



Parent-centred Communication in Neonatal Intensive Care Units: Needs and Sources of Information

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Abstract

This study intends to analyse the information needs reported by mothers and fathers of very preterm babies and their perception about the quality, comprehensibility, usefulness and availability of the main sources of information used to fulfil them. Parents (n=211) of very preterm infants hospitalised in all level III NICU in the Northern Health Region of Portugal were consecutively and systematically invited to participate in the study (July 2013-June 2014). Mothers attributed higher importance to information needs than fathers (Median (P25-P75): 3.8(3.6-3.9) vs 3.7(3.5-3.9), p<0.05). Parents focused on information regarding infants' health and treatment during hospitalisation that is provided by nurses and physicians, considering it of good quality, easy to understand and useful. Information provided by nurses was perceived as the easiest to obtain. Improvements in parent-centred communication in NICU depend on assessing gender-specific needs of information, diversifying the sources used during infants' hospitalisation, and assuring the quality of the information.

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Introduction

To experience the hospitalisation of a very preterm infant in a Neonatal Intensive Care Unit (NICU) constitutes a disruptive life event for mothers and fathers [1,2]. This experience interferes with the development of a immediate and secure bonding between parents and infants, which may result in feelings of incompetence regarding parenting roles [3]. The provision of clear, continuous and reliable information about infant's health status and care during the hospitalisation of a preterm infant in NICU

helps parents to positively handle with such adversity [4,5,6], since it increases parents' perception of control and strengthens their confidence on decision making regarding infants' care and wellbeing [7,8]. Appropriate and timely information not only improves parents' psychological health and satisfaction in NICU [9,10], but also benefits infants' health outcomes [11]. Overall, it enhances the quality of health services outcomes with a consequent reduction of costs [11], as well as health professionals' performance and job satisfaction [12,123].



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During hospitalisation in NICU, parents frequently report barriers to communication related with conflicting, vague, confusing, indirect or scant information regarding the diagnosis, treatment and prognosis of their newborn [14,15]. These perceptions often contrast with the views of health professionals, who frequently overestimate the amount of information provided to parents [16]. This mismatch may result in additional parental stress [17], considering the crucial role of nurses and physicians as the main source of information to parents during the infants' hospitalisation period [4,14].

An effective parent-centred communication in NICU [18,19], i.e. responsive to and respectful of parents' needs, is crucial to the provision of quality care, but empirical studies on this topic are still scarce [20]. Literature has been focused on how information needs, as well as information seeking behaviours, are influenced by gender [14,16], neglecting the analysis of parents' perception of the quality, usefulness, comprehensibility, and availability of the sources they used to overcome their information needs. It has been previously described that fathers tend to value the access to concise, accurate and consistent information about their infants, while mothers seem more concerned in establishing a collaborative relationship with the nurses, treating them as equal [16]. However, there is still a need to explore the gender-specific sources of information used during hospitalisation, as well as the mothers' and fathers' perceptions regarding communication practices, in order to promote a more open and tailored communication between the health providers and the parents.

Aiming to enhance parent-centred communication in NICU, this study analyses the information needs reported by mothers and fathers of hospitalised very preterm infants and their perception about the quality, comprehensibility, usefulness and availability of the main sources of information used to fulfil them.

Materials and Methods

The current study is compliant with the STROBE checklist for reporting observational cross-sectional studies (Supplementary File 1).

Between July 2013 and June 2014, all mothers and fathers of infants born before 32 weeks of gestation and hospitalised in all level III NICUs in the Northern Health Region of Portugal (n=7) were consecutively and systematically invited to participate [21].

The study was approved by the National Data Protection Commission and Ethics Committees of all the hospitals in which the study was performed (410/12(286-DEFI/348-CES); 042/CE/JAS; 105/13/OP; CA/27/2013; 12/CES (2013); CA-142/13-0t FS/AC; ENEPPG 132/2013), and written informed consent was obtained from all the participants.

Parents of very preterm infants were approached two weeks after birth during the hospital stay by a NICU health professional (neonatologist or nurse) who was responsible for the study presentation and participants' invitation. Only parents without serious illness that precluded NICU visitation (e.g., severe chronic conditions) and those who were present in the NICU during the hospitalisation period were considered eligible to participate in the study. Among the 126 eligible families, 122 (96.8%) agreed to participate, including 120 mothers and 91 fathers. During data collection, 2 mothers were absent due to medical complications, and 31 fathers were absent because of

professional commitments or emigration. After the exclusion of 8 participants with missing data on the questions regarding the sources of information and on the information needs subscale, 203 participants (116 mothers and 87 fathers) were included in the current analysis.

Structured questionnaires were administered by trained interviewers to mothers and fathers separately, during a face-to-face interview, 15 to 22 days after the child's birth. Data on sociodemographic characteristics (age, marital status, educational level and household monthly income), previous pregnancies, the use of assisted reproductive technologies for the current pregnancy, and sources of information in the NICU were collected through self-report.

Participants were asked to identify the first, second and third source of information during hospitalisation in NICU from a list of several possible sources, namely: physicians; nurses; family and friends; parents of other infants hospitalised in NICU; support groups; the internet; and written material (brochures, posters and books). The questionnaire also permitted the selection of "other" as an option, requesting the participant to specify other possible sources of information, as well as the option to choose none of the presented options. Afterwards, participants were asked to quantify their agreement level, using a 5-points Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree), regarding the following characteristics of the information provided by each source: "good quality", "easy to understand", "useful" and "easy to obtain". If the participants had never used a specific source, the respective item could also be classified as not applicable. For data analysis, the answers were categorised as "Disagree" (including the options 1 to 2); "Do not agree nor disagree" (option 3); "Agree" (including the options 4 and 5) and "Never used" (including the option not applicable).

Additionally, mothers and fathers filled in the Portuguese version of the NICU Family Needs Inventory [22,23], to measure the importance attributed to family needs. This self-reported scale consisted in 56 need statements, ranging from 1 (not important) to 4 (very important), grouped into 5 subscales: "assurance", "comfort", "information", "social support" and "proximity". Each item could be classified as not applicable, if the participants had never experienced the specific need. In the present study, we only analysed the items included in the subscale "information" (n=11). When items were classified as non-applicable, the score was calculated as the mean of all items answered multiplied by the total number of items in the subscale.

Data on pregnancy complications (infectious, placental, haemorrhagic and cardiovascular), multiple pregnancy, infant's birth weight and gestational age were retrieved from clinical records. Infants with birth weight below 1000 grams and a gestational age below 28 weeks, were defined as extremely low birth weight babies and extremely preterm infants [24], respectively.

To guarantee the validity and reliability of the current study, we employed valid and tested tools whenever possible. The questionnaire domains and individual items were developed based on the findings of a literature review describing parents' perspectives on the hospitalisation of preterm infants on [25], and the questionnaire was further pilot tested with 22 mothers and 17 fathers of very preterm infants hospitalized in the level III NICU with the largest number of very preterm infants in the North of Portugal. Also, the Portuguese version of the NICU Family Needs Inventory [22,23] was described as a valid instru-

ment with a high degree of reliability ($\alpha \geq 0.76$).

Statistical analysis was performed using Stata 15.1 (College Station, TX, 2009). Sample characteristics and data on sources of information were presented as counts and proportions. The overall score of the information needs subscale was presented as medians and percentiles (P25-P75) and compared using the Mann-Whitney test, stratified by gender.

Results

Approximately 70% of the mothers and fathers were younger than 35 years, and the majority were married or lived with a partner (Table 1). Nearly 40% described a household monthly income above 1500€, with 44% of the mothers and 31% of the fathers reporting more than 12 years of formal education. This was the first pregnancy for more than 50% of the participants, and approximately 12% had report the resort to assisted reproductive technologies for the current pregnancy. More than 45% presented at least one pregnancy complication, and almost a quarter of the pregnancies were multiple. Approximately 20% of the pregnancies resulted in extremely preterm delivery, while nearly 30% of the women delivered an extremely low birth weight infant.

A higher importance was attributed, by mothers, to information needs, in comparison with fathers (Median (P25-P75): 3.8 (3.6-3.9) vs 3.7 (3.5-3.9), $p < 0.05$) (data not shown). Parental needs of information were considered very important by 89.7% of the mothers and 81.6% of the fathers, with no parents considering such needs as slight important or not important (Table 1). As presented in Figure 1, the needs more frequently reported as very important were: “To know how my infant is being treated medically” (97.4% of the mothers and 93.0% of the fathers); “To know exactly what is being done for my infant” (91.4% of the mothers and 87.4% of the fathers); “To know which staff members could give information about my infant’s health and general well-being” (93% of the mothers); and “To know why things were done for my infant” (83.9% of the fathers). Contrariwise, “To be given information about individuals that could help with problems concerning my situation” (54.3% of the mothers and 45.1% of the fathers), “To be given reading material concerning my infant’s medical concerns” (55.2% of the mothers and 42.7% of the fathers), and “To have classes about premature infants and their special care needs” (68.6% of the mothers and 59.8% of the fathers) were the needs less frequently reported as very important.

More than 90.0% of the participants identified nurses (67.2% of mothers and 60.9% of fathers) or physicians (29.3% of mothers and 33.3% of fathers) as the first source of information (Figure 2). Physicians and nurses emerged as the second source for mothers (59.5% and 37.9%, respectively) and fathers (57.5% and 28.7%, respectively). Parents of other hospitalised infants constituted the third source of information for 32.2% of the mothers. More than one quarter of the fathers (27.6%) did not rely on a third source to answer their information needs during infants’ hospitalisation in NICU. A lower proportion of mothers and fathers mentioned the internet (18.3 % and 25.3%, respectively), family and friends (13.9% and 24.2%, respectively), written materials (6.1% and 10.4%, respectively), and support groups (5.2% and 1.2%, respectively) as one of the three main source used to fill their information needs.

Almost all mothers and fathers considered the information provided by nurses and physicians of good quality, easy to understand and useful (Figure 3), but the information was easier to obtain from nurses. The information provided by parents of other infants hospitalised in NICU, written materials and support groups were also classified as being of good quality, easy to understand, useful and easy to obtain by more than 80% of mothers and fathers who resorted to these sources of information during hospitalisation. Parents agree that information available on-line is easy to obtain, however a lower proportion considered such information of good quality (48.9% of the mothers and 56.1% of the fathers) and easy to understand (57.8% of the mothers and 58.5% of the fathers).

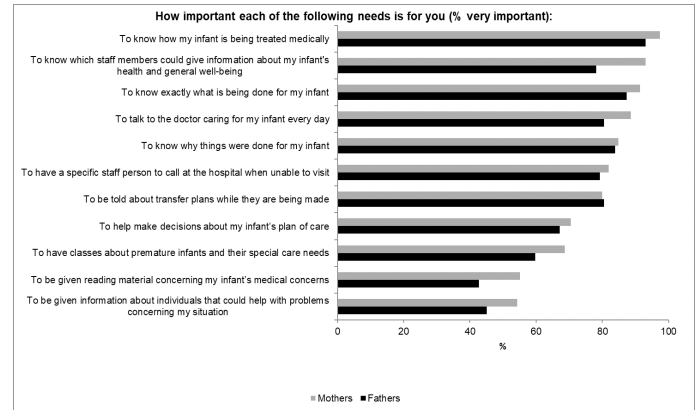


Figure 1: Parental information needs classified as very important during hospitalisation in NICU, by gender.

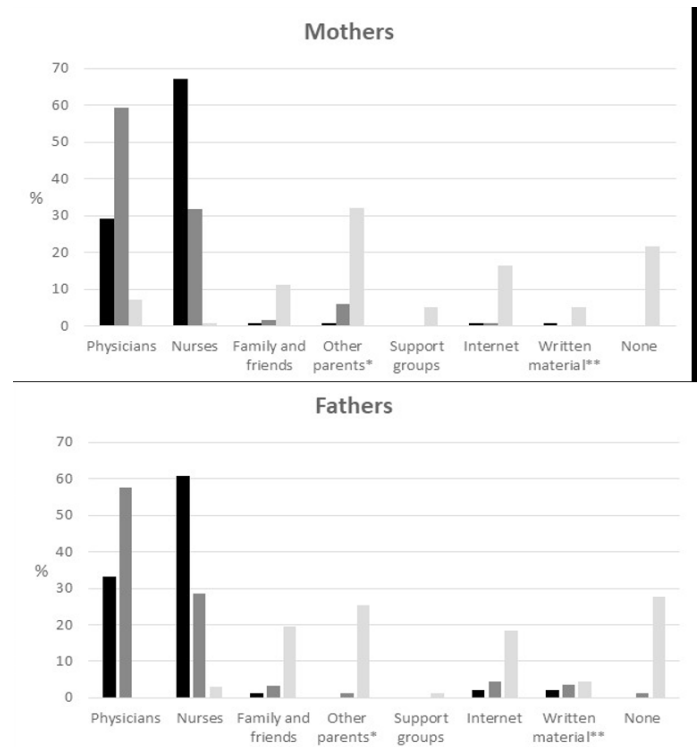


Figure 2: Three main parental sources of information during hospitalisation in NICU, by gender.

Table 1: Participants’ characteristics, according to gender.

| | Total (n=203) n(%) | Mothers (n=116) n (%) | Fathers (n=87) n% |
|---|-----------------------|--------------------------|----------------------|
| Age (years) | | | |
| <35 | 143 (70.4) | 83 (71.6) | 60 (69.0) |
| ≥35 | 60 (29.6) | 33 (28.4) | 27 (31.0) |
| Marital status | | | |
| Married/cohabiting | 177 (87.2) | 100 (86.2) | 77 (88.5) |
| Single/divorced/widowed | 26 (12.8) | 16 (13.8) | 10 (11.5) |
| Educational level (years) | | | |
| ≤12 | 125 (61.6) | 65 (56.0) | 60 (69.0) |
| >12 | 78 (38.4) | 51 (44.0) | 27 (31.0) |
| Household income (€/month) | | | |
| ≤1500 | 122 (61.0) | 70 (61.9) | 52 (59.8) |
| >1500 | 78 (39.0) | 43 (38.1) | 35 (40.2) |
| Number of pregnancies | | | |
| 1 | 113 (55.7) | 61 (52.6) | 52 (59.8) |
| ≥2 | 90 (44.3) | 55 (47.4) | 35 (40.2) |
| Assisted reproductive technology use | | | |
| No | 178 (87.7) | 102 (87.9) | 76 (87.4) |
| Yes | 25 (12.3) | 14 (12.1) | 11 (12.6) |
| Pregnancy Complications[§] | | | |
| No | 102 (54.0) | 60 (55.0) | 42 (52.5) |
| Yes | 87 (46.0) | 49 (45.0) | 38 (47.5) |
| Multiple pregnancy | | | |
| No | 156 (76.8) | 89 (76.7) | 67 (77.0) |
| Yes | 47 (23.2) | 27 (23.3) | 20 (23.0) |
| Extremely premature delivery* | | | |
| No | 159 (78.3) | 91 (78.4) | 68 (78.2) |
| Yes | 44 (21.7) | 25 (21.6) | 19 (21.8) |
| Extremely low birth weight delivery‡ | | | |
| No | 141 (69.5) | 79 (68.1) | 62 (71.3) |
| Yes | 62 (30.5) | 37 (31.9) | 25 (28.7) |
| Information needs | | | |
| Very important | 175 (86.2) | 104 (89.7) | 71 (81.6) |
| Important | 28 (13.8) | 12 (10.3) | 16 (18.4) |
| Slightly important | 0 (0.0) | 0 (0.0) | 0 (0.0) |
| Not important | 0 (0.0) | 0 (0.0) | 0 (0.0) |

Discussion

The present study offers a description of key aspects regarding the information needs of parents of very preterm infants, as well as, their perception about the quality, comprehensibility, usefulness and availability of the main sources of information used during the first three weeks of infants’ hospitalisation in NICU. Mothers attributed higher importance to information needs than fathers. Parents focused on information about infants’ health and treatment during hospitalisation, attributing lower importance to information regarding individuals that could help parents to deal with the current situation, and about the provision of reading material and classes about prematurity. Nurses and physicians emerged as the main sources of in-

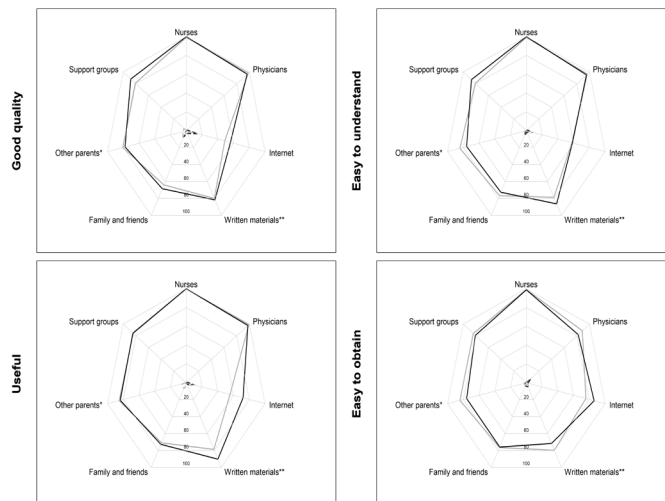


Figure 3: Three main parental sources of information during hospitalisation in NICU, by gender.

* Parents of other infants hospitalised in NICU;

** Brochures, posters and books.

Note: In order to improve readability, the category “Do not agree nor disagree” was omitted from the figure.

Mothers: ——— Agree - - - - - Disagree
Fathers: ——— Agree - - - - - Disagree

formation to fulfil their needs, while the resort to the internet, family and friends, written materials and support groups were less frequently reported. Information provided by health professionals, parents of other infants hospitalised in NICU, written materials and support groups was perceived as being of good quality, easy to understand and useful. Information provided by nurses was the easiest to obtain. The internet was the source of information less frequently perceived as being of good quality and easy to understand, both by mothers and fathers.

The high importance attributed to information needs by mothers and fathers is in accordance with previous literature, reinforcing the inclusion of communication and information as essential dimensions of neonatal care [4,7,26]. Our results suggest that health professionals should favour the provision of information related with infant’s health progress and treatment effectiveness. Similarly, previous studies revealed that the need for accurate information related to the infant was the major concern of mothers and fathers of hospitalised infants [22,27], which illustrates the dominance of intensive parenting where parents focus exclusively on child’s health and wellbeing and feel the need of guidance from health professionals [28].

Most parents look for information as a coping strategy to reduce anxiety and stress [4]. However, insufficient information about infants’ medical condition and poor staff communication constitute stressful factors for parents of hospitalised infants in NICU [29]. In this context, the enhancement of parent-centred communication is crucial, but face several challenges. Some parents use problem-focused strategies by asking questions, requesting updates with senior medical staff and accessing additional information sources, while other parents use strategies more focused on their emotions, namely avoiding receiving information and refusing offers of support [30]. Health professionals need to be empathetic to tailor the delivery of information to parents characteristics and expectations, the infant’s clinical status, parental socio and cultural background and previous experiences and knowledge [4].

The higher importance attributed to information needs by mothers than fathers described in our study suggests the existence of differences in the perception of parental needs in NICU according to gender [4,31]. Whereas mothers emphasized the importance of knowing which staff members could give them information about their infants' health and general well-being, fathers stressed the relevance of knowing why things were done for their infants. Such differences are associated with the traditional gender division of emotional work, where mothers remain as primary caregivers who establish daily interactions with staff, while fathers protect the whole family by being responsible for the child, the mother and the external environment [31,32]. In fact, mothers spend a higher number of hours in NICU and assume the responsibility for the care of the newborn, while fathers are more frequently absent during hospitalisation due to work or other family life commitments [32]. These results reinforce the need for assessing gender-specific needs of information with the aim of developing gender-sensitive strategies to improve parent-centred communication in NICU.

The reliance on nurses and physicians as the principal sources of information during hospitalisation in NICU indicates that parents experienced communication with the health professionals as crucial to manage their experience during hospitalisation [13,33,30]. It is noteworthy that more than 20% of mothers and almost 30% of fathers did not report any other source of information beyond nurses and physicians. The period of data collection, 15 to 22 days after the infant's birth, may explain the dominance of these health professionals as sources of information, since parents spend most of their time in NICU in the first weeks after delivery. Considering that networks with multiple sources of information tend to provide more emotional and instrumental support than less dense networks [34], the diversification of the information sources used by parents after a very preterm delivery may contribute to meet differential parental needs, including health mediators as family/friends, parents of other very preterm infants, psychologists, social workers and the internet.

Mothers and fathers perceived the information provided by health professionals, as being of good quality, easy to understand and useful. The fact that parents considered easier to obtain information from nurses than from physicians might be related with difficulties to obtain updated information from the latter [30], possible due to the lack of training regarding careful listening skills or to brief explanations of medical care [18]. Nurses have a key role in assisting mothers and fathers during infants' hospitalisation as they are the main providers of information on NICU routines, medical equipment and devices, and daily updates about the health status and clinical condition of the infant [29,30]. However, parents also valued opportunities to talk directly with physicians, even when they only reinforce previous information already provided by the nursing staff [27,30]. To reduce parenting anxiety and stress by promoting satisfaction and trust in the staff [35], it is crucial to ensure the availability of all health professionals to answer empathetically to the information needs of mothers and fathers. For this purpose, a high-fidelity communication system should be implemented, where the provision of information is a basic complementary dimension of the delivery of medical care [27]. In addition, there is a need to clarify the role of nurses and physicians regarding the provision of information, to avoid the dissemination of contradictory, ambiguous or vague information, as well as, to help parents to recognize what kind of information each professional can give them.

Mothers also mentioned the parents of other hospitalised infants as a common source of good quality information, easy to understand, useful and easy to obtain, which is in accordance with previous literature reporting that mothers, in comparison with fathers, experienced more support from other parents in the NICU [7]. A systematic mapping review of effective interventions for communicating with-, supporting and providing information to- parents of preterm infants reported the benefits of participating in support groups, either organised by NICU staff or by other parents who have experienced a preterm delivery [36]. Mothers and fathers tend to find helpful discussing their experiences and sharing information, especially with "longer-term mums" [27]. The reference to family and friends as a source of information was scarce, since their support to parents after a very preterm delivery is usually more instrumental and pragmatic, helping them to deal with activities of daily living, namely, cleaning the house, buying food and cooking [4]. Such supports the need of promoting educational groups with informal sources, namely peers and family members [37], especially for those without cases of premature birth in their close relations.

Our study challenges the idea that the internet is frequently used by parents of infants admitted in NICU [27,38]. Beyond the underuse of this resource, the participants do not trust in the quality and question the comprehensibility of the information available online. In fact, a recent study that identified and evaluated apps targeting parents of infants in the NICU for quality of information, usability and credibility, concluded that not even 50% of them should be considered acceptable as educational material, with the remaining revealed several problems in terms of quality and credibility [39]. The certification of the websites by independent health authorities is thus crucial to guarantee the quality of the available information [40]. The dissemination of this resource in the context of parent-centred communication it will only be useful after such certification.

A key methodological advantage of the present study is the inclusion of fathers, enabling the identification of gender differences in the perception of needs of information and on the sources used to fulfil them. Moreover, the consecutive and systematic data collected during 1 year in the 7 level III NICUs located in the Northern Health Region of Portugal, with a proportion of participation above 95%, ensures the representativeness of the sample. However, some limitations should be noticed. The cross-sectional nature of our study does not allow the assessment of possible changes during hospitalisation, in a context where parents tend to undertake some control regarding the information and communication processes over time, by initiating or influencing discussions with healthcare professionals [30], and reporting other sources of information [4]. Furthermore, it would be helpful to analyse how the parents' behaviour regarding information needs and sources is influenced by the infants' health and sickness trajectory [5].

This study addresses the information needs reported by mothers and fathers of very preterm infants in the third week of hospitalisation in NICU, and the quality, comprehensibility, usefulness and availability of the main sources of information used, contributing to the literature seeking improvements in parents-centred communication in NICU. The findings from the present study emphasise the need to be aware of the provision of information as an essential dimension of neonatal care, with health professionals taking responsibility for answering to information needs of mothers and fathers during infants' hospi-

talisation in NICU. The investment on the training of empathetic communication skills among health professionals, as well as the clarification of the role of nurses and physicians, emerge as crucial elements to support parents-centred communication. Such will contribute to avoid the dissemination of contradictory or ambiguous information while promoting the implementation of strategies that should include and facilitate opportunities for good communication between mothers, fathers and health professionals.

In conclusion, improvements in parents-centred communication in NICU depend on assessing gender-specific needs of information, diversifying the sources used during infants' hospitalisation, by rethinking the network of mediators involved, and assuring the quality of the information available.

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Conflicts of interest statement

The authors have no conflict of interests to declare.

Data availability statement

Data will be available upon request.

Biographical note

Elisabete Alves completed a PhD in Public Health from the Faculty of Medicine of the University of Porto (2012) and a degree in Psychology from the Faculty of Psychology and Educational Sciences of the University of Porto (2005). She is currently a postdoctoral researcher, integrating the Department of Health and Society of the Institute of Public Health of the University of Porto and the Laboratory for Integrative and Translational Research in Population Health (ITR). Her main line of research focuses on the study of the health and quality of life of caregivers. Since her graduation, she has participated in projects as principal investigator (n=2) or member of the research team (n=3). She published several articles in national and International peer-reviewed journals and books, and is responsible for supervision of master and doctoral students.

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