

An Essence of Authentic Presence as a Means of Caring for Children with Tetralogy of Fallot After Surgical Repair

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Abstract:- Nurses have the as duty to care for children especially those who are to be operated. Children living with tetralogy of Fallot, TOF, fall within this group of people as the key approach to its management is geared towards surgical correction. Therefore, postoperatively, the children need special care and one of them is just by being there so as to carry out the required therapeutic observations like hemodynamic monitoring, arterial blood gases evaluations, medication controls, and others as detected by the heart monitor or ventilator. The study was aimed at identifying the specific caring behaviors shown by the nurses towards children with a surgically corrected tetralogy of Fallot from their virtue of being fully present at the bedside of the child. This was a quantitative descriptive study in which data was collected from 303 nurses using a convenient sampling technique through questionnaires. Data was analyzed using statistical package for social science, SPSS, version, 25. This results showed that by being with the child who has undergone TOF repair, nurses demonstrated caring behaviors that gratified biophysical, safety and security, and psychosocial health problems of the children.

Keywords:- Being, Caring behaviors, Tetralogy of Fallot.

I. INTRODUCTION

A normal heart is a muscular, four chambered organ that appears slightly to the left of the sternum within a space separating the two pleural cavities. The main function of this organ, if properly formed, is to pump blood throughout human body. In Wong's Nursing Care of Infants and Children, Hockenberry and Wilson (2015) affirmed that a normal heart should have two upper chambers or atria and two bottom chambers or ventricles that is separated by a special tissue, the septum, which divides the heart into the right and left side, such that mixture of the left and right blood is not allowed. Moreover, Lewis, Dirksen, Heitkemper, and Bucher (2014) attested that for a normal heart, blood enters the right atrium from the inferior and superior venae cavae and reaches the right ventricle where it gets into the lungs via the pulmonary arteries for oxygenation. The body needs purified or oxygenated blood that is received from the lungs via the pulmonary veins (Lewis, Dirksen, Heitkemper, & Bucher, 2014). However, either because of genetic, environment or idiopathic causes, a child's heart might be malformed, or either fall within the group of acyanotic or cyanotic cardiac defects regarding the blood pumping action of the heart and result in mixture of blood

Tetralogy of Fallot, TOF, is one of the common congenital cyanotic cardiac defects that accounts for about 3.5-8% per 10000 live births of all congenital defects in the world (Bygstad, Pedersen, Hjortdal, 2011; Tchoumi et al., 2011, Worku & Allen, 2020) and 10-26% of congenital

cardiac defects in Nigeria (Animasahun, Madise-Wobo, Omokhodion & Njokanma, 2015; Woldu, Arya, Bacha & Williams, 2014). Egbe, UppThe rate of TOF is not well stated in Cameroon, however, in an article published by Giamberti et al (2018), the percentage of TOF stood at 28.4%. Most authors accepted that this cardiac defect of Fallot, has four conditions including pulmonary outflow tract obstruction (stenosis or atresia), ventricular septal defect (VSD), overriding aorta, right ventricular (RV) hypertrophy (Twite, Behir, & Richard, 2012; Englert III, Gupta, Joury, & Shah, 2018; Knuf et al, 2010; Galvin & Ahern, 2013; Animasahun, Madise-Wobo, Omokhodion & Njokanma, 2015).

Tantcho Tchoumi et al (2011) conducted a retrospective study from January 2006-November 2009 that stated out of 51,636 patients who consulted in the three referral centers, 505 patients took part in the survey and presented with the following symptoms: cyanosis, clubbing, and frequent respiratory tract infections, failure to thrive, growth retardation, pericardial murmur, and dyspnea. Results of this study demonstrated that 67.2% patients were diagnosed with congenital heart disease. This confirmed the fact that occurrence of congenital heart disease in Cameroon is 9.87% (Tantchou Tchoumi & Butera, 2013). In addition, Tantchou Tchoumi et al (2011) added that in Douala, in the littoral region of Cameroon, when compared to Shisong of the north region of Cameroon, more children were diagnosed with the following: isolated ventricular septal defect, interatrial septal defect, and isolated pulmonary valve stenosis. However, the authors concluded that tetralogy of Fallot was detected in Shisong Cardiac Center, the only surgical cardiac center of the country.

Cameroon is a multicultural environment where TOF, for many indigenes, would either have natural or supernatural causes or origin (Momah, 2017; Brannen, 2005). Cardiovascular diseases present with sudden death syndrome. The above authors reiterated that most cultures stipulate that when a child is sick from chronic illness, the first consultation is typically done through the soothsayers, diviners, or traditional healers, which may take up to two weeks before they realize the importance of consulting with a healthcare setting. If this happens to a child that needed timely repair due to haemodynamic dysfunction because of shunting of deoxygenated blood, the child might die during his/her first

days of life.

Caring, from the general and basic point of view, can be defined by many dictionaries as being concerned about or to like to do, while to care for meant to many either as to nurse, attend or look after something or someone (Kang, 2005). In the same way, dictionaries from American Heritage (2018) origin added that caring could be defined as to feeling interested, or to give care such as for the sick child having a surgically corrected TOF. Moreover, care, as defined from Teutonic or old English (2010), was still considered as being anxious for or having concern for someone, meanwhile Middle English defined care as having a charge or duty, oversight of something, surveillance with a view to protection, preservation, or guidance (Skeat & Mayhew, 2014).

➤ *Problem Statement*

TOF is a structural cardiac defect and effective management is surgical correction but needs well equipped surgical cardiac centers and intensive care units with well trained staff. In North Africa many cardiac centers strive to meet the target like in Egypt, Ethiopia and other countries, but in West Africa, only Saint Elizabeth Catholic General Hospital in the North West region has put up a qualified structure. This leaves a handful of children with this condition to die suddenly or, if surgically intervened, to report with poor outcomes like right ventricular outflow tract obstruction, pulmonary regurgitation, and arrhythmia whereby surgical re-interventions might be needed. In most cases, surgical intervention involves ventriculotomy to insert a trans-annular patch, and transatrial-transpulmonary where cases of ventriculotomy are reduced (Van der Ven, Eva van den bosch, Bogers & Helbing 2019). The authors added that most recently, incomplete repair of TOF done by using a modified Blalock-Taussig, mBT, has become a current method used (Ngwezi, Vanderdonck, Levin, & Cilliers, 2013) to increase pulmonary flow and reduce hypoxemia in children living with TOF. However, as mentioned earlier, surgical outcomes for Africa are still very poor and need a better approach to care for these children post-operatively.

As humans, individuals are born to care about and to care for others (Alligood, 2014). When a human being is delivered, there is a relationship of inter-connectedness between the mother-child coupling, such that the child refuses

to be taken by others as he/she grows in a trusting relationship with his/her mother. Some women do extract breast milk and keep for their children or take an option of artificial breastfeeding. One could see the impact of this disconnectedness on these children as some of them fall sick, not because of artificial feed or feeding process but at times because of the absence of that moment of contact with the mother. This article does not in any way exclude other means of reinforcing mother-child bonding should there be no practice of exclusive breastfeeding.

Moreover, the nursing theorist, Jean Watson, considers a balance between science and caring as the basis of nursing profession. Watson's theory of human care draws the western and Eastern philosophies, the notion of human care as a moral concept. Human care process in nursing seeks to preserve humanity and the inner life of patients, and the theorists introduces caring and healing as the basic of education and clinical practice (Watson, 2012). Hence, many Caring Science scholars promulgate that an act of caring could be physical, such as bathing and feeding a child, and emotional care of monitoring feelings and relationships, such as tender touch, supportive task, empathy, and affection Alligood, 2014). However, during most clinical experience, the researcher noticed that this attention and maintenance of these relationships in professional health settings was lacking as television series, telephones, social distractions and technology have taken over these moments of caregiving and receiving such that the distance between nurse-client relationships are shortened.

A child with a surgically corrected tetralogy of Fallot is prone to developing serious complications if hemodynamic monitoring and basic attention is not given. Oubeidat, Abu-Abboud, Al-Duhoun, and Gheeshan (2008) proposed that effective service to patients in clinical nursing within the context of caring involve authentic presencing for enough time to be spent with them, talking in a dynamic interactive way, and being receptive and expressive. Watson and Horton-Deutsch (2018), Alligood (2018) and Heidegger's (Alba, 2009) place emphasis on the importance of being and having presence around a patient, as it permits the nurse to observe and become sensitive to patient needs (Kandula, 2019). This purpose of this article is to highlight the specific caring behaviors demonstrated by nurses towards children with a

surgically corrected tetralogy of Fallot post operatively by virtue of their being fully present.

II. METHODOLOGY APPROACH

➤ *Design*

A descriptive quantitative study was conducted using the frameworks of Watson's and Swanson's caring approaches. The caritas processes form the basis of some of the caring behaviors as demonstrated in the questionnaire, focus of which is rooted in a transpersonal caring relationship. Swanson views caring as a nurturing way of relating to a valued other toward whom one feels a personal sense of commitment and responsibility (Swanson, 1991, p. 165). This together with the component of caring as knowing, being with, doing, for, and enabling, made up great portion of the questionnaire that was used to collect data. Sensitivity to self is clearly important on the preparation of the nurse to care, while sensitivity to others refers to a way of being in relation to clients. The research was conducted at Aswan Heart Centre, Egypt with the view of identifying and describing the phenomenon of caring behaviors existing among the nurses. The information gathered about caring helped to theorize nurses through their socially existed state of their caring actions in response to the expressed needs of the children living with tetralogy of Fallot (Fortin & Gagnon, 2016). This study was geared towards working with the nurses to get information on how they have cared for the children with a surgically corrected TOF so as to model an approach of care for these children.

➤ *Ethical Consideration*

Permission was obtained from the president of the Aswan Heart Centre research team and from the national ethical clearance committee. Anonymity and confidentiality were respected, and the ethical aspect of non-beneficence was maintained with rigor. In addition, aseptic technique and respect to barrier measures were highly maintained given that this study took place in a Covid-19 potential risk zone. As concerned risk, inconveniences, and discomfort, the researcher considered that a child who has undergone surgical correction of TOF needed close attention from the health personnel especially during immediate postoperative periods. In order to minimize time wasting, questionnaires and interviews were only organised during off-days or during their

holidays. Therefore, there was no risk or inconveniences or discomfort as the child was not manipulated upon, information was read from the cardiac monitor and from the nurses. Concerning direct benefits, the health status of the participants shall be improved if he/she is the child living with TOF. Refusal to participate in this study is legitimate or allowed, even if after having accepted to participate he/she decides to withdraw without incurring consequences. Your participation in this study relies very much on a voluntary base, you are entirely free to participate or not to do so and to withdraw anytime with no prejudice and without giving explanations. All the information gotten began with respect to strict confidentiality within the limits provided by the law. After which presentation of participant identity was ensured by allocating anonymous code numbers. Verbal consent was gotten from the participants.

➤ *Participants*

The 303 nurses who answered the questionnaires were selected based on the selection criteria of nurses that were working in the Centre, especially in areas where they could or must have had contact with a child with TOF admitted either before or after surgical correction. Other criteria for inclusion considered was having an undergraduate degree and a diploma that attested that he/she must have concluded intensive care nursing training in the Heart Centre under the supervision of the educational department of the Centre. Excluded from the study were those nurses who have not yet completed the intensive care course work as organized the hospital and who did not yet complete their first degree program in nursing. This corresponded with the selection criteria that the participant under the study should have been recruited to work in the hospital and should have cared for children with TOF repair amongst the other surgically corrected children with the congenital heart malformations. The researcher had to work with the educational department together with the unit coordinators so as to select the respondents. The non-probability convenience sampling technique was defined considering all the nurses by the units, the criteria of inclusion and exclusion, and the availability of the nurses. Sample size was exhaustive as all the nurses who gave their consent were eligible for the study such that the phenomenon of caring for children with TOF should be well explored, though only 303 nurses returned the questionnaires. Five questionnaires from among the nurses who had not yet completed a bachelor's

degree and had received the questionnaires were not counted.

➤ *Data Instrument and Data Collection*

The caring data tool was adapted from a tool that was developed from the questionnaire constructed and applied by the Department of Health Sciences of Hongkong Polytechnic University (Watson, 2009). The researcher was inspired by the tool and carried out a prospective study to adapt it.

The items in this tool were based on the caring processes or concepts as applied in Watson's Theory of Human Caring and the central basic caring concepts of Swanson's Caring Model. The tool has 56 items under the headings knowing (10 items), being with (10 items), doing for (20 items), enabling or helping (10 items), and maintaining belief (six items). The participants were asked to rank their agreement on a four-point scale: 1-disagree, 2-tend to disagree, 3-tend to agree, and 4-to agree. Reliability of the tool was done using Cronbach's Alpha coefficient and the calculated value of the coefficient stood at 0.858, which was acceptable as it was above the minimum value of 0.7. The focus of this article is based on the caring behaviors demonstrated by the participants when being with the children who were admitted for a surgical correction of tetralogy of Fallot either before or after the repair.

The questionnaire was distributed very early to the nurses who worked night and were exchanging the shift and during break for those who were for the day shift. The researcher answered questions from the respondents as need be and gave them at least 48 hours to fill the questionnaires.

➤ *Data Analysis*

Data collected was analyzed using exploratory factor analysis, using Statistical Package for Social Sciences (SPSS) software, version 25, and presented in table 1 and figure 1.

III. RESULTS

The nurses who took part under the study were expected to answer the question of ranking their degree of agreement on the 10 items that was to determine how well each item could describe them and their work as a caring nurse through "being with" a child with Fallot. The items sort to find out how the nurses could assist in the gratification of biophysical

needs of the child under the following areas: follow-up lasix (furosemide) administration as ordered, measure intake and output regularly, to respect the point of instant laboratory investigations of blood gases and electrolytes and maintaining air patency via head of bed elevation at 30°; assist in maintaining safety and security for the child in the areas of removing the catheter as need be, as well as observe to disconnect the tubes and lines and to be authentically present

besides the child to maintain constant hemodynamic monitoring. The results were presented in table 1 as shown below.

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Table

1 Caring behaviors of nurses based on the concept of “being there”

	I observe for signs and symptoms of Junctional	I check for scheduled furosemide or lasilix	I observe the central line (s) regularly	I observe the catheter outlets with the mind to	I remove the catheter as need be/ PRN	I respect the point of laboratory evaluations	I maintain head of bed elevated at 30° is respected	I check regularly if there is any tube or lines	I demonstrate willingness to explore patient feelings	I make sure i am authentically present beside
Agree	60%	67%	69%	62%	63%	67%	66%	63%	61%	57%
Disagree	0%	2%	0%	0%	1%	1%	0%	0%	0%	0%
Tend to agree	39%	30%	29%	35%	34%	31%	32%	35%	36%	41%
Tend to disagree	1%	1%	2%	2%	2%	1%	2%	2%	3%	2%

As shown on the above table, the results of this study, for each item under “being with” had the dominant modalities which included agree with a percentage range of 57% to 69% and ‘tend to agree’ with the percentage range of 29% to 41%. This was represented by figure 1 below.

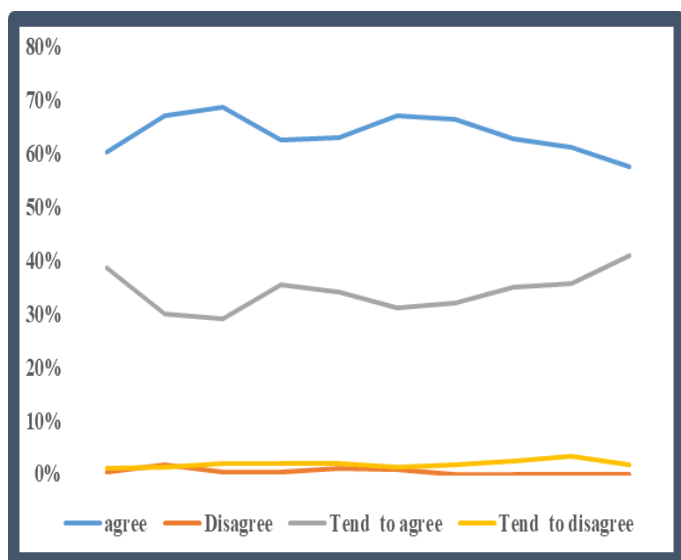


Fig 1 Caring behaviors demonstrated by nurses based on the concept of “being there”

In this study, under biophysical need gratification, the nurses’ demonstrated their caring behavior through active and passive observations towards fluid balance in favor of restoring a negative fluid balance by: 1) Focusing on doses of diuretics (67% agreed for this behavior and 30% tended to agree); 2) Monitoring the fluid input and output where 62% of the nurses agreed and 35% tended to agree to observe catheter outlets with the mind of checking for how much fluid was sent in and what quantity was estimated to flow out; 3) Sixty-three percent agreed and 35% tended to agree that regular checking of any tube or lines is very important to know when to disconnect or that patency is maintained; 4) Concerning good position of the child on the bed to ease venous return and adequate heart functioning, 66% agreed and 32% tended to agree towards maintaining head of bed level at 30 degrees; 5) As for point of laboratory evaluations, to detect need for fluid overload or replacement, 61% of the nurses agreed and 32% tended to agree on this behavior.

Moreover, the results of the study also revealed that at one time it was also necessary for the nurse to assure and maintain psychosocial state and the belief system of the child and family by demonstrating willingness to explore the child’s feelings, beliefs, and values regarding the status quo (61%

agreed and 36% tended to agree for this behavior). Again, the nurses also demonstrated behaviors that showed the importance of the being authentically, actively, and psychophysio-socio-culturally present to better understand the child's problems and detect changes as early as possible (57% agreed and 41% tended to agree).

In addition, being with the child showed a form of security and safety for the child as hemodynamic changes were detected easily via observations as 63% agreed and 34% tended to agree that based on fluid replacement or level evaluations, catheters could be removed at any time, patency of lines and tubes.

Particular attention was given to the child given that after surgical correction, caring depended on high technology where a cardiac monitor is quite essential. In this case, the nurse provided a supportive, protective, and corrective mental, physical, sociocultural, and spiritual environment for this child. The behavior of the nurse contributed to the child's development of autonomy that enabled child to regain knowledge, strength and/or will towards living with the corrected TOF.

IV. DISCUSSION

The aim of this study was to identify the various caring behaviors that were demonstrated by the nurses to promote the health of the child. The results showed that being with the child before or after surgical repair could help support both physical, psychological, as well as social needs of the child. Hospitalization, surgery, and intensive care unit stays depended on the nature of hemodynamic changes. The results of this study have shown that being with the child is a means of security and safety because the nurse provided a supportive, protective, and corrective mental, physical, sociocultural, and spiritual environment for this child. This confirms what Watson (1985) said that when nurses are authentically present beside the patients, they can problem-solve and enhance helping-trusting nurse/client relationships through cultivation of sensitivity to self and others. Khoshkesht & Zakerimoghadam (2021) affirmed that being present helped resolve emotional needs of the client as the nurse conveys availability and sharing of feelings (Swanson, 1991; Alligood, 2014; Rani, 2019).

According to Watson, (2008) the third *caritas* process acknowledges the sense of feeling in humans and advocates for recognition. In the same way, Watson (2006) stated that the act of sensitivity of the nurses to others and self makes them better able to learn about another's view of the world. When nurses engage in caring for children after corrective surgery, it further increases their concern for their comfort, recovery, and wellness especially in the area of intensive care (Wilkin & Slevin, 2004). As stated by Du Plessis (2016) and Boeck, (2014) caring presence helps to promote the use of sensitivity enabling the children to develop self-development and self-actualization.

The results of the study showed that 69% of the respondents performed an act of demonstrating willingness to explore patient feelings, beliefs, and values regarding the child's status. According to Swanson exploration of feelings and beliefs is about maintaining belief concept of Swanson's model of care. Meanwhile from Watson's point of view, it is about the third and fifth *caritative* processes where the nurse cultivate sensitivity to self and other and permits child and family to express their feelings.

In Africa, issues about causation and perception of congenital heart diseases, and choice of treatment plan to follow when suffering these heart anomalies varies amongst families and persons. Most Africans believe that diseases could either be caused by supernatural or natural means (Momah, 2017). Since sudden death sometimes follow heart diseases, perception of the population about the causes of this sudden death varies, and causation is oriented towards traditional beliefs and values. Engaging in exploring feelings of children operated on for the treatment of Tetralogy of Fallot is in the line of gratifying psychosocial needs, as shown by item 9 of the questionnaire, where the nurse was asked to demonstrate willingness to explore patient feelings, beliefs, and values regarding the child status (Watson, 1985; Watson, 2006; Alligood, 2014). This is noted as a feeling of fulfillment of age-related achievement needs like stacking blocks, drawing a tree, building a structure, and recreational games. Most of the children with tetralogy of Fallot, are sometimes prescribed chest physiotherapy, so most of them get involved in playing games, building structures and blocks as well as riding bicycles once discharged from the intensive care unit. As a means of having fulfilled their achievement need

postoperatively.

V. CONCLUSION

The aim of this article was to identify the different caring behaviors that were demonstrated by the nurses of Aswan Heart Centre towards caring for children with a surgically corrected tetralogy of Fallot. According to Swanson's Caring Model, caring behaviors could be demonstrated through the following aspects: knowing, being with, doing for, enabling and maintaining a belief system with the client. This article focused on identifying the caring actions of nurses from the aspect of being with the children living with TOF who were going to have a surgical intervention.

The study revealed that in the likert scale, most participants agreed with a percentage ranged between 57% and 69%, stating that observation of the central line regularly could limit infection was scored 69%, and 57% for being authentically present beside the child to monitor for hemodynamic balance or imbalance. In this study, caring attempted to illuminate the nature of intensive care nursing towards children living with TOF as acts of caring for another person when he/she could not care for self. In this study, nurses were being as caring nurses such as in moments that they displaced actions of compassion, kindness, and concern. These actions went ahead to satisfy the basic needs of children from the aspects of biophysical, psychophysical, and psychosocio-cultural through therapeutic observation and authentic presence.

IMPLICATIONS FOR NURSING AND HEALTH POLICY

It was evident that nurses did practice caring in Aswan Heart Centre. The study attempted to affirm the relationship and the importance of the Watson Human Caring Theory and Swanson's in caring for children with surgically corrected TOF. These theories formed the bases of the caring approach towards children living with a surgically corrected TOF from the aspect of being available for the child postoperatively. Further research on the concept of being as caring especially in critical care or intensive care units where children are admitted with critical care concerns is still needed. Nursing

education should include teaching and learning on the concept of being as caring and how it can contribute to caring values and attitudes in nursing. Being as caring is integrated in the transformation paradigm related care approach in which the clients become real partners or actors of their own health maintenance. Caring Science advocates application of nursing knowledge as stated by Fawcett (2006) in a structural scholarly manner to appreciate its philosophical clarity. Gdanetz (2019) added that this knowledge would serve as a strong pillar for the development of continuing education in a relational and caring online environment.

Research in this domain is paramount to determine the perception of the community caregivers about tetralogy of Fallot or cardiac disease, including how they define these diseases and what the plan of care is pertinent to them to assist in early diagnosis of these conditions. Furthermore, research is needed to propose a caring approach for those children that are living with an early or late surgically corrected TOF to help reduce the rate of mortality.

ETHICAL CONSIDERATION

Permission was obtained from the president of the Aswan Heart Centre research team and from the national ethical clearance committee. Anonymity and confidentiality were respected, and the ethical aspect of non-beneficence was maintained with rigor. In addition, aseptic technique and respect to barrier measures were highly maintained given that this study took place in a Covid-19 potential risk zone. As concerned risk, inconveniences, and discomfort, the researcher considered that a child who has undergone surgical correction of TOF needed close attention from the health personnel especially during immediate postoperative periods. In order to minimize time wasting, questionnaires and interviews were only organized during off-days or during their holidays. Therefore, there was no risk or inconveniences or discomfort as the child was not manipulated upon, information was read from the cardiac monitor and from the nurses. Concerning direct benefits, the health status of the participants shall be improved if he/she is the child living with TOF. Refusal to participate in this study is legitimate or allowed, even if after having accepted to participate he/she decides to withdraw without incurring consequences. Your participation in this study relies very much on a voluntary base, you are entirely

free to participate or not to do so and to withdraw anytime with no prejudice and without giving explanations. All the information gotten began with respect to strict confidentiality within the limits provided by the law. After which presentation of participant identity was ensured by allocating anonymous code numbers. Verbal consent was gotten from the participants.

LIMITATIONS

The study included the nurses as the population under study and a handful of parent experiences were not explored. The researcher suggests that this research be carried out with a large sample size including parent experience exploration as cases of dehumanization of care as aspects of dissatisfaction to caring by the nurses could have been an issue to be considered.

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