SURVIVING A CRITICAL ILLNESS THROUGH
MUTUALLY BEING-THERE-WITH EACH OTHER

Vico Chung-Lim Chiang
MHA (NSW), GDMS (Hull), BN (Newcastle), RN (NSW)

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for the degree of Doctor of Philosophy
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I hereby certify that the work embodied in this thesis is the result of original research and has not been submitted for a higher degree to any other University or Institution.

(Signed): ..................................................
ACKNOWLEDGEMENTS

A Chinese idiom reads, “There are always higher mountains to climb after the others”. The journey of exploring and developing new knowledge in this PhD Study is not an end but a beginning. There are more challenging opportunities to do further research and develop better care for patients with a critical illness and their families. Nevertheless, with the support and encouragement from my family, friends and colleagues, the journey of my Study has been a meaningful and less tortuous experience, than it might otherwise have been.

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GLOSSARY

Critically ill patient / Intensive care patient / ICU patient

In this Study, the meaning of these three terms is the same and interchangeable. They refer to patients who have stayed in ICU and received care there for at least 48 hours.

Lay person support

Lay person support refers to the informal support and care provided by a non-professionally trained member of the patient’s family who cares for the patient during his/her critical illness and the process of recovery.

Principal lay support person (PLSP)

A PLSP is the principal lay person who provides support for the patient. A PLSP may be a member of the patient’s family or a close friend. In this Study, however, PLSPs were patients’ spouses or partners. These PLSPs were not professional health care providers. They regularly visited the patients in ICU, continued to support the patients after they were transferred out of ICU to the general ward, and lived with the patients after discharge from hospital for up to 3 months (for the purpose of this Study). Principal lay person support is therefore the support provided by a PLSP to a patient when he/she is critically ill and during his/her process of recovery. Support in this instance means all aspects of informal care, including psychological and social care, and concern provided by this non-professional PLSP.

In this Study, a PLSP MUST ALSO BE the ‘person responsible’.
According to Lawlink NSW (1999, paragraph 3):

*If a guardian with the function of consenting to medical and dental treatment has not yet been appointed (by the Guardian Board), the ‘person responsible’ is;

- a spouse or defacto (sic) spouse who has a close and continuing relationship with the person.

If there is no-one in this category, the ‘person responsible’ is;

- the carer or person who arranges care on a regular basis and is unpaid (the carer pension does not count as payment); or
- the carer of the person before they went into residential care.

If there is no-one in this category, the ‘person responsible’ is;

- a close friend or relative (bracket content added).

**Process of recovery**

Process of recovery is a process of ongoing experience that comprises the short period of initial recovery in ICU and the later recovery of the patient in a general ward and at home in the community. Later recovery includes the experience of convalescence and rehabilitation, as well as possible changes and new adaptations to normal life during this process. In this Study, the transfer of ICU patients to the general ward initially signified the process of their recovery. It involved a gradual diminishing of the acute illness and the patient’s striving to regain what he/she had previously (prior to the episode of critical illness) experienced as wellness.
KEYS TO TRANSCRIPTS

The following abbreviations and symbols are used in the excerpts of transcripts from patient and PLSP interviews in this thesis.

**bold/highlight**  added emphasis in the excerpts of transcripts

I  interviewer (the student researcher of this study)

*italics*  used to indicate all excerpts of transcripts from patient and PLSP interviews

…  a pause of the interviewee during his/her conversation in the interview

…  unfinished sentence of the interviewee during his/her conversation in the interview

~~~~~~  non-essential content located in the quoted excerpts of transcripts not included in order to save space and maintain the flow of presentation of data
ABSTRACT

Support provided by non-professional family members is generally believed to be beneficial to the recovery of critically ill patients. Nursing researchers have conducted a number of studies about the experiences of critically ill patients and the needs of their families. However, few have investigated the experiences and interactions of both this group of patients and their main informal carers (principal lay support persons) simultaneously. This study has sought to rectify this situation by capturing and undertaking a theoretical analysis of the perceptions and experiences of both critically ill patients and their principal lay support persons. As a result a substantive theory has been developed through the use of grounded theory method in the Study. This theory identifies and explains the actions and interactions between critically ill patients and their principal lay support persons who participated in the Study, whom the researcher observed and interviewed during the data collection period. Data were collected during the critically ill participant’s hospitalisation and three months following his/her discharge from hospital. Implications of the study concern nursing practice as well as outcomes of the Study as these are described and explained through the substantive theory developed from it. Testing of this theory in the context of critically ill patients and their lay support persons provides opportunities for further research, as does the overall phenomenon of lay person support for critically ill patients.

Grounded theory was the method used in the Study. Data for the Study were collected by participant observation of, and face-to-face interviews with patients who had a critical illness and their principal lay support persons. Two
interviews were conducted with each of these participants. Patients and their principal lay support persons were initially interviewed separately to obtain information about their individual perspectives of what support meant to them during an episode of critical illness. A second interview was conducted three months later to facilitate the researcher’s understanding of both patients’ and principal lay support persons’ experiences during the recovery process. A total of sixteen (16) interviews were conducted in this study from eleven (11) participants before data saturation occurred. The data collected were analysed by constant comparative analysis integral to the grounded theory approach. Data analysis was also facilitated by a computer-aided qualitative data analysis software NUD*IST 4 (Non-numerical Unstructured Data Indexing, Searching, and Theorizing Version 4). This software aided the analysis to the extent that it provided an efficient data management system.

Three categories, 1) being-there-with, 2) independing, and 3) coping were discovered from the data. Being-there-with is an essential and mutual need between the patients and their principal lay support persons during the episode of critical illness and later recovery. Independing on the other hand is the process through which these patients experiment with regaining their independence. It involves their experiences of making decisions and re-building confidence. Coping is the process whereby the principal lay support persons and patients manage their stress during the critical illness and later recovery. During the coping process, there is an uncertainty in principal lay support persons about their loved ones’ situation. They experience ‘coping with each day as it comes’ and ‘learn to adjust’ to the stress arising from the changing and unpredictable
condition of the patients. Being-there-with is also a major coping strategy for both the principal lay support persons and patients to manage their stress. The three categories of being-there-with, independently, and coping arising from this Study provided the basis from which to identify its core category, ‘mutually being-there-with each other’, and to theorize the core process that represents the substantive theory about experiences and interactions of principal lay support persons and their loved ones during a critical illness situation. The core process that represents the developed substantive theory is ‘surviving a critical illness through mutually being-there-with each other’. This theory explains the complex, dynamic, and interactive nature of principal lay person support which both patients and principal lay support persons experienced during an episode of critical illness and later recovery. An understanding of this dynamic, complex and interdependent relationship between patients and lay support persons will better enable nurses to consider both these parties as the focus of their care. Furthermore, because the substantive theory emerging from this Study captures the process of patients’ and lay support persons’ recovery from an episode of critical illness it provides a conceptual map of how this process may progress. In this Study the theory enables nurses to gauge both patients’ and lay support persons’ progress along the road to recovery and to consider this in their plan of care.

Several implications for nursing practice emerged from this study. These relate to the needs of critically ill patients and their principal lay support persons during the process of being critically ill and recovering which they experienced together. Because this Study identified the importance to both patients and
principal lay support persons being-there-with each other, a key implication of the study is the need for intensive care units to adopt flexible visiting hours to maximise opportunities for this to occur. Nevertheless, at the same time nurses need to be vigilant that flexible visiting does not prove onerous and overtire patients or their principal lay support persons. A further implication of the Study for nursing practice closely related to its finding of the importance of the core category ‘mutually being-there-with each other’ to patients and their lay support persons in the context of critical illness and recovery, is the need for nurses (and other health professionals) to be willing to care for both parties as an inseparable dyadic unit. This Study also has implications relating to the care of critically ill patients following their discharge home. The experience of participants in this Study revealed the importance of careful discharge planning, post-ICU follow-up, and continuity of care in the community to enhance recovery of the patients and to address the special needs of their principal lay support persons.

From a researcher’s perspective the process of recruitment for this study demonstrated that recruitment of vulnerable populations (like ICU patients) is a challenge to the researcher in terms of ethical considerations, particularly when the researcher is attempting to meet the expectation of primary selection for theoretical sampling in grounded theory method. Suggestions are made in this thesis about how to tackle this challenge in future studies.

At the conclusion of the Study, a number of suggestions for further research are made relating to the findings. These include the recommendation that the substantive theory developed in this Study be tested with a larger population.
It is also suggested that a longitudinal follow-up study, which extends beyond a three months recovery period, be conducted to further understand the experiences and support needs of post-ICU patients and their principal lay support persons. In addition, more research is required to identify best practice regarding discharge planning, post-ICU follow-up care, and continuity of care in the community for critically ill patients and their principal lay carers.