capable of resuming prior social roles. As a result, they were eager to prove their physical competence as their health conditions stabilized postoperatively. However, many found themselves challenged by merely learning self-care. In particular, taking medication, without the aid of a nurse, during the first postdischarge month frustrated the abilities of many patients. Meanwhile, starting from the 6th month, postdischarge, some of the subjects also began to feel frustrated by unstable physical conditions related to impaired pulmonary function caused by graft rejection and infection. For instance, "You can't imagine what a terrible life I led before the surgery. After the surgery, I'm kind of living in a dream that every thing would be alright. I was so grateful for this new life, so I felt my quality of life was double better than it was in the preoperative stage. Later, I got mild rejection and infection, so, my perceptions of quality of life went down;" "My perceptions of quality of life depend on my recovery from physical strength and general well-being;" and "The reality testing woke me up... I realized that recovery takes a while, and pains and other discomforts would not just disappear over night after the surgery. I was frustrated, but this's the reality."

Struggling between the dependency on transplant professionals and the independent self-care. All the subjects reported struggling daily with the shift from dependency on transplant professionals to independent self-care during the first month after discharge from the hospital. They were uncertain about the progression in their health status and the efficacy of the treatment protocols since they were used to relying upon the decisions of health professionals. Some subjects who developed signs and symptoms related to rejection experienced this struggle again between the later 6th and 12th months, postdischarge stages. They remarked, "I'd been sick for a long time. I lacked confidence in myself. Frankly speaking, no one including physicians and nurses would tell me exactly what I can do or can't. I didn't blame them since little information about Taiwanese lung transplant recipients' recovery experiences can be shared;" and "As I opened my eyes in the ICU, I knew that I was alive. I told myself that from now on I should follow every thing that doctors and nurses told me to do no matter what it was. As my health condition became stable, I had a better quality of life, but I was cautious about my health condition all the time, and relied upon them very much;" and "I had no idea what I should do to facilitate my recovery. When they thought that I should be ready for discharge from the hospital, nurses and doctors told me that I should learn to

make decision on my self-care. But, depending on health professionals' decision and guidance has become part of my daily life for such a long time. I was simply not used to be independent on decision making about my daily activities."

DISCUSSION

As part of a larger project globally examining specific dimensions, including patient appraisal of physical, psychological, and social functional well-being related to HRQoL, this study examined Taiwanese recipients' global appraisal of HRQoL, WC, and related difficulties and stress encountered during the first posttransplant year. In order to strengthen the correlation between patients' and investigator's assessments of HRQoL after transplantation, a VAS scale was used to allow transplant recipients to give subjective appraisals of their global HRQoL and WC.^{10,11,15} Until now, only limited information has been available about either Taiwanese LT recipients appraisal regarding personal HRQoL, or relationship between their socioeconomic status and HRQoL during the first posttransplant year. In keeping with the findings of Western projects, this study suggested that LT contributes positively to the HRQoL and WC of Taiwanese LT recipients during the first posttransplant year. However, unlike most Western studies, this prospective project also closely examined the trend of changes in HRQoL and WC across seven, one pretransplant, two hospitalization, and four postdischarge transitional time points,^{3,6,16} while further examining factors which influence LT recipients' perceptions of HRQoL and WC during hospitalization and postdischarge periods.

Factors influencing the recipients' perceptions of HRQoL and WC during hospitalization period

The factors that contributed to the Taiwanese LT recipients' perceptions of their HRQoL and WC during the hospitalization period in this project included: (a) the efforts of health professionals in managing the recipients' health status; (b) the extent of sensory over-loaded due to inadequate psychosocial supportive environment in the ICU; and (c) the severity of experiences of physical discomforts related to disease.

Most subjects acknowledged the effort of lung transplant health professionals in managing their infection, rejection, and disease related symptoms during the pre- and post-transplant stages. This contributed largely to creating a sense of security that subsequently influenced the patients' self appraisals of quality of life; particularly when their health conditions were unstable. While in the ICU, many of the subjects complained of sensory overload due to the numerous stressors, such as lights and sounds from strange machinery, in a unfamiliar environment. The ICU, by its very nature, is a highly stressful environment for most Chinese; those in the study reported perceiving

themselves as nervous, under stress, vulnerable, and in need of spiritual protection.¹⁷ In this project, the ICU was found also to be, somewhat paradoxically, a sensory-deprived environment; in terms of psychosocial input, since the patients' family members were unable to be with them at all times and there was little, if any, entertainment available. Taiwanese LT recipients all called for a pain-free recovery experience. All of the recipients reported experiencing pain on a daily basis during their acute (ICU) and subacute (floor unit) recovery stages. The experienced pain primarily resulted from surgical wounds, tracheal suctioning, and sore shoulders and lower back. As such, the quality of sleep and rest afforded for the patients was impaired. Subjectively noted, sleep disturbances were associated with poor adjustment to changing environment and reduced quality of life.³ Current research warned that although VASs' scores of HRQoL of LT recipients were significantly higher postop, than they were pre-op, they continued to experience impairments in psychological functioning, such as anxiety and depression. Further research into the HRQoL of LT recipients focusing on ways to improve the subjects' psychological well-being is suggested.⁶

LT recipients within the study confirmed the belief that moving from the ICU to the floor unit was regarded by patients as a milestone of recovery.¹⁸ The health professionals continued to monitor the recipients' daily progression in the floor unit; however, discharge planning began immediately for each patient, once they were transferred. Prior to being discharged, each patient was aided in practicing more self-care and independency by the health professionals. Nevertheless, most of the subjects reported an inadequacy in resuming their independency in self care during the first month after they went home.

Factors influencing the recipients' perceptions of HRQoL and WC during postdischarge period

The factors involved in Taiwanese LT recipients' perceptions of personal HRQoL and WC during the postdischarge period in this project included: (a) adaptation to independency during the first month, postdischarge; (b) improvement in pulmonary function alleviation of physical discomforts during the first three months, postdischarge; and (c) development of graft rejection and infection related signs and symptoms during the 6th month, postdischarge. Using SIP, a 136-item instrument measuring health-related functional status, Western LT recipients reported more dysfunction in categories related to self-care than KT recipients. Also, LT subjects in the Western studies failed to demonstrate a significant improvement in self-care until approximately 1 month to 3 months posttransplant.^{16,19,20} Meanwhile, the improvement in self-care for Western LT, OLT and KT recipients were reported as most evident between 3 months and 6 months posttransplant.^{7,16} Nevertheless, these findings were not

kept by Taiwanese recipients' experiences.

Changes in HRQoL and WC perceived by LT recipients in this study and Taiwanese OLT or KT recipients in the previous studies^{10,11} were not identical across the seven time points. Contrary to constant improvement in HRQoL and WC perceived by KT recipients, the perceived HRQoL and WC of LT recipients at the 6th-month, postdischarge stage were lower than those at the predischarge stage. The best perceived HRQoL and WC during the first posttransplant year for Taiwanese LT recipients was experienced between the 1st and 3rd months after discharge from the hospital. Lauza et al¹⁵ reported that during the 1st and 3rd months posttransplant, the FVC, FEV₁, and FEF₂₅₋₇₅ reported by LT recipients were significantly improved compared to pretransplant values. Additionally, the FEV₁ also improved significantly from the 1st to the 3rd month posttransplant. Plausible explanation for these trends is that discharge from the hospital is a marker for recovery *per se*. Most recipients likely regarded being discharged from the hospital as evidence of hope for survival. Another explanation may be that during this critical period of time the recipients recovered from the preop and immediate postop physical discomforts from surgical wound, chest tubes, tracheal suctioning, sore shoulders and lower back pain etc. Finally, since 88% of the subjects were in their 30s, the patients likely assumed, psychologically, that they would be able to resume their prior social roles following discharge, and therefore, inadvertently and artificially inflated their perceived HRQoL and WC. Even more, it was noted that they were less anxious about their health status and, subsequently perceived a further augmented quality of life. However, despite optimism, most of the LT recipients found a certain degree of difficulty in even adapting to independency in decision making on self-care during the first postdischarge month.

Following the 1st-3rd months postdischarge period, further complications developed in the form of graft rejections and subsequent declines in pulmonary function during the 6th month postdischarge period. Recorded evidence shows that the perceived HRQoL and WC were lower in the 6th and 12th months postdischarge stages than they were in the previous four postoperative stages. Meanwhile, of these two time points, mean scores of HRQoL/WC appraised by Taiwanese LT (63/58%) were lower than for OLT (88/82%), and KT (83/80%) recipients. These findings suggest that the recovery process for LT involves more turmoil than recovery processes for KT or OLT patients. In addition, this fact may explain why LT recipients became frustrated, following discharge from the hospital, with development of unexpected unstable physical conditions such as extreme exertion, fatigue, hyperthermia and various other physical discomforts caused by rejection and infection.

In conclusion, a significant correlation between the changes in the perceived HRQoL and WC was detected in the preop, postop ICU, postop one-day pre-discharge and the 3rd month postdischarge stages for Taiwanese LT recipients. The most evident improvement in HRQoL and WC for LT recipients occurred between the 1st and 3rd months, postdischarge stages. It is suggested that lung transplant health professionals understand not only the degree of the recipients' appraisals of their HRQoL and WC, but also the context framing their perceptions. The HRQoL facilitating factors for Taiwanese LT recipients included: (a) a secure, quiet, and pain-free recovery environment; (b) an effective medical and nursing transplant protocols for in improving pulmonary function, and detecting and managing, early and effectively, graft rejection and infection; and (c) abundant psychosocial, as well as tangible, support from health professionals and family members in helping the recipients' adaptation to independency when needed. Transplant health professionals may need to consider the legitimacy of using effective pain control protocols such as pain-control-anaesthesia before sputum suctioning or position change, changing position at least every 2 hours, and practicing massage or accupressure. Weekly coaching programs should be evaluated with regards to the benefits they may offer to patients attempting to adapt to independency during the first post-discharge month. Finally, a monthly monitoring program starting from the 3rd month, through the 6th and 12th months should be considered as a means for early detection of the rejection signs, and necessary guidance in mandating quality of life and working competence.

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Table 1. Comparison Between Health Related Quality of Life (HRQoL) and Working Competence (WC) by Different Stage Groups (n = 8)

Stage	HRQoL (%)		WC (%)		t value	F value
	Mean±SD	Range (%)	Mean±SD	Range (%)		
(A) Preop day	37±16	20-60	18±12	0-30	3.05*	
(B) Postop ICU transition	67±13	53-90	56±9	48-70	4.30**	17.06
(C) Postop one day before discharge	67±13	53-90	59±10	48-70	3.07*	14.75
(D) Postop 1 month after discharge	71±16	53-90	61±13	48-80	4.66**	11.63
(E) Postop 3 months after discharge	71±16	53-90	64±16	48-90	2.29	9.42
(F) Postop 6 months after discharge	63±14	40-80	57±15	30-70	0.93	7.65
(G) Postop 12 months after discharge	63±10	50-80	58±17	40-90	1	6.48

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

Table 2. Summary Table for Health Related Quality of Life (HRQoL) and Working Competence (WC) by Different Stage Groups (n = 8)

Stage	HRQoL		WC	
	(A) Preop day		(A) Preop day	
	t value	F value	t value	F value
(B) Postop ICU transition	-7.05**		-9.44*	
(C) Postop one day before discharge	-7.05**	9.20**	-9.87*	29.63
(D) Postop 1 month after discharge	-21.65	6.99**	-8.31*	20.87
(E) Postop 3 months after discharge	-18.68	5.77**	-8.00*	14.93
(F) Postop 6 months after discharge	-2.61*	4.75**	-4.6*	11.04
(G) Postop 12 months after discharge	-3.73*	4.27**	-4.30*	8.33

* $p < .01$

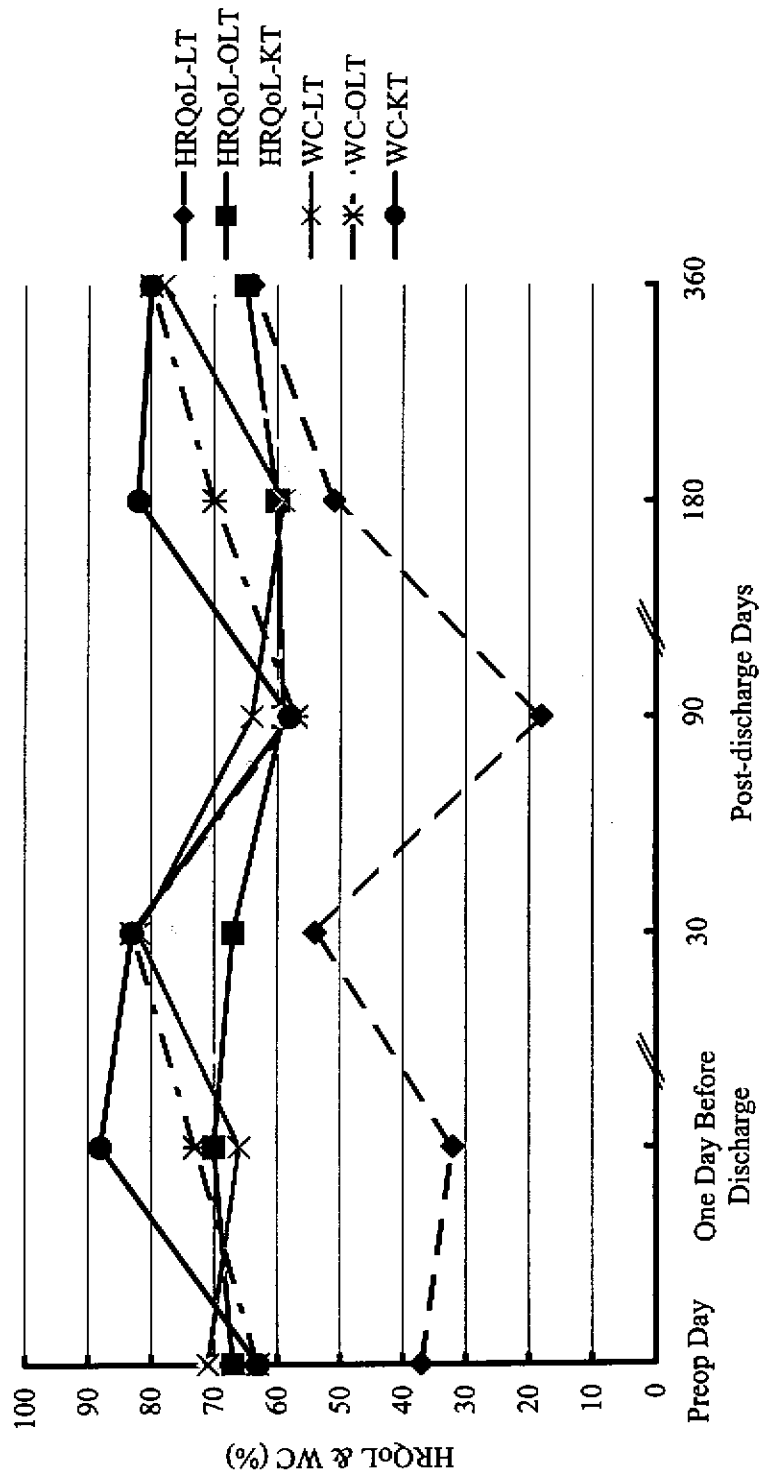


Figure 1. Changes in health related quality of life (HRQoL) and working competence (WC) before and after lung, (LT), liver* (OLT), and kidney** (KT) transplantation

*Reference no. 11

**Reference no. 10

行政院國家科學委員會補助國內專家學人出席國際學術會議報告

2001年6月23日

報 告 人 姓 名	施富金	服 務 機 構 及 職 稱	台大醫學院護理學系 副教授
會 議 時 間 地 點	自 2001/06/10 至 2001/06/15 丹麥哥本哈根	本 會 核 定 補 助 文 號	國科會研究計劃 NSC 89-2314-B-002-502
會 議 名 稱	(中文) 第 22 屆國際護理協會國際護士大會暨論文發表會 (英文) ICN 22nd Quadrennial Congress		
發表論文題目 (口頭報告)	(中文) 影響臺灣家屬於器捐前決定器官捐贈之因素 (英文) The Factors Contributing to Taiwanese Families' Decision to Donate Cadaveric Organs During the Pre-donation Transition		
(海報展示)	(中文) 臺灣精神分裂症患者父母提供居家照顧之困難 (英文) The Difficulties Encountered by Taiwanese Parents in Providing Home Care for Their Children with Schizophrenia		
(海報展示)	(中文) 臺灣手術室品質之改善情形 (英文) Quality Improvement in the Operation Room in Taiwan		
(海報展示)	(中文) 比較有宗教信仰及無宗教信仰之臺灣婦女喪夫後之調適過程 (英文) Comparison of Post-bereavement Adjustment of Taiwanese Women with and without a Religious affiliation		

此次在丹麥哥本哈根舉行的「第 22 屆國際護理協會國際護士大會暨論文發表會」，目的是將全球的護理學者聚集在一起，共享護理學界迎向公元二千年的展望及發展，並讓各國會員有彼此交流的機會。

本次大會共有來自全球超過 1,800 名與會人員，分別依下列十四種主題，發表超過 1,100 篇論文：Spanish language sessions、French language sessions、Associations in Action、Classification-Documentation、Education、Ethics、HIV/AIDS、History、Management-Policy、Practice、Regulation、Research、Quality-Cost-effectiveness、Socio-economic Welfare。

本人在此次會議中發表口頭發表 1 篇論文" The Factors Contributing to Taiwanese Families' Decision to Donate Cadaveric Organs During the Pre-donation Transition"，探討影響臺灣家屬於器捐前決定器官捐贈之因素。多位學者對本人所發表之題目甚感興趣，會後再與本人作更深入的討論。另有 3 篇海報展示論文" The Difficulties Encountered by Taiwanese Parents in Providing Home Care for Their Children with Schizophrenia"，"Quality Improvement in the Operation Room in Taiwan"，及" Comparison of Post-bereavement Adjustment of Taiwanese Women with and without a Religious affiliation"，亦獲與會人員之迴響。

綜觀此次大會，本人不但順利完成論文發表，亦有機會與國外友人建立感情及聯絡管道，同時也透過討論，在國際友人心對我國護理形象留下深刻的印象。中華民國護理學會亦於會議中積極爭取作下屆之主辦國，獲熱烈反應，此外，本人攜回各項最新護理研究課題及摘要，可供國內其他護理學者同仁參考。深信下次會議中，國人將發表更多國際水準之研究，大家有志一同，提昇我國醫學護理研究之國際地位。

Nursing: A New Era for Action

La enfermería: Actuar en una etapa n

Soins infirmiers: agir en des temps n



International Council of Nurses
ICN 22nd Quadrennial Congress
10 - 15 June 2001, Copenhagen

Consejo internacional de enfermera
22º Congreso cuatrienal del CIE
10 a 15 de junio de 2001, Copenhag

Conseil international des infirmières
22e Congrès quadriennal du CII
10-15 juin 2001, Copenhague



Abstracts for Concurrent sessions
and Symposia, List of posters

Resúmenes para las sesiones paralelas
y simposio, lista de paneles

Résumés sur les sessions parallèles et
les ateliers, liste des posters

ABSTRACTS

2001



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2001

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01

Title of abstract: AN INTERNATIONAL INTERVENTION STUDY TO ENHANCE TRANSFORMATIONAL LEADERSHIP STYLE OF HEAD NURSES

Name of author(s): P. Claessens¹, G. Cunningham¹, S. De Geest^{1,2} et al.

BACKGROUND: Nursing organisations today are part of highly interconnected and unstable global market environments in which innovation, adaptation and creativity are key elements in survival and in fulfilling one's mission. Nursing organisations therefore have to abandon old hierarchical ways of managing in favour of models that rely more on decentralised decision-making, information sharing and informal networking. Investing in the development of transformational leadership of head nurses seems to be a promising strategy for nursing in order to optimise its organisations' performance in the current health care turmoil. Empirical evidence indicates the positive effects of transformational leadership style on employee's satisfaction and demonstrates a positive association between employee's satisfaction and patient satisfaction, respectively. No study has been carried out to our knowledge to date, assessing the effect of transformational leadership on both employee's and patient outcomes.

AIM OF THE STUDY: The research questions of this study are therefore twofold: (1) Can an intervention to enhance transformational leadership in head nurses (Clinical Leadership Project, Royal College of Nursing (RCN)) successfully be transferred from the UK to a Belgian and Swiss setting?; (2) Does the intervention positively influence selected head nurses-, bed-side nurses- and patient-outcomes?

INTERVENTION: The 1-year clinical leadership intervention is based on an *action learning* approach. This refers to a circular dynamic of learning experiences which is initiated by identifying and addressing problems from daily nursing practice. Following instruments stimulate and guide the action learning: (1) patient stories; (2) observation of care; (3) personal development plans; (4) workshops; (5) action learning sets; (6) 360° feedback; (7) mentorship. The initial RCN clinical leadership project used patient-centredness as guiding paradigm. This study will use the concept of skilled companionship as guiding principle.

METHODOLOGY: This study uses a combination of action research and a quasi experimental design to answer the research questions, respectively. The sample consists of 58 Belgian and Swiss head nurses. Inclusion criteria are being a head nurse in one of the participating hospitals; voluntary participation; anticipated availability over the entire duration of the project; Dutch, French or German speaking; anticipated commitment to a nursing career for at least another two years; giving written informed consent. Exclusion criteria are inability to participate over the entire duration of the project; unwillingness of bed-side nurses, hospital administrator(s) or physicians to support the project; project interfering with the head nurses' participation in other projects. Nurses were allocated to a control (N=26) and an intervention group (N=32) using stratified randomisation. Selected head nurses-, bed-side nurses-, and patient outcomes were measured using established instruments or using interviews. Data collection for the pre-intervention tests started in August 2000. Data collection will be ongoing during the intervention (from 9/2000 to 9/2001) congruent with the action research approach. Post tests will be performed after completion of the intervention in autumn 2001. Both quantitative and qualitative methods will be used for data analysis.

Intended learning outcomes:

1. Participants will have knowledge of the content and process of the Clinical Leadership Project
2. Participants will gain insight in the methodology of action learning and its associated evaluation process

The Factors Contributing to Taiwanese Families' Decision to Donate Cadaveric Organs During the Pre-donation Transition

SHIH Fu-Jin¹, LIN Min-Huey¹, LIN Hui-Ying¹, LAI Ming-Kuen², CHU Shu-Hsun³
National Taiwan University, College of Medicine, Department of Nursing¹,
Department of Urology², Department of Surgery³, Taipei, TAIWAN

Purpose. For years, the Asian organ donors' family members' decision to donate during the pre-donation transition was not well discussed. The purposes of this study were: (1) to explore in-depth the needs of Taiwanese organ donors' families; (2) to investigate the factors which influence the Taiwanese families' decisions for organ donation; and (3) to discover the expectations of the Taiwanese donors' families for health care providers during the pre-donation transition. The pre-donation transition referred to the period of time from the family signing consent for organ donation to the organ-harvesting surgery on the donor.

Method. Forty family members who represented the donors' families to sign the donation consent form at National Taiwan University Hospital were individually approached. Thirty of them (16 men and 14 women) agreed to participate in this study and completed semi-structured interviews. The others reported that they were too sad to think or talk at that time.

Results. The participants ranged in age from 28 to 58 years (mean 47.6 ± 6.36 years). The type of kinship of the participants included the donor's father (40%), mother (26.7%), elder sister (13.3%), wife (8%), elder brother (6.7%), and husband (6.7%). The type of organs donated included the heart, kidney, liver, lung, corneas, spleen, skin, and bone. The subjects reported to have the following impending needs: to have clear knowledge of the cause of the donor's death provided by the physicians (100%); to give comfort and care to other family members as well as to receive it from physicians and nurses (100%); to receive help from health care providers in managing the legal issues related to the donor's death (93.3%); to smoothly manage the tangible issues related to the donor's (funeral and economic affairs) (86.7%); and to fulfill the donor's living will (66.7%). The factors which influenced the donors' families' decisions to donate were agreement from the important persons in the family (parents and elder siblings, in particular) (100%), cultural and religious beliefs related to the particular organs (80%), the donor's living will, if available (73.3%), the health care providers' caring attitudes and explanations (66.7%), and encouragement from the donor's close friends (50%). The most important decision-making person was reported to be the father, followed by the mother, elder brother, and elder sister, in that order. The donor's spouse was reported to play the least role in the decision to donate, although he or she was invited to participate in the decision.

Intended outcomes:

- (1) to explore in-depth the needs of Taiwanese organ donors' families; (2) to investigate the factors which influence the Taiwanese families' decisions for organ donation; and (3) to discover the expectations of the Taiwanese donors' families for health care providers during the pre-donation transition.

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 Ho, Mei-Hua; Chien, Yih-Yin
Developing the self-management behaviors of parent with asthma children with qualitative and quantitative method
 Chiang, Li-Chi; Huang, Jing-Long; Chao, Shu-Yuan
 ✓ *The difficulties encountered by Taiwanese parents in providing home care for their children with schizophrenia*
 Shih, Fu-Jin; Shu, Ying-Mei; Shiau, Shu-Jen; Hwu, Hai-Gwo
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