Parents' perception of health education practices in Neonatal Unit

Percepção dos pais sobre as práticas de educação em saúde na Unidade Neonatal

Percepción de los padres sobre las prácticas de educación para la salud en una Unidad Neonatal

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Abstract

Objective: to analyze parents' perception of health education practices developed by nurses in a Neonatal Unit that facilitated the acquisition of parenting skills for an informed decision-making. **Method:** this is an exploratory, descriptive and qualitative study. We included 13 parents with children hospitalized for the first time in a Portuguese Neonatal Unit. Data were collected between February and August 2020, through focus groups, processed in the software *Interface de R pour Multidimensionnelles de Textes et de Questionneires*, through Descending Hierarchical Classification and Similitude Analysis. **Results:** four classes emerged from the Descending Hierarchical Classification: "Information needs"; "Information gaps"; "Availability to inform"; "Facilitating health education practices". **Conclusion and implications for practice:** parents considered digital technology combined with nurses' availability to inform and explain, as well as provide an empathetic and informal environment as facilitating practices for health education. These results can support health education nursing interventions for parents at the Neonatal Units using digital technology.

Keywords: Neonatology; Nursing; Parents; Health Education; Health Literacy.

Resumo

Objetivo: analisar a percepção dos pais sobre as práticas de educação em saúde desenvolvidas pelos enfermeiros na Unidade Neonatal que facilitaram a aquisição de competências parentais para uma tomada de decisão fundamentada. **Método:** estudo exploratório e descritivo, com abordagem qualitativa. Participaram 13 pais com filhos internados, pela primeira vez, em uma Unidade Neonatal portuguesa. Os dados foram colhidos entre fevereiro e agosto de 2020, por meio de grupos focais, processados no *software Interface de R pour Analyses Multidimensionnelles de Textes et de Questionneires*, através da Classificação Hierárquica Descendente e da Análise de Similitude. **Resultados**: da Classificação Hierárquica Descendente, emergiram quatro classes: "Necessidades de informação", "Lacunas na informação", "Disponibilidade para informar"; "Práticas facilitadoras da educação em saúde". **Conclusão e implicações para a prática:** os pais consideraram como práticas facilitadoras da educação em saúde a tecnologia digital aliada à disponibilidade dos enfermeiros para informar e explicar, bem como propiciar um ambiente empático e informal. Tal resultado pode subsidiar o desenvolvimento de intervenções de enfermagem de educação em saúde para pais na Unidade Neonatal, com recurso à tecnologia digital.

Palavras-chave: Neonatologia; Enfermagem; Pais; Educação em Saúde; Letramento em Saúde.

Resumen

Objetivo: analizar la percepción de los padres sobre las prácticas de educación en salud desarrolladas por enfermeras de la Unidad Neonatal que facilitaron la adquisición de habilidades parentales para la toma de decisiones informada. **Método:** estudio exploratorio descriptivo, con abordaje cualitativo. Participaron 13 padres con hijos hospitalizados, por primera vez, en una Unidad Neonatal Portuguesa. Los datos fueron recolectados entre febrero y agosto de 2020, a través de grupos focales, procesados en el *software Interface de R pour Multidimensionnelles de Textes et de Questionneires*, a través de la Clasificación Jerárquica Descendente y el Análisis de Similitud. **Resultados:** surgieron cuatro clases de la Clasificación Jerárquica Descendente: "Necesidades de información"; "Brechas de información"; "Disponibilidad para informar"; "Prácticas facilitadoras de la educación para la salud". **Conclusión e implicaciones para la práctica:** los padres consideraron prácticas facilitadoras para la educación en salud la tecnología digital combinada con la disponibilidad de enfermeras para informar y explicar, además de brindar un ambiente empático e informal. Este resultado puede apoyar el desarrollo de intervenciones de enfermería de educación para la salud para los padres en Unidad Neonatal, con el uso de tecnología digital.

Palabras clave: Neonatología; Enfermería; Padres; Educación para la Salud; Alfabetización en Salud.

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INTRODUCTION

Admission to a Neonatal Unit (NU) can affect the identity and performance of parental tasks[1]. Thus, Family-Centered Care (FCC) approaches stand out in this context, as they promote collaborative care in partnership with parents and informed decision-making[2].

Underlying these approaches is an understanding of parents' preferences and needs. Among the identified parental needs, those related to information have been highlighted in scientific studies[3,4]. Parents express the need to obtain accurate, timely and understandable information to feel competent to care for their child at home[5]. In this context, several programs have been implemented. However, their adoption remains a challenge[6]. Scientific research has contributed to the identification of factors that facilitate or inhibit these practices. A facilitating factor is parents' trust in the source of information[7], with healthcare professionals being identified as the most reliable source[8] and the nursing team as the best source of information, as they spend more time explaining and validating understanding[6]. Parents' ability to understand and assimilate information is another facilitating factor[7]. This ability is affected by the stress associated with hospitalization, the amount of technical information transmitted[9] and the level of parental Health Literacy (HL)[10]. Information can even become useless when it is not communicated in a timely manner, understanding is not monitored or when clarifications are inconsistent[6]. Given the above, it is essential to have a health education practice that overcomes these inhibiting factors.

Organized and structured health education has been considered the main way to improve HL, that is the person's ability to obtain, understand, assess and use health information to make decisions, according to their choices, and implement actions in health[11]. However, it requires an approach that encompasses all levels of HL (functional, interactive and critical) and not just functional literacy, using more interactive methodologies that are not limited to the transmission of information, but that are empowering[12]. In addition to individual abilities and social conditions, the ability to interpret health information will depend on how demanding health systems present it[13]. Traditionally, the practice of health education is characterized by the oral transmission of information, demonstration and practice with healthcare professionals, complemented with printed information[6]. Currently, we find other practices associated with the expansion of digital technologies, such as online educational modules and mobile applications (app), with the potential to reduce gaps in access to knowledge[14]. A scoping review of the effectiveness of communication interventions between parents and professionals at the NU showed the importance of implementing these technologies to promote FCC[15] and parents' preference and receptiveness to their use[16].

Given the multiplicity of potential inhibiting factors to health education of parents at the NU, there is a need for a greater understanding of how nurses will be able to make these practices more suited to the educational needs of parents, what parents consider to be facilitators and to what extent digital technologies can be an asset. Thus, this study aims to analyze parents' perception of health education practices developed by NU nurses that facilitated the acquisition of parenting skills for informed decision-making.

The results will allow the development of a health education project to promote HL of parents at the NU through a digital intervention using an app.

METHOD

Study design

This is an exploratory, descriptive and qualitative study, with two focus groups (FGs) carried out in February and August 2020. In the group interview, data are generated by the group debate on the phenomenon under study, streamlined by a moderator[17] and allows deepening and contrasting different perspectives, opinions and experiences between similar people[18].

Sample

The study included 13 parents who had children admitted for the first time in a NU.

Selection criteria

Parents (mother or father) of Portuguese nationality who speak Portuguese and who had a child admitted to a NU in the past six months were included. Parents who did not answer the phone after three contacts or did not have availability on the scheduled date were excluded. Considering that the length of hospital stay may influence the parents' perceptions of health education practices, the sample was divided into two groups. The first FG included parents whose children stayed in the NU for more than 15 days, and the second FG included parents whose children's NU stays lasted less than 15 days. In the selection of parents, the following variables were considered: gender, length of the NU stay and being the first NU stay experience. This diversification of participants, integrated in the FGs, made it possible to fulfill the assumption of parents' heterogeneity. The recruitment of participants was carried out by telephone and complemented with an invitation via email.

Data collection

The FGs took place in a private room. The Principal Investigator moderated the FGs and was assisted by a researcher with functions of observation of non-verbal communication, time management and registering of pertinent information[17]. Data collection methods included audiovisual recording, complemented with annotations and participatory observation. The data collection instruments were a semi-structured guide, a participant characterization questionnaire, and an observation grid. At the beginning of each FG, the moderator presented the FG's objectives and general rules. A summary of the topics discussed was carried out at the end, which allowed summarizing and clarifying the main conclusions. The two FGs had an average duration of 60 minutes.

Data analysis and treatment

A descriptive analysis of the demographic data was performed. The verbatim of the audio recordings was transcribed and later analyzed and complemented with information from the audiovisual recording and the annotations made. Data analysis was based on the FCC theoretical framework[2] and the software *R-interface pour Analyzes Multidimensionnelles de Textes et de Questionneires* (IRAMUTEQ®), version 0.7 Alpha 2[19,20], was used to perform a lexicographical analysis using Descending Hierarchical Classification (DHC) and Similarity Analysis (SA).

Ethical aspects

The study was approved by the Research Ethics Committee of the Hospital Institution on 2019/07/03 (opinion E.E909519). All participants were informed orally and in writing that their participation was voluntary, that they could stop participating at any time without any punishment, and that the confidentiality and anonymity of data would always be guaranteed. In addition, all the participants signed the Informed Consent Form.

RESULTS

Of the 18 eligible parents, five were excluded for non-attendance, so that seven mothers and six fathers participated in the FGs. The mean age of participants was 29 years. As for education, 38.5% have higher education, 23.1% have secondary education, and 38.5% have primary education. 53.8% of the participants were parents for the first time, while 46.1% already had a child. The gestational age at birth ranged between 26 and 35 weeks.

The textual *corpus* of the two FGs was composed of 30 texts organized monothematically in a single file in the program Apache OpenOffice. Each of them was separated by a command line and characterized by gender (p), the number of children (f) and education (e) (e.g., **** *q_1 *fg_1 *s_2 *f_2 *e_2) for the three issues (q) of FG: Q1 – the need for information, Q2 – health education practices, Q3 – the use of digital technologies. Thus, 112 text segments were obtained, of which 99 (88.39%) were used by IRAMUTEQ®. This result indicates a good content consistency and adequacy submitted for this type of analysis[20,21]. Also, 889 words that occurred 3,761 times were counted, with an average frequency of 33.58 words for each form. The cut-off point used for the inclusion of words in the dendrogram classes was 0.67.

DHC identified four classes that were named after their descriptors. The first content breakdown demarcates Classes 3 (Information needs), 2 (Information gaps) and 1 (Availability to inform) of Class 4 (Facilitating health education practices). The second division delimits Class 3 from Classes 2 and 1. To better understand the process of dividing textual content and the constitution of classes, we present Figure 1 (DHC dendrogram), with the words associated with each class, which met the criteria of chi-square ≥3.84 and p-value less than 0.05[20].

Class 3 comprises 26.26% of the total analyzed *corpus*. Parents' perceptions of information at the NU were related to the words *pamphlet, talk, schedule, deliver, shock, prepare, search,* *participate, have, enter* and *little by little*. The speeches of parents in this class referred to the need, adequacy, and way in which they obtained the information. Most parents expressed satisfaction with the information transmitted at the NU: *I was always informed* (fg2), *having information made it easier* (fg1) and *the information was provided timely* (fg1). Although, one of the parents stated that *the information was given little by little* (fg2), which made him think that the daughter was not well: *was regressing*. Parents also mentioned the need to improve preparation before entering the NU or reception on the first visit: *could explain to the mother and father what could happen for us to prepare psychologically* (…) *have more information, maybe, I wouldn't suffer so much* (fg1). Parents reported that the first contact with the NU was a shock, which made communication with healthcare professionals difficult and, above all, understanding the information: [professionals] *spoke, spoke but nothing came in* (fg1), *spoke I don't know what, I don't remember, this part I don't remember* (fg1). Most parents mentioned that the shock was mitigated by the previous experience of hospitalization of a family member in an intensive care unit and by the possibility of seeing children's pictures *before seeing them in person* because *it helps to be more prepared and not have that first shock* (fg2) right away.

They also reinforced that the delivery of pamphlets as a complement to the information orally transmitted allowed them to review some of the information provided. As for the reception pamphlet, parents emphasized *visiting time* (fg2) and the *information about the unit* (fg1). Two mothers mentioned the pamphlet alluding to the Kangaroo Method (fg1), and another mother mentioned that the only pamphlet *given to me was the Heel Prick Test* (fg2). One mother mentioned that she still had the pamphlet on breastfeeding at home and emphasized its usefulness for *knowing the freezing part* (fg1). However, other parents reported that *they didn´t deliver any pamphlet* (fg2) during hospitalization at the NU, which may be linked to the initial shock of the first contact with the NU. Parents also looked for information, specifically on the *Internet: I searched for myself* (fg2); *I even went to the Internet and looked for a lot of stuff* (fg1), *we looked for information on Dr. Google* (fg1). On the one hand, it seemed to be useful: *searching the Internet demystified some things* (fg1); on the other hand, it also generated some confusion: *is interesting but there is also a lot of confusion* (fg1). A mother mentioned that she turned to a family nurse as a source of information, while a father mentioned that he *didn´t look for information anywhere, but I believe it is necessary* (fg1).

Class 2 constitutes 22.22% of the total *corpus* analyzed. Associated words were *stay*, *intensive care*, *possible*, *moment*, *wait*, *said* and *pass*. In this class, parents' speeches referred to aspects that could be improved. They considered that *it would be important to visit the unit beforehand, especially in situations that it is possible to foresee* (fg1), in order to meet the unit, the team and know that they were prepared to receive their daughter. They mentioned lack of information about the length of stay, *because while they are saying that everything is fine, they are also prolonging length of stay* (fg2), about admission to the NU,
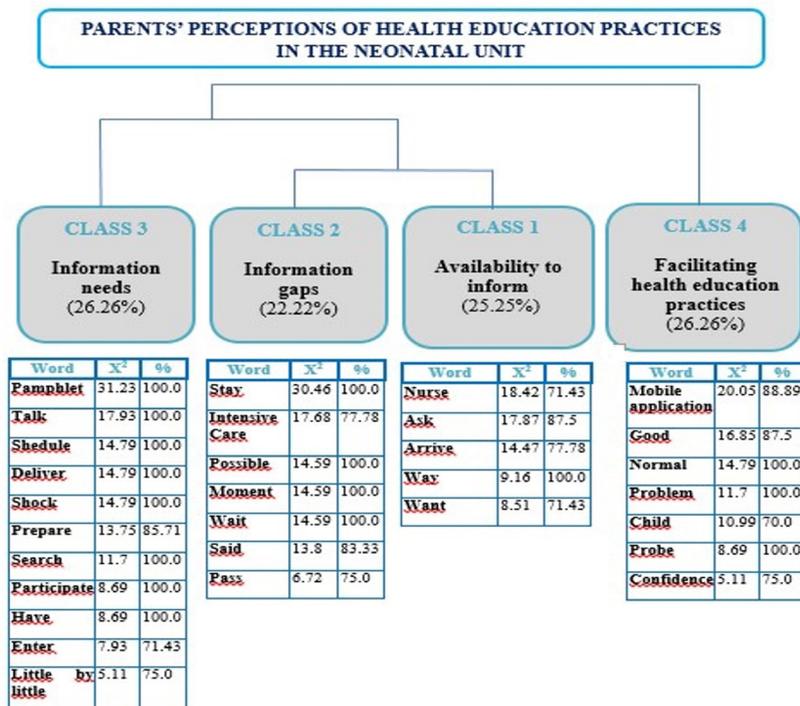
Figure 1. Component classes of the textual *corpus* dendrogram. Prepared by the authors. Portugal, 2020.

because *we were not told she was going to the intensive care* (fg2), *they said they were going to take exams, the father realized through the letters that it was the intensive care* (fg2) and about the possibility of breastfeeding at the NU (fg2).

Class 1 comprises 25.25% of the total *corpus* analyzed and was named "Availability to inform", based on words *nurse*, *ask*, *arrive*, *way* and *want*. In this class, it was found that the parents valued the information given by the nurses and the fact that they were available to explain and immediately clarify doubts, regardless of the time. Parents mentioned that *even without asking, the nurse would come to meet me and say she is like this because this happened, and this* (fg2) and that *they explained at the moment, if not at the moment, when there was a doctor or nurse who knew the situation, they explained* (…) *I think that just the fact that they asked us also made us want to do more and better* (…) *and these are the lessons that we then take home* (fg1). Another father also valued the availability of nurses even at night (fg2).

Finally, Class 4 corresponds to 26.26% of the total *corpus* analyzed. This class gathered words *mobile application*, *good*, *normal*, *problem*, *child*, *probe* and *confidence*. Parents' speeches revealed that they value other ways of transmitting information, such as having access to a NU app: *would make perfect sense* (fg1), *would help* (fg2), *was a good idea* (fg2), especially *if it was an app of the unit, we have another trust* (fg1), *we have the certainty that the information is trustworthy* (fg1), which does not happen with what we find on the *Internet*. One of the parents pointed out that having an app *would be*

useful for admissions for a few or many days (fg2) and that it could contain *information about our child* (…) *the various types of problems that could happen during the stay* (fg1), *a personal section with the children's own data* (…) *generic information on what is a normal complication of a premature baby* (fg1). Other practices considered facilitating were the sending of text messages via mobile phone, *with the children's status* (…) *write good morning mom, I'm like this* (…), *have access to children's pictures in real time* (fg2) and *a video to know that there is a load of wires connected to the children and catheters and everything that is completely normal* (fg1). Parents also valued active participation in care, *was very good and this is what exceeds expectations after* (fg1), as well as the informal environment, because *feeling that the child is at home, a less formal environment, gives confidence* (fg1).

SA synthesizes the lexical content found from the classes presented. In this analysis, the greater clarity of connections between words reflects their relevance for understanding the phenomenon studied. This was based on the co-occurrence between words *say*, *give*, *information* and *unit*, shown in Figure 2.

The word *say* was the most recurrent and has a higher correlation with *give* and *nurse* and lower correlation with *time* and *intensive care*. From the word *give*, branched the words *information* and *unit*. Thus, the results show that, associated with *information*, are *know*, *pamphlet* and *mobile application*, which reveal practices that parents consider to be facilitators; words *good*, *important*, *feel* and *home* are related to *unit*, which express what parents value. Word *nurse* is associated with *arrive*, *ask*
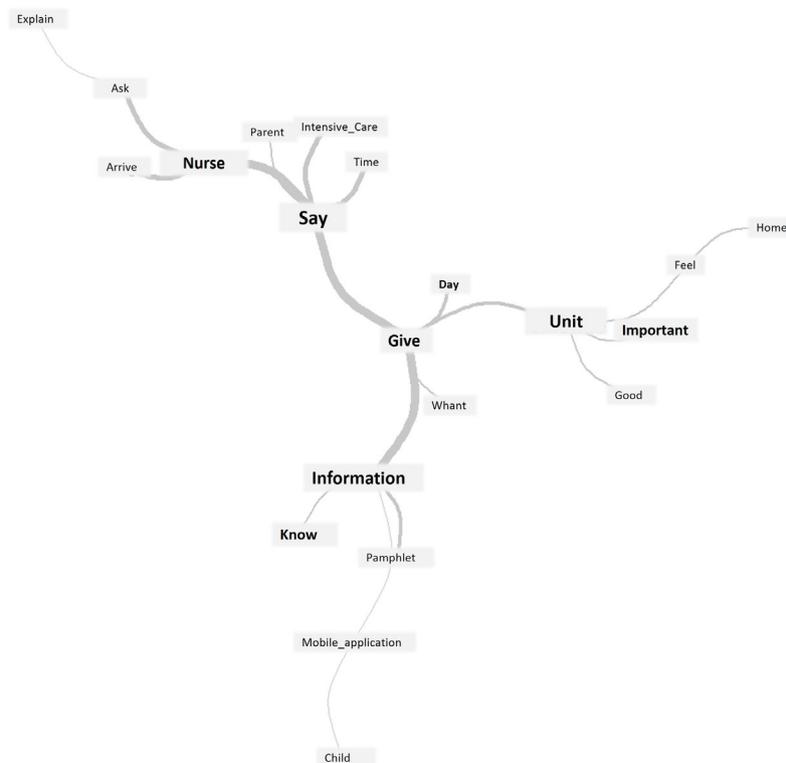
Figure 2. Similarity Analysis of the textual corpus. Prepared by the authors. Portugal, 2020.

and *explain*, which correspond to the availability demonstrated by this professional.

DISCUSSION

Analysis of parents' perception of health education practices carried out by nurses at the NU allowed identifying needs and gaps in the information transmitted, practices that could facilitate the acquisition of parenting skills for informed decision-making, as well as the attitude of availability of nurses to inform them.

In Class 3, parents valued the information and stressed the importance of considering the amount and time it is transmitted, as it influences their preparation and emotional control. These results are corroborated by a literature review[21], which showed that the information needs of these parents are great and dynamic and that, when the information is incomplete or difficult to understand, their stress increase. The parents in this study expressed the need for better preparation to enter the NU for the first time due to the emotional shock they felt, what made difficult for them to remember the information. They also emphasized as beneficial the prior availability of children's pictures, which is consistent with the results of a review study by Brett et al.[6]. Parents also valued the information leaflets delivered by nurses, which was also considered an effective intervention to communicate, support and provide information to parents of premature newborns in the same review study[6]. However, they expressed the need for additional information as they resorted to family members who worked in

the health area and to the Internet to obtain more information. This fact is consistent with the results of a study by Lima and Mazza[4], which identified that the information needs of parents are broad and that they use traditional but also technological resources to meet them.

Gaps in information (Class 2) identified by parents were the lack of a previous visit to the NU to meet the team and the location, in addition to the lack of information about admission and length of stay. These gaps are related to the results of a review by Brett et al.[6], who referred to the potential of previous visits to the NU, and a study by Lebel et al.[14], which proved to be beneficial for parents to receive information before birth and admission to the NU and during hospitalization. Lack of information about admission and length of stay was also reported in a scoping review by Ballantyne et al.[3] as a source of stress associated with the absence of involvement in the decision and of adequate information to prepare for transition.

In turn, nurses' availability to inform and explain (Class 1) was also valued in the study by Williams et al.[22], which related the reduction of parental stress with the quantity and quality of communication between healthcare professionals and parents. In investigating the information needs of families at the NU, Lima and Mazza[4] concluded that parents want professionals to spend time explaining and clarifying doubts on technical terms regularly. In turn, the review study by Brett et al.[6] showed that parents prefer nurses as a source of information, as they dedicate more time explaining and validating understanding. This attitude of availability supports what is recomended in CCF approaches[2].

Finally, parents identified as facilitating health education practices (Class 4) the use of digital technology, namely through a NU app, sending text messages, video calling, and videos of the children and the NU. These results are in line with other studies that revealed that parents want and consider beneficial to make a neonatal app available at the NU[14] and that they prefer digital resources instead of printed, particularly those indicated by NU professionals because they are more trustworthy[16]. Sending text messages with information about the children was also mentioned as a facilitator in another study by Globus et al.[23]. In turn, according to an integrative review by Epstein et al.[24], the use of digital technology, through video calling, is appreciated by parents when they could not stay at the NU. The parents in our study also valued active participation in care, the informal environment and the previous visit to the NU. These results are similar to those of a review study by Brett et al.[6], that associated these practices with increased parental trust and involvement with their children.

The results of this study highlighted the need for professionals to reduce parental stress and optimize parental involvement in care through effective communication, presence and empathy, which are inherent to FCC approaches[25]. We also emphasize that, despite the differences in length of stay, there were no differences in terms of health education practices at the NU when comparing the results in the two FGs.

CONCLUSION AND IMPLICATIONS FOR PRACTICE

Parents considered the use of digital technology as facilitating health education practices, emphasizing the provision of a NU app by nurses, together with the availability to inform and explain in an empathetic and informal environment. These results show that digital technologies are not substitutes but complementary resources and promoters of existing health education practices based on the relationship and communication between parents and professionals. Nurses should increase FCC approaches principles as a pillar of health education practices for parents at the NU and use digital technologies, based on scientific evidence, as a complementary resource and facilitator. A limitation inherent to study design is related to the fact that the included participants may not be representative of parents' perception at the national level, restricting the generalization of results.

AUTHORS' CONTRIBUTIONS

Study design. Nisa Rubina Pereira Souto Rosa. Maria Adriana Pereira Henriques. Maria Alice dos Santos Curado

Data collection and production. Nisa Rubina Pereira Souto Rosa.

Data analysis. Nisa Rubina Pereira Souto Rosa. Maria Adriana Pereira Henriques. Maria Alice dos Santos Curado

Interpretation of results. Nisa Rubina Pereira Souto Rosa. Maria Adriana Pereira Henriques. Maria Alice dos Santos Curado

Writing and critical review of the manuscript. Nisa Rubina Pereira Souto Rosa. Maria Adriana Pereira Henriques. Maria Alice dos Santos Curado

Approval of the final version of the article. Nisa Rubina Pereira Souto Rosa. Maria Adriana Pereira Henriques. Maria Alice dos Santos Curado

Responsibility for all aspects of the content and integrity of the published article. Nisa Rubina Pereira Souto Rosa. Maria Adriana Pereira Henriques. Maria Alice dos Santos Curado

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