Review

Critical care nurses’ understanding and experiences of patient advocacy in the critical care setting: A systematic review

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Abstract: Objectives: The purpose of this systematic review was to ascertain critical care nurses’ understanding and experiences of patient advocacy in adult critical care settings. The specific objectives were to identify how critical care nurses define patient advocacy, to explore the understanding and experiences of critical care nurses regarding patient advocacy, to explore critical care nurses’ role in patient advocacy, and to ascertain the barriers to encouraging advocacy in the critical care setting. Research design: Systematic literature search of CINAHL and Medline databases, Google Scholar, and Cochrane Database of Systematic Reviews, as well as grey literature search was conducted. Search dates were restricted from January 2005 to 2015 in both CINAHL and Medline. Findings: 62 studies were identified, of which 6 qualitative research papers were included. Nurses gave varied definitions of patient advocacy, which were categorized into three themes: communication, protection, and doing. Nurses perceive advocacy as truly listening to patients and their family. Conclusion: For critical care nurses to be effective advocates, there must be support, collaboration, and improved working relationship between professional groups. Moreover, nurses must be empowered to be able to give power to patients and family.

Keywords: Critical care nurses; Critical care setting; Experiences; Patient advocacy; Systematic review; Understanding

1. Introduction

The responsibility of nurses in advocating for patients and their families is well recognized in literature (Tammelleo, 2002) and deep-rooted in the nurses’ code of ethics by nursing regulatory bodies in various countries (Erickson, Lindahl and Bergbom, 2010). This role is even more distinct in the critical care setting where nurses are faced with huge patient vulnerability as a result of the critical disorder itself, coupled with the technology-governed unfamiliar setting (Pryzby, 2005), which, according to O’Keefe-McCarthy (2009), ostensibly presents barriers that strengthen the imbalance in power among healthcare professionals and patients. The Department of Health (2000) defined critical care as a specialized care of patients whose conditions are life-threatening and who require comprehensive care and constant monitoring, usually in critical care units.

The idea of patient advocacy is somewhat ancient, with its foundation being in the movement for patient advocacy in the 1970's (Page, 2004; Hanks, 2008). Several authors (Trapani, 2014;
McGarth and McGarth, 2006; Snowball, 1996; Mallik, 1997) have proposed a number of different models for the role of a nurse advocate, which implies that there are numerous interpretations and that it is difficult to offer any clear conceptualization (Vaartio and Leino-Kilpi, 2004). This, Vaartio et al (2006) stated that, it has a bearing on both the implementation of patient advocacy and on research regarding advocacy in nursing. The difficulties associated with engaging in advocacy has been explored by researchers including Choi (2015) and Mallik (1998). For example, in a study comprising of senior nurses in Britain, Mallik (1998) revealed the inconsistencies associated with practicing advocacy in the clinical setting, which could result in conflicts among professional bodies within the healthcare system.

Thus, the notion that patients need advocates is not in dispute. However, what remains debatable, is whether or not nurses, especially those working within the critical care setting, are in the best position to undertake such duty, or whether the role of advocating for patients should be allotted to professional associations within nursing (Welchman and Griener, 2005). In order to properly explore these answers, however, it is important to first consider what advocacy is, how it is defined, understood and experienced by critical care nurses, as well as the barriers encountered by critical care nurses during an advocacy intervention.

**Clinical implications**

- Registered nurses working in the critical care setting, who act as advocates for critically ill patients, have some experiences, roles, and are confronted with obstacles in the process.
- Nurses perceive advocacy as truly listening to patients and their family.
- Critical care nurses perceive their role in patient advocacy as protection, acting as a liaison between family and the healthcare team, acting as a guide, acting to support the meaning of the illness to the patient and family, collaboration, and helping.
- External and internal limits, Conflict between the professional groups, powerlessness, intimidation, ineffective collaboration, and destructive physician behaviour were all identified as barriers that affected the nurses’ ability to act as patient advocates.
- For critical care nurses to be effective advocates, there must be support, collaboration, and improved working relationship between professional groups.

2. Background

2.1 The Concept of Advocacy

Advocacy in healthcare has been examined in relation to various aspects of care such as public health, perioperative care, and mental health (Munday, Kynoch and Hines, 2014). According to Schroeter (2007), the concept has been defined by many nursing scholars, with the use of a dictionary as a starting point. The Oxford dictionary (2015) defines advocacy as an active support, especially of a cause. Perhaps the greatest concern about any effort to study the responsibilities required of nurse advocates is that there are numerous meanings of the concept (Hamric, 2000). Definitions of advocacy must include responsibilities required of a nurse advocate. However, the nursing literature relies on a legal description of an advocate, as a person who protects the patient against infringements of his/her rights (Matthew, 2010).

The nursing literature reveals several presumptions about the practice of advocacy in nursing. Gadow (1983) and Curtin (1986) affirmed that advocacy is the primary foundation for nursing practice and completely clarifies the core principles of nursing. Curtin (1986) described Advocacy as an ethical art in nursing that develops from past experiences, shared vulnerability and benevolence in the nurse-patient relationship. Curtin’s assumption indicates that to effectively
practice advocacy, a nurse also needs an understanding of ethical principles and models (Parker, 2007).

Gadow (1983) recommended a model of existential advocacy in which nurses aid patients to use their right to self-determinism accurately, during healthcare decision-making. According to Gadow (1990), advocacy does not only protect, but contributes positively to the practice of self-determinism.

Kohnke (1982) asserted that a nurse advocate is an individual who advises patients of available options and then supports whatever decision the patient makes. However, the potential problems regarding this assertion must not be overlooked. As an advocate, a nurse is expected to uphold his or her “duty of care” by acting in the patient’s best interest, especially when such patient is deemed to lack the mental capacity to understand and retain information or to make a decision (Buchanan and Brock, 1990; Mental Capacity Act, 2005). If a patient lacks the ability to decide, the nurse must assist the person to decide based on his or her values, expectations and beliefs (Ahern and McDonald, 2002). Nevertheless, Kohnke (1982) argued that advocacy is a form of kindness and caring in nursing practice, and that it is a learned skill that may develop through diverse experiences, particularly if the concept is perceived as valuable.

Tschudin and Hunt (1994) proposed three intrinsic features about advocacy; a nurse advocate’s view is proactive rather than passive and subordinate, they speak up and act on a patient’s behalf, and there are certain kinds of difficulties that require the need for advocacy. This, according to Altun and Ersoy, (2003) suggests that patient advocacy also involves utilizing patients’ right, and not only to assist the patient in decision-making. Besides, Badman and Badman (2002) explained that the argument surrounding patient advocacy originates from the recognition and appreciation of patient’s rights and the role of nurses as advocates for the rights and welfares of individuals.

Though these assumptions appear different, Hyland (2002) argued that they all stress the role of the nurse as a realistic observer of the patient’s circumstances, which, according to Vaartio et al (2006), indicates an ethical obligation in making certain attribute of care. Ethics are especially prominent in nursing practice (Shroeter, 2014). Several authors (Beauchamp and Childress, 2001; Vaartio, 2008) have stated that advocacy involves active support of autonomy, beneficence, non-maleficence, human dignity, and justice. However, due to the intricacy of the critical care setting, critical care nurses acting as patient advocates are usually confronted with unique moral and ethical dilemmas when caring for patients (Azouley et al, 2000). These moral and ethical dilemmas may include patient’s right to die or discontinue treatment or ventilation, and Do Not Resuscitate (DNR) status (Alichnie, 2012). Though there is no scientific approach in solving these problems, Black (2014) recommends the use of ethical decision-making process to assist the nurse in making judgments when two or more ethical principles are in conflict. Similarly, Butt and Rich, (2008) suggest that knowledge of these ethical principles arms the nurse with power to be a major player in the decision-making process regarding patient care and urge them to act when the safety or rights of patients are risked (McDonald and Ahern, 2000).

Despite these suppositions regarding patient advocacy, however, particular models for the practice of advocacy in nursing have refused to essentially highlight on the actual understanding and experiences of critical care nurses in their role as patient advocate (McSteen and Peden-McAlpine, 2006; Mortell et al, 2018).

2.2. Advocacy in the critical care setting

A patient who is restricted to bed as a result of a critical illness and strict observation, usually experiences changes in self-image and pain, which makes them vulnerable Melia (2001). Hence,
Grace (2001) recommends that, critical care nurses act as advocates so as to empower vulnerable patients and relief them from needless pain and discomfort. Vaartio et al (2006) supported this claim by stating that patients need to be safeguarded from the actions of unskilled healthcare professionals. Though it is generally believed that critically ill patients are both physically and psychologically vulnerable due to their illnesses, the actual impact of the patient’s vulnerability on his/her autonomy was only recently acknowledged (Curtis et al (2001), thus prompting the need for patient advocates in the critical care setting (Parascandola, Hawkins, and Danis, 2002).

Nevertheless, some authors (Hewitt, 2002; Timmers, van Merode and Landeweerd, 2001) believe that it is not only vulnerable and weak patients that need advocates. Every patient is at risk of being in a situation of “learned helplessness” due to the presence of an “all-knowing and uncommunicative” doctor, which results in the inability of the patient to speak up for themselves (Hewitt, 2002)

Sorensen and Iedema (2007) believe all health care personnel, notwithstanding their best intentions, practice some kind of benevolent paternalism that limits the patient’s self-determinism. However, with the rise in information technology resulting in a more informed members of the public, Hanks (2010) contended that the trust in the omniscience of the health professional started to disappear in the 80’s with the patient becoming a well-informed service user, possessing the right to query treatment. Consequently, Hanks (2010) believes that the patient is able to speak up for him or herself, and so does not require an advocate.

The various research articles that support the urgent need for patient advocates have failed to back their claim with substantive evidence Vaartio et al (2006). Indeed, several authors (Hewitt, 2002; Schroeter, 2007; Snowball, 1996; Eriksson, Lindahl and Bergbom, 2010; Happ, 2000) have stated diverse opinions as to whether the main cause of the need for patient advocacy in the critical care setting is due to the phenomenon of learned helplessness, or whether it is as a result of patient vulnerability. Bu and Jezewski (2007) gave a description of the activities that may initiate an advocacy intervention (antecedents) on the micro, as well as the macro social level. Patient vulnerability was cited as the main antecedent of advocacy intervention on the micro social level, whereas, inequalities in health care and the lack of access to health care were mentioned as major antecedents of advocacy intervention on the macro social level.

Other antecedence of advocacy includes patients who have been neglected, treated incompetently or unethically (Blanchard and Alavi, 2008). Clarke and Aiken (2003) described vulnerable patients as those who may be suffering from a debilitating illness, such as cancer, as well as, illiterates, the mentally ill or unconscious patients. Nonetheless, Tammelleo (2002) noted that patients who are otherwise capable and in normal conditions become shy, scared and tongue-tied, in the doctor’s presence. This buttresses the need for patient advocates.

Cypress (2011) investigated the experiences of patients admitted to a critical care unit, and revealed that, the experiences of critically ill patients included perceived loss of communication, lack of interpersonal relationship, anxiety and disorientation. Thus, critically ill patients require nursing interventions such as advocacy in order to meet their needs (Cypress, 2011).

3. Aim

The aim of this systematic review was to ascertain critical care nurses’ understanding and experiences of patient advocacy in the critical care setting. The specific objectives were as follows:

- To identify how critical care nurses define patient advocacy
- To explore the understanding and experiences of critical care nurses regarding the concept of patient advocacy
To explore critical care nurses’ role in patient advocacy in the critical care setting
To ascertain the barriers to encouraging advocacy in the critical care setting

The systematic review aimed to answer the following research questions:

1. How do critical care nurses define patient advocacy?
2. What are critical care nurses’ understanding and experiences of patient advocacy?
3. What are critical care nurses’ roles in patient advocacy in the critical care setting?
4. What are the barriers to encouraging advocacy in the critical care setting?

4. Method

4.1. Inclusion criteria for considering studies in review

The study title was split into PEO (Population, Exposure, Outcome) parts so as to provide a focus around the research question of the study (Parahoo, 2014). This is illustrated in Table 1 below:

| P | E | O |
|---|---|---|
| Critical care nurses | Patient Advocacy | Experiences and understanding |

Based on the PEO and the objectives for this study, the inclusion and exclusion criteria used in the review is presented in Table 2 below.
### Table 2. Inclusion and exclusion criteria.

| Types of Participant | Type of Exposure | Type of Outcome | Type of Study |
|----------------------|------------------|----------------|--------------|
| **Inclusion Criteria** | - Registered nurses, enrolled nurses, licensed practical nurses, or licensed vocational nurses with at least one-year post-qualification experience within an adult critical care setting (wherever critically ill adult patients are found, excluding psychiatric units, public health units, and Obstetric/Gynaecological units), including intensive care units (ICU), emergency departments, perioperative units, cardiac care units, and High Dependency Units (HDU). | - This systematic review considered studies that explored the understanding and experiences of registered nurses working in an adult critical care setting (ICU, emergency departments, perioperative units, cardiac care units, HDU) in acting as patient advocates. | The outcome measures for this review includes studies with interviews that involve: | - This systematic review included all qualitative studies that sought to explore critical care nurses’ understanding and experiences of patient advocacy, including, but not limited to phenomenology, grounded theory and ethnography. |
| **Exclusion Criteria** | - Registered nurses, enrolled nurses, licensed practical nurses, or licensed vocational nurses with less than one-year post-qualification experience within an adult critical care setting | - Patient advocacy issues in areas other than the critical care setting, including PICU, LDU, mental health units and midwifery. | Studies that do not explore: | - All forms of quantitative studies |
| | - Registered nurses working in Paediatric Intensive Care Units (PICU) | | - Critical care nurses’ definition, understanding, and experiences of patient advocacy | - Review documents, commentaries, and case studies. |
| | - Registered nurses working in either high or low dependency mental health units | | - Critical care nurses’ role in patient advocacy in the critical care setting | | - Registered nurses working in Low dependency units (LDU) |
| | - Registered nurses working in Low dependency units (LDU) | | | - Midwives |
- Student nurses, temporary nursing staff, and non-registered nurses

- The barriers to encouraging advocacy in the critical care setting
For the purpose of this study, a critically ill patient is defined based on the levels of critical care for adult patients (level 2 criteria) proposed by the Intensive Care Society Standards (ICSS) (2009). Thus, this systematic review considered all studies that sought to explore the understanding and experiences of registered nurses providing care for adult patients requiring:

- A pre-operative optimization
- Extended postoperative care
- Single organ support
- Basic respiratory support
- Basic cardiovascular support
- Advanced cardiovascular support
- Renal support
- Neurological support
- Dermatological support.

4.2. Search strategy

In this study, a systematic review was deemed appropriate to answer the research questions as the study aimed at using a standardised unbiased method to synthesise data from multiple qualitative peer reviewed articles. The use of qualitative research articles is suitable as most qualitative studies aim to explore the experiences of persons involved in providing, and/or receiving interventions (Joanna Briggs Institute, 2008), such as advocacy.

The online databases used for the study were the Cumulative Index for Nursing and Allied Health Literature (CINAHL) and Medline. This is because, the CINAHL database contains relevant references from a range of nursing and allied health journals, whereas the Medline database is the main source for biographic coverage of biomedical literature (Bruce, Pope and Stanistreet, 2008; Alderson and Green, 2002). Also, grey literatures from sources such as Google Scholar, ProQuest dissertations and thesis, as well as conference papers and proceedings were searched in order to obtain all unpublished sources of evidence that may be relevant to the study. In addition, other peer reviewed articles and specific journals (Journal of Critical Care Nursing, 2014 edition) were hand searched, as well as checking the reference list of journal articles to ensure that no relevant studies are overlooked. This technique also helped to locate relevant articles that were either inaccurately indexed or unindexed (Bettany-Saltikov, 2010).

The search for evidence in CINAHL and Medline involved a number of steps. First, the study title was converted into a search by creating a list of keywords based on the PEO (Participants, Exposure, Outcome) anagram of qualitative research (Popay, Roberts and Sowden, 2006). Secondly, synonyms were identified with the help of a thesaurus, and then, the keywords were combined using Boolean operators (OR, AND) (Boolean, 2008). Thirdly, other reviews done on a similar topic, as well as a dictionary were looked at, to help identify abbreviations for keywords. This is presented below (Table 3).

| Terms combined with | AND Participant | AND Exposure | AND Outcomes |
|---------------------|-----------------|--------------|--------------|
| OR                  | 1."Critical care nurs"* | 5."Patient advoca"* | 9.Experience* |
| OR                  | 2."Acute care nurs"* | 6."Nursing advocacy"* | 10.Understand* |
|                     |                  |              | 11. Attitude* |
Then, the keywords and synonyms were all translated into a search strategy list. Table 4 below shows a list of the exact words that were typed into the identified databases (CINAHL and Medline).

**Table 4 Search streams.**

| Search streams                                                                 | 1. “Critical care nurs*” | 2. “Acute care nurs*” | 3. “Intensive care nurs*” | 4. “Emergency care nurs*” | 5. 1 OR 2 OR 3 OR 4 | 6. “Patient advoca*” | 7. “Nursing advocacy” | 8. “Speaking up” | 9. “Patient support” | 10. 6 OR 7 OR 8 OR 9 | 11. Experience* | 12. Understand* | 13. Perception* | 14. Knowledge | 15. Attitud* | 16. 11 OR 12 OR 13 OR 14 OR 15 | 17. Combine 5 AND 10 AND16 |
|--------------------------------------------------------------------------------|--------------------------|----------------------|--------------------------|--------------------------|---------------------|----------------------|----------------------|-----------------|---------------------|---------------------|----------------|----------------|----------------|----------------|----------------|----------------|--------------------------|
| Search dates were restricted from January 2005 to 2015 in both CINAHL and Medline. This was done to ensure that initial publications relating to patient advocacy within the critical care setting have the potential for inclusion in the systematic review. Also, Search language was restricted to only reports and articles published in the English language. This was to avoid potential issues with language translations, which may have a negative impact on the validity of the study (Munday, Kynoch and Hines, 2014).

At the end of the search, CINAHL returned 27 papers after being limited to only full text articles, whilst Medline returned 31 papers. Hand searching of the 2014 edition of the Journal of Critical Care Nursing produced no results. However, an unpublished thesis was obtained during a grey literature search. Additionally, 2 research articles (Hanks, 2008; Boyle, 2005) were obtained from Google Scholar. Also, the reference lists of some articles were searched, which produced 1 research article (Vaartio et al, 2006). Consequently, the total number of papers located during the search were 62 (See Fig. A.1 PRISMA chart)
4.3. The process of selecting papers for inclusion in the review

This section of the review consisted of two parts. The first part involved scrutinizing the title and abstracts of all the studies retrieved from the literature search. The second part involved a review of the full content of the articles to ascertain whether or not the articles should be excluded from the study, or whether they should be included for a full methodological analysis (Dickersin et al, 2002).

4.3.1. First selection of papers

Out of the 62 papers obtained, 27 of the Medline articles were replicates from CINAHL. The titles and abstracts of the remaining 35 articles were screened to find their eligibility with regards to the inclusion criteria. This process was carried out by two reviewers (EAK and PB) in order to increase the reliability of the selection process, and to strengthen the validity of the selected studies (Petticrew and Roberts, 2006). To ensure inter-rater reliability (Oremus et al, 2012), disagreements
were resolved by discussion among reviewers. Based on the inclusion and exclusion criteria for this review and based on the recommendations of the Cochrane Collaboration (Higgins and Deeks, 2011), a standardised form was developed to assist in selecting the studies that were most suitable to answer the research questions (Craig and Smith, 2007). Studies were selected based on the PEO components of this review’s research question, as well as the type of study.

The developed standardised form was pilot-tested on five randomly selected articles and refined accordingly. Each of the inclusion criteria (Participants, Exposure, Outcome, type of study) was given a score of 1; an article that fulfils all of the inclusion criteria received a total score of 4. Articles that fulfilled two or more of the inclusion criteria were included for a second round of screening. Refer to supplementary material supplementary table S1 for details. The scores allotted to each of the articles in table S1 is an average of the scores given by each reviewer.

The first round of screening yielded 5 Systematic reviews, which were automatically excluded since it is considered important, to use only unsynthesised primary data so as to effectively answer the research question (Craig and Smith, 2007). Also, 16 other research articles that did not fulfil two or more of the inclusion criteria were excluded from the study. Hence, at the end of the first round of screening, 21 research papers were excluded. Thus, 14 articles were left after the initial review.

4.3.2. Second selection of papers

The full text of each of the 14 papers was reviewed thoroughly to determine their eligibility based on the predetermined inclusion criteria (Participants, Exposure, Outcome, Type of study). The same criteria described above for the first selection of papers was used to identify papers for inclusion in the review. Refer to supplementary material supplementary table S2 for characteristics of included studies based on reading the full text.

At the end of the second screening of papers, 8 papers were excluded. Among the 8 excluded studies, 4 articles did not meet the primary inclusion criteria. 3 of the studies were not relevant to the main subject of this study, while 1 study had no available full text. Therefore, 6 qualitative research articles were left after the second round of screening, which formed the basis for this review.

5. Results

5.1. Characteristics of included studies

Table 5 below presents a summary of all the included studies based on all components of the PEO (Participants, Exposure, Outcome).

As shown in the table, the primary participants (sample) in each of the six (6) included studies were registered nurses, with at least one year post-qualification nursing experience in a critical care setting. All the studies explored the perception, attitude and behaviour of nurses who had experienced advocacy in caring for critically ill patients. The outcome criteria for the studies were nursing advocacy role, nurses’ perception of behaviours that represent advocacy, the impact of negative work place behaviour on communication between nurses and doctors, and its influence on the nurses’ role as patient advocate; as well as the activities of expert nurses who act as patient advocates in ethically difficult care situations of the dying.

The majority of the participants in each of the 6 studies were female, and the racial and ethnic background was largely white. All the included studies were qualitative, with a purposive method of sampling. Among the 6 included studies, Five (Boyle, 2005; Kimes, Davis and Bishop, 2015; Arbour and Wiegand, 2013; McSteen and Peden-McAlpine, 2006; Cypress, 2011) were conducted in the United States of America (USA), and one (Sorensen and Iedema, 2007) in Australia.
Table 5. Summary of all the included studies based on all components of the PEO.

| Study | Participants | Exposure | Outcome |
|-------|--------------|----------|---------|
| Sorensen, R. and Iedema, R. (2007) ‘Advocacy at end-of-life. Research design: An ethnographic study of an ICU’, *International Journal of Nursing Studies*, 44, pp. 1343-1353. | **Sample selection:** Nurses and doctors of an ICU unit were invited to participate in the study. | Patient Advocacy in the Intensive care unit | Nursing advocacy role within nursing practice |
| | **Number of participants:** 84 | | |
| | **Number of Nurses:** 33 | | |
| | **Post-Qualification Experience:** ranges form 2-17 years | | |
| | **Characteristics of nurses:** Nursing unit manager (2), nurse educators (2), experienced nurses (9), intermediate nurses (8), less experienced nurses (12) | | |

| Boyle, H.J. (2005) ‘Patient advocacy in the perioperative setting’, *Association of Operating Room Nursing Journal*, 82(2), pp.250-262. | **Sample selection:** The sample consisted of perioperative Registered Nurses from a hospital in Eastern New York | Patient advocacy | Nurses’ role as advocates, and nurses’ perceptions of behaviors that represent advocacy |
| | **Number of participants:** 33 | | |
| | **Number of nurses:** 33 | | |
| | **Years of post-qualification nursing experience:** Ranges from 7-36years | | |
| | **Characteristics of nurses:** Predominantly associate degree holders. All participants were white. Nurses who advocate for vulnerable surgical patient population were specifically interviewed | | |
| Study | Participants | Exposure | Outcome |
|-------|--------------|----------|---------|
| Kimes, A., Davis, L. and Bishop, M. (2015) 'I’m not calling him: Disruptive physician behavior in the acute care setting', *Journal of Medical Surgical Nursing*, 22(4), pp. 223-227 | **Sample selection**: Acute care Nurses at two nonprofit community hospitals in the metropolitan Atlanta, GA, area volunteered to be interviewed | Communication and Patient advocacy | The impact of disruptive physician behavior on communication between nurses and physicians in the hospital setting |
| | **Number of Participants**: 15 | | |
| | **Number of nurses**: 15 | | |
| | **Post qualification experience**: Ranges between 5-35 years | | |
| | **Characteristics of nurses**: Registered nurses with bachelor’s degree in nursing, and a minimum of 5 years experience in the medical-surgical care setting | | |
| Arbour, R.B and Wiegand, D.L (2013) 'Self-described nursing roles experienced during care of dying patients and their families: A phenomenological study', *Journal of Intensive and Critical Care Nursing*, 30, pp. 211-218 | **Sample selection**: Study participants were recruited from the medical and surgical critical care units of a tertiary care medical center. Inclusion criteria consisted of having had the experience of caring for dying patients and their families in the critical care setting including when care transitioned from aggressive to palliative and end-of-life care | Role of the nurse during care of dying patients | The experiences of critical care nurses during care of the dying, and the perception of critical care about the activities and roles they performed while caring for patients and family |
| | **Number of Participants**: 19 | | |
| | **Number of Nurses**: 19 | | |
| | **Post-qualification experience**: Ranged from 1-25 years | | |
| | **Characteristics of nurses**: The majority of the participants were female (n = 17, 89.4%) and the racial and ethnic background was largely Caucasian (non-Hispanic) (n=14, 73.7%). There was a spectrum of educational | | |
**Study Participants**

- Backgrounds with 10.5% having an associate degree, 47.4% with a nursing diploma, 36.8% with a BSN and 5.3% had Masters in nursing.
- Most participants (84.2%) had the experience of transferring a patient from the ICU following withdrawal of life-sustaining treatments. The mean number of years in clinical practice was 9.9 (range 1—25) years and in critical care practice was 7.2 (range 1—25) years.

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**Sample selection**

A purposeful peer-nominated sample of seven registered nurses who were experienced in caring for dying or terminally ill clients participated in audiotaped, unstructured, narrative interviews for this study. Inclusion criteria required at least 5 years of nursing experience in their fields working with dying or terminally ill patients.

- **Number of Participants:** 7
- **Number of nurses:** 7
- **Post-qualification nursing experience:** at least 5 years

**Characteristics of nurses**

- The sample included one male and six female nurses, aged 28 to 55 years, with a mean age of 36 years. The nurses' years of experience ranged from 5 to 22 years, with a mean of 14 years. All participants in the sample were white. The nurses worked in critical care and oncology settings.
| Study                                                                 | Participants                                                                                                                                  | Exposure       | Outcome                                                                                           |
|----------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------|----------------|--------------------------------------------------------------------------------------------------|
| Cypress, B.S. (2011) 'The lived experience of nurses, patients and family members: a phenomenological study with Merleau-Pontian perspective', *Journal of Intensive and Critical Care Nursing*, 27, pp. 273-280 | Sample selection: A purposive method of sampling was also used to recruit participants for this study in which they were selected for their knowledge and experience of critical illness in the ICU. Recruitment continued until data saturation was achieved. | Patient advocacy | The lived intensive care unit experience of nurses, patients and family members during critical illness. |

**Number of participants:** 15  
**Number of nurses:** 5  
**Post-qualification nursing experience:** Ranged from 3-25 years  
**Characteristics of nurses:** The nurses were made up of 4 females and 1 male with a minimum of a Bachelor of Science degree in Nursing.
5.2. Procedure for the assessment of methodological quality

The critical appraisal framework for qualitative studies developed by the McMaster University (Letts et al, 2007) was used to assess the methodological quality of each of the remaining 6 qualitative papers. The reason for this choice is that, it provides a guided, self-explanatory approach to assessing the methodological quality of research articles (Petticrew and Roberts, 2006). The appraisal was done by two independent reviewers (EAK and PB) so as to increase the reliability of the study findings. For inter-rater reliability, disagreement among reviewers was resolved by discourse. If no agreement could be reached, it was agreed that the reviewer (RD) would decide.

The McMaster’s qualitative appraisal framework (Letts et al, 2007) consists of twenty-four questions. For the purpose of this review, each of the questions in the framework was given a numeric quality score of 1, totalling an overall score of 24. Studies that scored 15 or more were adjudged to be of very good quality, while studies that scored between 14 and 10 were considered to be of good quality. However, a score of less than 10 was marked as poor. The appraisal results (See supplementary material table S3) indicated that, five studies (Sorensen and Iedema, 2007; Boyle, 2005; Arbour and Wiegand, 2013; McSteen and Peden-McAlpine, 2006, Cypress, 2011) are of very good quality (scored between 17 and 23), while one study (Kimes, David and Bishop, 2013) is of good quality (scored 11). All the 6 appraised articles were included in the review, regardless of its score.

5.3. Data Extraction

This process usually involves extracting data related to the population included, the intervention, and particularly the outcomes of included research articles (Lahlafi, 2007). Based on the suggestions of Dickersin et al, (2002), a data extraction form was developed, to harmonize the process and increase the validity of the findings, and to ensure that data extracted from one article to another, and between different reviewers is similar.

Data was extracted independently by two reviewers (EAK and PB) using a standardized data extraction form; the results were then compared and discussed to reach a consensus. Based on the recommendation of the Cochrane collaboration (2009), the standardized form was pilot-tested on a randomly selected paper before starting the data extraction, to confirm whether it is suitable and beneficial to extract all pertinent data (The Cochrane Collaboration, 2009). Specific information on the participants, and exposure, as well as the outcome criteria of the articles was collected to answer the research questions of this review. In order to place more emphasis on the outcome, different colour codes were allotted to each identified outcome.

The process of data extraction was based on Burnard’s (1991) thematic content analysis. Firstly, the whole content of each of the 6 articles were read, with special emphasis on the results section, to become completely engrossed in the data.

Secondly, all the text highlighted in different colours were cut out and pasted in the appropriate section of the form. Consequently, data or texts relating to the various outcomes (critical care nurses’ definition of patient advocacy, understanding and experiences of critical care nurses regarding patient advocacy, critical care nurses’ role in patient advocacy, and barriers to encouraging advocacy in the critical care setting) were placed under the appropriate heading in the data extraction form. The page, column, and line numbers for each extracted data were noted, so as to make future reference easy (Ogilvie et al, 2005).

Thirdly, after extracting all the data from the articles, each section was re-read a couple of times, and the major sub-themes were written along the margins of the form. Table 6 below presents the data extraction form used to extract data in this study.

| Date of data extraction |
|-------------------------|
| Reviewers              |
| Bibliographic details of study |
| Purpose of study       |
Study design
Population (Sample)
Exposure
Outcomes:
Critical care nurses’ definition of patient advocacy - (turquoise)
Understanding and experiences of critical care nurses regarding patient advocacy - (yellow)
Critical care nurses’ role in patient advocacy in the critical care setting - (red)
Barriers to encouraging advocacy in the critical care setting - (green)

Refer to supplementary material table S4 for the completed data extraction forms for all the six included papers.

Following data extraction, similar sub-themes (from the data extraction forms of the 6 papers) were grouped in the same section together. These groups were then categorised into main themes to synthesise the results. This is illustrated in supplementary material table S5.

5.4. Data synthesis
Based on the outcome of the data extracted from the 6 articles, the result is synthesised as follows:

Theme 1: Critical care nurses’ definition of patient advocacy

Data on the definition of patient advocacy was available in three out of the six articles (Boyle, 2005; Arbour and Wiegand, 2013; McSteen and Peden-McAlpine, 2006). The recurrent themes included protection, communication, and doing. Below are samples of participants’ definitions of patient advocacy:

“A nurse advocate is open and empathetic to differing perspective. Setting aside their own values, priorities, and agenda and acts to affirm the decisions and choices that the patient and family have made according to their own values, goals, and priorities”. McSteen and Peden-McAlpine (2006), pg.265, col. 1, lines 41-45.

“Fighting for the patient’s rights. Doing the right thing for the patient if they are unable to make the decision. But you are fighting for the patient, you’re standing up for them, making sure that they are getting safe and effective treatment, and what’s in the best interest for them.” Boyle (2005), pg. 258, lines 1-3.

“Patient advocacy also takes the form of truly listening to the patient”. Arbour and Wiegand (2013), pg. 214, col. 2, lines 50-51.

Theme 2: Understanding and experiences of critical care nurses regarding patient advocacy

All of the 6 included papers (Sorensen and Iedema, 2007; Boyle, 2005; Arbour and Wiegand, 2013; Kimes, Davis and Bishop, 2015; McSteen and Peden-McAlpine, 2006; Cypress, 2011) reported on critical care nurses’ understanding and experiences of patient advocacy. The recurring themes included communication, comfort and caring, providing holistic care, and ethically difficult care situation. The following are examples of how participants shared their understanding and experiences of patient advocacy:

“The nurse described a patient who, ‘really needed the power of attorney and an advanced directive before she got worse’. The nurse went on to say ‘so we got the case manager, social worker and her (the patient’s) person of choice in the room, sat down and talked with her. We got all the paperwork that needed to be done and it went smooth. I felt good about the referral and being able to follow through’. Arbour and Wiegand (2013), pp. 214, col 2, lines 30-32.
“Nurses experience distress caring for patients in intensive care. Distress related not only to nurses’ powerlessness to intervene on behalf of patients; it was also pronounced in their interaction with doctors”, Sorensen and Iedema (2007), pp. 1349, col. 2, lines 1-6

“Protecting patients by being alert and taking appropriate actions to prevent undue harm”, Boyle (2005), pp. 257, col. 2, lines 25-27.

“The nurses often recalled feeling as if they were being an annoyance to physicians when they contacted them for order clarification regarding patient care”, Kimes, Davis and Bishop (2015), pg. 226, col. 1, lines 5-9.

“An hospice nurse recounted an ethically difficult care situation in which a man was dying but his family would not let anyone tell him that his prognosis was poor”, McSteen and Peden-McAlpine (2006), pp. 263, col. 1, lines 30-33.

“Nurses in this study perceived advocacy as one important aspect of their role in providing holistic care to the critically ill and their family members”, Cypress (2011), pp. 277, col. 2, lines 37-39.

Theme 3: Critical care nurses’ role in patient advocacy in the critical care setting

In five out of the six studies (Sorensen and Iedema, 2007; Boyle, 2005; Kimes, Davis and Bishop, 2015; McSteen and Peden-McAlpine, 2006; Cypress, 2011), critical care nurses expressed their views on their role as patient advocates. Recurrent themes included protection, acting as a liaison between family and the healthcare team, acting as a guide, acting to support the meaning of the illness to the patient and family, collaboration, and helping. Below are excerpts from each of the five articles:

“Nurses advocated for the patient and family members by working with the family for the patient’s well-being”, Cypress (2011), pp. 277, col. 2, lines 39-41.

“Upholding nursing values that privilege disclosing information to patients about their condition and their prognosis, that maintain patients’ engagement with decisions about their care in principle, and that support individual nurses when these values are breached in practice, is an essential advocacy role within the organization”, Sorensen and Iedema (2007), pp. 1350, col. 1, lines 17-23.

“A hospice nurse recounted a story that illustrates the importance of understanding the meaning of the illness to the patient. She talked about a challenging case in which the patient had severe pain that was difficult to control partly because she would not be following the prescribed medication regimen. The family, the doctor, and the nurse were all extremely frustrated. The situation finally began to improve after the nurse was able to understand the meaning of the illness to the patient. Only then was she able to advocate for her by supporting her needs and goals”, McSteen and Peden-McAlpine (2006), col. 2, lines 14-24.

“You make sure that you stay close by, hold their hands and make sure they know that I’m right there”, Boyle (2005), pp. 259, lines 32.

Theme 4: Barriers to encouraging advocacy in the critical care setting

Of the six articles, two (Sorensen and Iedema, 2007; Kimes, Davis and Bishop, 2015) reported on barriers or limits to patient advocacy. The recurrent themes that emerged were internal and external factors, non-economic factors, powerlessness, intimidation, destructive physician behaviour, ineffective collaboration, and conflict between medical and nursing clinicians. Below are excerpts from the two articles:

“The nurse called the physician to report the abnormal pain and request analgesia. The physician was rude and “barked” at the nurse over the telephone. In response, the nurse “said it was my job to inform you about what’s going on with your patient...” The call ended abruptly and did not result in any new orders for the patient. The physician rounded eventually and ordered some analgesia for the patient. However, this response caused an interruption that affected quality of care for the patient”, Kimes, Davis and Bishop (2015), pp. 225, col. 3, lines 32-47.
“External limits included the economic imperative of conserving scarce resources, the primacy of medical authority to treat, and conflict between medical and nursing clinicians about patient management decisions. Limits internal to the profession included the lack of operational autonomy that would allow nurses to contribute their assessments of the non-medical status of the patient in terms of likely outcomes, and the lack of organizational authority to formally structure nursing knowledge and practice into patient care decisions, Sorensen and Iedema (2007)”, pp. 1348, col. 2, lines 2-11.

6. Discussion

Through a systematic review of 6 qualitative papers, a number of themes emerged, which will be discussed in relation to theories and literatures on patient advocacy. All the studies included in this review had an element of phenomenology, which is concerned with the lived experience of people (Parahoo, 2014). Polit and Becks (2012) posit that the purpose of a phenomenological study is to ascertain the essence of the phenomena and seeks to determine the meaning of those who experience it. Though phenomenology aims at making clear the experience of real events, Kibble (2012) argues that the irresolute nature of the concept “advocacy” may mean it is essentially impossible to discuss the results of phenomenological studies with any consistency.

By using a phenomenological approach and enquiring from critical care nurses what their definition, understanding, experiences and roles, as well as the barriers they face as patient advocates, we are able to determine the answers to these questions. However, we are unable to determine critically the exact advocacy interventions and evaluate whether or not it was indeed an advocacy intervention. This is a limitation of phenomenological methodologies, and an undeniable limitation to this review.

This notwithstanding, the results of this review reveals, with some certainty that registered nurses working in the critical care setting, who believe they act as advocates for critically ill patients, have some experiences, roles, and are confronted with obstacles in the process. The themes that emerged from the review represent the essence of the nurses’ definition, personal experiences, roles and barriers they have faced when advocating for critically ill adult patients. These themes were seen by the researchers as overlapping and interrelated. Detailed discussion of the themes is given under the following headings:

Theme 1: Critical care nurses’ definition of patient advocacy

The interpretation of patient advocacy can vary among health care providers (Hanks, 2008). Baldwin (2003) highlighted through a concept analysis that in most instances where nurses act as patient advocates, they do so by trying to influence a third party on behalf of their patient. In this review, nurses gave varied definitions of patient advocacy, which were categorized into three themes (communication, protection, and doing).

With regards to communication, critical care nurses described patient advocacy as: informing patients and their family members about their rights and providing facts about their health care (Boyle, 2005); effective communication among healthcare professionals, as well as truly listening to the patient (Arbour and Wiegand, 2013). However, effective communication with patients who are critically ill and on artificial support is likely to be challenging at best and probably non-existent at worst (Nelson, Puntillo and Pronovost, 2010). Munroe and Savel (2013) argue that good, effective communication amongst critically ill patients, their families and health providers is often challenging and complex.

The importance of good communication in critical care decision-making (Billings, 2011) was evident in the nurses’ definition of patient advocacy. This is supported by the findings of a systematic review by Frost et al (2011), where they highlighted the complexity of decision-making process in critical care, and underscored the role of good communication, deliberation and information exchange among nurses and family members.
The result is also supported by Yolanda (2014)’s assertion; communication within the critical care setting becomes even more challenging during decision-making regarding treatment options. In many of these instances, health professionals turn to family members, as surrogate decision makers for their critically ill loved one (Yolanda, 2014). Yet, for many family members, Frost et al (2011) observed that decision-making could be filled with anxiety and negative emotions, particularly if the families do not know the wishes of the patient.

An editorial by Munroe and Savel (2013) revealed that communication with patients’ family, and among healthcare providers is now recognized as a key component of end-of-life care. Moreover, findings of a study by Truog, Campbell and Curtis (2008) affirmed that family satisfaction improved and psychological distress decreased when critical care clinicians utilized communication skills that inform and support patients and their families.

Foley, Minick and Kee (2002) found nurses defining patient advocacy as truly listening to the patient and acting as patients’ voice. Similarly, O’Connor and Kelly (2005) stated that nurses felt that by providing communication they were bridging the gap between patients and other healthcare providers in the healthcare environment. These observations support the findings of this review where nurses’ described advocacy as truly listening to patients and their family (Arbour and Wiegand, 2013).

In a qualitative study by Nelson, Puntillo and Pronovost (2010), shared definition of advocacy and high-quality intensive care among respondents (nurses, patients and family) included clear, compassionate and timely communication. This is in support of the findings of this study where nurses perceived communication as an important aspect of patient advocacy.

Providing protection and “doing” were also recurrent emerging themes. These themes were found to be interrelating. According to the nurses, providing protection for patients included maintaining privacy and confidentiality, protection from harm, fighting for patient’s right and autonomy, and maintaining patients’ dignity. With regards to “doing”, nurses referred to patient advocacy as helping, intervening, and assisting the patient to the best outcome.

These descriptions of patient advocacy are supported by findings from a study by McCallum and McConigley (2013), where they concluded that patient advocacy involves protecting patients’ privacy, which is essential in upholding patient dignity. Likewise, Beauchamp and Childress (2001) confirmed that patient advocacy involves active support of autonomy, privacy and the maintenance of patient’s dignity. However, Espinosa et al (2008) argued that upholding these ethical principles in the critical care setting could be challenging. Advocacy does not only protect but, contributes positively to the practice of self-determinism (Gadow, 1990). The practice of self-determinism includes the right to accept or refuse treatment (Beauchamp and Childress, 2001). Curtin (1979) takes a similar perspective, which she calls human advocacy. According to Curtin (1979) human advocacy is the basis of the nurse-patient relationship. The nurse expresses advocacy by creating an environment that is open and supportive to decision making (Mallik, 1997).

When patients are able to communicate their preferences and possess autonomy, the definitions of advocacy by Curtin and Gadow are clear. Nevertheless, in the critical care setting where patients may be unable to communicate, disempowered or incapacitated as a result of the disease condition, they are unable to practice autonomy, and thus the descriptions of advocacy by Gadow and Curtin may not hold. In some cases, nurses may not know the patients’ wishes and may not have family members who can act as surrogates for them. In cases such as this, nurses may need to act in the patients’ best interests, which inadvertently can move advocacy into medical paternalism (Iedema et al, 2005).

According to Kohnke (1982)’s definition of advocacy, the nurse supplies the patient with the information needed to make an informed decision, however, the nurse has the right to choose whether to advocate by revealing the most recent and accurate information. The nurse must decide whether to support the patient’s decisions when the nurse feels that the patient has made the right decision (advocacy) and must desist from rescuing the patient when the nurse considers that the patient has made the right decision (Paternalism) (Kohnke, 1982). However, it has been argued that when nurses rescue persons by guiding their decision-making, they are denying the person’s rights.
and autonomy, and promoting heteronomy (Valente, 2004). Thus, nurses must be aware of when they are supporting or rescuing the patient and apply the principles of beneficence and autonomy in both.

Hewitt (2002) reported in his study that participants had moved beyond descriptions of advocacy and had developed a view of patient advocacy that was based on their philosophy of professional practice; however, this was not found in the present review.

Theme 2: Understanding and experiences of critical care nurses regarding patient advocacy

Many nurses described their understanding and experiences (knowledge) of advocacy as providing holistic care, comfort and caring, the experience of ethically difficult care situation, and communication. These themes incorporated and overlapped the themes identified in the nurses’ definition of patient advocacy. However, these themes emerged in the context of the nurses’ experiences and understanding of patient advocacy. Concerning communication, Critical care nurses shared their understanding of patient advocacy as the patient knowing their prognosis, having been involved in discussions and decisions about their care, and being comfortable and pain free (Sorensen and Iedema, 2007).

Several researchers (Beckstrand and Kirchhoff, 2005; Bratcher, 2010) have reported that a clear understanding of patient prognosis and what life-saving measures entail helps the patient and family members to make an informed decision on treatment options, including advanced care planning. This assertion supports the results of this review.

Other researchers (Puntillo and McAdam, 2006; Beckstrand, Callister and Kirchhoff, 2006) have stressed that open channels of communication among healthcare personnel will improve patient care, with team members working towards achieving the same goal. According to Beckstrand, Callister and Kirchhoff, (2006), for improved communication to occur, a change in critical care culture must be attained. The realization that curative care and end-of-life care can co-exist in the critical care setting can lead to improved communication among all professional groups (McCallum and McConigley, 2013). The findings of this review support these observations, where nurses emphasized the importance of effective communication among healthcare teams, and its influence on patient care.

The need for advocacy often occurs in the critical care setting, where clinicians are confronted with ethically difficult care situations (McSteen and Peden-McAlpine, 2006). Nurses in this review reported the experience of ethically difficult care situations involving care of the dying. As previously stated, this situation becomes even more challenging when the patient is not able to make healthcare decisions. Gadow (1980) confirmed that when patients with cancer were faced with extremely difficult decisions that had to do with quality versus quantity of life, it was the nurse who was in a position to explain the treatment objectives, and clinical information that supplemented the subjective, personal information that only the patient could give. According to Gadow (1980), patients may conform if they are inexperienced in making healthcare decisions and are given no assistance in developing their autonomy. The role of the nurse as an advocate therefore, is to overcome initial inequality by assisting patients to self-determinism, rather than conform out of inexperience or difference (McCallum and McConigley, 2013; McSteen and Peden-McAlpine, 2006)

Also, nurses’ accounts in this review integrated discussions of comfort and caring for patients, by offering a hand to hold, working late to stay with a patient and visiting a patient when they are discharged from the hospital (Sorensen and Iedema, 2007; Boyle, 2005). The results of previous studies (Foley, Minick and Kee, 2002; Snowball, 1996) support and are congruent with these themes.

Another theme that emerged from nurses’ accounts of their experiences is the provision of holistic care. The provision of holistic care integrated documenting patient’s wishes, helping patients to make advanced directives, and to make a choice for a power of attorney, and ensuring that the patient is comfortable and pain free. The nurses revealed that holistic care respects patients’ dignity in the critical care setting. Previous studies reported similar findings. Davis-Floyd (2001) revealed that holistic care respects human dignity. Tjale and Bruce (2007) emphasized that the relationship between the providers of health care and the patient is based on respect, relative openness, equality
and mutuality, and according to Olive (2003), patients participate in decision making in this kind of caring.

Providers of holistic care consider a patient as a whole within his/her environment and realize that a patient is made up of body, mind and spirit (Morgan and Yoder, 2012). Respecting patient’s role in the treatment process, having him/her take part in the process and encouraging self-care is another aspect of holistic care which was reported by nurses in this review. Thompson et al (2008) reported that holistic care leads to therapeutic relationship, hope, dignity, self-discipline, social growth, a sense of autonomy, vigour and vitality.

Theme 3: Critical care nurses’ role in patient advocacy in the critical care setting

Regarding the roles of critical care nurses in patient advocacy, the themes that emerged were overlapping and interrelated, including protection, acting as a liaison between family and the healthcare team, acting as a guide, acting to support the meaning of the illness to the patient and family, collaboration, and helping (Boyle, 2005; McSteen and Peden-McAlpine, 2006; Arbour and Wiegand, 2013).

Acting as a guide occurred during times of transition for the patient and family and included educating patients and family about the disease, teaching specific skills, and clarifying information and options (McSteen and Peden-McAlpine, 2006). It also consisted of reflecting observations and assumptions about their situation and care back to the patients (Boyle, 2005). Acting as a liaison between the healthcare team and the family included involving the various individuals and healthcare personnel involved in the care of the patient (McSteen and Peden-McAlpine, 2006; Arbour and Wiegand, 2013). Nurses saw themselves, as a vital link that served to ensure that all involved parties understood the goals and plan of care for the patient.

The nurses also spoke of their role as acting to support the meaning of the illness to the patient and family (McSteen and Peden-McAlpine, 2006). Perhaps this is one of the most challenging and significant components of patient advocacy for the nurses. This role requires that the nurse advocate set aside their own values, agenda and priorities and act to affirm the decisions and choices that has been made by the patient and family according to their own goals, values and priorities (Melia, 2001). According to Bishop (2003), this role requires that the nurse be open and empathetic to divergent perspectives. Thus, as previously discussed, the nurse must be able to balance the competing ethical values of autonomy and beneficence to “do good for the patient” (Godkin and Markwell, 2003) since choices that patients make for themselves are sometimes in conflict with the nurses’ vision of what is best for the patient. This finding is also supported by the work of Parker-Oliver (2002), who established that palliative and hospice care allows dying patients to attach meaning to their lives so as to give value to their unique experiences.

The nurses’ role as advocates also required that the nurse acknowledge the significance of the meaning of the illness, and the death for the family (McSteen and Peden-McAlpine, 2006; Arbour and Wiegand, 2013; Boyle, 2005). This finding is supported by the assertion of hospice pioneer, Saunders (1989), “How people die remains in the memories of those who live on”. As a person experiences terminal illness, the nurse advocate acts as a supporter to offer much-needed comfort and reassurance to the family members as they try to make sense of their impending loss and a future without their loved one (McSteen and Peden-McAlpine, 2006).

The advocacy role of the nurse has been impeded by little practical guidance provided on how this role should be interpreted in clinical practice (Vaartio and Leino-Kilpi, 2004). According to Hyland (2002), the dependent or semi-dependent nature of many patients in the critical care setting puts a demand on the nurse to shoulder the role of a patient advocate. Though a number of authors (Sorensen and Iedema, 2007; Kilbi, 2012; Tan et al, 2006) have expressed their reservations about the suitability of nurses to act as patient advocates, Hewitt (2002); Lindahl and Sandman (1998) argued that the nurse has a moral duty to protect patients’ rights and autonomy, which according to them, includes acting as a guide and a liaison between the healthcare team and the patient, and to create holistic approaches to care. However, according to Breeding and Turner (2002), this may be seen as
a lower priority for critical care nurses, who have their focus on surviving the shift, thereby exposing patients to as few risks as feasibly possible.

Lindahl and Sandman (1998) concluded that, in order to promote the patient advocacy role; health professionals need to hand over power to the patient, which can be achieved through theory and practice.

**Theme 4: Barriers to encouraging advocacy in the critical care setting**

External and internal limits, Conflict between the professional groups, powerlessness, intimidation, ineffective collaboration, and destructive physician behaviour were all identified as barriers that affected the nurses’ ability to act as patient advocates (Sorensen and Iedema, 2007; Kimes, Davis and Bishop, 2015).

External factors as barriers to patient advocacy role included the economic imperative of conserving scarce resources, the primacy of medical authority to treat and conflicts between medical and nursing clinicians about patient management decisions. Barriers identified to be internal to the nursing profession included the lack of operational autonomy that would allow nurses to contribute their assessments of the non-medical status of the patient in terms of likely outcomes, and the lack of organizational authority to formally structure nursing knowledge and practice into patient care decisions (Sorenson and Iedema, 2007). These findings are supported by the work of Willard (1996), who reported of hierarchical structures within the United Kingdom’s National Health Service (NHS), which limits the nurses’ ability to advocate.

In this review, conflict especially arose between the nurse and the physician during an advocacy activity by the nurse. Consequently, nurses resorted to “hiding” information about patient care from doctors so as to avoid being shunned, which negatively impacted on patients’ care (Kimes, Davis and Bishop, 2015).

For nurses to be effective at advocating for patients, they will need to discover ways to challenge decisions based on conventional medical authority, including those that rely on false economic grounds to limit treatment, and those that support continuation of aggressive treatments that disallows time for discussion, disclosure and support, through which patients and families make psychological transitions from the hope of survival to the awareness and acceptance of imminent death (Iedema et al, 2005).

In this review, nurses struggled with the moral and ethical concerns of providing aggressive medical interventions to prolong life when it seemed futile (Sorensen and Iedema, 2007; Kimes, Davis and Bishop, 2015). Treatment options that prolong death have previously been reported to be a major cause of distress to nurses and to cause conflict among professional groups in the critical care setting (Oberle and Hughes, 2001; Nordgren and Olsson, 2004; Beckstrand, Callister and Kirchhoff, 2006).

Although it is the intention of both nurses and physicians to improve the care of the critically ill, this seems to occur more in hypothetical terms (Tschannen et al, 2011), and as it relates to each profession’s opinion of good patient outcomes, instead of being carried through into practice (Sorensen and Iedema, 2007). In this review, rules were explicit in the critical care units as to who speaks to whom, how decisions were made and who makes them (Kimes, Davis and Bishop, 2015; Sorensen and Iedema, 2007). Consequently, the quality of nurses’ interaction with physicians and patients, and their ability to act as patient advocates was organized into continuing interactions of power and domination (Kimes, Davis and Bishop, 2015). Sorensen and Iedema (2007) argued that this resulted in the powerlessness of nurses to advocate for individual patient’s rights and values, and the powerlessness of the nursing profession to advocate for its own rights and values.

Nevertheless, despite the fact that nurses repeatedly mentioned physicians’ attitudes as the chief barrier to a patient advocacy role, nurses themselves did not involve each other to confront destructive behaviour, to form coalitions with like-minded health professionals, or to devise and advocate alternate means of interaction. Nurses rather shied away from observing the actions and values of other nurses as responsible healthcare professionals, including the ways in which their
perceived powerlessness is reproduced in their encounters with doctors and the impact that this has on patient outcomes.

By its very nature, patient advocacy in the critical care setting triggers dissimilarities of belief concerning patients’ best interests that may challenge power relations among health professionals. It is necessary to resolve such variations; where they are left unresolved, they could worsen or instigate conflict to the disadvantage of patients and the health personnel who treat them (Breeding and Turner, 2002).

Contrary to the results of this study, however, some nurses have recognized the nature of conflict as positive, integral and an expected part of advocacy rather than an obstacle (Ahern et al, 2002).

7. Conclusions

Nurses are the major group of healthcare professionals (Robeznieks, 2015), which places them in a unique position as patient advocates (Hanks, 2008). This systematic review explored critical care nurses’ definition, understanding, experiences, and roles as patient advocates, as well as the barriers they face during an advocacy role in the critical care setting.

The unique environment of the critical care setting has influenced the development of the nursing role as a patient advocate, ensuring that a recovery or a good death can be achieved (Boyle, 2005; Sorensen and Iedema, 2007). Acting as a protector, a guide, a liaison between the family and the healthcare team, and acting to support the meaning of the illness to the patient and family, is pivotal in maintaining the dignity of a critically ill patient.

Nurses in the critical care setting endeavour to provide excellent care notwithstanding environmental, organizational and professional barriers. For critical care nurses to be effective advocates, there must be improved working relationship between professional groups, support, and collaboration. Moreover, nurses must be empowered to be able to give power to patients and family (Kimes, Davis and Bishop, 2015).

The study findings reveal that critical care nurses perceive patient advocacy as communicating with patient and family, protecting patients, helping (doing) patients and family, and providing comfort and caring for their patients, which they feel satisfied doing them. Evidence shows that supporting the development of strong nursing advocacy skills has the potential for a positive impact on nurses’ satisfaction, which will eventually impact positively on patient care (Walwrath, Dang and Nyberg, 2010).

Perhaps the best indicator for determining a strong patient advocate is the satisfaction level of patients and their family (Sorensen and Iedema, 2007). Critically ill patients and their families deserve no less than someone who will guide them in their search for needed information, represent their stated desires and care objectives to other healthcare team members, and support them through the disease process (Hewitt, 2002). Strong patient advocates ensure that patients are comfortable and secured, with their dignity intact and their values respected (McSteen and Peden-McAlpine, 2006).

The researcher contends that nurses partake in the politics of emancipation in order to change the rules of workplace interaction to include nurses’ voices in choices that affect them and their patients through a strengthened professional power base, improved critical care expertise and a rejuvenated and politicized organizational effectiveness, which may bring to bear both internal and external influences. Combined within a multidisciplinary model of care, nursing knowledge and medical knowledge can collectively tackle the seemingly conflicting pressures inherent in patient advocacy within the critical care setting.

Additional research and systematic reviews should be done, using primary studies from different countries such as the United Kingdom and Canada. It is unknown how nurses working in settings such as the paediatric intensive care unit, psychiatry, and obstetrics/gynaecological units perceive patient advocacy (Vaartio et al, 2006). Future investigations may explore these areas and possibly compare the differences in patient advocacy role and experiences, if any.

Authors’ contribution: EA Kumah developed the review protocol as well as the search strategy. She also drafted the final review manuscript; P Boadu was involved in the first and second screening of papers, as well as data
extraction and synthesis. He also contributed to drafting the final manuscript; R Duncan resolved disagreements between reviewers and contributed to drafting the final manuscript.

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