e-ParWelB: Preventing Premature Family Maladjustment: a multidisciplinary e-health study protocol on preterm parent's well-being

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Abstract

Background: The consequences of preterm birth extend beyond the clinical conditions of the newborn, profoundly impacting the functioning and well-being of families. Parents of preterm infants often describe the experience of preterm birth and subsequent admission to the Neonatal Intensive Care Unit (NICU) as a disruptive event in their lives, triggering feelings of guilt, helplessness, and fear of being unable to protect their child. Although various research examines changes in parents' well-being and perception of self-efficacy during the stay in NICU, there is a lack of research analyzing what happens in the delicate transition phase at home after the baby's discharge. Recently, scholars have advocated for the use of web-based and app-based support programs both to monitor and prevent preterm family maladjustment and to assist parents struggling with the transition home.

Objective: The main aim of this interdisciplinary research project is to develop a socio-psychological model focused on assessing the well-being of parents of premature infants during and after their stay in a NICU. Specifically, the study aims to (1) monitor the mental health of parents of premature infants, both at the time of the child's discharge from the NICU and in the first six months after discharge to prevent family maladjustment, (2) deepen our understanding of the role of digital tools in monitoring and supporting the well-being of parents of premature infants, and (3) study the potential impact of the relationship with healthcare professionals on the overall well-being of parents.

Methods: The project combines mixed methods of social research and psychological support with an e-health approach. The well-being of parents of premature infants will be assessed using validated scales administered through a questionnaire to parents of preterm infants within six NICUs at the time of the child's discharge. Subsequently, a follow-up assessment of parental well-being will be implemented through the administration of the validated scales in a web app. Additionally, an ethnographic phase will be conducted in the NICUs, involving observation of the interaction between healthcare professionals and parents, as well as narrative interviews with healthcare staff. Lastly, interactions within the digital environment of the web-app will be analyzed with a netnographic approach.

Results: It is expected to shed light on the determinants of well-being among parents of premature infants, in relation to varying levels of prematurity severity, socio-demographic characteristics such as gender, age, and socioeconomic status, and parental involvement in NICU care practices. With the follow-up phase via web app, the project also aims to prevent family maladjustment by providing psychological support and utilizing an e-health tool.

Conclusions: By developing a piloted model for preterm parents’ socio-psychological assessment, e-ParWelB will produce knowledge about the best practices to be implemented in NICU, enhancing parents' and family's well-being and give the opportunity for stakeholders and policy makers to make neonatal care protocols less regionally uneven and more efficient especially concerning the collaboration between parents and health care staff.

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Keywords: Preterm birth; Parental well-being; Sociology of Health; Digital-Based Monitoring; Mixed-method Research; e-Health

Background

The World Health Organization defines as preterm a birth that occurs before 37 weeks of gestation [1] - in Italy, about 6% of newborns are preterm [2]. Preterm birth is a multi-problematic event with three main consequences: first, it poses a medical risk to the newborns, as many of these infants are in critical condition and can experience a range of significant and potentially life-threatening medical complications. The second consequence concerns the economic and medical cost of caring for these babies, given the advances in perinatal and neonatal care that have contributed to a substantial increase in the survival rate of these infants, particularly for extremely premature ones who, until a few decades ago, had no chance of surviving [3]. Third consequence, the premature birth of a child and the subsequent admission to Neonatal Intensive Care Unit (NICU) are distressing experiences for parents. Parental stress and parenting difficulties in the first years of the child's life are well-known consequences [4]. Moreover, many longitudinal studies have described how prematurity negatively affects infants' development [5; 6] and evidence has been gathered supporting that parent well-being and infant's long-term developmental outcomes are closely related [7]. Parents often describe premature birth and the subsequent hospitalization in a NICU as an emotional roller coaster and a disruptive life event [8]. An unexpected birth can trigger feelings such as guilt for not completing the pregnancy, helplessness, and fear of not being able to protect one's child [6]. Moreover, parent-infant separation once admitted to the NICU, represents a major source of stress for both parents and their infants [9]. Prematurity doesn't just affect the child and parents as individuals (for example, by delaying the exploration of the parental role), but also the family triad (and potential siblings), as it hinders the initiation of mutual understanding and the consolidation of affectionate and meaningful relationships. Indeed, the hospital environment limits the parent-child relationship, which primarily develops through the incubator's windows [10]. These restrictions, while serving to protect infants from pathogens, complicate the interaction between parents and newborn, making it even more challenging to activate caregiving modes necessary for the infant's psychological development, a task primarily undertaken by medical staff for clinical reasons [11]. Another important factor to consider, highlighted by Russo et al. [12], is that the socio-demographic characteristics of parents act as independent stress predictors, with gender, occupational status, and age particularly playing a role in the levels of stress and depression among parents of hospitalized children. Furthermore, few studies investigated fathers' experiences in these particular circumstances [6]. In Italy, especially during the COVID-19 pandemic, many NICUs applied restrictions regarding the frequency and the time of parents' admission, and fathers are usually less involved than mothers in practices such as skin-to-skin contact and Kangaroo Care, managing to start building a relationship with their babies only after discharge. As researchers pointed out [13], it is important to consider the characteristics and points of view of both mothers and fathers, as both parents are at risk after preterm births. Research suggests how parents' negative feelings can be reduced by giving them value as actors who can make decisions for the newborn [14]. The Family Integrated Care (FICareTM) model represents an example of a way to address the need for humanization and parent participation in health care for high-risk newborns admitted to the NICUs. Through this approach, parents have the opportunity to become increasingly engaged in their responsibilities and their active involvement in care is a prerequisite for the consolidation of parenting skills, which are essential to cope with the separation from the NICU [15]. However, a recent study pointed out that although most units in different European countries reported a neonatal care policy that encourages parents to take part in the care of their infants, parental involvement is still generally limited in Italy [6]. Although various research examines changes in parents' well-being and perception of self-efficacy during the stay in NICU, there is a lack of research analyzing what happens in the delicate transition phase at home after the baby's discharge [16]. To fill this gap, both in literature and supporting actions, the intervention and participatory project Voicing preterm parents' experiences. An interdisciplinary study to set neonatal practices and enhance families' well-being (XXX) was designed by the XXX and funded by XXX. Starting in May 2021, XXX is promoting constructive communication and collaboration among and between caregivers and parents in the NICU.

Parental self-efficacy and social support play a crucial role in adapting after an adverse situation such as preterm birth [17]. Scannel [18] recently suggested how interventions that target the development of parental self-efficacy and social support can strongly impact on the sense of competence, satisfaction in the parenting role, and resilience of all members of the family. Furthermore, Ionio et al. [19] in their work highlight that having more information on how parents perceive neonatal care and an understanding of their needs also after the discharge of their newborn, may allow healthcare staff to identify parents at risk, plan early interventions to meet their needs, and promote the family functioning. Given the importance of building parents’ self-efficacy, new neonatal practices (for upcoming preterm infants and parents) should be shaped not only on the biomedical knowledge perspective but also on preterm parents’ values, lived experiences, and perspectives.

Our study is an interdisciplinary research that, building on the premises of the XXX project, strives to assess preterm parents’ well-being during and after the hospitalization in NICU by combining mixed methods (using research strategies such as standardized questionnaires with internationally validated scales and ethnography) and psychological support with an innovative and technology-driven approach. Recently scholars have championed the use of web and app-based support programs to both monitor and prevent preterm family maladjustment and assist parents who struggle with transitioning home [20; 21]. Furthermore, the work of Garfield et al. [22] with very low birth weight infants showed that parents who received an app-based support program had improved parental self-efficacy and discharge preparedness compared with the control group. Therefore, the XXX decided to team up with the XXX to design an e-health (ICT use to the advantage of human health) research project that assessing the impact on parents' well-being, particularly at the crucial time of discharge and the first six months at home, offering support to parents who are more fragile.

Parenting self-efficacy has been understood as the way parents perceive their ability to care for their child [23] and has been associated with positive parental outcomes [24]. The well-being of parents refers to the fact that, given that preterm birth is a highly stressful event for parents [25], taking into account the difficulties and uncertainties they experience during this acute phase is of significant importance in order to prevent family maladjustment. [26]. Families’ involvement in the care of their high-risk neonates at NICUs represents the main axis of parent-partnered care initiatives. Each preterm parent develops a personal way to evaluate the situation based on the NICU lived experience. Specific characteristics may also influence the response to hospitalization of one's child. Significant effects have been identified in relation to gender (mothers and fathers seem to differ in responses and relation to certain measures), and to the degree of social support that parents have access to. The latter has been found to impact positively on the resiliency factor associated with coping strategies by families who have a child with a chronic illness [27] and there is a great need for studies investigating its impact on preterm parents.

Thus, the main focus of this research project is to develop a socio-psychological model focusing on the assessment of preterm parents' well-being during and after admission to a NICU with the use of e-health.

Objectives

Stemming from these premises, our research’s main aims could be synthesized as follows: (1) to monitor the mental health of parents of premature infants, with a plan for early intervention and a six-month follow-up to prevent family maladjustment; (2) to stimulate e-health growth, by advancing knowledge on the role of digital-based tools in monitoring and supporting the well-being of parents whose infants have been hospitalized in the NICU for critical health situations (prematurity, but also a wide spectrum of invalidating and/or fatal diseases) and (3) to study the potential impact of the relationship with healthcare staff on the overall well-being of parents. In addition, our research aims to investigate potential differences in psychological well-being between parturients and non-parturients by also studying the impact of certain social characteristics (e.g., nationality, educational qualification, employment status, cultural enjoyment).

Methods & Research Design

Ethical Considerations

Participation in the study will be on a strictly voluntary basis. According to the Declaration of Helsinki, respondents will receive written and oral information about the study and provide signed consent. They could withdraw consent at any time with no consequences for future treatment of themselves or their infants. The e-ParWelB project is financed and approved by the Italian Ministry of University and Research (MUR) with NextGEn EU in 2022 as a PRIN project (Project of National Relevance Interest, Prot. 20225R7XB3). The project was submitted for approval to the Ethics Committees of the involved universities (University of Milan-Bicocca and Catholic University of the Sacred Heart of Milan), and subsequently to the six different Territorial Ethics Committees, to which the hospitals involved in the study are affiliated.

Recruitment

The study will be conducted simultaneously in six different Italian NICUs. Focusing on several units simultaneously has several advantages. Firstly, it enables us to build a sample of satisfactory size within a reasonable time frame. Italy has a low birth rate, and therefore, concentrating on only one unit would pose a significant risk of obtaining an inadequate sample for any complex statistical analysis. Additionally, the presence of various NICUs introduces a comparative dimension to the study. Previous research on neonatal intensive care [28] has shown that each unit has its unique identity with different routines, idiosyncrasies, and decision-making processes. This identity is strongly influenced not only by the cultural context in which the unit is embedded but also by the administrative structure of the hospital and the legislative framework foreseen for neonatal care practice. This is particularly relevant in the Italian case where the management of the public health system happens mainly at the regional level with relevant differences between different regions[1]. Moreover, the study includes five NICUs who are located in the public sector and one belonging to a private hospital, adding another possible layer of differences in the work culture of the units.

The research focuses mainly on the population of preterm parents. More specifically, parents of children born before 36+6 of gestational age (GA) and hospitalized in intensive or/and sub-intensive or/and sub-intensive care units for at least ten days (critical threshold of hospitalization length). Considering the research objectives, it is crucial to distinguish infants according to the severity of prematurity because of the strong impact that the latter has on the health of the child, and the duration of the hospitalization period. Therefore, there will be three groups: children born before 28 GA, infants born between 28+1 and 32 GA, and children born between 32+1 and 36+6 GA.

To be included, parents of preterm infants must present the following traits: (1) they must speak fluent Italian or English; (2) they must be at least 18 years old; (3) their children must not have other genetic pathologies or other pathologies not linked to the preterm birth.

These three limitations help us in creating a more consistent sample and therefore in obtaining more focused results. Situations like teenage pregnancies or genetic pathologies further complicate a family's life and therefore the task of assessing its well-being. While we acknowledge that they are both worthwhile topics of research, they go beyond the scope of what could reasonably be studied within the framework of this research.

To determine a satisfactory sample size for the research we calculated with G*Power that the minimum sample size required, considering a probability of alpha error .05, power (1 - β err prob) 0.95, and effect size 0.345, will be n=175 preterm infants (350 parents).

We want to stress the fact that, due to the very peculiar nature of the studied population, this will not be a probabilistic sample but rather a "convenience sample". As explained before, the decline in

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[1] The research includes three NICUs located in Lombardy (north-west of the country), two NICUs in Veneto (north-east of the country) and one in Sardinia, an island-region far from the mainland. This last region also has a special institutional status which may further increase the differences from the other areas.

Italy’s birth rate does not allow us to use the yearly average estimation of preterm babies born in each of the partner hospitals as a reliable predictor for constructing our sample.

Research design

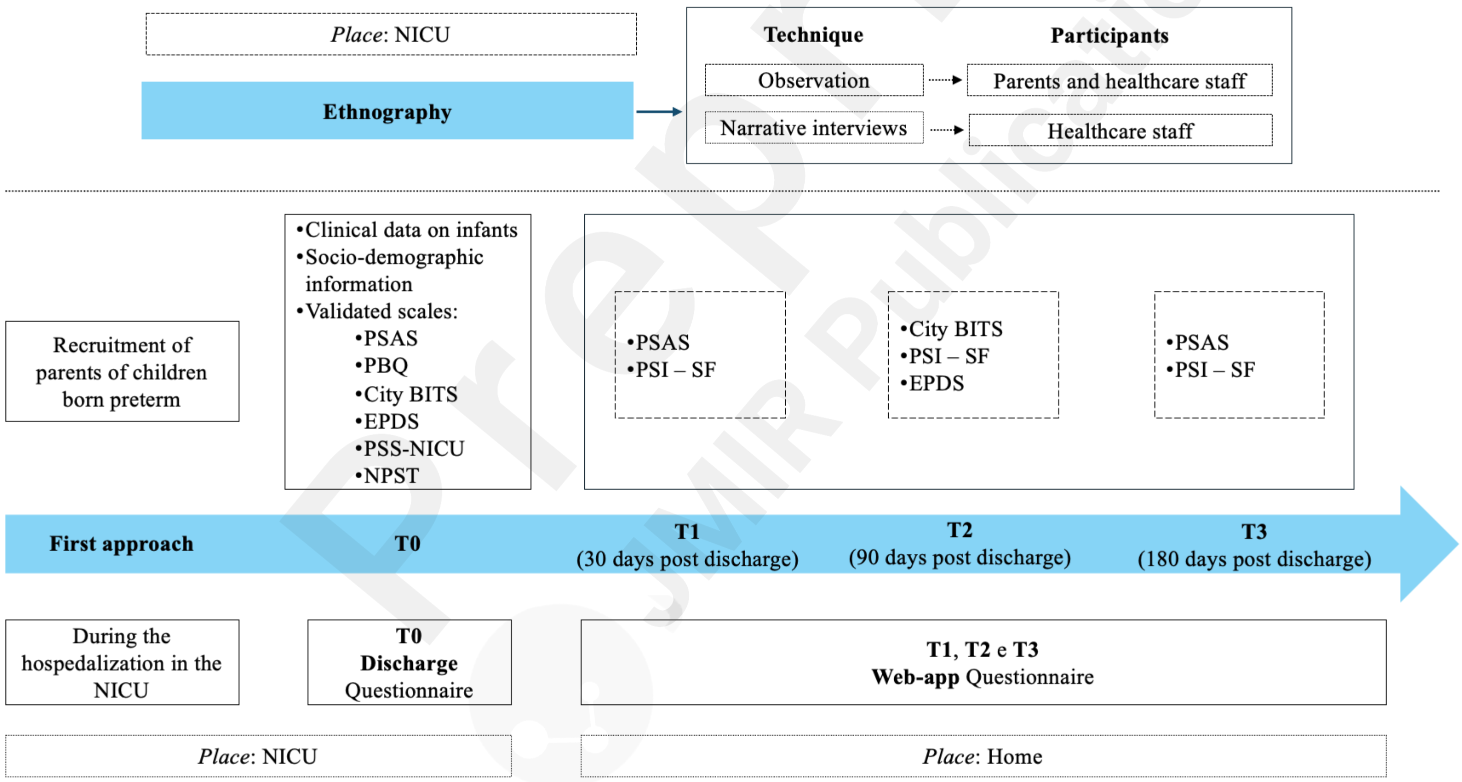
In order to achieve the research objectives, this study will use a mixed-methods approach that combines ethnographic observations with standardized questionnaires. The goal of this approach is to enhance the results by complementing the strengths of different methodologies [29]. The quantitative aspect of this research aims to investigate the potential impact of preterm birth on the psychological well-being of parents during the early months of their child's life. Recent literature emphasizes that preterm birth can have a significant impact on parental well-being, exposing them to a high likelihood of developing anxious, depressive, and sometimes even post-traumatic stress symptoms [30]. The questionnaires with validated scales employed in this research will be used to create composite statistical indices that measure, for each responding parent, levels of stress, depression, anxiety, perception of parental self-efficacy, quality of the bond established with their child, as well as the perception of social support received. The reasons that prompted us to consider such tools stem from the literature highlighting the necessity of utilizing specific instruments in investigating parental distress in the postpartum period, in order to adequately capture the specific reasons leading to the experience of such unique feelings [e.g., 31]. Moreover, questionnaires with validated scales are a valuable tool in psychological research. They allow data to be collected from a large number of participants in an inexpensive and standardized manner. The ease of administration and access to personal information encourage the disclosure of candid data, reducing the social reaction effect, as well as allowing people to respond more freely. The qualitative aspect of this research involves the use of the range of methods provided by ethnography, considered particularly suitable for studying the dynamics of critical health practice in action [32; 28], as the ethnographic approach allows an understanding how medical discourse (e. g., protocols, standards, and knowledge) forms within everyday medical practices (e.g., informal actions, skills, behaviors, and the doctor-patient relationship) that are involved in care trajectories [33]. The e-ParWelB project will utilize a focused ethnographic research approach with different methods. During the NICU stay, we will combine research strategies including focused ethnography, which entails: observing of the relational dynamics between different staff members and between staff and parents; discussing with neonatologists their notes and accounts regarding the neonate's care pathway; observing the habits and procedures of healthcare staff to reveal how prognostic knowledge is shaped; and finally, conducting narrative interviews with the staff to capture narratives about family needs and perceptions of care practices.

Parents will be approached and recruited by a psychologist within the NICU/sub-NICU when the medical staff announce their children’s discharge. At this stage, the project will be thoroughly explained to them, and they will be requested to provide written informed consent. Parents of premature infants will be invited to participate in the study a few days before the discharge. The timing of recruitment will be individually determined based on the assessment conducted by the neonatologist, taking into account the infant's prognosis. When the healthcare staff informs the parents that their baby will be discharged, allowing them to envision their return home, an interview will be conducted within the NICU wards (T0). During this session, a structured interview will be administered along with specially designed questionnaires, combining internationally validated scales with socio-economic standardized questions (**Fig. 1**). The administration of the self-report questionnaires will be carried out via the QUALTRICS XM platform (managed by the scientific coordinators of the XXX), accessible through the Qualtrics offline app using tablets.

Subsequently, the study includes a follow-up phase to monitor the psychological well-being of parents of premature infants after discharge. The follow-up will be conducted through the use of a specially designed web app accessible only to participants, which will allow monitoring of parents' adaptation and psychological well-being for up to six months after the newborn’s discharge from the

NICU. Parents will be asked to complete validated scales at three specific time intervals: 30 days (T1), 90 days (T2), and 180 days (T3) after discharge from the NICU (Fig. 1). The presentation order of the validated scales will vary during the three follow-up surveys. This choice will ensure that no mechanisms of response automation based on memory are created. The responses provided by parents to the validated scales used within the web app will trigger automated alerts signaling difficult or potentially risky situations. Parents whose responses have triggered an alert will be contacted by a psychologist to offer them psychological support and possible referral to dedicated services. In addition, during this monitoring period, a series of support forums will be implemented within the e-ParWelB web app: in fact, the web app will incorporate a space for peer discussion, where issues related to e.g., daily care practices or family well-being can be discussed. daily care practices or family well-being; a private messaging channel for psychological support, where each user will be able to turn to an experienced psychologist(s) for support in case of need; and finally, a technical forum will be implemented where each user can report malfunctions and/or request technical support regarding the web app's functionality.

Fig. 1. Study Model



Below is a brief overview of the validated scales used in the surveys (in the discharge questionnaire and the follow-up questionnaires) and the topics covered by the standardized questions, which are more sociologically oriented, present in the discharge questionnaire. Finally, a brief description of the netnography and of the focused ethnography that will take place in the NICUs and the related data collection techniques is presented.

Measure and instruments

Measures at T0 (Discharge Questionnaire)

The birth of a premature infant and their subsequent admission to the neonatal intensive care unit can pose a significant challenge for parents, leading them to develop considerable distress. The literature stresses that the experience of this unexpected and highly stressful event is susceptible to the development of distress in parents [34], contributing to them feeling less confident in their ability to be adequate parents, judging their own skills too harshly, and considering themselves less capable than they actually are [35]. The development of such symptomatology should not be underestimated, not only because of the potential negative consequences on the well-being of the parents and the child, but also because of the potential difficulties in the development of bonding between them [36; 37], which is the emotional, cognitive, behavioral, and neurobiological bond that forms between a parent and their child from conception onward [38].

For these reasons, at the time of the child's discharge from the NICU, the investigation will focus on assessing anxiety, depressive, and post-traumatic symptomatology, while also investigating parents' perceptions of their self-efficacy in bonding with their child within the chaotic and stressful environment of the NICU.

For this purpose, some validated scales will be used:

- ***Postpartum Specific Anxiety Scale (PSAS)*** [39; 40]. Most of the literature on postpartum anxiety [41; 42; 43] refers to measures of generalized anxiety, which often can prove problematic from a psychometric perspective [44]. To date, the only available questionnaire specifically measuring postpartum anxiety is the PSAS. Furthermore, the instrument has demonstrated excellent psychometric properties (ω ranging from 0.72 to 0.90 across the four scales, and λ4 ranging from 0.71 to 0.92 across the four scales). For these reasons, the research team deemed it the most sensitive and appropriate tool for capturing the construct under investigation in the target population.
- ***Edinburgh Postnatal Depression Scale (EPDS)*** [45; 46]. Postnatal depression is the most widely measured disorder in the postpartum population, which today, in Italy, is mostly subject to routine screenings for this condition. Following a careful analysis of the most recent literature [e. g. 47; 48], the EPDS emerges as the most widely used self-report questionnaire for measuring postpartum depression due to its ease of administration, cultural adaptability, and excellent psychometric properties. The validated Italian version has demonstrated good validity and reliability (Cronbach's α = 0.7894), confirming the validity of the EPDS in identifying postnatal depression. For these reasons, the research team deemed it the most sensitive and appropriate tool for capturing the construct under investigation in the target population.
- ***City Birth Trauma Scale (City BiTS)*** [49; 50]. Research on Post Traumatic Stress Disorder (PTSD) during postpartum has typically adapted questionnaires developed for other populations, such as war veterans, which often prove poorly suited for capturing the specificities of childbirth trauma. Perinatal research comparing general PTSD measures with specific postpartum PTSD measures has found that, although highly correlated, the agreement between these scales in identifying PTSD diagnoses is low [51]. Therefore, the choice of measurement type is crucial for identifying cases of postpartum PTSD. Additionally, the criteria of the American Psychiatric Association (APA) for PTSD

measurement have significantly changed in the transition from DSM-IV to DSM-5. It is therefore essential to adhere to these new measurement criteria. The City BiTS is a tool specifically developed to measure childbirth-related post-traumatic stress disorder according to the recent DSM-5 criteria and is, to the authors' knowledge, the only instrument with these specificities. This instrument has previously demonstrated excellent reliability (Cronbach's α = 0.92). For these reasons, the research team deemed it the most sensitive and appropriate tool for capturing the construct under investigation in the target population.

- ***Parental Stressor Scale: Neonatal Intensive Care Unit (PSS:NICU)*** [52; 53]. This scale aims to capture parents' perception of distress experienced during their children's stay in the NICU. To reconstruct parental distress, the underlying model of the scale considers the interaction between various psychological and physical stress factors, such as stress related to sounds, lights, noises, and other sensory experiences typical of a highly technologized healthcare setting [52]. The PSS: NICU provides the opportunity to obtain various types of information: levels of stress related to specific situations experienced by parents with preterm infants; overall stress levels; individual stressful elements, and overall tension levels provide additional information. The translation and validation study in Italian has found good psychometric properties of the tool [53].
- ***Postpartum Bonding Questionnaire (PBQ)*** [54; 55]. Scientific research on the complex experience of preterm birth increasingly emphasizes that such an experience can pose significant challenges for parents, particularly in the construction of bonding, which is the early relationship that develops postpartum between mother and child (e. g. 56). A careful analysis of the literature [e. g. 57; 58] has allowed us to select a questionnaire widely used in investigating bonding in the postpartum period: the PBQ, a tool designed to measure the quality of the bond between parents and children and identify if there are disturbances in the relationship. The Italian adaptation of the PBQ, was developed using the back-translation procedure [59]. Studies demonstrate that the Italian version of the PBQ has good psychometric properties and can be implemented in the Italian cultural context to assess early mother-child relational difficulties [55].

Moreover, the assessment at the discharge will also take into account further aspects, in light of the fact that several studies have shown that some minor stress factors, such as the distance of your home from the hospital where the child is hospitalized, may contribute to a higher level of maternal discomfort [60]. The socio-economic characteristics of family units, such as education, social class, job insecurity, employment status, and migration background have also been examined as risk factors for preterm birth [61; 62]. Additionally, Miles et al. [63] study revealed that the marital status of the mother is also a significant factor in predisposing to or preventing the development of a mood disorder. Specifically, married women who perceived a high level of support from their partners reported lower levels of postpartum depression compared to unmarried women. Conversely, among women with preterm infants, maternal age or level of education do not appear to be correlated with the onset of mood disorders [64]. Another factor that seems to mitigate the onset of mood disorders in parents of preterm infants is a high level of social support [65]. For these reasons, the discharge questionnaire will investigate basic socio-demographic information from parents, such as gender, age, nationality, geographic origin, family composition, and education level. A series of self-assessment questions will be used to evaluate the perceived social support of

parents of premature infants. In particular, we have designed six items that inquire about perceived social support from partners, family members, friends, and healthcare personnel. Furthermore, respondents will be presented with a series of questions regarding the frequency of cultural activities, which will serve as indicators of their level of cultural capital, along with a series of questions aimed at capturing their occupational situation.
Lastly, a validated scale will be used to gather information regarding parents' perception of nursing support during the infant's hospitalization:

- ***Nurse Parental Support Tool (NPST)*** [66]. Scientific research has highlighted the crucial role of parents' perceptions of the actual support provided by nursing staff in mitigating the stressful effects of the NICU stay [67]. In light of this evidence, Miles et al. [66] devised the NPST, a scale specifically addressing the educational and informational aspects of staff support as perceived by parents, which is widely used in NICUs today [e.g., 68]. The NPST is a 5-point Likert scale questionnaire consisting of 21 items divided into four groups: Informational Support, Emotional Support, Appraisal/Parental Esteem Support, and Caregiving Support. Each item is rated on a scale from 1 ("Almost never") to 5 ("Almost always"), with higher scores indicating a higher perceived level of support provided by the nursing staff. The validity and reliability of the Italian version of the NPST were assessed by Montirosso et al. [69].

Follow-up measures at T1, T2, T3 (Web-App Questionnaire)

At the time of discharge, the involved parents will be invited to register on the web-app specially designed for this research. Through the web-app, participants will independently complete three short questionnaires in the three different times designed for follow-up (time T1 at 30 days post-discharge of the newborn; time T2 at 90 days post-discharge of the newborn; time T3 at 180 days post-discharge of the newborn) to monitor their mental health status. In the web-app, some validated scales already proposed at the time of discharge will be implemented. The scales are presented to participants in different moments, in order to minimize potential bias due to response based on learning or recollection. Specifically:

- *During T1*, participants will be invited to independently complete the Postpartum Specific Anxiety Scale (PSAS) and the Parenting Stress Index - Short Form (PSI-SF).
- *During T2*, participants will be invited to independently complete the City Birth Trauma Scale (City BiTS), the Edinburgh Postnatal Depression Scale (EPDS), and the Parenting Stress Index - Short Form (PSI-SF).
- *During T3*, participants will be invited to independently complete the Postpartum Specific Anxiety Scale (PSAS) and the Parenting Stress Index - Short Form (PSI-SF).

The only validated scale for which completion will be required at every follow-up moments is the Parenting Stress Index - Short Form (PSI-SF):

- ***Parenting Stress Index - Short Form (PSI-SF)*** [70; 71]. The literature on existing research has highlighted the possibility of early identification of stressful parent-child systems in order to develop interventions aimed at reducing stress that could decrease the frequency and intensity of emotional and behavioral disorders in children in our society [72; 73]. The characteristics of the child, those of the parent, the family context, and particularly stressful life events are some of the elements of the parent-child system that have been identified as important [70; 74]. The Parenting Stress Index (PSI) was developed in response to the need for an assessment measure of these characteristics. For the purposes of this scientific research, the PSI-SF was adopted, which is an abbreviated version of the PSI that investigates parental distress, dysfunctional parent-child interactions, and difficult child behaviors. The brevity of the PSI-SF allows primary healthcare providers to identify families most in need of follow-up services [75]. Furthermore, the Short Form of the PSI represents an extremely interesting, agile, easy-to-administer, and interpretable tool. The Italian version of the PSI-SF has been translated and validated by Guarino and colleagues [71] and investigates stressful systems through three subscales: Parental distress, Dysfunctional parent-child interaction and Difficult child.

Our intention is to use the PSI-SF as a potential "risk screening tool," namely a technique that can identify parent-child systems under excessive stress and thus serve as an important component within prevention programs aimed at reducing the frequency and intensity of emotional and behavioral disorders [71]. The responses provided by parents to all validated scales used within the Web-App, where they exceed the threshold values established for each scale, will indeed allow for the automated activation of alert signals for situations of difficulty or potential risk.

Nethnography

As mentioned earlier, the web-app will feature three specific communication channels with which users can interact:

1. a public forum for peer discussion only, where users will be able to post messages and share opinions and ideas or to ask questions on issues related to the daily child care at home;
2. a private communication channel through which users can contact the psychologist, to ask for support in case of discomfort, uneasiness or other states of distress;
3. a forum dedicated to the technological tools available to participants, in which it is possible to both report technical malfunctions to IT staff and discuss among parents and researchers the impacts of the e-health tool on its users and their well-being.

The textual corpora produced by users will be downloaded and will form the empirical basis for data analysis, through an approach of digital ethnography.

For many years now, computer-mediated communication has been fully integrated into people's daily lives, blurring the distinction between offline and online social worlds, as they both coexist and fully overlap [76], therefore, it has become increasingly important and relevant for social researchers to study society in and through the internet. Although methodological reflections around digital research have been manifold and have also given rise to different terminologies and definitions, in this contribution we refer to the term ‘netnography’ coined by Kozinets [77] to illustrate our digital ethnography approach that adapts the typical techniques and tools of ethnography in the study of online communities, which interact through a computer-mediated communication. The presence of the researchers, as well as the fact that messages written in the forums will be subject to analysis is clear to the participants from the outset, so our netnography will employ an overt observation technique.

In our project, the online community is closed, meaning that the web app and its tools can only be accessed through an username and password if one participates in the study and has agreed to take part in the follow-up phase. Some methodological perspectives on online research place great importance on the medium [78] and, by consequence, on the specific digital environment and its characteristics that shape the spaces, times, opportunities and constraints under which online interactions take place. In our case, one of the main constraints is that messages in the public forums (n. 1. and n. 3) will be published subject to approval by the members of the research team, to avoid the use of inappropriate language or extremely off-topic communications. If some messages are rejected, they will also end up in the analysis, but obviously they will not affect the overall interaction, as they will not be visible to other users. Time is another important feature that will have consequences for the flow and volume of communications, as the web app will see the asynchronous access of participants, who are gradually recruited over time. Although the messages in the public forums will remain fixed and always visible, participants who accomplish the 180 days follow-up period may have less incentive to access the web-app, resulting in no further discussion with other newly recruited participants. On the other hand, the accumulation of messages over time could stimulate other interactions, also providing an incentive for participants to use the web-app not only as a tool for filling out periodic questionnaires. From a research point of view, we are particularly interested in the volume, modalities and content of the digital interactions between participants, aware of the constraints to which such communications are subjected. It will be useful to understand the representations, perceptions and perspectives of premature parents, the impact of prematurity and of the care practices in daily life; moreover, we will pay attention to the adaptation processes carried out to cope with the transition period after discharge from the NICU, and how they deal with their new domestic life. In the analysis, even though the participants are pseudo-anonymized through a unique alphanumeric code, we can trace and use as a segmentation variable the one that discriminates between the giving birth and not giving birth partner, for example to account for differences in the prevalence and occurrence of the messages and topics reported. Furthermore, the forum n. 3. has the goal to explore how digital-driven changes affected families. It is dedicated to specifically discussing the tools in the web-app, through a process of facilitation by a member of the research team stimulating dialogue around dedicated questions. As previously said, this section of discussion about the web-app is not only intended as technical support, but as a space for group reflection on the impact of the digital tools introduced by e-ParWelB to support families' wellbeing. Then, the material created by users in this section will be analyzed with the aim to explore whether web assisted alerts, experts and peer support online were beneficial to families' wellbeing and eventually how these tools might be improved in the future. This phase of research will also allow us to reflect upon the implications of introducing a digital medium in the relation between the healthcare staff and families [79], as in the tradition of sociology and STS (Science and Technology Studies) working together on healthcare issues [80].

Ethnography

The qualitative part of this research aims to study the NICU environment through the use of focused ethnography [81; 82]. This term indicates a research method based on brief and intensive observations with the aim of analyzing well-defined phenomena within a specific context. While the classical form of ethnography is centered around the study of broad topics, like the holistic observation of social groups or institutions, focused ethnographies narrow their perspective on the analysis of specific actions, interactions, and social situations. This implies a few changes in the position of the observer compared to the situation of traditional ethnography. Firstly, the researcher cannot face the fieldwork unprepared but must be at least theoretically confident with the context of the actions which are to be studied. Secondly, whereas traditional ethnography provides a range of observer positions from participant-as-observer to observer-as-participant [83], focused ethnography does not involve the same opportunity for observing as a participant because of the nature of the object of study. It would be both highly inappropriate and technically impossible for the focused ethnographer to participate actively in, for example, a medical examination or an operation. Instead, a more distant observer position is possible. In this way, the focused ethnography researcher may be precluded from contextual factors of importance. While traditional ethnography affords the chance to actually participate in the life of the studied social milieu, focused ethnography does not offer the same opportunities of active participation. This usually happens due to the inherent characteristics of the subjects under investigation. Active participation in skill-intensive activities would be both highly unrespectful and unfeasible for the focused ethnographer. Consequently, it is said that in focused ethnography researchers are not doing observant participation, but that they are participating as observers.

A brief recap of the main traits of focused ethnography and its difference with traditional ethnography are shown in **Table 1**.

Table 1. Comparison between focused ethnography and traditional ethnography, derived from Andreassen et al., 2020 [84]

	Focused ethnography	**Traditional ethnography**
Subject matter	- Episodes in social fields - Clear research focus - Familiar cultures - Background knowledge prior to data collection - Applied research	- Entire social fields - Broad research purpose - Foreign cultures - Gaining knowledge from engagement in the field - Basic research
Data collection	- Relatively long planning phase - Intermittent visits with particular time frames - Focused exploration - Video or audio recordings or detailed, focused field notes - Often multi-sited - Time intensity	- Relatively short planning phase - Full-time participant observation over a longer period - Open exploration - Extensive and in-depth written field notes - Often single-sited - Time extensity
Researcher role	- Alterity - Observer-as-participant - Selected informants who hold a specific knowledge serve as key participants	- Strangeness - Participant-as-observer - Participants are often those with whom the researcher develops close relationships
Data analysis	- Analysis intensity - Collective data analysis sessions	- Experiential intensity - Solitary data analysis

Focused ethnography is a particularly appropriate technique for our research due to the traits of medical practice which comprises bounded and clearly delineated social occurrences or scripted exchanges. This statement has been proved true by an increasing number of studies employing this technique within the hospital setting in recent years [85; 86; 87; 88]. This technique affords the means to investigate particular episodes or interactions within social milieus like NICUs, facilitating nuanced and comprehensive insights into the influence of sociocultural factors in the interaction between the NICU staff and preterm parents. This specific effort of focused ethnography will be divided in two steps, each involving the staff members of NICUs in hospitals collaborating with the project. Firstly, the researcher will observe the routine practices that constitute what is defined as "ward life" trying to create as little as possible interference with the staff's activities. At this stage, the researcher's focus will not be pointed on individuals but rather on the overall context of neonatal intensive care and the social interactions occurring within it. Secondly, the researcher will employ narrative interviews to gather additional information from the NICU staff. The use of interview is quite common in focused ethnography as explained by the relevant literature on the topic: “The focused ethnography researcher may be precluded from contextual factors of importance. Applying method triangulation as a cornerstone in ethnography is a way of overcoming this dilemma. For example, combining short observations with interviews will give opportunities to ask about the context in which the observations take place, as well as to explore how the participants experience being observed" [84]. In these narrative interviews, the researcher will aim to involve staff members with profiles as diverse as possible regarding their roles, length of service, gender, and age. The objective is to achieve what the literature calls a "maximum variation sample" [89], maximizing sample diversity (while acknowledging that this is a non-probabilistic convenience sample) across certain characteristics to capture the complexity of the studied reality.

Throughout both of the aforementioned steps this research tries to analyze the meaning and the effects on the parents' well-being of the NICU staff decisions and practices. This focus on the analysis of existing procedures in skill-intensive contexts, especially medical-related ones, has been referred to by previous research as "exnovation". "Exnovation refers to the attempt to foreground what is already present – though hidden – in specific practices, to render explicit what is implicit in them [90]. A focus on exnovation allows us to bring to light implicit matters of actual practice and to develop a fresh perspective on the ingenuity of the professionals and the specific structure of their practices. It offers insights into their specific modes of ordering day-to-day practices [91]. Exnovation, in other words, elucidates competencies of coordination and alignment of these modes of ordering of which those involved are not always aware" [28]. In other words this research aims to reflect on existing practices of care aimed at preterm parents and their children and deepen our understanding regarding their effects with the aim of preventing family maladjustment after a traumatic event like preterm childbirth.

Regarding the organization of the qualitative tools for the research, the access to the field will be negotiated separately in each NICU to take measures to avoid disrupting staff work and minimizing impact on organizational routines. In order to conduct an ethical and respectful data gathering process, NICU staff will be informed about the research in advance by the department heads, with whom a partnership has been established for the project, thus ensuring they are aware of the research procedures. Once access is granted, the researcher present in the department will autonomously organize interviews with the staff.

Expected Results

The e-ParWelB central impact will be developing and piloting a model of socio-psychological assessment tailored for parents whose infants have been hospitalized in NICU for critical health situations connected to prematurity. The model, by increasing the preterm parent's perception of self-efficacy and well-being, would allow to prevent family maladjustment [5; 6] and therefore to indirectly improve the preterm child health outcomes [7]. The mixed methods social research we designed is expected to achieve the following results:

1) To reduce the discomfort and maladjustment caused by prematurity, on preterm parents and to assess their perceptions of social support (by family, friends, potential employer, and colleagues), perceptions of preparedness and parental self-efficacy from the time of discharge and for the following 6 months.

2) To analyze the difference between mothers and partners' responses to preterm birth in terms of stress, negative feelings, and perceptions of parental self-efficacy and social support.

3) To determine which neonatal care practices, forms of communication and environmental settings of NICU are more likely to reduce negative feelings and foster well-being of preterm parents.

4) To advance the knowledge on the role of a digital-based tool in monitoring and supporting families' well-being during the follow-up.

On the latter point, e-ParWelB intends to engage in the relationships among science, technology, and society by addressing how the hospitalization experience of preterm families may inform technology and science development; at the same time, we aim at identifying the effect of the introduction of a digital technology driven assessment and support model on families' well-being and on care practices in the neonatal intensive care wards. In particular, the project e-ParWelB directly connects with the objectives of:

a) developing a public health system enhancing investments in terms of human, digital, structural, instrumental and technological resources;

b) improving scientific research in the biomedical and health field.

Indeed, the interdisciplinary approach to promote e-health in premature families enhances the dialogue between science (healthcare and medical knowledge) and society (families' perspectives) on the topic of preterm birth, through the aid of digital technology. This will be possible with the implementation of the e-ParWelB web-app, which will follow processes of responsiveness and adaptation, as well as considering criteria of accessibility, following RRI (Responsible Research and Innovation) principles. As the web-app envisions both a tool to periodically monitor parents' wellbeing and a digital space for sharing and discussion, both with a psychologist and among peers, the project has a multi-side technological and scientific impact.

At the same time, we aim at identifying the effect of the introduction of digital technology on families' well-being and on care practices. For instance, through the netnographic exploration of the online space of discussion within the e-ParWelB web-app, we aim at addressing the eventual health care online community of practice forming in the forum [92]. Drawing upon the idea of Timmermans and Berg [93], an orientation of "technology-in-practice" allows a critique by scholars in the social sciences regarding the complicated modalities in which the "social" and the "material" intertwine in technologies for health care, as well as possibly influencing their creation and implementation. Referring to what in STS (Science and Technology Studies) literature is known as "socio technical approach", we are thus interested in how the social and health care aspects influence the development of the digital technology and, at the same time, in modalities through which the digital medium affects families' and the care process, especially after discharge [94; 95]. Therefore, we also aim to understand the impact of the web-app on families' well-being.

Impact

Not only the e-ParWelB project contributes to scientific and technological development, but its impact on the social and economic dimensions stems from the premise that by increasing the well-being of preterm-parents it is possible to indirectly improve their infants' health outcomes. As scholars argued, the abrupt disruption of the establishment and development of parental mental representations, combined with the possibility that both the baby and the mother are in critical conditions, can make preterm birth a traumatic event for parents [96]. Reducing family's maladjustment, therefore, enhances future health - including mental health - in premature children [7]. Moreover, parents' mental health is supported, as well as their self-efficiency, preventing a large set of repercussions. For society at large, this also means to introduce factors of prevention in terms of social and economic costs that unhealthy individuals and families might entail. Furthermore, the situation of premature birth care in Italy sees scattered NICUs applying different protocols for what concerns the role played by the parents of hospitalized newborns. As the last report of the Italian Society of Neonatologists (SIN) shows, for instance, just 63% of the NICUs allow free time access to parents [97]. When looking at the regional location, we can observe an unequal distribution of the free time access wards. Indeed, in the Northern regions the 88% of NICUs do grant free time access, whereas in the South just the 34% percent does [97]. Thus, by developing a piloted model for preterm parents' socio-psychological assessment, e-ParWelB will produce knowledge about the best practices to be implemented in NICU, enhancing the opportunity for stakeholders and policy makers to make neonatal care protocols less regionally uneven and more efficient when concerning the collaboration between parents and health care staff.

Strengths and limitations

The e-ParWelb project was preceded by the XXX project (XXX) and, although with a different institutional set-up[2] and collaborations with different NICUs, the two projects stand in a relationship of continuity, building on the same theoretical and methodological premises. Therefore, practical experiences and careful analyses regarding actual strengths and limitations have already been carried out for the previous project [10].

In general, the greatest strength of the entire research project lies in listening to and empowering the parents of premature children who participate in the study, making them more aware of and helping them to deal with the challenging situation of prematurity, advancing deep reflections that do not stop at purely medical practices, but also promoting a person-centered approach to stimulate new neonatal practices and foster the well-being of families.

In this context, it is essential to reconnect the social dimension to the medical experience, thanks also to the support of technology, and this is one of the main objectives of the project.

Indeed, we aim to study a model for monitoring and assessing parental well-being and look at the relationship between the medical-nursing staff and the parents of premature babies from a sociological and psychological perspective with the aim of promoting public awareness and participation, also by involving the medical-nursing staff with respect to the values, personal experiences and point of view of the parents.

These strengths are accompanied by deep reflection in mapping out the potential limitations of the project and strategies to mitigate them.

Among these, access to the study is worthy of consideration, because an actual constraint on access for preterm parents upstream of the project is language: the lack of cultural mediators and translators in the project does not allow participation except for people fluent in Italian and English. Since Italian and English are also the only languages in the previous XXX project, we have already ascertained that a non-negligible proportion of parents, often with migration backgrounds, were unable to participate in the study and we expect this situation to be repeated again. This is uncomfortable for mainly two reasons: firstly, it does not allow a specific population of parents, who often are more likely to be in situations of marginality and/or social isolation, to access the direct and indirect benefits of the project, such as stimulating (self-)reflections on their parental role and gaining access to psychological support after discharge. Furthermore, from a purely scientific point of view, there is less opportunity to investigate how certain cultural differences and social support (which is often lacking or expressed in different ways with people with a migratory background) impact on the well-being of preterm parents and on their experiences in the NICU.

One of the main aspects to consider when reflecting upon pros and cons of this project is the possible bias introduced by the implementation of the web-app, which is a digital technology not necessarily available to all social groups. Digital literacy, availability of connection to the Internet, access to digital devices are all necessary conditions to participate in the study and the lack of one of these aspects may act as an additional exclusion factor, possibly affecting marginalized social groups or groups with specific needs [e.g. 98; 99]. Nonetheless, parents excluded from the digital space are necessarily excluded from tools of experts and peer support.

In addition to access barriers to the study, the project faces other possible limitations regarding engagement and participation during the research activity that can be reversed. In the previous XXX project, due to the Covid-19 pandemic, researcher access to the NICU was precluded, so parents recruitment, discharge survey administration, web-app registration was performed entirely by NICU staff, usually by psychologists or neonatologists. Overall, in this way NICU staff were more involved, but some methodological forms of control by the researchers were lacking both regarding modalities of study presentation and survey administration to parents[100]. In the new e-ParWelB

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[2] The previous XXX project envisaged a deeper integration of the two NICU hospital units involved, whose representatives were effectively co-researchers together with the XXX University team. In the e-ParWelB project the staff of the NICU units collaborating on the project are not assimilated as research partners.

project, while no longer having the limitations of the pandemic, a blended approach was chosen, as we will maintain a deep involvement by NICU staff, especially psychologists, in recruitment, survey administration and web-app enrollment at the discharge. Above all, previous experience has shown that the relationship of trust built between the NICU staff and parents is central to engaging the latter in the project. It is therefore in the project's interest to maintain these relationships, both to provide parents with referents whom they consider reliable and with whom they have already become familiar during their stay in the NICU, but also to engage the medical-nursing staff further, stimulating an even closer relationship between these two social actors, beyond purely medical practice. On the other hand, in the previous project, the participation rate dropped by 10 percent for parents recruited in the second half of the project timeline, an indicator that the motivation and consequent convincing power of the NICU staff toward parents has been slightly declining over time [100]. Therefore, the presence of a researcher can also be decisive in rekindling motivation and emphasizing the importance of parental participation throughout the recruitment phase. In the e-ParWelB project in some NICUs there will be a constant presence of a project researcher, who will act together with the staff in recruitment and will personally take care of survey administration at discharge and inviting the participant to register to the web-app. In NICUs where the constant presence of the researcher is not expected, it will take place if necessary, for example if the research team notices a decline in the participation rate or if the NICU staff needs support for carrying out the activities related to the project. Therefore, this flexible choice allows us to maintain and strengthen the bond between the parents and the NICU staff and, at the same time, to provide help and support to the participants or NICU staff and to ensure correct conduct of the research from a methodological and ethical point of view.

In conclusion, one of the critical aspects of the ParWelB project was the high dropout rate during the follow-up surveys using the web app. To address this issue, the new project e-ParWelB proposes a lighter monitoring approach, with a shorter total period and lower frequency (6 months of monitoring instead of 1 year, 3 surveys instead of 12), thus impacting participants to a lesser extent. A less intrusive follow-up, both in terms of frequency and volume of questionnaire completion, will not affect the capacity of researchers to monitor the well-being of participants, while it will unburden the commitment required from users, allowing them to allocate their time and energy in other activities connected to the web-app, such as forums.

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Abbreviations

GA: Gestational Age
MUR: Ministero dell’Università e della Ricerca
NICU: Neonatal Intensive Care Unit
APA: American Psychiatric Association
PTSD: Post Traumatic Stress Disorder
PSAS: Postpartum Specific Anxiety Scale
PBQ: Postpartum Bonding Questionnaire
PSS:NICU: Parental Stressor Scale: Neonatal Intensive Care Unit
EPDS: Edinburgh Postnatal Depression Scale
PSI-SF: Parenting Stress Index - Short Form

City BiTS: City Birth Trauma Scale
NPST: Nurse Parental Support Tool
STS: Science and Technology Studies
SIN: Società Italiana dei Neonatologi
PI: Principal Investigator
RPI: Responsible Research and Innovation
SRIP: Society of Reproductive and Infant Psychology
FICare: International Family Integrated Care

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Supplementary Files

Figures

Study Model.

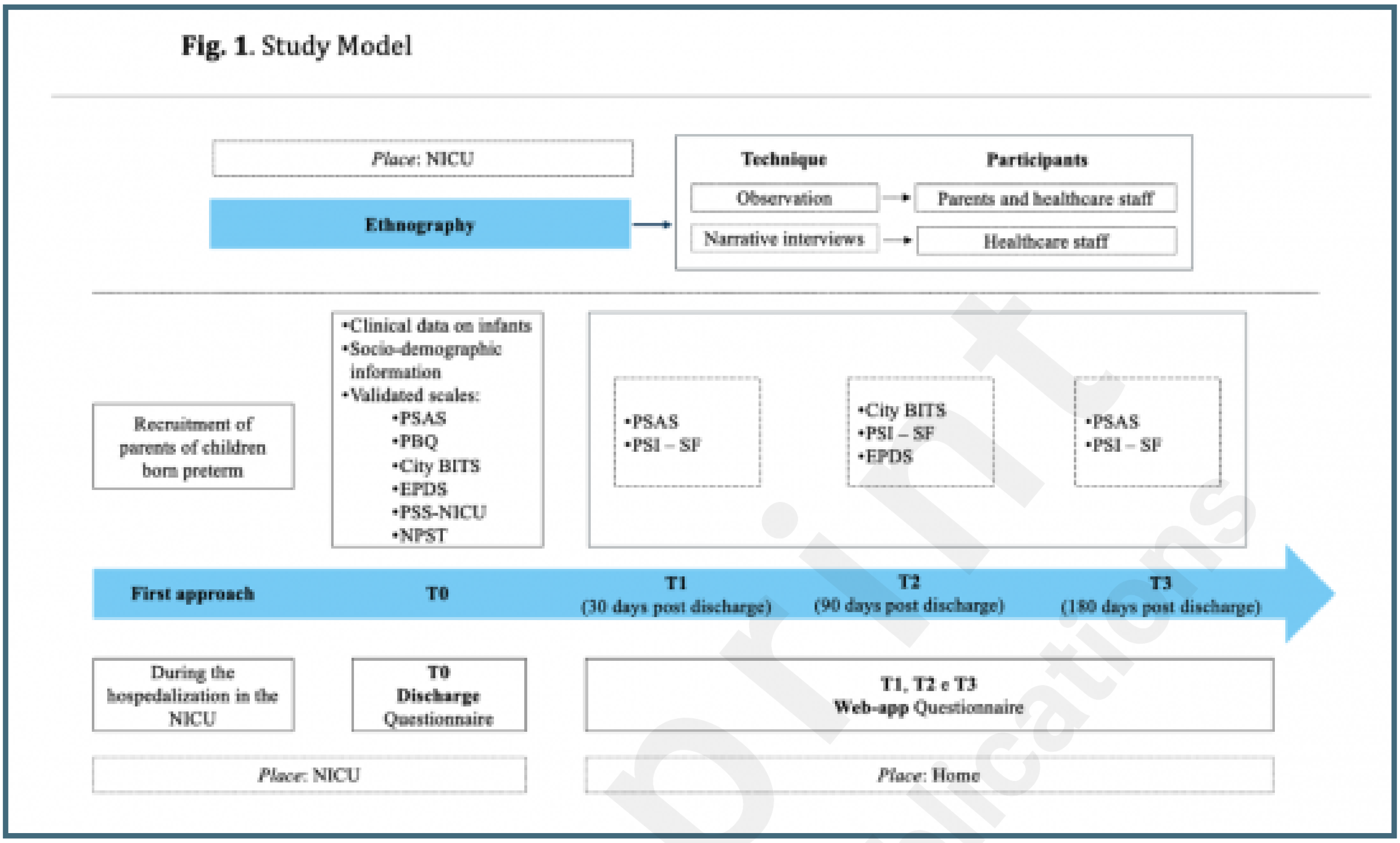
Fig. 1. Study Model
Place: NICU
Ethnography
Technique
Participants
Observation
Parents and healthcare staff
Narrative interviews
Healthcare staff
Recruitment of parents of children born preterm
•Clinical data on infants
•Socio-demographic information
•Validated scales:
•PSAS
•PBQ
•City BITS
•EPDS
•PSS-NICU
•NPST
•PSAS
•PSI – SF
•City BITS
•PSI – SF
•EPDS
•PSAS
•PSI – SF
First approach
T0
T1
(30 days post discharge)
T2
(90 days post discharge)
T3
(180 days post discharge)
During the hospedalization in the NICU
T0
Discharge
Questionnaire
T1, T2 e T3
Web-app Questionnaire
Place: NICU
Place: Home