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# Disclosure of difficult news in primary health care: aspects that hinder or facilitate communication from the perceptions of nurses

Comunicação de notícias difíceis na atenção básica à saúde: barreiras e facilitadores percebidos por enfermeiras

Comunicación de noticias difíciles en la atención básica a la salud: barreras y facilitadores percibidos por enfermeras

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### **ABSTRACT**

**Objective:** To identify aspects that hinder or facilitate the work of nurses in primary health care when disclosing difficult news **Method:** Qualitative, descriptive and exploratory study addressing 15 nurses from ten primary health care units located in the south of Brazil. Data were collected from February to April 2017, using a semi-structured interview. Interviews were audio-recorded and analyzed based on discourse analysis.

**Results:** The aspects that hinder communication include the demand for services; work organization; the characteristics of patients; and personal aspects. Facilitating aspects include privacy and being in the community. Also hindering or facilitating communication: the way the network functions and the staff; academic training; professional experience; personal aspects.

**Conclusion:** This topic is seldom addressed during academic training and this lack of preparedness is one of the main barriers hindering the disclosure of difficult news. Hence, it is essential that teaching institutions establish a discussion regarding this topic. **Key words:** Health Communication. Primary Health Care. Ethics, Nursing. Nursing.

### RESIIMO

**Objetivo:** Conhecer as barreiras e facilitadores que as enfermeiras da Atenção Básica à Saúde encontram no momento da comunicação de notícias difíceis

**Metodologia:** Estudo qualitativo, descritivo e exploratório, com 15 enfermeiras de 10 Unidades Básicas de Saúde no sul do Brasil. A coleta de dados ocorreu no período de fevereiro a abril de 2017, através de roteiro de entrevista quase estruturado e áudio-gravadas. Os dados foram analisados conforme análise textual discursiva.

**Resultados:** Barreiras: demanda; organização do trabalho; características dos usuários; e aspecto pessoal. Facilidades: privacidade; e estar na comunidade. O funcionamento da rede; a equipe; formação profissional; experiência profissional; aspecto pessoal; e conhecimentos encaixaram-se em ambos os aspectos.

**Conclusão:** A escassa abordagem do tema durante a formação profissional torna-se uma das principais barreiras à comunicação de notícias difíceis, sendo fundamental esse debate nas instituições de ensino.

Palavras-chave: Comunicação em saúde. Atenção primária à saúde. Ética em enfermagem. Enfermagem.

### **RESUMEN**

**Objetivo:** Conocer las barreras y facilitadores que las enfermeras de la Atención Básica a la Salud encuentran en el momento de la comunicación de noticias difíciles.

**Metodología:** Estudio cualitativo, descriptivo y exploratorio, con 15 enfermeras de 10 Unidades Básicas de Salud en el sur de Brasil. La recolección de datos ocurrió en el período de febrero a abril de 2017, a través de un guión de entrevista casi estructurado y audiograbados. Los datos fueron analizados según el análisis textual discursivo.

**Resultados:** Barreras: demanda; organización del trabajo; características de los usuarios; y aspecto personal. Instalaciones: aislamiento; y estar en la comunidad. El funcionamiento de la red; el equipo; formación profesional; experiencia profesional; aspecto personal; y los conocimientos se encajaron en ambos aspectos.

**Conclusión:** El escaso enfoque del tema durante la formación profesional se convierte en una de las principales barreras a la comunicación de noticias difíciles, siendo fundamental este debate en las instituciones de enseñanza.

**Palabras clave:** Comunicación en salud. Atención primaria de salud. Ética en enfermería. Enfermería.

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### **■ INTRODUCTION**

Communication is a process in which two or more people establish contact with the objective to exchange information. It is characterized by the transmission and reception of messages involving an emitter and a receptor. There is verbal and non-verbal communication. Verbal communication includes all kinds of information conveyed through speech or writing, while non-verbal communication encompasses other forms of communication not expressed by words, including facial expressions, gestures and physical touch<sup>(1)</sup>. For the communication process to be effective, one has to be aware of the existing types of communication and the relevance of each.

The objective of communication in the health field is to transmit information that is well understood by people. Patients, however, do not always fully understand the information they receive due to aspects such as lack of active and attentive listening on the part of workers and barriers in health services that increase the complexity of care delivery or cause it to be fragmented, which has the potential to harm the quality of communication in interpersonal relationships<sup>(2)</sup>.

In this sense, ineffective communication or difficulty conveying information in the context of health reveals the existence of the term "bad news" or "difficult news". Conceptually, bad news or difficult news is information that concerns a risk to someone's life, safety, or comfort, or threatens the peace of a family or society due to the impact such information might cause to its receptor. That is, such information is often associated with a severe illness or family loss. The definition of bad news, however, depends on subjective unfolding, on unique and individual experiences<sup>(3)</sup>.

When talking about the communication of difficult news within Primary Health Care Services, we should note the work provided by *Redes de Atenção à Saúde (RAS)* [Health Care Networks], which are reputable polyarchical health service organizations, connected by common goals, cooperative and interdependent actions, and a single mission, that of providing continuous and integral healthcare to the population in accordance with Primary Health Care (PHC)<sup>(4)</sup>.

PHC services are the entrance door to the public health system<sup>(4)</sup>, being responsible for most of the health care provided to the population. Thus, information concerning the health conditions of patients are disclosed daily with the objective of guiding and referring patients to medium- and high-density technology services for follow-up. This situation is precisely what configures the research question of this study: What are the hindrances and aspects that

facilitate the work of nurses within PHC, found at the time of communicating difficult news?

In view of the preceding discussion, this study's objective was to identify the aspects that hinder or facilitate the work of nurses within PHC at the time of communicating difficult news.

This study is justified by the need to identify the elements involving the communication of difficult news within PHC because this type of information has the potential to disturb both those receiving and disclosing it<sup>(5)</sup>. Therefore, knowledge of such elements can contribute to effective communication, which in turn can benefit patients by helping them to better cope with the disease process<sup>(3)</sup>.

### **■ METHOD**

This paper was extracted from a final paper defended at FURG in 2017<sup>(6)</sup>. The monograph was based on a qualitative, exploratory and descriptive study conducted with 15 nurses from ten PHC units and Family PHC units located in a city in the extreme south of Brazil. The participants were selected through non-probabilistic convenience sampling. The nurses of each PHC unit were invited via a telephone call, in which the study's objective was explained and a day and time was scheduled to collect data. There were no refusals.

Inclusion criteria were: having worked in the unit for at least six months; having a work contract with the city's Health Department; and currently working in their respective functions. Exclusion criteria were: nurses on vacation, on strike, or on leave for any other reason.

Data were collected on the premises of the PHC units from February to April 2017, using a semi-structured interview. Interviews were audio recorded and lasted 40 minutes on average. Specific rooms on the units' premises were determined by the head nurses to ensure privacy and confidentiality. Discourse analysis was used to analyze the data. This technique is based on four elements: unitization, categorization, identification of emergent concepts, and self-organized process, which allows for new understanding based on previous studies. The first element, unitization, refers to the deconstruction of texts with the objective of assessing data in detail and elaborating a more comprehensive meaning and perceiving different meanings within the text<sup>(7)</sup>.

The second element, categorization, refers to reorganizing the parts that were initially deconstructed, by grouping elements with similar meanings. Additionally, categorization is intended to name and define the categories that emerge. This step can be achieved through three methods:

deductive, when the researcher, even before reading the text, is able to establish categories in agreement with the study's theoretical framework; inductive, in which categories are established after reading the text by comparing and organizing similar elements; and finally, intuitive, which is a method that requires great knowledge regarding the topic under study because it allows the researcher to reconcile the methods previously described based on his/her insights<sup>(7)</sup>.

Identification of emergent concepts is the third element of the discourse analysis and it seeks to describe and interpret common meanings of what was produced over the course of the research, making it comprehensible for readers<sup>(7)</sup>. After successfully achieving these three elements, the researcher reaches the fourth and final element, the self-organized process, which allows order to be established and the acquisition of a new understanding of the material gathered in the previous steps<sup>(7)</sup>.

Ethical aspects were observed in accordance with the recommendations of Resolution 466/12, Brazilian Council of Health. After agreeing to participate, the participants signed free and informed consent forms; only after this were interviews initiated. This study was approved by the Institutional Review Board at the Federal University of Rio Grande - CEPAS/FURG No. 11/2017 and CAAE: 62444116.5.0000.5324. The participants' discourses are identified by letter N, followed by sequential numbers (N1, N2, N3...), in order to keep their identities confidential.

# ■ RESULTS AND DISCUSSION

In order to understand what elements hinder and what elements facilitate the work of nurses when communicating with patients and when disclosing difficult news, this study's results are organized by categories, some of which are classified both as elements that hinder and that facilitate communication

# **Facilitating aspects**

This category presents the factors that facilitate communication in general and consequently the disclosure of difficult news. Privacy and being in the community appear as elements that facilitate communication because they favor embracing the individual and establishing a bond. That is, these four elements together bring nurses closer to patients and favor lighter and more attentive communication.

Well, usually I like to talk in private with patients; I don't like to talk in front of other people, even if it is a very simple explanation. I invite the person to sit, I look in their eyes and I guess this makes people feel more welcome; it shows that someone is paying attention to what they are saying [...]. (N 2)

[...] There is no better tool than really being there for someone, so you properly welcome patients [...] so, there is nothing better than listening, trying to resolve things, explaining, talking [...]. (N 12)

I think that the main work tool is communication, really, trying to get closer, in this case, to families and patients and trying to understand their situation and circumstances, so you can provide guidance and necessary information for people really to get the appropriate treatment, get the care that is necessary and appropriate at the time [...]. (N 13)

Regarding having a place where there is privacy to talk with patients, nurses consider privacy to be an element that facilitates communication because it aids them in establishing bonds and properly welcoming patients. This finding is corroborated by a study<sup>(8)</sup> that reports that a safe and confortable environment allows patients to be physically and psychologically at ease with nurses, in addition to facilitating the use of communication skills and the establishment of effective communication and bonds. It is essential that workers pay attention and show empathy at the time of communication, also allowing patients to manifest emotional responses.

# **Barriers**

This category shows that the demands and the way work is organized at PHC units represent aspects that hinder the communication of difficult news.

The nurses report that the high demand from patients and activities that do not directly involve the delivery of care hinders the communication process, because workers have to perform several activities in order to meet such demands, which results in them paying less attention to the communication process.

[...] And a large part of our tasks are not scheduled in advance, considering that nurses have to perform many tasks, such as solving daily problems. And when solving these problems we often are not able to program and plan everything that is happening and that will happen. (N 1)

Well, I guess the service's demands. Demands that... spontaneous demands that very often absorb our attention, we often want to sit down with patients and talk but there are a

million things to do and you just aren't able to dedicate your time to that specific patient so you end up just giving the information, but not in as attentive a way as you should... and at that time some things, some stuff, some things you could detect, such as some fragility, go unnoticed [...]. (E 2)

I guess the overload of work, I guess that if we had more time or didn't have this type of issue, what there is in the primary health care is what is supposed to happen in primary health care

[...] It is humanly impossible nowadays; because you are supposed to take care of the administrative part, the managerial part, care delivery, education..., so I guess this overload of tasks, which is inherent to primary health care service [...]. (N 14)

The high density of patients in health services and the amount of tasks in the daily routines of workers complicate the communication process because some situations are considered more urgent when compared to these demands and routines.

The characteristics of patients and the personal aspects of workers may also negatively influence communication. Personal aspects related to one's psychological dimension may affect the process, even influencing the private lives of workers, affecting their response even before they communicate the news, and during and after they communicate it. That is, having the responsibility to disclose difficult news may influence the responses of workers and hinder the communication process and the disclosure of difficult information.

- [...] but it's complicated, because only we are capable of developing, I think so, only we can develop a method, a way to deal with it, because we first need to work it out in our minds, learn to deal with it, to then deal with others, you know. (N 2)
- [...] all this, the professional dimension, much comes from our emotional side, you know, anguish, concerns, you know. (N 15)
- [...] we deal with things but we have feelings, and for me, personally, it's difficult. We have to deal with things but it is difficult. (N 15)

In regard to personal aspects, the psychological dimension, the participants report how news can affect

them and how they deal with their own responses. One study<sup>(3)</sup> reports that the disclosure of bad news is seen by some health workers as an arduous task because dealing with the emotional aspects associated with it, in addition to potential lasting repercussions, is difficult for all those involved. Thus, health workers also require care to remain whole when facing such barriers, because bad news affect both those receiving it and those communicating it. Workers may be socially and psychologically affected and, for this reason, the importance of providing psychological support to workers dealing with these situations has to be considered<sup>(9)</sup>.

The characteristics of patients in psychological, psychosocial and cognitive terms were mentioned as elements that hinder the communication process, because it is impossible to foresee how patients will respond and what to do with a response. In this sense, one needs to be prepared to communicate and deal with the responses of patients.

- [...] Shock, anger, it's, I don't know, denial. The most difficult situations are when people lose control, cry... and we don't know what to do [...]. (N 2)
- [...] because we feel their pain you know, it is difficult to talk about it because we never know how a person will respond in these situations [...]. (N 4)

After receiving the news, patients may respond with despair and sorrow, however, these responses may be intensified if workers disclose news in a insensitive or careless manner<sup>(10)</sup>. Anxiety from not knowing how patients will respond to information is a great challenge<sup>(11)</sup> that may lead workers to make decisions that delay or hinder proper communication. For this reason, workers need to be prepared to deal with the emotions of patients, as an intervention may be necessary to manage the negative effects information may cause.

Some aspects, however, were mentioned as being aspects that can either facilitate or hinder communication, as they may fall under both categories, as explained by the study's participants.

The network and staff work were considered facilitating aspects because they provide a support system to workers, support that workers can count on for the communication process in general and for the disclose of difficult information. Additionally, knowing how the network functions enables the professionals to provide the right guidance and refer patients to the right services, avoiding the fragmentation of care.

So, having knowledge of the various mechanisms that will enable the supply of the best health care and help patients to cope with difficult news, is the best way to go. (N 1)

I guess that the aspects that facilitate communication is having autonomy at work, being able to resolve things, go forward, to communicate with the hospital, to access information, make appointments, explain [...]. (N 4)

[...] there is this physician [...] when there is a difficult situation we need to address, we go together, we talk together with the family, with the patient. (N 13)

I tell you that when we have this type of diagnosis, we never communicate it alone. I have her and she has me; always physician and nurse giving support to each other. When we have these diagnoses, whether she gets it or I get it, we take some time to talk about the patient and the diagnosis, then we call the person and go together. One supports the other. I've never seen myself alone in this type of situation and never has she. (N 15)

The way the health care network and the staff work were also considered a barrier because for the service to work well, these elements need to be attuned, especially in terms of the flow and counter flow of patients within the healthcare network

[...] The bureaucracy of the system, which makes people go from place to place before finding the right place. So when the person gets here, she's already furious. This is something that hinders communication a lot, because the person gets here already armed, thinking that you will not be able to solve her problem, that you're going to send her to somewhere else [...]. (N 2)

[...] I have a big problem with my relationships with two teams of health agents [...]. (N 4)

Difficulties because we start working without prior orientation on how routines work, so there are things we don't really know how they work and we have to go and figure out how they work. (N 10)

The care provided by a multidisciplinary team is presented as a valuable element because it enables the delivery of integral care that is relevant in the relationship between workers and patients<sup>(12)</sup>. Healthcare actions provided by the multidisciplinary team enable the identification of

new strategies to meet the demands of the population and avoid the fragmentation of care<sup>(13)</sup>.

The work performed together with multidisciplinary teams is considered a practice to be promoted in health-care services, because this partnership strengthens health promotion networks and connects different types of knowledge, enabling collaboration and solidarity that favors patients and facilitates meeting their needs<sup>(14)</sup>. Additionally, the various guidelines provided by the RAS include organizing the flow of patients within the PHC network, a component that is essential for the reorganization of practice and the public health system<sup>(15)</sup>.

The RAS have overcome a fragmented healthcare system; that is, they aim to reach a system that provides integral health care, going from a hierarchical to a polyarchical organization (4). Polyarchical organization establishes the health care system as a horizontal network where there is no hierarchy among the different points of care delivery, but rather a horizontal network with different technology densities and their support systems, without rank or degree of importance among them. All the points where health care is delivered are equally important to meeting the goals established by the health care networks (4). Therefore, the delivery of integral health care, rather than fragmented care, is ensured.

In this sense, RAS structures, for instance, the longitudinality of care, are advantages and are consistent with the act of disclosing difficult news, because it allows care to be continued throughout the instances with different technology densities, favoring empathy and humanization of care for the unfolding of difficult news.

Even with all the advancements achieved to this point, services and actions are still sometimes fragmented. It is not an easy task to implement the delivery of integral heath care, considering that the system is complex and there is a multifactorial nature involved in the system's functioning, such as workers with different backgrounds and specialties, structural differences and technological resources, in addition to the variety of people seeking the public health system<sup>(16)</sup>. Therefore, teamwork in addition to problem-solving capacity and continuity of care is paramount at the different levels of care delivery.

Personal relationships and interactions are subject to conflicts and estrangement within the staff. These conflicts, however, need to be overcome for teamwork to take place, because these are intervenient situations affecting performance<sup>(13)</sup>.

Breaking barriers to good communication and promoting information and dialogue are not merely a need, but a

way to lead to collaborative and solidary practice. Thus, educational actions can be a way to facilitate and strengthen interpersonal relationships and promote communication skills among healthcare teams<sup>(17)</sup>.

The nurses addressed in this study considered that an individual's academic training, professional experience, and personal aspects may facilitate communication because they believe that having previous knowledge of communication tools, as well as technical-scientific knowledge, can be of aid at the time of disclosing difficult news. On their own initiative, nurses seek to learn how to deal with their personal aspects, that is, aspects related to their personalities, using strategies to acknowledge this aspect of themselves and improve the ways they communicate with patients.

[...] You learn better techniques to tell, to talk, the tone of voice becomes more controlled, we start controlling the way we look to patients, control our hands, and it makes a lot of difference in reassuring patients. (N 2)

[...] I guess that undergraduate studies prepare us well. Only that sometimes there are certain things that do not depend on your preparation, but depend on the person, you know, it depends on one's personality [...]. (N 7)

We are never really prepared; we never acquire total control of communication. I guess we are always trying to acquire more knowledge, improve our skills to communicate better. I guess that it is a matter of the person wants to learn and in fact access such knowledge, and there is also continuing education [...] so, you have to know, you have to have competence, responsibility, knowledge, and keep searching, because fully mastering communication, well... we always have to improve it. (N 11)

On the other hand, academic training, professional experience and knowledge were also mentioned as factors that explain lack of effective communication, mainly due to the fact that undergraduate programs do not address strategies on how to disclose difficult news. In general, workers learn how to implement techniques and procedures but are not prepared for communication processes, let alone the communication of difficult news or how to deal with this type of situations.

[...] So, what I can tell, the various things we have to do, the different ways to get prepared, studies, qualification, these usually do not prepare us to disclose difficult news, they usually prepare us to perform procedures [...]. (N 1)

[...] it's a very complicated thing, very difficult, because we are not prepared for this (N 2)

I was not prepared for this in college. We always focus on health care, prevention... so I've never been prepared for this. I've learned over time, with my experience and I still don't know how to do it well, even to this day [...]. (N 3)

[...] But I guess that prepared, really prepared, no, I haven't been prepared, not even at college ok, I guess that I've learned with my experience in primary health care. (N 13)

The fact that academic training, professional experience and knowledge were considered, by some participants, to be barriers impeding good communication, is related to gaps existing in their academic training, especially in college. Even though the disclosure of difficult news is a complex issue that is frequently faced in the routines of health workers, it is still seldom addressed in the curricula of nursing and undergraduate medicine programs<sup>(18)</sup>. Such a gap renders communication even more difficult, unnecessarily increasing the suffering and leading to repercussions for all those involved, especially for those situations in which there is no possibility of cure, as reported by the participants.

The content of difficult news implies some restricteed/ specific information will be disclosed, which may interfere in the response of both workers and family members. Many workers have difficulty communicating difficult news because have never received any training to develop or improve these skills<sup>(2)</sup>. The way to establish good communication between workers and patients is associated with workers' level of preparation and sensitivity<sup>(19)</sup>, and it is during undergraduate training that these skills are supposed to be promoted.

Communication is considered a specific skill that can be more deeply explored and studied among health care workers, especially the communication of difficult news, which is a complex task<sup>(2)</sup>. Investing in Continuing Education programs is an alternative to develop these skills, essential in the delivery of care<sup>(18)</sup>.

Continuing education is intended to transform and qualify healthcare delivery, training processes, and health education practices, in addition to promote the organization of actions and services from an intersectoral perspective<sup>(20)</sup>.

The Política Nacional de Educação Permanente em Saúde (PNEPS) [Continuing Health Education National Policy] is a strategy of the Unified Health System (SUS) to train and improve the skills of health workers in order to establish a connection between teaching, service and community, in

addition to the regionalization of the management of the SUS as the basis for the development qualified initiatives to meet the needs of and cope with the difficulties the system presents. This strategy is intended to promote a transformation in work practices based on critical reflection, proposing a connection between training and the context of practice, by establishing an intersection between learning and teaching in the context of services<sup>(20)</sup>.

Undergraduate programs need to address this topic, which can be done by using psychodramatic techniques together with continuous education. Continuous education can be an ally in developing and improving communication skills. Hence, investing in these programs can be an initiative to develop essential communication skills to perform the task of disclosing difficult news<sup>(17)</sup>.

This study shows there is a concern regarding the quality of communication in disclosing difficult news, while many doubts surrounding this topic still remain. A possibility to circumvent these limitations is to invest in training, though this strategy may be inefficacious for acquiring the necessary skills. Health education programs may be a sustainable alternative to achieve the changes intended to improve the disclosure of difficult news because of the way these programs promote learning.

### CONCLUSION

This study enabled identifying the aspects that hinder and facilitate the work of nurses when disclosing difficult news, considering the importance of such communication in the relationships established between workers and patients. The most relevant barriers reported by the nurses include the fact this is not a topic addressed during academic training, while the main aspects facilitating communication involve teamwork and the way the network functions; that is, the system represents support for workers. Additionally, having privacy to talk with patients and being close to the community enable the establishment of bonds and facilitates the reception of patients.

The communication established among health workers, patients and families is extremely relevant considering that appropriate communication enables providing patient-centered care, taking into account the particularities of each patient. Therefore, communication strengthens the relationship between the staff and patients and humanization is considered the best way to qualify such a relationship. More empathic and more humane behavior is essential, because it enables the establishment of bonds and ties of trust among people, facilitating the disclosure of difficult news.

Additionally, issues involving communication and the disclosure of difficult news need to be more deeply explored and discussed in institutions providing training to workers because not addressing this topic during academic training triggers doubts and fears among future workers, who consequently may fail to communicate efficiently.

Two of this study's limitations is the fact it was conducted with only one group of nurses while the perspective of multidisciplinary teams was not addressed. Additionally, there is a lack of studies addressing this topic, which reinforces the need to focus on a topic that not only is disregarded from an academic point of view, but is also seldom acknowledged in the routine of primary healthcare services.

The contribution of this study to the nursing context is that it proposes reflection upon this topic, leading to the identification of aspects that hinder or facilitate communication and that are faced during the disclosure of difficult news. Hence, strategies can be adopted to implement appropriate and humanized communication in times when patients are the most vulnerable, in order to promote their comfort and wellbeing, bearing in mind the benefits of effective communication.

In this sense, other studies are needed to expand and improve knowledge-based communication strategies to enables nurses to communicate difficult news in the best possible manner.

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