

## Use of narrative as an awareness strategy for a Family-Centered Care model

*Uso da narrativa como estratégia de sensibilização para o modelo do cuidado centrado na família*

*Uso de la narrativa para sensibilización en el modelo del cuidado centrado en la familia*



**Daniela Doulavince Amador<sup>a</sup>**  
**Fernanda Ribeiro Baptista Marques<sup>b</sup>**  
**Adriana Maria Duarte<sup>c</sup>**  
**Flavia Simphronio Balbino<sup>d</sup>**  
**Maria Magda Ferreira Gomes Balieiro<sup>e</sup>**  
**Myriam Aparecida Mandetta<sup>f</sup>**

### ABSTRACT

The aim of this study was to comprehend the meaning of using illness narratives to raise awareness among nursing students and healthcare professionals toward the family-centred care model. The adopted methodological framework was Qualitative Content Analysis based on the philosophy of Family-Centered Care. Data were collected by means of assessments provided by 29 participants at an event in 2013, in São Paulo. The resulting analytical category was “transformed by the family narrative”, which consisted of three sub-categories: Favours a better understanding of the family’s experience; facilitates learning of family issues; and triggers thought on family-centered care. Results showed that hearing the family narrative on experiences with illness and hospitalization raises awareness among nursing students and healthcare professionals toward the family-centered care model, and facilitates learning of this model of care.

**Keywords:** Family. Hospitalization. Education. Narration. Nursing.

### RESUMO

O objetivo foi compreender o significado do uso da narrativa de doença para a sensibilização de estudantes e profissionais de saúde para o modelo do cuidado centrado na família. Estudo de abordagem qualitativa fundamentado na filosofia do Cuidado Centrado na Família e conduzido pela Análise Qualitativa de Conteúdo como referencial metodológico. Para a coleta de dados, foram utilizadas as avaliações realizadas por 29 participantes de um evento realizado em 2013, em São Paulo. A categoria analítica “sendo transformado pela narrativa da família” compôs-se das subcategorias: “favorece a aproximação com a experiência da família”; “facilita o aprendizado sobre família”; e “gera reflexão sobre a prática com a família”. O estudo evidenciou que ouvir a narrativa das vivências da família com doença e hospitalização da criança promove a sensibilização do profissional de saúde e do estudante para o modelo do cuidado centrado na família, sendo facilitadora para sua aprendizagem.

**Palavras-chave:** Família. Hospitalização. Educação. Narração. Enfermagem.

### RESUMEN

El estudio se realizó con el objetivo de comprender el significado del uso de la narrativa de enfermedad para sensibilizar estudiantes y profesionales de salud en el modelo del cuidado centrado en la familia. Estudio cualitativo fundado en la filosofía del modelo del cuidado centrado en la familia y en el Análisis Cualitativo de Contenido. Las evaluaciones realizadas por 29 participantes en un hecho realizado en 2013, en São Paulo fueron utilizados para la recolección de datos. La categoría analítica que emergió fue “siendo transformada por la narrativa de la familia”, compuesta de las subcategorías: favorece la aproximación con la experiencia de la familia; facilita el aprendizaje sobre la familia; y genera reflexión sobre la práctica con la familia. El estudio evidenció que enterarse de la narrativa de la familia, con base en las vivencias reales, promueve la sensibilización de los estudiantes y de los profesionales para el cuidado centrado en la familia y promueve el aprendizaje de este modelo del cuidado.

**Palabras clave:** Familia. Hospitalización. Educación. Narración. Enfermería.

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<sup>a</sup> Nurse. Master of Nursing. Doctoral degree student of Nursing of the Graduate Nursing Programme at the Universidade Federal de São Paulo (UNIFESP). Member of the Núcleo de Estudos da Criança e do Adolescente (NECAAd). São Paulo – SP, Brazil

<sup>b</sup> Nurse. Master of Nursing. Doctoral degree student of the Graduate Nursing Programme at the UNIFESP. Member of the NECAAd. São Paulo – SP, Brazil.

<sup>c</sup> Nurse. Master of Nursing. Doctoral degree student of the Graduate Nursing Programme at the UNIFESP. Member of the NECAAd. São Paulo – SP, Brazil.

<sup>d</sup> Nurse. Doctoral degree student of the Graduate Nursing Programme at the UNIFESP. Member of the NECAAd. São Paulo – SP, Brazil.

<sup>e</sup> Nurse. Doctor of Nursing. Adjunct Professor at the Escola Paulista de Enfermagem da UNIFESP. Leader of the NECAAd. São Paulo – SP, Brazil.

<sup>f</sup> Nurse. Doctor of Nursing. Associate Professor at the Escola Paulista de Enfermagem da UNIFESP. Leader of the NECAAd. São Paulo – SP, Brazil.

## ■ INTRODUCTION

One of the challenges of promoting learning of the subject of family in healthcare and use of this topic in clinical practices in all care contexts is the creation of awareness strategies for professionals. Awareness is the willingness of professionals to act with the family based on an understanding of the daily lives and experiences of family members. To be aware does not imply knowledge on how to work with families, but the willingness to search for the necessary information to interact with families by using resources and new ways of being and acting with them<sup>(1)</sup>.

Although families are present in the daily practice of paediatric units they are not always considered a care unit. The care provided by healthcare professionals does not include the children's families or consider their needs. Studies<sup>(2-4)</sup> show that families feel unassisted by healthcare professionals who limit their care to the biological aspects of getting sick without considering them as units of care that suffer and must be included in comprehensive care.

Consequently, involving families means to make them active and participators of the care provided to their loved ones. Institutions should therefore adopt the Family-Centered Care (FCC) model that is based on four concepts: dignity and respect, shared information, participation and collaboration, mediated by continued negotiation between the healthcare team and the patients' families<sup>(5)</sup>.

Inviting families to narrate their experiences is a way of helping them give some meaning to their own experience. Listening to other people's narrative can be considered a reliable way of gaining access to their personal lives and provides a powerful resource to learn about the human experience. Narrative is included in the living process and it is a spontaneous activity insofar as it is delivered in an appropriate environment<sup>(6)</sup>.

The narrative approach is brought into the clinical practice as a tool that enables perception and interpretation of the illness process, and as a way for healthcare professionals to incorporate new wording to the interpretative repertoire, thus extending the dialogic, hermeneutic and comprehensive dimension of knowledge and the clinical practice<sup>(7)</sup>.

In this sense, narrative can be a reflexive and transforming educational practice and is considered an active method for learning about families. Active teaching and learning methodologies are applied to allow students to build knowledge on real experiences and situations, enabling the development of a critical-reflexive vision of the

presented content and the autonomy and responsibility for obtaining this knowledge<sup>(8)</sup>.

In the context of illness and hospitalization, narrative is woven by a human being that invites us to relive his or her experience and give meaning to an experience that is often imperceptible to those who provide care.

With this perspective in mind, a workshop on the core topic of Family-Centered Care was held. The two-day programme consisted of round tables and conferences on strategies to promote learning of FCC. On the first day, awareness activities were presented with the narrative of a family on the illness and hospitalization of their child, which lasted two hours. The mother of a two-year old child with a diagnosed brain tumour presented a video on the trajectory of the child's family. Subsequently, a family nursing specialist conducted a conversation with the mother, bringing to light the family experience during the child's treatment, their concerns and difficulties and interactions with the healthcare team. Finally, the speakers allowed time for questions from the audience, providing yet another opportunity to extend individual thoughts.

The question of how participants attributed meaning to the use of narrative to promote learning of the family illness experience subsequently arose. Consequently, the aim of this study was to understand the use of the illness narrative to create awareness among nursing students and healthcare professionals in relation to the family-centered care model.

## ■ METHOD

This study was based on the Family-Centered Care philosophy and the adopted methodological framework was Qualitative Content Analysis.

FCC is based on mutually beneficial partnerships between healthcare professionals, patients and their families, founded on the pillars of dignity, respect, collaboration, participation and shared information<sup>(5)</sup>.

Qualitative Content Analysis is a systematic research method that aims to provide a condensed and extensive description of a phenomenon, resulting in descriptive concepts or categories<sup>(9)</sup>.

*The 2<sup>nd</sup> Family-Centered Care Workshop: Strategies for teaching Family-Centered Care* was held in August 2013 by a study and research group linked to a Higher Learning Institution (IES) in the municipality of São Paulo. The IES offers undergraduate nursing courses and provides benchmark learning hospitals. The workshop was extensively electronically advertised at the IES.

Data were collected at the end of the event and inclusion criteria were students of the nursing undergraduate course or healthcare professionals that were practicing and/or teaching. Those who were conducting exclusively managerial activities during the research period were excluded from the study group.

A total of 32 individuals attended the workshop. Of these participants, 29 formed the study samples, of which 17 were students of the nursing and psychology undergraduate courses and 12 were professionals of several healthcare areas practicing in hospitals, as professors and/or completing graduate specialization programmes.

Data were collected by means of a questionnaire with open questions on the thoughts and feelings triggered by family narrative, that is, the perception of participants in relation to the use of narrative to create awareness on family-centered care and the significant aspects of narrative for their professional and personal growth.

The collected empirical material was analysed according to the foundations of Qualitative Content Analysis. Firstly, data were fully transcribed, followed by exhaustive reading with special attention to the particularities of each response and the answers as a whole, according to the established steps of data identification, codification and categorization<sup>(9)</sup>.

This study observed national and international research ethics standards involving human beings, as established in Resolution 466 of December 12, 2012, of the National Health Council. All participants signed a written consent form prior to data collection. To protect the privacy of participants, assessments completed by students were represented with the letter "E" and the reports completed by professors were represented with the letter "P". The project was approved by the Ethics and Research Committee of the Higher Education Institution under Protocol 569.848/2014.

## ■ RESULTS AND DISCUSSION

The analytic category that emerged from data analysis, "transformed by the family narrative", represents how participants attributed meaning to the use of narrative to promote family-centered care, consisting of three sub-categories: Narrative favours a better understanding of the family's experience; narrative facilitates learning of family issues; and narrative triggers thought on family-centered care, thus allowing a better understanding of the transformation of workshop participants and revealing important elements that should be applied to education to promote awareness on family-centered care.

### **Narrative favours a better understanding of the family's experience**

Participants that paid close attention the family's narrative were touched by it, which favours a better understanding of the family's experience. They mentioned feeling immensely moved and singularly transformed by the narrative. The family narrative reveals past care experiences, making them more sensitive, empathetic and open to these experiences and the family's coping strategies.

The participants realized, in their own time, that the family presented aspects that helped them better understand the experience. The family's narrative strikingly revealed their pain and joy, as the context is one of intense suffering due to the fear of losing a loved one. The participants were thus drawn closer to the family's suffering.

*It moved me. I perceived the frankness and sensitivity of the statements (P3)*

*Important, I realized how sensitive the family gets after it goes through a hospitalization and chronic disease. The family's side should be considered and we should familiarize ourselves with the difficulty of coping (E2).*

*It was thought-provoking, and I wanted to understand how that family coped with the disease. I managed to hear their strength and identified it objectively and subjectively (E6).*

Both professionals and students became more aware, through the narratives, of the family's experiences with illness and hospitalization of the child.

In this sense, the narrative plays an important role and the oral and written discourse is essential to narrow the gap between all the subjects. It is translated as a shared testimony, a way to draw people together and reveal an experience that must be heard and observed by healthcare professional to ensure its materiality. The listeners must consider aspects of the discourse and the stories and attitudes of individuals that can best express the experiences they are going through. Elements that make up the form and sense of the narrative are thus valued and analysed. Referring to the narrative as a construction and constitution of reality based on experiences in the world implies a different way of observing and appreciating the temporal dimension of stories, that is, to consider them a dimension that transcends the mere chronological ordering or sequencing of facts, like signs and symptoms<sup>(7)</sup>.

Furthermore, narrative provokes empathy for the pain of others by bringing participants closer to the family's reality. This forces participants to think about how they should be and act.

*It is easier to see things from their perspective, to see all that suffering, the struggle to help their daughter get better. The healthcare professional can get a better idea of how the family feels in this situation and can make him want to improve care for this child and its family (E1).*

*No matter how hard we try to imagine the sadness and suffering the experience can cause, it was shocking to hear the mother's statement, I could put myself in her place (E13).*

*It helps to directly share the family's experience. The professional relives the experience with the family [...].It's possible to feel/see the non-verbal, which helps feelings to emerge, triggering empathy and awareness toward the family's needs (P6).*

By learning about the family's experience and becoming more familiar with the problems it faces, the participants perceived the impact of illness in the lives of all family members and were forced to learn about the difficulties they face on a daily basis, and their interaction with the disease and the healthcare team. It also forced them to see that the family is not weak and powerless to make decisions, and that it in fact has the power and capacity to overcome adversities.

The bond between professionals and families can be an important tool to strengthen relationships. Carefully and empathetically listening to the families is essential to promote their empowerment<sup>(4)</sup>.

### **Narrative facilitates learning of family issues**

Narrative can facilitate the consolidation of theoretical learning as, by listening, participants were more eager to seek additional elements for learning and felt inoculated by the idea of providing care for the family. They also perceived that they still lacked the instruments to help them provide this care for the family as a whole. The chance to hear the statement of a family that is going through a illness experience is enriching, as it encourages healthcare professionals to act in favour of the family during their practices.

*[The narrative] presented concepts I was unaware of, and despite trying to work with families during my professional*

*practice, I was still lacking some instruments. This experience encouraged me to read more literature on this subject (P4).*

*I think that the statements are the best learning strategy we could possibly have. It's possible to identify the needs, difficulties and potentialities of the family (P5).*

*There are several studies and theories on family-centered care that we could study, but the practical experience is unique and we can individually form our own ideas on how to face these situations, and understand what is truly important to these patients (E7).*

Education is hugely responsible for the extent to which students and, consequently, professionals are made aware of family-centered care. Awareness through learning that considers the family as a care centre is essential for how the professional practice is later conducted<sup>(10)</sup>.

The use of narrative helps students learn how families experience treatment and their difficulties in coping, causing professionals to reflect on possibilities that may help these families. Learning about the families, based on narratives of their experiences, enable students to better fixate and bring theory into practice by translating what they have read in books and articles to a real-life scenario.

*We managed to clearly understand the difficulties and moments of weakness the family goes through and that, many times, we do not pay attention and do not provide the necessary assistance (E15).*

*It was very positive in that I was in contact with family-centered care beyond the theoretical description in books or class presentations, that are undoubtedly very valid, but irreplaceable by practice (E11).*

*Seeing an example coming from someone who knows Family-Centered Care helps to better target our approach as healthcare professionals and value the importance of assisting the families (E4).*

The education of healthcare professionals is being challenged by a new perspective that demands the search for new references anchored in paradigms that interconnect education, health and human development, and sustain the importance of education from a thought-provoking perspective<sup>(11)</sup>. In the educational process, stimulating the critical and reflexive capacity of students facilitates the teaching and learning process and enables the autonomy of all the parties involved<sup>(12)</sup>.

The experience of participants was transformed by the family narrative and was considered unforgettable because it is different to everything they were accustomed to. After this gathering, both students and professionals considered that their learning experience was intensified and became richer in meaning.

*Outstanding! I will never forget it. It was a very relevant learning experience, I was deeply moved (E17).*

*Hugely important, as it moved us both as professionals and as individuals, humanizing us in relation to the care we provide.(E8).*

*Very important, it brought us closer to reality (P9).*

*An unforgettable experience (P8).*

Education that is committed to others, with their values and relationships, especially family relations, based on reciprocity and solidarity, allows the construction of ethical and humanized conduct<sup>(13)</sup>.

### **Narrative triggers thought on family-centered care**

The experience forced participants to rethink their actions with families when providing care. They perceived the possibility of focusing not only on the sick child, but on the family as a whole. They understood and extended their focus, which was previously centered on the body and treating signs and symptoms of the disease, to include a practice that involves biological, social, spiritual and cultural care. Awareness promoted by narrative triggered an internal disposition to think about the family.

*[...][...] it makes us think about our practice (P10).*

*It makes us look not only at the patient, but at the people who must live with this disease [...], not only at the child, but at the entire family (E3).*

*I realized how important it is for healthcare professionals to be straightforward with the family. The emotional support is usually non-existent as the greatest concern is providing care for the hospitalized patient, but there is a family that is suffering with this situation, that is tired, so support is essential (E14).*

The family narrative forced them to rethink their individual conduct in relation to the family and what they could

do to change their practice in the sense of including the family in the care they provide. Questions on how to help families minimize their suffering and how to cope with the illness became a part of their individual thinking process.

Narrative forced these professionals to think about their actions and triggered the willingness to adopt a more welcoming and empathetic attitude toward the families. In the specificity of healthcare, it is important to reflect on the conducted practices and question the institutional and professional idea that the suffering of family members is secondary or non-existent<sup>(10)</sup>.

Comprehensive care includes the development of technical and subjective knowledge - the capacity for critical thought, among others - expressed by means of self-dedication and dedication toward others. It is therefore important to invest in professional education that strengthens the ethical and humanistic vision, and promote critical and reflexive thinking that targets the development of competencies and skills that include the family as the object of care<sup>(14)</sup>.

This thought process forced participants to perceive a practice that includes families as a unit, as their suffering and interactions are supported by a humanism that was pushed aside to make room for daily routine practices. The narrative revived the humanism of these professionals and forced them to perceive the suffering and pain of others. This enabled them to be more open in relation to the needs of the family and to rethink a practice that can meet these needs.

*I was very moved by the story. Sharing this experience was very thought-provoking, personally and professionally: What can I do to minimize this suffering? What can I do to help these families better cope with the disease?(E10).*

*Listening and seeing examples like this one makes us think about how we conduct our work. We stop to evaluate what we can improve to provide the best possible care and help these families in such a delicate moment (E12).*

*We see similar stories all the time and get used to it, forgetting the human side. We need moments that force us to face reality (P1).*

*I have to study this subject further and pay more attention to human relationships (P12).*

Although the Family-Centered Care model was proposed almost four decades ago, the theory is still considered an ideal, as it is not widely applied by professionals during their daily practice. More efforts should be put into



using the knowledge acquired in clinical practices with families to transform the current scenario and include the families as participating agents of care in a collaborative manner that respects their expertise and potentialities<sup>(2)</sup>. Healthcare teams need the awareness and instruments to provide family-centered care and propose interventions that minimize their suffering and promote their empowerment, such as sharing information and encouraging the participation of families in care and respecting them in their own time<sup>(15)</sup>.

## ■ CONCLUSION

During the assessment, the participants revealed that the narrative of illness and hospitalization increased their awareness of a family-centered care model by: a) familiarizing them with the family experience and forcing them to perceive the impact of illness, the difficulties and strength of family members when coping with adversities; b) helping them learn about the families, considering the narrative helped them assimilate theory and practice and encouraged them to seek more learning elements; c) triggering thought on their practice with families, making them reconsider how they act and become more willing to include the families as a target for care.

A study limitation was that it was conducted in a workshop on FCC in which the participants could have had a predisposition to talk about the subject. Furthermore, data collection by means of a questionnaire could have limited the exposure of participants in relation to their experiences with the use of narrative. New studies on the use of narrative at several stages of professional education and practice may shed further light on the benefits of narrative to better understand the real experiences of families during the illness and hospitalization process of their children.

The use of this strategy at all levels of education is highly recommended.

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## ■ Author's address:

Daniela Doulavince Amador  
Rua Napoleão de Barros, 754, Vila Clementino  
04024-002, São Paulo, SP  
E-mail: dani\_doulavince@yahoo.com.br

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