

# Surviving a critical illness through mutually being there with each other: A grounded theory study

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## *Abstract*

*Objectives:* The objectives of this study were to conduct a theoretical analysis of the critically ill patients' perceptions of the impact of informal support and care from their main family carer (MFC) during the time of their stay in the hospital (ICU) and thereafter (and vice versa).

*Research design and setting:* The grounded theory method was used to investigate the target phenomenon in the ICU of a large general hospital, and three months later in the community after the patients were discharged. Qualitative data were collected through participant observation and interviews for constant comparative analysis until theoretical saturation.

*Results:* A substantive theory emerged and it illustrated and described the dynamic actions and interactions between critically ill patients and their MFC during the process of recovery. Three categories, 1) being there with, 2) coping and 3) self-relying, comprise the essential components of this theory.

*Conclusion:* The theory represents the core process of 'surviving a critical illness through mutually being there with each other' in which both the patients and their MFC are involved. Implications and recommendations were proposed to provide a basis for further research and nursing practice on the phenomenon of informal support and care of critically ill patients and their recovery.

## Introduction

It is generally believed that the informal support provided by non-professional family members is beneficial to the recovery of critically ill patients. Numerous researchers have conducted studies of the experiences of critically ill patients and the needs of their family members (Beach et al., 1992; Burr, 1996; Davies, 2000; Fridlund et al., 1993; Chien et al., 2006; Chui and Chan, 2007; Foster and Chaboyer, 2003;

Geary et al., 1994, 1997; Gortner et al., 1988; Holl, 1993; Johnson et al., 2001; Mishel and Murdaugh, 1987; Mutran et al., 1997; Parker, 1997; Saxe-Braithwaite and Chapman, 1992; Simpson, 1991). However, few have investigated the experiences and interactions that make up the informal support and care of both these groups of patients and their main family carers (MFC) simultaneously. This study sought to fill this gap by capturing and undertaking an investigation of the perceptions and experiences of both critically ill patients and their main carers or support persons in the family. The objectives were to conduct a theoretical analysis of critically ill patients' perceptions of the impact of informal support and care from their MFC during the time

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of their stay in the hospital (ICU) and thereafter (and vice versa), in order to develop a substantive theory describing and explaining the phenomenon, with implications for nursing practice and future research.

## Methods

### Literature review

The question of just how much reading or how extensive a literature review is sufficient prior to commencing a grounded theory study remains a matter of debate (Cutcliffe, 2000). Stern (1985) pointed out that a detailed pre-study literature search and review for a grounded theory study was disadvantageous because the search might lead to pre-judgement and affect the premature closure of ideas and research inquiry, i.e. increasing the chance of a researcher's bias or pre-conceptions and possibly leading to an insufficient interpretation of the phenomenon (which is critical for a qualitative study).

Uncertainty about the extent of a literature review might be considered by some researchers as a weakness or difficulty in the grounded theory method. Nevertheless, Glaser and Strauss (1967) argued that a concurrent review of the literature should be used as a slice of data to be compared with data being generated by other means, e.g. interviews. When the analyst considers literature as a slice of data (Glaser and Strauss, 1967) that is concurrently used to compare with the emerging categories from the data, it makes sense that more relevant and appropriate literature specific to the emerging categories will be used to rigorously complete the analysis. This minimises the risk of the researcher's pre-conceptions about these categories; it may also trigger new questions and further data collection, and provide the basis of verification for the researcher to draw conclusions until theoretical or data saturation occurs (Strauss and Corbin, 1998).

### Design of the study

The target phenomenon was investigated using the grounded theory method (Glaser and Strauss, 1967; Strauss and Corbin, 1998) with a philosophical underpinning of symbolic interactionism (Swanson, 1986), which fits well to explore a social process. The developed theory was intended to identify and explain the actions and interactions between critically ill patients and their MFC, whom the researcher would observe and interview during the data collection period.

### Data collection methods

The methods of data collection were participant observation of, and face-to-face interviews with, patients and their MFC. Two interviews were conducted with each of these two types of participants. Patients and their MFC were first interviewed separately to obtain information about their individual perspectives and their perceptions of what support meant to them during an episode of critical illness. Second interviews were conducted three months later to facilitate understanding of both individual patients'

and their MFCs' experiences during the recovery process. Participant observation was conducted for the environments, social contexts, and interactions (e.g. non-verbal behaviours) between patients and their MFC when they were in the hospital (ICU or general ward) and at home three months post discharge. Apart from audio-recording for the interviews, field notes were written for the participant observation.

### Sampling and setting

Theoretical sampling (Glaser and Strauss, 1967; Glaser, 1978; Strauss and Corbin, 1990, 1998) is an essential technique through which the grounded theory researcher decides, following analysis of the most recent set of data, what data to collect next and where to find them from other participants, sites and/or events or incidents so that the theory emerges through this ongoing process. The theoretical sampling process is controlled by the emerging theory, and the initial decisions are not built upon a preconceived theoretical framework (Glaser and Strauss, 1967). Although more participants may be theoretically sampled for the analysis, the aim of theoretical sampling is to achieve data saturation primarily focusing on the events or incidents identified from the collected data, which may not necessarily depend on a larger sample size (Strauss and Corbin, 1998, p. 202), i.e. an adequate *amount* of data sufficient for coding and constant comparative analysis, not a larger number of participants (Morse, 1989, 1994). Researcher's anxiety to have unlimited access to carry out sampling (Morse, 1989) and to know everything is unnecessary for theoretical saturation if s/he is satisfied that the data are saturated within the process of constant comparative analysis (Glaser and Strauss, 1967). The temptation to wait for 'just in case something new' in the field often prolongs the study unnecessarily (Glaser and Strauss, 1967, p. 73). Polit and Beck (2008) also pointed out that if participants are good informants who are able to reflect on their experience and communicate effectively, saturation can be achieved with a smaller sample size. With the very rich amount of data *per se* collected in this study, the numbers of participants, interviews and hours of participant observation conducted were not large at the time theoretical saturation was realised (Glaser and Strauss, 1967; Glaser, 1978; Strauss and Corbin, 1998; Morse, 1994).

The study setting was an adult intensive care unit (ICU) at a local teaching hospital. Apart from the ICU, some of the data was collected in the general wards if the participating patients had been transferred out of the ICU. The study involved a vulnerable population like the critically ill. Therefore, lengthy discussions had been undertaken with the clinical partners in order to establish a mutually agreed recruitment protocol with the measures that ensured ethical protection. The protocol was then approved by the relevant ethical clearance boards of the related hospital and the researcher's affiliated institution. There were two essential ethical measures which ensured autonomy, non-coercion and informed consent of the potential patient participants (and their MFCs) in this study, 1) senior nurses, who were involved in patient care in the unit but not involved in the study, assisted in initial identification of potential participants for secondary recruitment by the researcher, and 2)

for the unconscious patients, fully informed consent was obtained from the "person responsible" based on the principles set by the local Guardianship Act. In order to be eligible for this study, the 'person responsible' also needed to be the MFC of the unconscious patient.

Conscious and unconscious patients identified as potential participants were those who had been in the unit for at least 48 hours. If the conscious patients and their MFC expressed interest in participating in the study after reading the relevant information letter and explained by the senior nurses, the nurses would contact the researcher, who subsequently met with these potential participants to explain further details of the study. If they agreed to participate, written consent was obtained from both of these parties prior to the data collection. Data were collected during the critically ill patients' hospitalisation and three months following their discharge from the ICU.

If a potentially suitable unconscious participant (a patient with an MFC) was identified by the senior nurse, his/her MFC was subsequently introduced to the researcher. If the MFC agreed to take part in the study, written consent was obtained. Since participant observation would involve the unconscious patient in the initial stage, the MFC gave his/her consent on behalf of the patient as his/her "person responsible". After the patient had recovered from unconsciousness for at least 48 hours (and provided that he/she was physically stable, and cognitively capable according to a Mini Mental Status (MMS) assessment (Folstein et al., 1975), the researcher would explain the study to him/her. If he/she agreed to participate in it, consent was also obtained. If the patient did not wish to participate, permission was sought from him/her to use the data collected through participant observation during the period when he/she was unconscious.

With the attrition of one patient and a few requests by patients and their MFC to be interviewed together in the second interviews, a total of sixteen (16) interviews were finally conducted with eleven (11) participants before theoretical saturation occurred in this study. The number of participant observation hours with these 11 participants at the point of saturation was 14.4. Nevertheless, there was adequate amount of data (meaningful incidents and events) generated from the interview transcripts, which occupied 290 pages and comprised 110,389 words, for the analysis. Table 1 provides information about the participants of this study.

## Data analysis

The qualitative data collected by participant observation and interviews were analysed through constant comparative analysis, which is integral to the grounded theory method (Glaser and Strauss, 1967; Strauss and Corbin, 1998) and aims at the emergence of core categories and theory development (Strauss and Corbin, 1998). The data analysis was also facilitated by a computer-aided qualitative data analysis software (CQDAS), NUD\*IST 4 (Non-numerical Unstructured Data Indexing, Searching, and Theorising Version 4, N4). This software aided the analysis to the extent that it provided the investigator with a highly efficient data management and audit trail system (Halpern, cited in Lincoln and Guba, 1985).

The procedure of using N4 in this study was not commenced with a specific pre-determined set of template codes in mind for the coding at the Index Tree of the program. This is because the minimisation of any pre-conceived concepts or codes that may interfere or bias the process of coding and theorizing in grounded theory is crucial (Glaser and Strauss, 1967; Glaser, 1978; Amankwaa, 2010). Furthermore, in this study, the researcher designed a set of alternative procedures that enabled N4 to fit better with the three levels of coding (open, axial and selective) (Glaser, 1978) for constant comparative analysis. These procedures were comprised of three stages.

### Stage 1 of the analysis

Open codes (Strauss and Corbin, 1990) were constructed in the Free Nodes of N4 during a deductive process from each interview transcript, and stored as a separate N4 project file for further comparative analysis. Therefore, there were two separate project files created for the analysis of the very first two interviews, that is, a project file for the first interview of the first patient and the first MFC respectively. Eventually, based on data concurrently generated and compared with these two initial interviews, more open codes were added to these separate project files. There were also another two separate project files created to contain all data analysed from the second follow-up interviews (three months after the first ones) of all patients and MFCs. In all these files, the Free Nodes in N4 (open codes) were also stored with their relevant memos. These codes and memos changed according to subsequent axial coding and theoretical sampling (Strauss and Corbin, 1998). Field notes written during participant observation were used to supplement this ongoing data analysis process.

Axial coding was the next step of analysis in Stage 1 to reconstruct open codes that carried different underlying conditions, circumstances, properties and dimensions, i.e., new codes or working sub-categories were created. Axial coding was an inductive process through which the initial concepts or working sub-categories were formed (Strauss and Corbin, 1998). From the continuous open and axial coding, a detailed index tree was cumulatively formed from more interview transcripts of the patients and MFCs. A part of an index tree is shown as an example in Fig. 1 (a complete index tree of a project file is too large to be shown). Data collected from the second interviews of patients and MFCs conducted three months later were analysed through the same process of open and axial coding with N4. This completed Stage 1 of the analysis process of this study.

### Stage 2 of the analysis

In Stage 2 of the analysis, all index trees that represented the initial concepts or working sub-categories developed from all the collected data were further compared to develop initial categories. The delineation of conditions, circumstances, properties and dimensions during axial coding in this stage differentiated one category from other categories and gave it precision (Strauss and Corbin, 1998). The analytic process of open and axial coding in Stages 1 and 2 was guided by a coding paradigm which consider

**Table 1** Details of participants and number of interviews.

Pseudonyms	Age	Sex	Occupation	Diagnostic categories	ICU LOS (days)	Interview venue	MMS score	Remarks
Family A – John (MCF: husband)	76	M	Retired	N/A	N/A	1st – home 2nd – home	N/A	interviewed together during 2nd interview
Family A – Mary (patient: wife)	77	F	Retired	Respiratory	3	1st – home 2nd – home	1st – 29/30 2nd – 30/30	
Family B – Jane (patient: wife)	60	F	Nursing Home Carer	Gynaecological cancer	2	1st – general ward	25/30	<ul style="list-style-type: none"> <li>• husband not interested in taking part in the study</li> <li>• 2nd interview not undertaken due to distance</li> </ul>
Family C – Pauline (MCF: partner)	63	F	Retired nurse	N/A	N/A	1st – home 2nd – home	N/A	
Family C – Paul (patient: partner)	51	M	Retired machine operator	GI problem	14	1st – home 2nd – home	1st – 23/30 2nd – 29/30	
Family D – Jill (MCF: wife)	66	F	Housewife	N/A	N/A	1st – ICU waiting room 2nd – home	N/A	<ul style="list-style-type: none"> <li>• 1st interview completed with the presence of their daughter – Lily</li> <li>• Jill &amp; Jack interviewed together during 2nd interview</li> </ul>
Family D – Jack (patient: husband)	70	M	Retired telecommunication supervisor	Respiratory	15	1st – home 2nd – home	1st – 29/30 2nd – 29/30	
Family E – Karen (MFC: wife)	65	F	Housewife	N/A	N/A	1st – ICU sitting room	N/A	both Karen & Peter withdrew
Family E – Peter (patient: husband)	67	M	Retired	Respiratory	18	not interested in taking part in the study	N/A	
Family F – Elsa (MFC: wife)	73	F	Retired school teacher	N/A	N/A	1st – waiting room of a general ward 2nd – home	N/A	1st interview completed in the presence of their three daughters
Family F – Simon (patient: husband)	72	M	Retired train maintenance worker	Respiratory	14	1st – home 2nd – daughter's home	1st – 26/30 2nd – 29/30	

Number of interviews in each family set	
Completed set	Total number of interviews (first and second three months later)
Family A	3 interviews (John and Mary were interviewed together in the second interview)
Family C	4 interviews
Family D	3 interviews (Jill and Jack were interviewed together in the second interview)
Family E	1 interview (both Karen and Peter withdrew after the first interview with Karen)
Family F	4 interviews
Sub-total	15 interviews
Incomplete set	Total number of interviews
Family B – Jane	1 interview (2nd interview with Jane not done due to distance)
Sub-total	1 interview Total interviews conducted = 16
	Reasons for incompleteness
	PLSP not interested in taking part

the broader social context (Strauss and Corbin, 1990). The coding of individual actions/interactions derived from interviews and participant observation in the first place was micro in nature. The researcher of this study examined and brought different broader social conditions, contexts and consequences into play with the coding of individual actions/interactions that were identified from the data collected at the micro level. Manually drawn conceptual diagrams (Fielding, 1993; Strauss and Corbin, 1998) were produced at this stage. These diagrams allowed visualisation of the codes of individual actions/interactions and their broader environments, contexts and consequences; the inter-connectivity of these codes would be compared in further analyses during the selective coping in Stage 3. With the assistance of data management by N4, the two levels of open and axial coding proceeded quite naturally together (as described by Strauss and Corbin, 1998) in Stages 1 and 2, which represented the process of interplay between the deduction and induction of all the micro and macro aspects of data collected from the first and second interviews of patients and MFCs.

### Stage 3 of the analysis

Selective coding is the process of selecting the core category and systematically relating it to other categories (Strauss and Corbin, 1990). This process was aided by the software QSR Merge (Revision 1.0c) (QSR, n.d.), which was included in the N4 package. QSR Merge helped to merge all the previous index trees of separated patients and MFC project files developed through N4 into one big collection of index trees where similarities and differences of data in the categories developed from Stages 1 and 2 could be revisited for changes, combination and refinement in order to discover the core category. Overall, there were 106 codes in Free Nodes and 890 codes in the index trees of all project files for merging and selective analysis. With the discovered categories that connected to their relevant environments and social contexts, a core category was identified and theorisation of the entire phenomenon of MFC support for patients with a critical illness was made from the perspectives of MCFs and patients. A diagrammatic summary of the entire analysis process is provided in Fig. 2.

### Trustworthiness

The trustworthiness (Lincoln and Guba, 1985) of this study was established in several ways. Two experienced qualitative researchers met regularly with the author and reached consensus on the categorisation and coding. This assured the *confirmability* of the findings, which were purely grounded on the data with the most accurate representation. The categories developed were communicated to the participants after the analyses, and they agreed with them, hence aiding them in establishing *credibility*. The analysis of negative cases can also strengthen *credibility* (Patton, 1999) but such a group of critically ill patients without any MFC support would have been very vulnerable. Hence, it was deemed ethically inappropriate for the researcher to include them in the study, in order to avoid any possible harm that might come to them during the interviews. An audit trail



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Index Tree
(107) persisting in the journey
  (108 208) experimenting at the start (independence)
    (108 208 82) 'wobbly'
    (108 208 209) lacking time
    (108 208 210) inconsistent treatment
    (108 208 211) becoming more independent
    (108 208 212) motivated
    (108 208 214) not fully returned yet

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  (1031) features of support - being with me
    (1031 1) non-familial support
      (1031 1 33) support from colleagues
      (1031 1 42) friends' support
      (1031 1 124) support from other patients and people in
        the ward - companionship
    (1031 2) familial support
      (1031 2 1) regular support
        (1031 2 1 39) daily
        (1031 2 1 40) ever ready
        (1031 2 1 41) easy access
      (1031 2 2) family vs professional support
        (1031 2 2 202) ineffective PLSP reassurance
      (1031 2 31) 'always come with me'
      (1031 2 32) seeing me
        (1031 2 32 114) 'come and see me'
      (1031 2 34) support from siblings
      (1031 2 35) daily calling
      (1031 2 38) taking comprehensive care
      (1031 2 47) no specific expectations
      (1031 2 48) returning support

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Figure 1 An example of an index tree.

(Halpern, cited in Lincoln and Guba, 1985) was maintained and managed with the use of N4, which contributed to the study's *dependability*. Thanks to the audit trial, the vigorous course of data analysis in grounded theory method produced thick and detailed descriptions of the process and experience being studied, and hence the *transferability* of such findings was readily assessed per the individual's professional decision making for clinical applicability (knowledge translation) or further research in other settings (Marshall and Rossman, 1999).

## Findings

As described in detail for the data analysis, constant comparative analysis was rigorously performed in this study. Three categories, 1) being there with, 2) coping and 3) self-relying, were emergently discovered through the analytical stages. There were dynamic relationships and complex interactions amongst these three categories and their components regarding the patients and their MFCs.

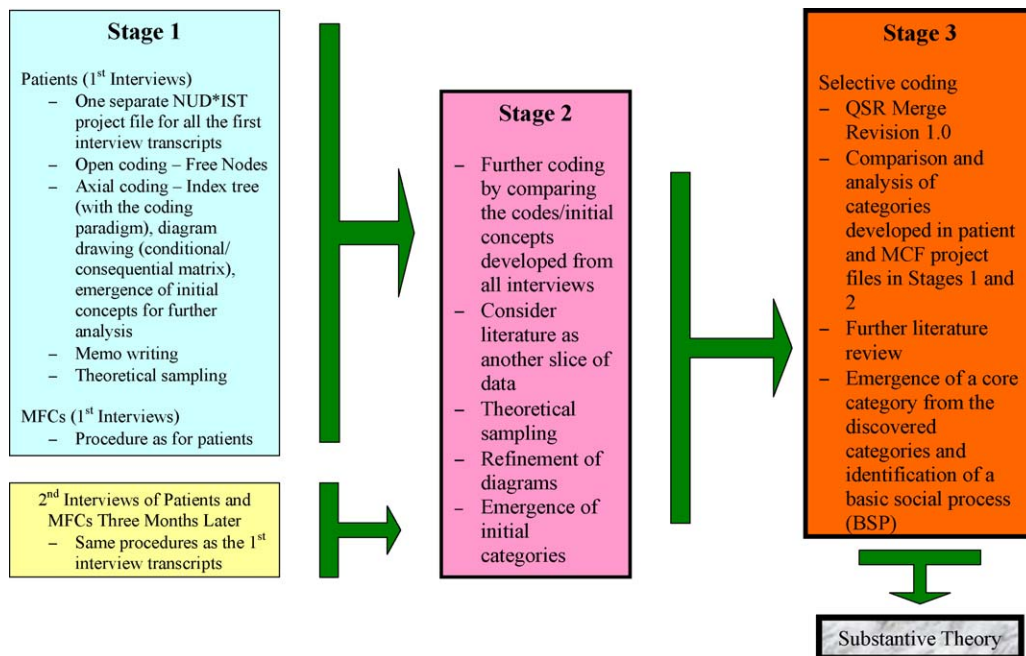


Figure 2 Process of data analysis with the use of NUD\*IST 4.

## Being there with

In the first interview with patient Jane (all names are pseudonyms), she clearly demonstrated her need for the presence of her family and her MFC. When asked what was important to her when she was in the ICU, she demonstrated a sense of support when her family and MFC were present with her. She said,

*My sister or my husband would come to see me, or my sister or mother or somebody ... but there was always somebody with me ... everyday they always popped in and saw me* (Family B – Jane I, text units 164–168).<sup>1</sup>

An *in vivo* open code ‘always somebody with me’ was initially created, and further analysis of her interview found that Jane felt ‘good’ when her family and MFC could be there with her. She also felt good when they could be contacted easily by phone when required. She went on to share her experience in the ICU, ‘*I feel good about what my family do for me ... Just being there on a daily basis*’ (Family B – Jane I, text units 236 and 248). Amongst others, the open code ‘being there’ then set the major direction of further interviews. In another interview, patient Jack said,

*And no-one was there. And I was very, very frightened and Jill (the MFC) couldn't come in quick enough. As soon as she came through the door, washing her hands, the relief was tremendous* (Family D – Jack I, text units 256 and 260).

When Jack was also asked what might have happened to him if Jill (his wife) or any other family members had not been there when he regained consciousness, Jack said,

*I would be climbing the wall. I'm honest with you. The fact that Jill and William and Lily were there was a calming influence* (Family D – Jack I, text unit 238).

Jack was desperate to have his MFC there with him when he was critically ill (conscious but on mechanical ventilation) in the ICU.

For the MFC, Karen (Peter's wife) was asked what she could do to help Peter when he was in the ICU. She said,

*I only thought if I was here, my husband could feel it. ... I rushed over to see him and hold his hand. When he was under sedation I talked to him and so ... if he heard me or not, I didn't know. ... And I just wanted to be here. That's all. I just wanted to be with him* (Family E – Karen I, text units 229–237).

Karen further spoke of her need to be with her sick husband in the ICU, saying that,

*And I just wanted to be here. That's all. I just wanted to be with him ..... Just be there (in a very*

*affirmative tone). Even the doctors do everything, the nurses do everything, all the medical things you have no idea, but I feel it is good for the patient. At least I hope so, and it was good for me* (Family E – Karen I, text units 237 and 643).

As discussed earlier, constant comparative analysis in this study included literature as a slice of data for comparison with the data collected by interviews and participant observation. A literature review at this point confirmed that ‘being there’ was consistent with the nursing concept of ‘presence’, which has been widely explored and discussed by nursing theorists and scholars as an essence of the nurse-patient relationship, and a therapeutic nursing intervention in the care of patients (Benner and Wrubel, 1989; Osterman et al., 1996; Bernardo, 1998; Fleming, 1998; Doona et al., 1999; Gaut, 1992; Holzemer, 1997; Easter, 2000; Gardner, 1992; Fredriksson, 1999; Gilje, 1992; Godkin, 2001; Snyder et al., 2000). Apart from the use of presence by nurses, nursing research also explored the influence of social support from family members on critically ill patients. In general, the contribution of family support to patient recovery has been described as a part of the much broader social support system (Kupferschmid et al., 1991). Geary et al. (1994) reported that ‘*someone with you*’, e.g. a family presence with the patient, was one of the major themes developed from their interviews with 20 critically ill patients prior to liver transplant. Together with the literature, the analyses of data from both the patient and MFC interviews eventually revealed more details, namely confirming ‘being with’ as an essential phenomenon, further emerging as a component of the broader category ‘being there with’. ‘Being there with’ is a mutual and crucial need between the patients and their MFCs during the episode of critical illness and later recovery. There are different forms of this experience. ‘Being there’ means physical presence and ‘being with’ refers to the mental presence for both patients and their MFCs. From the analyses of many other interview data, the different combinations are ‘being there and being with’; ‘being there and not being with’; ‘being with and not being there’; and ‘not being there and not being with’. The details of these various types of presence are illustrated in [Diagram 1](#).

When patients and their MFCs are ‘being there and being with’ each other (hence categorised as ‘being there with’), the patients feel fully supported and the MFCs perceive that they have done something very important contributing to the recovery of their loved ones. If the patients are unconscious, they are ‘being there but not being with’ their MFCs. On the other hand, there are times when the MFCs are thinking of the patients but not physically with them, and this is ‘being with the patients and not being there’. This type of ‘being with’ the patients also makes them feel that they are supported at all time. Although their MFCs are not physically there with them, they perceive a sense of security. When patients have no MFC, they do not have any informal carers there with them and hence do not perceive a sense of support from their families.

## Coping

Apart from the essential category of being there with, as conceptualised in [Diagram 1](#), there were other key

<sup>1</sup> The reference (Family B – Jane I, text units 164 – 168) refers to the locations of text units in the transcript of Jane's (Family B) first interview. In all the discussion about data analyses to follow, this pattern of quoted text units (family – participant – number of interview – number of text units) will be used to identify the locations of text in the interview transcripts from which each quotation was drawn.

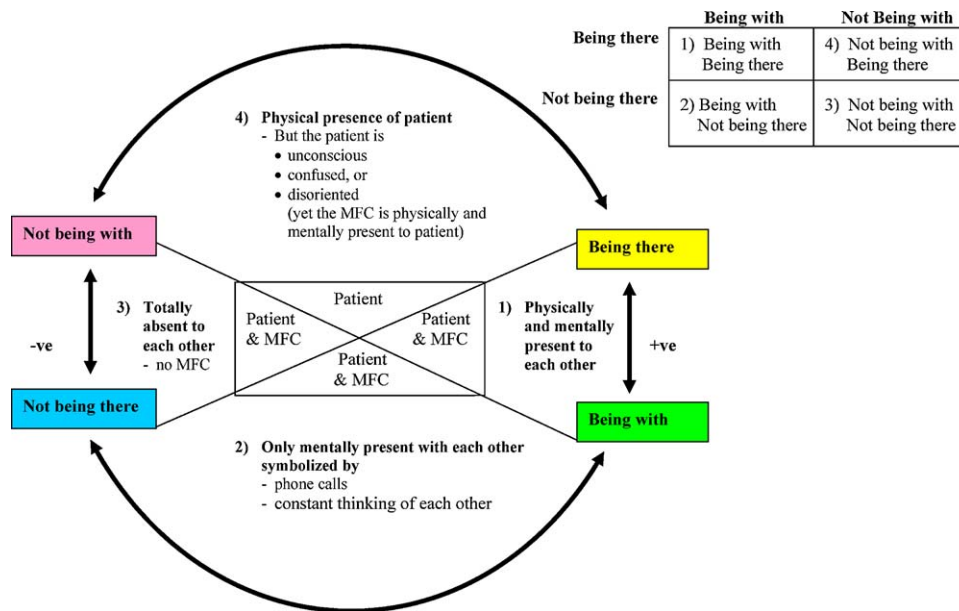


Diagram 1 The model of 'being there with' from patients' and MFCs' perspectives.

experiences of patients and their MFC in the process. Further analysis of these experiences supports the finding that patients' need for their MFC to be being there with them can also be understood as a coping strategy to manage their high levels of stress during their stay in the ICU (Byers and Smyth, 1997). For instance, patient Jack said, "The fact that Jill (MFC) and William (son) and Lily (daughter) were there was a calming influence" (Family D – Jack I, text unit 238). Being there with Jill and other family members was a coping strategy ("calming influence") to enable Jack to manage his fear in the ICU. From this study, coping is also the process used by the MFCs to manage their stress during the course of critical illness and later recovery. As quoted above, Karen (MFC) expressed her need to be there with her husband Peter when he was critically ill:

*Just be there (in a very affirmative tone) . . . . . I feel it is good for the patient. At least I hope so, and it was good for me (Family E – Karen I text unit 643).*

From Karen's experience, her need to be there with Peter was also a way for her to cope ("good for me") with Peter's critical illness, not only her desire to be there and with him. Further coding of more data showed that there were many direct and indirect strategies employed by the patients and their MFCs that were congruent to the classic stress and coping theories (Lazarus and Folkman, 1984; Folkman and Lazarus, 1988; Lazarus, 1991, 1993, 1999). Direct coping is equivalent to problem-focused coping, whilst indirect coping is comparable to the emotion-focused coping postulated by Lazarus (1999). During such processes, the data indicated that there was an uncertainty in MFCs about their loved ones' situations, with which they needed to cope. Many codes for their types of coping strategies were discovered from the data, and the essential findings were that they experience 'coping with each day as it comes', e.g. *Day by day, even today. Even today I would never take it for granted that he (patient Peter) is 100%* (Family E – Karen, text unit

333); and 'learn to adjust' to the stress arising from the changing and unpredictable condition of the patient, e.g. *It was just something you had to adjust to and I learned to adjust* (Family A – John and Mary II, text unit 525). There was adaptation work for them to do in order to cope with such sources of stress (Holahan et al., 1996; Zeidner and Saklofske, 1996). Failure to learn or utilise effective coping strategies leads to negative consequences (Diagram 2). Nevertheless, being there with was the major coping strategy discovered in this study to help both MFCs and patients to manage their stressors. To a certain degree this was a direct coping strategy that contributed to the sense of well-being for both patients and their MFCs during the critical illness episode, but also an emotionally laden coping strategy (Lazarus, 1991, 1999).

### Coping in the broader environments

During the hospitalisation and recovery process, the MFCs appraised their stress (Lazarus, 1999), which was related to the fact that their loved ones were critically ill and later to the burden of care-giving at home when the patients were recovering. This process included the simultaneous stages of 'coping with each day as it comes' and 'learning to adjust' as explained above at the individual (micro) level. In addition, broader conditions that had an impact on the coping of the patients and MFCs were discovered during participant observation. They comprised the resources available in the hospital and community for the care and support of patients and their families. The environments explored in this study were not merely interpersonal but the broader macro conditions of organisational environments, communities, social contexts and/or cultures, whereby the interpersonal actions/interactions occurred as micro conditions (Strauss and Corbin, 1998). The environmental and contextual factors discovered from participant observation in the hospital and community



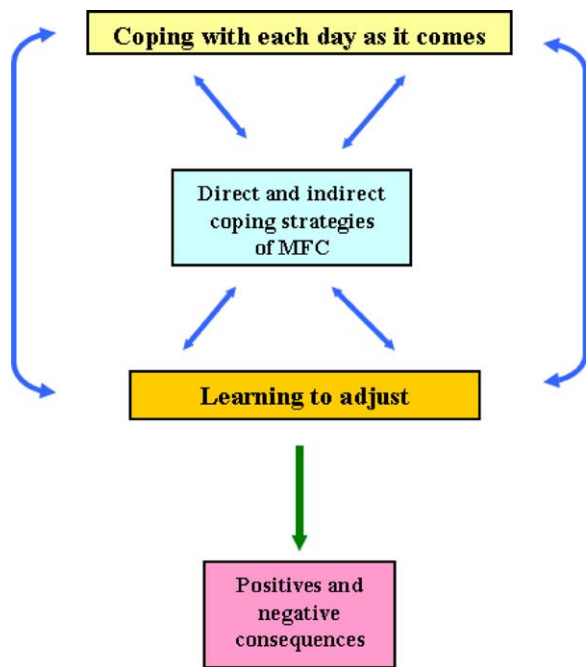


Diagram 2 The process of MFCs' coping.

appeared to have an impact on the perceptions of stress in patients and their MFCs. These factors comprised an apparent lack of 1) some resources in the hospital, and 2) professional follow-up support in the community. These macro conditions might be isolated incidents but they influenced the coping and perceptions of stress in patients and MFCs during their difficult time. In addition, the unfavourable macro conditions increased the burden of MFC support to patients and caused a certain level of difficulty or impact, making it harder for the patients to recover. For instance, regarding the resources available in the hospital, during the second visit to Mary (patient) and John (MFC) in the general ward, the researcher observed that Mary had more pillows than the other patients. She had four pillows on her bed. John told the researcher that he had had to buy two extra pillows for Mary to use in the ward. Mary expressed in her first interview at home that the shortage of pillows had been a significant concern to her. She said,

*Well I had to sit up and there was one pillow on the bed when they took me upstairs (general ward); I said (to the nurse), 'You know, can I have some more pillows?' So she (the nurse) went away and came back with another one. But two weren't enough. When John came in he went down (to the store) and bought four (Family A – Mary I, text unit 216).*

Mary was sometimes short of breath and needed more pillows to support her back whilst sitting up in bed, to ease her breathing. Pillows were important for her comfort. Mary further commented that "I know it is not their (staff's) fault. It is the cutbacks" (Family A – Mary I, text unit 22). She also brought to the researcher's notice that the bed sheets had not been changed every day whilst she was in the hospital.

Professional support in the community was also found by a few patients and MFCs to be limited. For instance, when the

researcher chatted with Paul (patient) and Pauline (MFC) in their home (participant observation) before the first interview with Paul, Paul was very keen to organise a general practitioner (GP) to see him and follow up on his condition as soon as possible. However, there was no GP in the small town where they lived (about 45 km away from the closest business district) because the local GP had just retired. For an unknown reason, Pauline was unable to locate from the phone book a suitable GP for Paul in the closest suburb. She appeared quite helpless and did not respond to Paul when he spoke of his urgent need to make a GP appointment for follow up. Pauline appeared to be stressed about the situation because she believed that Paul had been discharged too soon (in fact Paul looked quite pale that day and had just been discharged from the hospital the day before). Pauline usually did not drive and this had probably added further stress to her. She would need to drive Paul 45 km away to see a new GP. She recalled this stressful situation later during her first interview,

*I thought his (Paul's) colour wasn't good. I didn't think he was ready to come home when I brought him home ..... because I said there was just no medical care. What help could I get? And they said, what help do you want? So I felt there was not a lot of follow up once he was discharged from Intensive Care (Family C – Pauline I, text units 360 and 364).*

Jack and Peter and Karen also demonstrated and shared similar experiences; overall, it appeared that they needed better support in the general wards of the hospital and continuity of care in the community. It is important to recognise the extent and significance of these issues to aid better hospital care and recovery of post-critically ill patients. It is reasonable to suggest that this group of patients and MFCs might experience less stress and make better progress together towards recovery if sufficient professional support and continuity of care was structured in advance in the general wards (or ICU), and before discharge back home in the community.

### 'Self-relying'

'Self-relying' (a gerund created in the tradition of grounded theory study, which captures the ongoing and dynamic nature of the social process of recovering from a critical illness), on the other hand, is the dynamic process through which the patients experiment with regaining their physical and psychological independence. Patients in the ICU demonstrated maximum psychological dependence (attachment) to their MFCs. Patient Jack said, "I am trying to find the right word. If Jill (MFC) wasn't there ... I would be looking for her all the time" (Family D, Jack I – text unit 230). And later at home, during Jack's continued recovery, Jill said,

*When we are in the house I am somewhere in the house but I mean he (Jack) goes looking in all the rooms. He goes outside. ... Are you there? Where are you? (Family D – Jill & Jack II, text units 314–320)*

This high level of psychological dependence was reduced with further recovery, and the patients also gained independence from the heavy physical assistance provided by

their MFCs. For instance, Elsa (MFC) said, *For the first couple of weeks, we were sort of ... doing things like getting his clothes and organising his shower and all that sort of thing. I practically was just running around doing little bits for him, organising what tablets he had to take and all this sort of thing* (Family F – Elsa II, text unit 104).

The data showed that the degree of patients' psychological and physical dependence on their respective MFCs was steadily reduced by their progress towards an optimal recovery. On the other hand, MFCs were also becoming more independent from providing support and satisfying patients' needs, based on the progress of recovery of the patients. Jill (MFC) said,

*But then when you start seeing him (her sick husband Jack) getting better, it is more back to normal everyday life. You can see he is getting better and that makes you feel better ...* (Family D – Jill and Jack II, text unit 498).

Clearly, Jill felt better psychologically as Jack became more independent. Hence, there was an interdependent relationship and dynamic interactions between them throughout the recovery process. From the data, this interdependence process involved their experiences of 'making decisions' and 're-building confidence'. For instance, patient Mary made her stepwise decision in her progress to resume her physical activities: *'I played the 18 holes (golf) the first day (not the first day right after returning home but the first day she started her exercise). I came home and I said, well, I was going to keep going now'* (Family A – John and Mary II, text unit 307). On the other hand, Pauline (MFC) thought that Paul was discharged from hospital too early. She said that he was still very pale and weak when the hospital allowed him to go home. She felt a lot of stress in looking after him at home in the beginning. However, despite her worries about Paul's health at that time, she realised that he had suddenly returned to his *'old self'* after he made the decision to experiment with driving again two weeks later. These data provided the basis for another code, 're-building confidence', in the self-replying process. A new code was created: 'experimenting with the regaining of independence', incorporating these experiences and the process of 'making decisions' and 're-building confidence' for the patients, of which the dynamics required a harmony of interests between the patients and their MFCs to enable them to re-build their confidence and returning to independent living (Diagram 3).

). When reviewing the literature for the development of the coding and categorisation in this study, we found that Thibaut and Kelley's theory of interdependence (Thibaut and Kelley, 1959; Kelley and Thibaut, 1969, 1978; Rusbult and Van Lange, 1996) illustrated a similar premise, that mutually related strategies and behaviours (the state of interdependence) were interdependent variables in a dyad relationship that explained the support phenomenon being explored between the patient and the MFC in this study. Also that the characteristics of social interactive processes in such a relationship, like 'rebuilding confidence', 'making decisions', and different degrees of physical assistance and psychological attachment are the variables. In such a social context, the variables blended into an interdependent dynamic state (Chadwick-Jones, 1976). The interdependence theory

provides a framework to analyse dyadic relationships at a microscopic level. Using this theory, the interdependent nature of support between patients and MFCs during recovery from critical illness as it emerged from this study was explained and supplemented.

In summary, although the patients regained independence with the informal support of their MFCs, both they and the MFCs were actually returning to the original state of interdependently independent (Racher, 2002) before the critical illness occurred. With the patients' full recovery, they were physically and psychologically independent of their MFCs. Meanwhile, the MFCs had peace of mind for their loved ones, and hence psychological independence from them. Since patients and their MFCs are usually partners in life, returning to their previous state of life means that they are independent from their burdens in regard to the critical illness and recovery, yet interdependently independent of each other again as partners in their daily activities of life.

## Overview of the theory

The three categories emerging from this study – being there with, coping and self-relying (including the issues discovered from broader environments) – provided the basis on which the core category/process was identified, i.e., 'mutually being there with each other'. Within the framework of the grounded theory method, the categories were examined rigorously to theorise the core process, which represents the substantive theory about the experiences and interactions of MFCs and patients during a critical illness episode and subsequent recovery. The developed substantive theory which represents the core process incorporating the above three interactive categories is 'surviving a critical illness through mutually being there with each other' (Diagram 4). The core process is a dynamic passage that incorporates being there with and coping within a continuum of dependence and independence ('self-relying') involving both the patients and their MFCs. A detailed description of the core process is provided in Box 1.

## Discussion

Several implications for nursing practice emerged from this study. They were related to the needs of patients and their MFCs during the process of the patients' critical illness and recovery, experienced by both parties together. Since this study identified the importance of being there with each other to both patients and their MFCs, a key implication from the study is the need for ICUs to adopt and ensure, or reinforce, flexible visiting hours to maximise opportunities for this to occur. Nevertheless, frequent visits were sometimes observed clinically from participant observation to be tiring and too draining for some ICU patients and their relatives. Hence, nurses need at the same time to be vigilant and sensitive that flexible visiting does not become too draining or overtire patients (and/or their MFCs). On the other hand, although it did not emerge from the narrative data as a major category, regular communication of the nurses with the MFCs regarding patients' progress was helpful in reducing the stress and concerns of MFCs about the current condition of their critically ill loved ones.

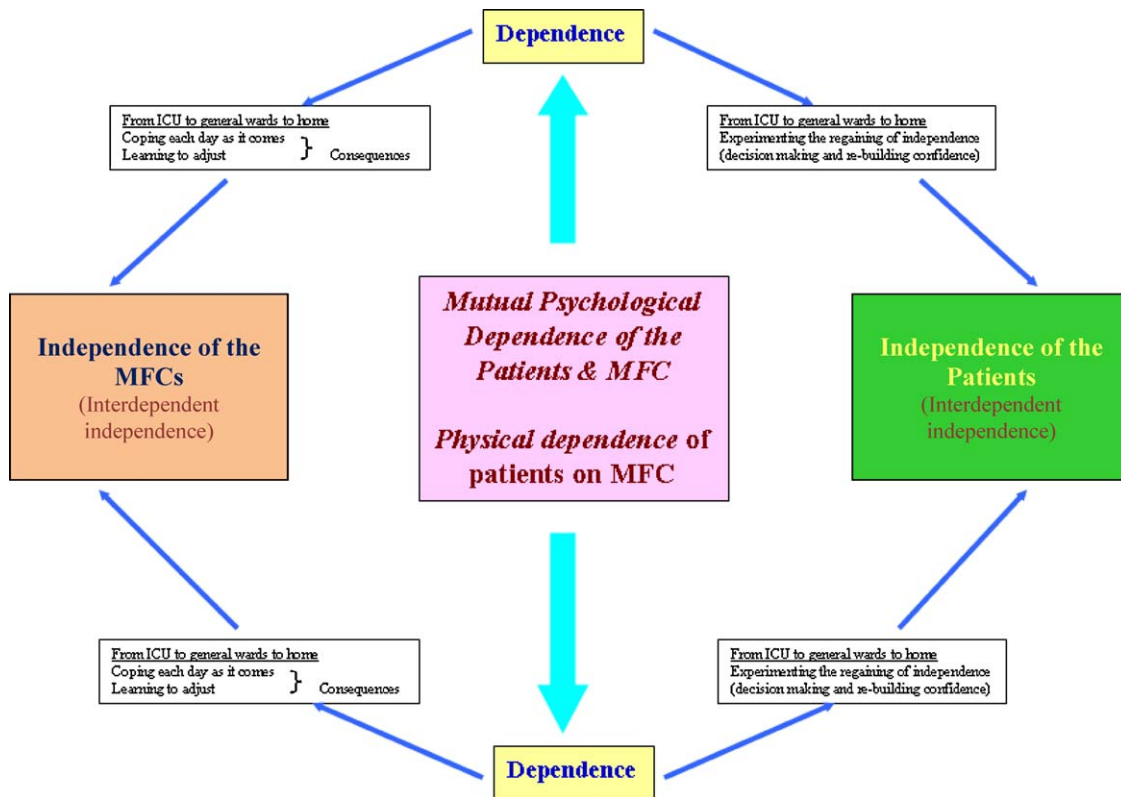


Diagram 3 The process of 'self-relying'.

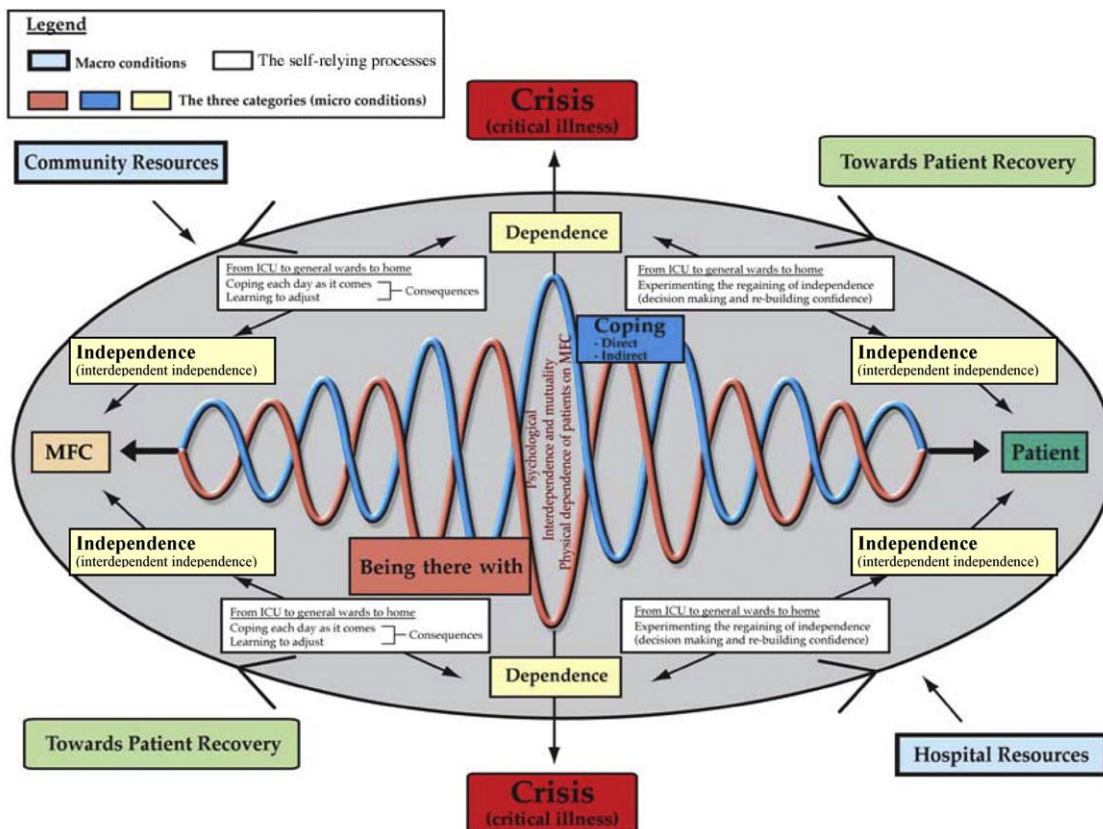


Diagram 4 The process of surviving a critical illness through mutually being there with each other.



Since 'mutually being there with each other' is essential to both patients and their MFCs as a means of support in the context of critical illness and recovery, a further implication of this study for nursing practice is the need for nurses (and other health professionals) to be willing to care for both these parties as an *inseparable dyadic unit*. The planning of care for critically ill patients should not exclude their MFC at all.

This study also suggests implications relating to the care of critically ill patients following their discharge to the general ward and home. The experience of participants in this study (for instance, see the section on coping in the broader environments) revealed the importance of careful discharge planning, post-ICU follow-up, and continuity of care in the community in enhancing patients' recovery and in addressing the special needs of their MFCs when they are required to care for their loved ones after discharge (Burr, 2002; Chaboyer et al., 2002; McCallum et al., 1996; Pearson et al., 2004). Although evaluation and searches for substantive evidence of such follow-up care like the critical care outreach service (CCOS) have been conducted by various researchers and their effectiveness is being debated (Ball et al., 2003; Cuthbertson, 2003, 2007; Esmonde et al., 2006; Gao et al., 2007; Garcea et al., 2004; Priestley et al., 2004; Prinjha et al., 2009), nurses should not underestimate the value of CCOS as indicated by the experiences of patients and their MFCs in this study. According to Deacon (2008) and Whiting and Edbrooke (2006), it is recommended that continuing work or further evaluation be established in hospitals to employ or deploy specialist intensive care nurses to conduct wider ICU follow-up care, e.g. CCOS, of post-ICU patients who have been transferred out to the ward or returned home to the community. Adopting the philosophy of 'intensive care without walls' proposed by Gwinnutt (2006) and the CCOS established in the UK a decade ago (Audit Commission, 1999; Department of Health, 2000), intensive care nurses worldwide may give more consideration to following up with post-ICU patients and their MFCs for a longer period of time. Although the question as to whether the resources allocation has been or will in the future be fully justified for such follow-up care as CCOS is difficult to say (Whiting and Edbrooke, 2006), intensive care nurses may continue to work on and evaluate such services on the assumption that successful follow-up and better continuity of care may reduce complications and mortality in post-ICU patients, minimizing the chance that these patients will be re-admitted to the ICU or to hospital (Garcea et al., 2004; Priestley et al., 2004).

From a researcher's perspective, this study demonstrates that the recruitment of vulnerable populations (like ICU patients) is a challenge to researchers in terms of ethical considerations, particularly when the researchers are attempting to meet the expectation of primary selection for theoretical sampling in the grounded theory method (Glaser, 1978; Glaser and Strauss, 1967; Strauss and Corbin, 1998). There were tensions between the issues of ethical demands and the need for primary selection for ICU patients and their MFCs. However, despite the length of time necessary to negotiate all stakeholders' interests in order to gain entry to the field, with trust, consideration, collaboration and participation with the stakeholders, such recruitment challenges can be resolved to allow original and

important research to be conducted (Chiang et al., 2001). Furthermore, the workable recruitment protocol of potential participants in the situation of critical illness should be developed collaboratively with the stakeholders, with the aim of making the criteria as situationally appropriate as possible whilst maintaining the ethical standards (Madjar and Higgins, 1996), in order to recruit the highest number of participants possible. The inclusion of more than one site for recruitment is also helpful in the recruitment of suitable participants from the targeted vulnerable population.

The substantive theory developed in this study should be further empirically investigated with a larger population. A longitudinal follow-up study extending beyond the three-month recovery period may be conducted to further understand the experiences and support needs of post-ICU patients and their MFCs in the longer term. In addition, more studies are required to identify best practice regarding the extended post-ICU follow-up care (e.g. CCOS) and continuity of care in the community for critically ill patients and their MFCs in the immediate short period after discharge from hospital.

## Limitations

The majority of the participants in this study were older people, and most of them were suffering from a primary diagnosis of respiratory origin. This may limit the transferability of the results that emerged from this study to particular other groups of patients and their MFCs. The use of negative cases would strengthen the analyses and better assure the findings of this study, but given the ethical concern explained above, this was not done.

## Conclusion

The theory developed from this grounded theory study explained and highlighted the very complex, dynamic and interactive nature of informal support provided by MFCs (Lidell, 2002), experienced by both patients and their MFCs during an episode of critical illness and the later recovery. An understanding of this complex continuum and the interplays of 'being there with' (e.g. see Vandall-Walker and Clark, 2011), 'coping' and 'regaining interdependent independence' (self-relying) between critically ill patients and their MFCs during the process of recovery may better enable nurses to consider both of these parties as the focus (an inseparable dyad) of their care. Since this emerged theory captured the mutual experiences of informal support and care between patients and their MFCs during the course of recovery from critical illness, it also provided a conceptual map for nurses of how this process may unfold. Both patients and their MFCs perceived a sense of support or being supported when being there with each other, which functioned in such a way that coping and the regaining of independence were enhanced. The theory would enable nurses to gauge both patients' and MFCs' progress along the road to recovery, and to consider the relevant nursing support or interventions in their plan of care. Intensive care nurses have a major role in facilitating the mutually being there with each other of patients and their MFCs, and hence a possible better course of recovery. So what is your best practice

as an intensive care nurse when it comes to “handing off critically ill patients to family caregivers” (Alspach, 2009)?

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