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"BE MY VOICE" PLACED ON AUGMENTATIVE AND ALTERNATIVE COMMUNICATION DEVICE

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ABSTRACT

Several studies revealed that patients who are undergoing invasive mechanical ventilation (IMV) reported psycho-emotional distress, as they are not able to speak or to communicate their needs. Invasive mechanically ventilated patients want to be heard, to have control over their treatment. Using technology at the bedside can play a significant role in making this realism. Thus, the authors of this study designed an electronic augmentative and alternative communication (AAC) application that includes Arabic messages supported with picture format. The electronic AAC is supposed to be used in communication with Arabic only language oriented patients when they speechless.

***KEYWORDS*:** *Communication, Critical Care, Invasive Mechanical Ventilation, Communication Strategies, Intensive Care Unit*

Article History

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INTRODUCTION

Background

Invasive mechanically-ventilated (IMV) patients suffer from communication barrier due to the presence of an endotracheal tube (ETT) or tracheostomy tube, which makes them unable to communicate through speech. Therefore, they try to use different communication methods such as head nods, spoken words, gestures, and writing [1]. Most of IMV patients have experienced moderate to high level of frustration while communicating their needs [2]. When the health care providers use communication strategies such as eyes blinking with IMV patients, communication can be extremely annoying because the patient may be directed by one staff member to blink once for "yes" and blink twice for "no" while another staff member may hint the patient otherwise. As a result, the inaccurate, inefficient and profoundly improper message exchange would occur [3].

Invasive mechanically-ventilated patients' communication abilities could be enhanced by augmentative and alternative communication (AAC) that is considered as a vehicle to increase the efficiency and reduce the stress of communication. The American Speech Language Hearing Association [4] defines augmentative and alternative communication (AAC) as the means of communication when oral speech cannot be achieved. Augmentative and alternative communication has been used since 1973 to support communication skills through providing a mode for sending or receive messages in children whose speech comprehension skills may be limited [5]. There is a wide range of

communication aids from basic to high technology, but the selection of the most effective, efficient and safe method is based on the patient's clinical condition.

Each day the number of Arabic speakers is increasing, now there are over 290 million native Arabic speakers. And the total of Arabic speakers is over 400 million [6]. Arabic is the official language in twenty-two countries spanning Northwest Africa to Southwest Asia that includes Algeria, Bahrain, Comoros, Chad, Djibouti, Egypt, Eritrea, Iraq, Jordan, Kuwait, Lebanon, Libya, Mauritania, Morocco, Oman, Palestinian National Authority, Qatar, Western Sahara, Saudi Arabia, Sudan, Syria, Tunisia, United Arab Emirates, and Yemen. However, there is a low number of Arabic AAC to be used with Arabic-only oriented patients.

Study Purpose

The purpose of this study is to examine the intensive care unit nurses' experiences using an internet application named "Be My Voice" associated with augmentative and alternative communication assistive device during communication with invasive mechanical ventilated patients.

Significance of the Study

Sharing information between nurses and patients is an integral part of care. Communication with IMV patients can be quite challenging, especially for nurses who are interacting with patients not only for therapeutic reasons, but also for better understanding of patients' needs [6]. Most of the studies had little use of assistive communication devices or materials, the outcomes of using AAC with IMV patient were not adequately empirically tested [2]. The communication barrier is the most reported distressing problem for IMV patients in ICU setting [1]. According to Karlsson [8], not being understood was significantly upsetting since it meant not being recognized as a person. Thus, no patient should be treated without acknowledgment of his or her uniqueness or without care of his or her needs and wishes.

The authors of this study designed internet application named "Be My Voice" in Arabic phrases and integrated picture format associated with the AAC that was installed in a 10-inch touchscreen tablet personal computer. "Be My Voice" is used for patient symptom communication, basic and social needs communication to enhance the patients' ability to communicate properly and efficiently. It is equipped with an Arabic keyboard to facilitate written communication and also contains a pain intensity scale to assess pain severity as well as an anxiety scale (consisting of a collection of different facial expressions) to assess anxiety levels. Assessing the usability of "Be My Voice" by IMV patients may provide administrators and policy makers with valuable information regarding the future needs in the field of patient-staff communication strategies. Evaluation of "Be My Voice" is essential for assessment of its accuracy, usability and acceptability which may help researchers design communication devices that are user-friendly to fulfill patient's needs. Further evaluation of AAC is essential in determining whether patients' needs are met or not from the patient perspective.

LITERATURE REVIEW

Nurse and Patient Communication in ICU

Intensive care unit nurses and patient interaction study reported that nurse-patient interaction was typically less than one minute in length per interaction [1]. The time of nurse-patient interaction indicates the imperative need for nurses to communicate effectively with patients for optimum care and positive patient outcomes. Alasad [9] study about patients'

experiences in the ICU showed that 64% of patients wished they knew more about their health status progress, which reflects that the majority of IMV patient communication with nurses was directed towards informing them procedures rather than providing an explanation of their health conditiSon.

The importance of providing communication channels for patients in the ICU is well-documented [2]. For example, effective communication improves patient recovery through enhancing a sense of safety and security, and it might decrease the length of stay in ICU [10]. Effective communication is considered as an important vehicle to convey physiological and psychological needs, plan of care, and end of life decisions [3]. Thus, there is a need for a standardized and easy or simple communication tool to reflect the ICU patient needs, especially for IMV patients who are unable to speak.

Alternative Communication

Many health conditions indicate the use of AAC such as post-stroke patients with aphasia and patients who have been diagnosed with a degenerative motor neuron disease, head injury and dementia [11]. Patients require using AAC devices when they are intubated or have a tracheostomy tube while under mechanical ventilation [2]. Augmentative and alternative communication systems are classified as either aided or unaided. The unaided AAC systems are those in which the physical functioning of the body is used as a means to communicate, for example by gesturing, pointing, or another body language [4]. Aided alternative communication systems are either electronic or non-electronic and are used to send and receive messages [4]. This may include the use of low-technology aids that do not need electronic programming. Low technology AAC includes books, boards, cards and visual support systems. Low technology AAC uses pictures, alphabets, and phrases based on communication tools to facilitate nonverbal patient communication with health care providers. The advantages of using high-technology aids are many such as permitting storage and retrieval of the electronic message and allowing a speech-generating device. Multiple AAC systems may be used in ICUs, depending on the patient's physical and cognitive status [12].

As noted before, there are different communication tools and interventions that can be used when verbal speech cannot be achieved. Overall, "Be my Voice" application has some advantages by using both Arabic phrases and picture-format icons to help all IMV patients to communicate their needs besides using full-screen pictures with audible messages when the patient touches the specific icon. In addition, once the patient can't find his/her required message, he/she can typewrite their message using tablet keyboards as in figure1.

Figure 1: Opening Screen

Be My Voice

The software named “Be My Voice” associated with the AAC was integrated in to a 10-inch, touch-screen tablet personal computer. ”Be My Voice” was developed for use on an Android-based tablet and iPhone-based iPad. Since a specialist is necessary for programming the application before use, a professional computer programmer was hired to install the application in an Android tablet and iPad. The software application called “Be My Voice” was developed based on literature with input from a group of experts in critical care and speech-language pathology. “Be My Voice” is programmed from both nurses’ and patients’ perspectives. It combines what the nurses say they want to know (obtained from the literature) and what the patient’s state they need (obtained from the literature) [13]. ”Be My Voice” content validity was tested by three-speech language pathologists. The experts were requested to rank each icon in the application for clarity, representativeness and relevancy from 1 to 5 according to Extremely (5), Very (4), Moderately (3), Slightly (2), and Not at all (1). The experts’ responses were fedback to the researcher in order to analyze the results. The results of the analysis were reported by the researcher to the experts who participated in this survey to ensure the content validity of the application icons. Necessary changes were made before setting up the application on Android-based tablet, which includes altering colors, increasing font size and removing one icon, considering cultural sensitivity issue. Based on ICU nurses’ survey about their experiences with IMV, the researchers asked ICU nurses to rank the application icons from 1 to 10 according to the frequency of requested needs or symptoms that IMV asked for. Thus, the most frequent needs or symptoms are moved to the top of the menu for easy and quick selection by IMV patients.

The patient needs and symptoms are categorized under two icons named (I want, I feel), whereas the patient’s want to be visited by someone is named (I want to see), and once the patient wants to type a message, he/she can choose (I want to write). As they enter what they want, the program offers suggestions of clustered needs or symptoms that they may be trying to share with others. When the sentence is complete, the application will present the message as an audiovisual presentation to have the sentence read aloud in order to confirm the required message. Lastly, a function was added so that the researcher can download the user’s selections for analysis purposes.

The functions were chosen based on common IMV patients’ reported needs that include basic physiological needs such as eating and drinking, as well as psychological needs [13]. Moreover, they display the need for nursing care (suctioning, positioning, and bathing) shown in Figure 2 and the patients’ spiritual needs to see their religious man, and their social needs, for example, to see their family, shown in Figure 3. Other functions can be used to report IMV patients’ subjective symptoms such as dyspnea, feeling cold or hot, and fatigue shown in Figure 4.

Figure 2: Patient Wants Screen

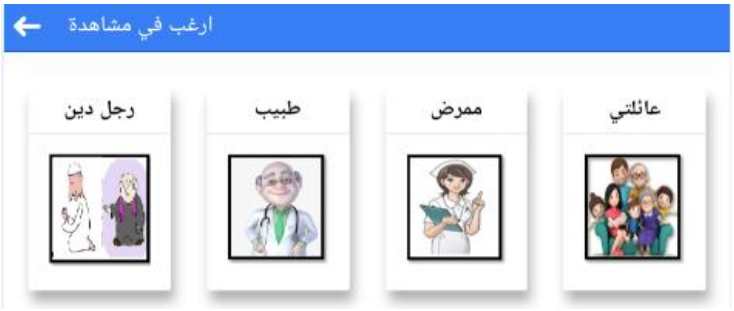

Figure 3: Patient Social and Spiritual Needs Screen

Figure 4: Patient Symptoms Screen

METHODOLOGY

Sample

Data was collected using semi-structured focus group interviews with ICU nurses. The interview was typically initiated through general question that the participants can answer easily; following this, the researcher proceeded with more difficult and sensitive questions according to the interview study guide. The length of each interview spans for 60 minutes for each focus group. All interviews were tape recorded and later transcribed in verbatim. The researcher served as moderator and recorder for each focus group. Thus, the researcher facilitates the group discussion without leading it. Three face-to-face interviews were conducted. Five registered nurses from each hospital were recruited to explore nurses' knowledge, skills, and perceptions as well as the barriers and needs during communication with ventilated patients according to the interview study guide.

Data Analysis

The purpose of qualitative analysis is to give meaning to data. Data analysis begins simultaneously with data collection. The process of analysis is dynamic and creative process [14]. The analysis includes conceptualization and conceptual ordering by identifying categories of events along explicitly stated dimensions. Afterwards, themes were developed from the analyzed data through reading and re-reading the texts several times.

RESULTS

Different Communication Strategies with IMV Patients

Intensive care nurses reported using different communication strategies with IMV patients in order to grasp their needs. Most of nurses reported using lips reading, body language, paper and pen writing. One nurse reported questing what the patient need through “we asked the patient are you in pain, do you need wate etc.” trying to find what the patient want, then the patient can answer by” yes or no” using their body language. One ICU nurse said that he used the patient family member to help him to find what IMV patient need was as he said: “families understand their patient better than us”. At the same time, a large number of ICU nurses reported that the above-mentioned traditional communication methods were “"عقيم as it take a long time and huge efforts finding what the IMV patient want to say. On other hand, it can result in inaccurate message revived by ICU nurses.

No Single AAC Tool Fit All

Considering the diversity of IMV patients’ cognitive, sensory and motor abilities, ICU nurse should be a resource person who select the appropriate communication strategy to communicate with IMV patient. There is a wide range of AAC devices, but the usage of any AAC device should be based communicative competence of IMV patient. The ICU nurses reported many patient psychological factors affect patient communicative competence regarding high technology AAC devices; firstly, motivation to communicate as one nurse mentioned: “the most important issue is the IMV patient desire to communicate with us”. The second factor, the IMV patient capacity to recover from communication barrier and failure which can be named as resilience that is mentioned in one nurse note” IMV patient acceptance to their situation and desire to overcome their condition is key factor to overcome their communication barrier”. The third factor is IMV patient attitude toward technology AAC device whether it is positive (Techophilia) or negative (Technophobia).

Technophobia and Techophilia

Technophobia (rejection of technology) and technophilia (attraction to technology) are two extremes of the relationship between human being and technology. Intensive care nurses mentioned technophobia as one barrier that affect the AAC Tab usage during the study especially with elderly patient as one ICU nurse report “most of elderly patient refuse to use the Tab “.However, the idea about technophobia affects only the elderly people has been disproved since a long time ago [15].On the other hand, some ICU nurses think that most of people nowadays are familiar with new technology, as technology is everywhere in life especially with the use of smart phones, so the ICU nurses report that IMV patients who are familiar with new technology prefer to use AAC Tab to assist them in communication during MV period, as one ICU nurse report’ before, I used the AAC Tab with my patient, I had one patient who bring his smart phone to write a message for us to understand his needs during IMV period”.

Be My Voice Enhance Time Management

Time management in a patient with complex needs and life threatening situations is demanding aspect of critical care nursing as one ICU nurse mentioned: “ what the patient need is just to touch the icon, then easily we can know what he want”. Thus, many ICU nurses mentioned that Be My Voice improve the quality of nursing care in ICU, using the time saved for guessing what are the patient needs to fill full that needs that are easily identified using Be My Voice application. One ICU nurse mentioned that “using Be My Voice help me to assess the patient pain by giving full description of pain

then I asked the doctor for order a pain medication then the patient sleep ". Other ICU nurse mentioned that they prefer that if this application is connected to a patient monitor so, he can know his patients need as soon as possible when the patient touch the needed icon.

Be My Voice Can Tell What We Can't Know

One of ICU nurses reported that he considered that his patient was not conscious, but once he used the AAC application the patient start active conservation with him, he claimed that "the application can tell about our patient what we can't tell, I know my patient level of consciousness using the application while previously I think my patient is not oriented ". Other nurse mentioned that some IMV patients especially post road traffic accident patients admitted to ICU and being intubated for a period of time, when they become awake it is very difficult to explain what happened with them, at this time using AAC application can make explanation to their situation, where they are, and the need for IMV easier.

Barriers that Affects Be My Voice Application Usage

Intensive care unit nurses mentioned some barriers that affect Be My Voice application usage, which can be classified to patient related factors or environmental related factors. Examples of patient related factors are elderly patient, low educational levels and muscle weakness condition and patient with hearing or vision loss. One ICU nurse reported that patient culture, language and accent can interfere with AAC use especially for non-Jordanian patients such as Yamani or Sudan patients. Other ICU nurse mentioned that IMV patients with long term sedation they became confused which make it impossible to communicate with them. In addition, one ICU nurse add that patient families may become anxious using computer tab with their patient "they worry that we take photo or video for their patient" as he suggested to take informed consent for each patient before using such device.

Environmental related factors include low availability of AAC devices, low public awareness of IMV patient's rights and no funding for AAC technology and services as one nurse mentioned" Before we use Be My Voice, I found a similar application in my mobile. And, once I tried to use it they asked me to pay for installment of that application". The nurses' role to work on modifiable barriers such as advocacy for policies that enhance communication with IMV patients and ensure the availability of wide range AAC devices. In addition, to the nurse role as a teacher to increase patient and public awareness about IMV patients' rights especially their rights to make decision about their treatment plan. On other hand, one ICU nurse highlighted that ICU environment is noisy environment with a lot of alarms from monitors, pumps and machines. As he add that because of noisy ICU room patient can't hear the application audible message then he suggested to increase the volume sound or to use head set for better device use.

Giving them Voice Once they Become Voiceless

Intensive care unit nurses agreed that communication with IMV patient is basic human right as one nurse said" when you talk to IMV patient this mean you deal with him as human not a machine". On another hand, finding appropriate communication strategy with IMV patient is IMV patients' families reported priority that is mentioned by one nurse" once we explained to our patient's families that their patient will not be able to speak due to IMV, they asked so how we can know what he want". Thus, ICU nurses' advocacy role is required to ensure hospital policies that support access and wide range of AAC devices. As most of ICU nurses reported using traditional ways to communicate with their patients such as; yes or no question based on guessing what patient need or patients hand movement or writing. One nurse add "communication with IMV patient made patient feel better, he will become more oriented about what we

did and more comfortable and cooperative with our nursing care". In the other side, one ICU nurse reported his experience that when he use yes or no question during communication with IMV patient resulted in misunderstanding of what patient want to express which leads to patient became anxious and try to remove the ETT and at the end the nurse need to restrain the patient.

DISCUSSIONS

Although there are many benefits of increased acceptance of high technology AAC, the diversity of AAC application raised the priority towards improving the design of AAC applications that don't need excessive operational demands e.g. double click, multiple touch screen in order to facilitate its use. Thus, the development of culturally competent, friendly use application named BE My Voice by multidisciplinary team with experts feedback in speech language pathology is an innovation in this study. At the same time, BE My Voice application needs further evaluation from end-users who are IMV patient who can be met post removing IMV to take their feedback about Be My Voice application.

Technophobia is described as the 'abnormal fear or anxiety about the effects of advanced technology', affecting one third of the population, causing health problems and the inability to work efficiently [16]. Computer phobia as an example about technophobia is a complex relationship of cognitive, behavioral and emotional components. Technophobic behaviors range from negative emotions and fear to excessive fear and avoidance attitudes toward technology. In studies about technophobia relating to both age and gender, there is clearly no consensus that technophobic people do not have particular demographics [17]. However, many nurses in the focus group reported that the elderly patients in the study refuse to use the application because it is integrated in computer Tab.

Findings from this study support further research aimed at investigating the efficacy of "Be My Voice" application from patients' perspectives regarding the ease of communication and fulfillment of patients' needs. Additional research is also required, to further examine how using "Be My Voice" application assist pain and anxiety management among IMV patients. On another hand, future studies are recommended to compare the effect of high technology AAC devices versus low technology AAC on patient outcomes. The current findings are considered as a baseline for future studies, which includes other variables and different assessment methods.

CONCLUSIONS

There are many problems associated with IMV patient's inability to speak. However, the literature lacks the quantitative data on the volume of these problems. Studies on nurse-patient interaction have shown that nurses communicate minimally with IMV patients. The literature addresses the lack of using AAC systems in the ICU. Moreover, research on examining protocols about current practice for AAC use in the ICU is still deficient. Thus, the development of this application named "Be My Voice" in Arabic" كن صوتي associated with the AAC and integrated in a 10-inch, touch-screen can be considered as a user-friendly application to be used with Arabic patients who are unable to speak due to being connected to the mechanical ventilator. The researcher recommends that future studies evaluate "Be My Voice" from the patients' point of view to make the appropriate modifications based on end users feedback.

Summary of Key Points

Invasive mechanically ventilated patients want to be heard, to have control over their treatment and to contribute to decisions about their health.

Communication in all areas of care is vital, especially when the patients become suddenly speechless.

There is a need for the establishment of effective nurse-patient communication strategy, using technology at the bedside can play a significant role in making this realism.

Conflicts of Interest

Authors declared no conflicts of interest.

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