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Significant Others of Critically Ill Patient: Their Challenges and Traumatic Experiences

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Abstract The significant others of critically Ill patients played an important role in taking care of their patient confined at any hospital. They are considered morale and support booster, they were utilized for any errand activity in the hospital and lookout of the rest of members in the family and the for the patients This study sought to determine the perceptions of the selected 10 significant others whose critically ill patients were confined at the Intensive Care Unit of Dr. Paulino J. Garcia Memorial Research and Medical Center (PJGMRMC) Cabanatuan City, Nueva Ecija, Philippines. Qualitative research through case study was utilized. Prior consent from the respondents was sought prior to the conduct of research. Questionnaire, unstructured interview, and observation were the main tool utilized. Percentage, ranking, and weighted mean were the statistical tools utilized. Findings revealed that significant others fear are death of their patient. Anxious about the hospital bills, personal debt, and financial constraint. They were optimistic that their patient can survive. Experienced psychological distressed when their patient was at ICU. They are optimistic that their patients be healed, survived or recovered for their consciousness. They agreed that their greatest fears were helplessness and losing their loved ones. They cannot help but cry especially when their patients are unconscious and life saver equipment's are attached to their patients. They were in distressed, experienced headaches, no enough rest or sleep. They do not have money for any emergency.

Keywords: *significant others, critically ill patients, challenges, education, and public health, Cabanatuan City, Nueva Ecija, Philippines*

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1. Introduction

Meeting Intensive Care Unit family needs can be achieved by supporting and involving families in the care of the critically ill family member. More emphasis should be placed on identifying the family needs in relation to the influence of religion held by the family members, the medical practitioners and working area in the Intensive Care Unit. [1]

Significant others who are taking care of their patients who were confined at the Intensive Care Unit (ICU) in the hospital experiences distress and depression.. The family members of the patients confined at ICU tends to feel nervous, distress and discomfort especially if they saw the doctor busy performing lifesaving activities to their patients. At time these significant others speculate that they has false hope that the medical practitioner are not performing well of their obligation to their patients thereby they may loss trust to the medical practitioner. [2]

The significant others ask for spiritual support to overcome their challenges, the desire to express their feelings, wish their patients to return to family life. Their patient worried about their external events, members of the family concerned with the practitioner report to them. These significant others met challenges, unfavourable experiences in the hospital particularly if they are financially handicapped. They hope that their patients be cured and alive. [3]

The researcher is interested to know and determine the perceptions of the significant others whose patients were confined at the Intensive care unit of the hospital specifically their fears, expectations, problems and measures adapted to lessen their emotional and psychological burdens. Furthermore, to know how these significant others cope with the prevailing situations.

1.1. Objective of the Study

1. To identify the fears of the significant others while their critically ill patient is confined at the Intensive Care Unit.
2. To find out the expectations of the respondents while their patients are on critically ill condition.
3. To identify the problems encountered by the respondents while their critical ill patients are confined at the Intensive Care Unit..
4. To familiarize the respondents' adaptive measures while their critically ill patients are confined at the Intensive Care Unit.

The study focused on the fears, expectations, problems, and adaptive measures of the significant others of their

critically ill patient confined at the intensive care unit, at Dr.Paulino J. Garcia Memorial Research and Medical Center, Cabanatuan City, Nueva Ecija, Philippines.

It was conducted from January 1–31, 2015, the respondents were 10 significant others whose critically ill patients were confined at ICU, PJGMRMC, Cabanatuan City, Philippines This does not include respondents after the survey was conducted. Respondents were only those who actively cared their confined patients at the Intensive care Unit.

The qualitative research through case study was used using purposive sampling to discover the whole picture of their social aspect of the respondents. This study explored how respondent reacts and how they managed themselves into real situation.

Conflict around End of Life (EOL) issues can occur between clinicians, between patients and their relatives; or between the relatives of patients, especially when the patient is incompetent, or between relatives and clinicians who disagree about the most appropriate management plan. There is also an inherent conflict between society and its expectations around what modern medicine can potentially offer. [4]

As perceived by the researcher, the medical practitioner and the significant others has a common idea that once a patient is admitted in the hospital implies treatment will be available that will positively address their medical problems. [5] However, we have little information on the number of patients who are admitted to hospital where active treatment will make little difference to outcome. And yet, the expectation of society is usually that hospitals will provide improvement in the clinical condition, not that patients are admitted to hospital knowing that death is the most likely outcome.

One area of need detailed in previous studies, comfort, did not appear to be an unmet need for the participants in this study. The respondents did not even appear to have considered their comfort needs. They had very little to say when asked for details about their experiences and feelings in this area. Family members also did not see a need for the health care team to offer them emotional support, another aspect of comfort. Families commented that they were focused on the patient not on themselves. This is an interesting finding worthy of further discussion and exploration. [6]

Family members requested to communicate directly with attending physicians rather than resident doctors or nurses but found this option was hampered by the constant rotation of staff. The rotation of staff hindered the establishment of relationships and appeared to seriously damage the development of trust in the health care team. One family related an inability to even identify the attending physician, the health care 74 provider ultimately responsible for the direction of the care and treatment of their family member. The need for “vigilant participation” rather than the mere need for proximity to the patient is also an area varying from the literature. Some families in the study took the need to be close to the patient to an extreme. Family members indicated concerns that if they were not present with their family member, monitoring the care provided and monitoring the patient’s condition in close detail, he or she, may die. The perceived need for this level of vigilance to protect the patient is potentially a new finding of interest.

Intensive care was created to provide intensive medical treatment to the most ill or injured patients in the hospital. These patients require constant monitoring and sophisticated medical intervention or therapy. The unit is filled with the hum of machines and the constant ringing of alarm bells requiring the immediate attention of the healthcare team. The treatment of the patient’s family in the intensive care unit varies from ICU to ICU. Policies about visitation, and thus access to the patient by loved ones, are inconsistent not only from hospital to hospital but within the same hospital. This inconsistency appears to be a significant source of stress for families and thus for patients. While the patient is receiving constant care and attention, the patient’s family is often left without adequate supports to meet his or her needs. Delva and colleagues (2002) indicated that during the first few days of a patient’s hospitalization, the patient is the center of attention while communication with the family by doctors and nurses takes a lower priority. Families must rely on their own supports during this challenging time while also attempting to support their loved one in the ICU. “Family adaptation or resiliency can affect patients’ outcomes, both short-and long-term, either positively or negatively” (Bond, Draeger, Mandelco, et al., 2003, p. 64). Patients are admitted to intensive care after experiencing a significant illness or injury. Admission to intensive care may be planned, such as following a scheduled surgery, but the admission is often unexpected and jarring to the patient and his or her family. The patient’s medical condition is usually unstable and his or her chances for survival unclear. The admission to the intensive care unit is stressful for both the patient and his or her family and may trigger a variety of negative psychological symptoms (Williams, 2005). [7]

The patterns of life, disease, dying, and death have changed dramatically in recent years across the world, and research is essential to develop evidence-based public health policy. Further research should include evaluation of pathways for the appropriate care of terminally patients in the ED (such as the LCP), comparison of services across countries such as the UK where GPs are required to do home visits on sick people and are financially penalised for hospital admissions and Australia, where this is not the case. Finally, we support the identification of robust rules for patients receiving inappropriate advanced life support care.

The specialty of intensive care medicine, including the care of neonates, children and adults is increasingly being involved in critical care. Twenty per cent of comatose patients die in ICUs. More than a quarter of intensive care patients will die before leaving hospital. The majority of patients who die in intensive care do so after a decision to limit therapy as opposed to dying despite continuing full and active treatment.

Moreover, evidence suggests that end-of-life care for the critically ill is inadequate with a high prevalence of pain and other distressing symptoms; as well as poor communication from clinicians; and discordance among families and clinicians about care plans and goals Intensive care clinicians report awareness that their

treatment of dying patients is often sub-optimal and recognize their own deficiencies in knowledge and skills for critical care.

The Institute of Medicine in the Philippines has identified improved quality of critical care as a major goal and several documents, position statements and practice guidelines have been published around this area. There are increasing pressures to admit patients into ICUs. The majority of Filipinos now die in institutions, rather than at home. Even terminally ill patients in the barrios sometimes find their way into acute hospitals. Once they had altered level of consciousness they are often assessed and admitted to hospital as the history and prognosis may not be clear initially; and because it is usually easier, in purely practical terms, to admit a terminally ill elderly patient rather than arranging appropriate support in the community. Once in an acute hospital there are expectations, realistic or not, that there is some hope. The conveyor belt to intensive care is further facilitated by increasingly specialized physicians who often do not understand the way different co morbidities and multi-organ involvement influences the patient's prognosis. [8]

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Family members requested to communicate directly with attending physicians rather than resident doctors or nurses but found this option was hampered by the constant rotation of staff. The rotation of staff hindered the establishment of relationships and appeared to seriously damage the development of trust in the health care team. One family related an inability to even identify the attending physician, the health care 74 provider ultimately responsible for the direction of the care and treatment of their family member. The need for "vigilant participation" rather than the mere need for proximity to the patient is also an area varying from the literature. Some families in the study took the need to be close to the patient to an extreme. Family members indicated concerns that if they were not present with their family member, monitoring the care provided and monitoring the patient's condition in close detail, he or she, may die. The perceived need for this level of vigilance to protect the patient is potentially a new finding of interest.

Factors which drive patients to be admitted to an ICU, especially unrealistic expectations, are also the factors which can give rise to conflict, usually around whether further active treatment is appropriate. The conflict can occur as a result of a difference of opinion between an admitting clinician and an intensive care physician or even between intensive care clinicians. These are usually resolved in-house. Conflict can occur between relatives/friends of a patient who is incompetent, where there is a difference of opinion about the appropriateness of further treatment. These are also usually resolved without referral to a third party outside the hospital system.

The most challenging conflict occurs when relatives/friends of an incompetent patient, usually in an ICU, do not agree with the caring clinician/s. This document covers all these forms of conflict but concentrates on the latter form of conflict and explores ways in which it can be resolved. However, reference is made to this type of conflict throughout the document. One of the major challenges in the preparation of the document was to specifically support the different options for resolving near death conflict with conventional scientific evidence. There are many documents and studies around strategies that potentially may decrease conflict, such as policy statements from governments and professional bodies; and large bodies of work on concepts such as communication and mediation.

Nobody challenges the importance of the existence of technology, because it is not good or bad in itself; it'll depend on how it is used. The ICU needs and must use technological resources that become more advanced each day, but professionals should not forget that machines will never substitute the human essence.

People outside the healthcare area hold several beliefs and fantasies about ICUs. For those who do not know the hospital environment, the ICU is considered as a critical place where people go to die; when they are about to die or when it is severe. Stereotypes like these could be undone with adequate definitions, as well as communication and efficient interaction with the families of patients admitted into ICUs.

The nurse could be indicated to establish communication with the family about the ICU routine, its devices, procedures, as well as offering emotional and spiritual support. However, this type of care, considering both the patient and the family, is certainly one of the most difficult to be implemented. The complex daily routine involving the ICU environment induces the Nursing team to forget touching and talking-to the patient in front of them.

The hospitalization of a family member in an ICU generally occurs in a severe and unexpected way, leaving a short time for family adjustments. This stressful situation may cause the family to feel disoriented, abandoned and with difficulties to mobilize, bringing up different types of needs the family tends to experience fear, anxiety and insecurity. These feelings emerge from difficult situations following hospitalization, such as the possibility of the patient's death, the search for information about the health status of the patient and the working dynamics of the intensive care unit, with its technology and specific professional knowledge.

On the other hand, nurses realize that, in certain situations, the family feels safe in leaving their relative in this well-equipped environment, which comes from the idea that the patient will be well cared for when under Intensive Care. As such, the nurse realizes that family experiences ambiguous feelings about ICU: a strange place which frightens but offers security in caring for the patient with a severe condition, always wishing for the person to leave the ICU as soon as possible.

The foreign study deals on End of Life Care while local study deals on the Importance of Advance Technology to the Care of Comatose patients. While this present study deals on the fears, expectations, problems and measures

adapted to lessen their emotional and psychological burdens of significant others whose patient is admitted at ICU, PJGMRMC, Cabanatuan City, Nueva Ecija, Philippines. The similarity of these studies are all on improving the care of confined patients at the Intensive Care Unit but also for the significant others of the patients.

2. Methodology

The qualitative research data was gathered through a structured and unstructured interview, observations, content analysis and focus group discussions.

The instrument was a survey questionnaire type divided into four (4) parts. The first part assessed the fears of the respondents which entail the physical appearance of the patients, financial aspect of the respondents, psychological aspect of the respondents, beliefs and fears of the respondents. Part 2 is the expectations of the respondents while their patients are on critically ill condition. Part 3 was on problems encountered by significant others. These included their health status, financial capability, emotional sufferings, the doctor advice and medical care given to the patient.

The part 3 includes the measures adapted by significant others to lessen their emotional and psychological burden.

The researcher utilized qualitative research through case study method. Purposive sampling was utilized to select the respondents. The respondents were selected from among the more than fifty (50) respondents in the lists but only ten (10) respondents were selected based on the following criteria set forth: (1) their patient was actually admitted at the ICU for any cause; (2) significant others should be nearest kin of the family such as: wife, husband, son, daughter by consanguinity or affinity; and (3) that she/he is trusted among members of the family and can decide when problems occurs. The study was conducted at Dr. Paulino J. Garcia Memorial Research and Medical Center located at Cabanatuan City, Nueva Ecija, Philippines during the school year 2014 - 2015.

The respondents were selected based on the criteria, utilizing checklist, survey questionnaires, semi-structured interviews, and observations in data gathering.. The instruments focused on the fears, expectations, problems and measures to adapt by a significant others. Prior to the conduct of the study, the researcher sought permission from the respondents who agreed to the research process. Interviews, observations and answering the checklist were under the supervision of the researcher. The respondents were all composed in answering the instruments and the interviews. The researcher used frequency counts, percentage, ranking and weighted mean. Interview responses were analysed separately.

3. Results and Discussion

The presentation of the findings is based on the questionnaires, interviews, and observations.

1. Demographic Profile of the Respondents

1.1 Age

Majority (30%) of the respondents were 31 to 35 years of age, more matured as compared to the younger age brackets. This only implies that they can decide better when problem arises while their critically ill patients are confined at the Intensive Care Unit of the hospital.

1.2 Gender

The respondents were dominated by female (80%). This result shows that females are more caring and compassionate by nature, which made them more suitable to take their critically ill patients.

1.3 Civil Status

Majority (60%) of the respondents were married. We can infer that married significant others are more acquainted and knowledgeable in taking care of a patient.

1.4 Relationship of the respondents with the critically ill patient

The data shows that the wives (40%) are fulfilling their promise to their husbands that they will be on their side for better or for worst.

2. Fears of Significant Others of the Critically Ill Patient

2.1 Physical

The patient' death with wm=4.7 and verbal description of strongly agree turned out to be the greatest fear of the patient's significant other. Complication of illness with wm=4.5 and a verbal interpretation of strongly agree ranked second.

Majority of the patients' significant others fear the death of their patient and the complication of illness to the condition of their patient.

2.2 Financial

In terms of the financial aspect, hospital bills with wm=4.8; personal debts with wm=4.6; and personal constraints with wm=4.2 got the strongly agree verbal description and personal resources with wm=3.9 and a verbal description of agree.

Majority of the respondents were anxious about the hospital bills, debts, financial constraints, and financial resources; however, they are optimistic that their patient can survive the challenges they are facing.

2.3 Psychological: Psychologically, significant others regarded that they strongly agree on the following items: agony with wm= 4.5 and stress with wm=4.2. On the other hand, grief received a verbal description of agree with wm=3.3.

Majority of the respondents were psychologically stressed at the time when their relative was in critical condition.

2.4 Belief: Healing with wm=4.5, good prognosis with wm=4.2 has a verbal description of strongly agree. Can survive with wm=3.7 was verbally described as agree. Can be conscious again with wm=3.2 received the verbal description of agree.

Majority of the respondents strongly agreed that their patients who were critically ill at the ICU will be healed, having a good prognosis, will survive or recover for their consciousness either in short span of time or even longer. They are optimistic that their patients can recover very soon.

2.5 Fear

For fear of the significant others, helplessness with wm=4 has strongly agree as a verbal description. Losing of their loved ones with wm=3.5 has a verbal description of agree.

The respondents agreed that their greatest fear was helplessness. And fear of losing of their loved ones. They

cannot help but cry especially when their patients are unconscious and life saver equipments are attached to them.

3. Expectation of the Respondents while their patients are on critically ill condition.

That they always expect for the efficient health service to be rendered by the medical personnel, thus, they rated the following statements as strongly agree: medical management with wm=4.5; nursing management with wm=4.5; information dissemination with wm=4.4; prognosis with wm=4.2. Meanwhile, diseases process with wm=3.3 got the verbal description of agree.

Majority of the respondents strongly agree that they always expect for efficient and effective medical management, nursing management, information dissemination, and prognosis. Moreover, they look forward for prompt treatment and quality services for their patient.

4. Problems encountered by significant others while their critically ill patient is confined at the Intensive Care Unit

4.1 Health Status

Flu with wm= 4.5 and insomnia with wm=4.4 has a verbal description of strongly agree. Anemia with wm=3.3 appeared to have moderately agree as verbal description. Vertigo with wm=2.4 and eating disorder with wm=2.4 has a verbal description of disagree.

Majority of the respondents had encountered health problems, viz: flu, since the climate is not stable, most of the time they do not have enough rest or sleep that weakens their immune system.

4.2 Financial

The significant others encountered problems on their financial support of their patients. Personal debts with wm=4.2 was verbally described as strongly agree while financial constraints with wm=3.7 has a verbal description of agree.

The respondents have no savings. They were not able to save money for any emergency. They borrowed money from their relatives just to sustain medication, diagnostic examinations, treatment, and hospital bills.

4.3 Emotional

The respondents regarded themselves emotional. Sadness with wm=4.4 and sorrow with wm=4.2 and verbally described as strongly agree. Irritable with wm=3.7; restless with wm=3.5; and angry with wm=3.1 has a verbal description of moderately agree.

Majority of the respondents were really sad and sorrowful about the health status of their relatives who were confined at the Intensive Care Unit. Mixed emotions were evident to the significant others as they wait for the result of doctor's evaluation on the status of their patient.

4.4 Doctor's Advice

The patient's of significant others rated the following statement as strongly agree: doctors do not talk to us regularly with wm=4.2; and the condition of patient is unexplained well with wm=3.3 moderately agree.

Majority of the respondents were longing for the doctors in charge to talk with them regularly and explain to them the real status of their patients so as to be updated on their condition.

4.5 Medical Care.

The statement 'the medical care given to each of the critically ill patients in the intensive care unit is good" with wm=4.0 were verbally described as strongly agree. On the other hand, the following statements both with wm=2.4: best medical care and needs improvement medical care has a verbal interpretation of moderately agree.

Majority of the respondents perceived that the medical care provided to their patient at the Intensive Care Unit is good.

5. Measures adapted by the significant others of critically ill patient to lessen their Emotional and psychological burden

The significant others also adapted measures to lessen their emotional and psychological burden. As such, they strongly agree to the following measures: pray/seek spiritual help with wm=4.5; talk to friends with wm=4.5; talk to family with wm=4.5; engage in diversion activities with wm= 4.5; and talk to patient every time they visit with wm=4.5. The following measures got the verbal description of moderately agree: blame the patient with wm=2.9; and cry with wm=2.4. Apparently, the statement blame health personnel with wm=1.9 has a disagree verbal interpretation.

Majority of the significant others always pray and seek spiritual help, talk to friends, talk to family, engage in diversion activity, and talk to patient every time they will visit. But they disagree on blaming the health personnel.

3.1. Results of Observations

The following are the common observations of the significant others, at the Intensive Care Unit, PJGMRC. It was observed that the respondents look sad when they saw the doctor keep on monitoring their patient, particularly when the doctor keeps on monitoring the oxygen, blood pressure and pulse rate. They cried when their patients are unconscious. They keep on praying that their parents will get well soon. Some sat down and keep on asking from the medical personnel on the status of their patients. The respondents can hardly sleep and cannot eat on time.

3.2. Results of the Interview

The respondents were very eager to see their patients to recover from their illness. They have different reasons and story to tell, but to sum up they have common experiences where almost everybody wanted that their patients can surpass the need they are stressed. They revealed that if their patient cannot recover at the ICU their great fear is the untimely death of their patients,. They were financially problematic because they have much debt from their neighbors and relatives. They confided that they were anxious about their hospital bills because they do not have money. They prayed that their patients can survive and recover soonest. They were psychologically distress if they saw their patients to be weak and down. They wanted that their patients be healed immediately; they hope that the medical practitioners assisting their patients do their best to survive their patients.

4. Conclusion

Majority of the respondents belonged to aged 31 to 35 years, female, married, wife, matured, assumed to decide better when problem may arise, more caring, compassionate

which made them more suitable to care for a critically ill patient, the fear the death of their patient and complication of illness¸ were anxious about the hospital bills, personal debts, financial constraints, and financial resources, optimistic that their patients can survive the challenges they are facing and can recover very soon, were psychologically distress at the time when their patient was in critical condition.

The respondents perceived that their patients who were critically ill at the ICU will be healed, having a good prognosis, will survive or recovered for their consciousness, agreed that their greatest fears were losing their loved ones. They cannot help but cry especially when their patients are unconscious and life saver equipment's are attached to them, were in distressed, has headaches, not enough rest or sleep that weakens their immune system. The respondents have no savings for any emergency. They borrowed money from their relatives just to sustain the medication, diagnostic examinations, treatment, and hospital bills. They were really sad and sorrowful about the physical condition and present health status of their relatives. Mixed emotions were evident among the significant others as they wait for the result of doctor's evaluation.

The respondents were longing for the doctors in charge to talk with them regularly and explain to them the real status of their patients so as to be updated on their condition. They perceived that the medical care provided to their patient at the Intensive Care Unit of the hospital was good enough. They strongly agreed that they expect an efficient and effective medical management, nursing management, information dissemination, and prognosis; Prompt treatment and quality services to be rendered by the medical team are expected by the significant others. They pray and seek spiritual help, talk to friends, talk to family, engage in diversion activity, and talk to patient every visit. They disagreed on blaming the health personnel.

5. Recommendation

1. Significant others must be physically and psychologically stable to be able to cope with the distressful situation of their critically ill patient confined at the Intensive Care Unit of the hospital.
2. Health team should be tactful in giving information concerning the patient's health status. Medical team on duty must be humane enough to deal with the significant others particularly when they are asked about the status of their patient.
3. The information regarding the condition of the critically ill patient must be explained well to the significant others. Medical and health practitioners should always give their best services. Especially to the critically ill patient confined at the Intensive Care Unit.
4. The hospital leadership shall provide watchers' lounge so that significant others can rest, relax or even compose themselves.
5. Significant others shall have sufficient money for emergency expenses.

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