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Original Article

Mothers of premature children and their social networks in pandemic times: A qualitative study

Mães de crianças prematuras e suas redes sociais em tempos pandêmicos: investigação qualitativa

Madres de niños prematuros y sus redes sociales en tiempos de pandemia: investigación cualitativa

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Abstract

Objective: to identify the relationship between mothers of premature babies and their social networks in caring for these children during the pandemic. **Method:** this is a qualitative study conducted with 12 mothers of premature babies followed by a high-risk maternal and child outpatient clinic in the interior of São Paulo, Brazil. Data were collected through semi-structured interviews and the creation of social network maps, which were analyzed using reflective thematic analysis. **Results:** the maps showed reduced and weakened social networks, with the family being the main source of meaningful bonds. Two final themes were identified, entitled "Challenges of adaptations in a fragile social support context" and "Restrictions on social relationships in facing COVID-19". **Conclusion:** it is important that healthcare for premature babies and their families include attention to the social support of caregivers, with efforts to implement intersectoral and territorial and community-based care.

Descriptors: Social Networking; Infant, Premature; Maternal and Child Health; Nursing; Qualitative Research

Resumo

Objetivo: identificar a relação de mães de crianças prematuras com suas redes sociais no cuidado destas crianças, em tempos pandêmicos. **Método**: pesquisa qualitativa, realizada junto a 12 mulheres mães de filhos prematuros acompanhados por um ambulatório materno-infantil de alto risco, no interior de São Paulo, Brasil. Os dados foram coletados por meio de entrevistas semiestruturadas e elaboração de mapas da rede social, sendo analisados pela análise temática reflexiva. **Resultados**: os mapas demonstraram redes sociais reduzidas e fragilizadas, sendo a família a principal fonte de vínculos significativos. Identificaram-se dois temas finais, intitulados

“Desafios das adaptações em contexto de apoio social fragilizado” e “Restrição nas relações sociais frente à COVID-19”. **Conclusão**: é importante que o cuidado em saúde à criança nascida prematura e sua família inclua a atenção ao suporte social das cuidadoras, com esforços para efetivar intersetorialidade e cuidado de base territorial e comunitária.

Descritores: Rede Social; Recém-Nascido Prematuro; Saúde Materno-Infantil; Enfermagem; Pesquisa Qualitativa

Resumen

Objetivo: identificar la relación entre madres de niños prematuros y sus redes sociales en el cuidado de esos niños en tiempos de pandemia. **Método**: estudio cualitativo realizado con 12 madres de niños prematuros en seguimiento en un centro ambulatorio materno-infantil de alto riesgo en el interior de São Paulo, Brasil. La recolección de datos se realizó mediante entrevistas semiestructuradas y la creación de mapas de redes sociales, que se analizaron por medio de análisis temático reflexivo. **Resultados**: los mapas mostraron redes sociales reducidas y debilitadas siendo la familia la principal fuente de vínculos significativos. Se identificaron dos temas finales, titulados «Desafíos de adaptación en un contexto de soporte social debilitado» y «Relaciones sociales restringidas ante el COVID-19». **Conclusión**: es importante que la atención a la salud de los recién nacidos prematuros y sus familias incluya la atención y el soporte social de los cuidadores, con esfuerzos para implementar la intersectorialidad y la atención territorial y comunitaria.

Descriptores: Red Social; Recién Nacido Prematuro; Salud Maternal-Infantil; Enfermería; Investigación Cualitativa

Introduction

Prematurity is defined as birth at less than 37 weeks of gestation, and constitutes an event of interest and concern for public health.[1] Its prevalence in Brazil is approximately 11%, a rate which remained predominantly constant between 2011-2021,[2] including the initial years of the COVID-19 pandemic.

Prematurity is related to the quality of prenatal care[3] and its health outcomes (among other factors), as well as the child’s growth and development, which are influenced by timely access to and quality of neonatal care and follow-up of the child and family.[4] The social determinants of health affect the phenomenon and its consequences, highlighting the importance of paying special attention to the barriers that arise in scenarios marked by social and economic vulnerability.[4-5] Thus, parental care depends on the social context, especially the social support that is effective in it, with social support often being a predictor of maternal self-efficacy.[6]

Social support derives from meaningful bonds, understood as those that promote affection, information or various resources to people. These relationships are established in the social network, and in the context of prematurity, bonds with the family and with services and their professionals are relevant. Nurses tend to provide emotional support to those involved and for the caring practices for premature children,[5] especially when developed from a family-centered approach.[7] The family's experience in caring for and promoting development of a premature child requires the support of the social network (among other aspects).[8-9]

Social relationships are unique and interact with individual, cultural, local and life-period aspects, and understanding these bonds is essential for promoting and implementing social networks.[8] Social networks are based on individual relationships, perceived with family members, friends, people and communities/services, and are decisive for individual, family and community care coping and perspectives.[10]

However, it was observed that the COVID-19 pandemic created a tendency for families of premature children to be neglected by health professionals and services.[8] The pandemic had repercussions on the care provided to premature children and their families, with emphasis on their presence in hospital settings and early discharges.[9] In addition, social distancing impacted caregivers, which increased the burden and restricted the relationship with the social network.[9] These pandemic repercussions in premature children are associated with the tendency for changes in child development justified by the context of fragile healthcare, challenges in home care and altered support network.[11]

In this sense, looking at the support coming from the social networks of families of premature babies, especially for the main caregivers who are mostly mothers, is essential in Brazilian scientific production, especially during the COVID-19 pandemic. In view of the above, this study took the social network of women with premature children during the COVID-19 pandemic as its theme. The objective was to identify the relationship between mothers of premature children and their social networks in caring for these children in pandemic times.

Method

This is a qualitative research study,[12] anchored in Sluzki's concept of social network.[10] This framework was chosen due to its centrality in healthcare which considers the individual in their family, territorial, and community context.[10] According to Sluzki's concept, significant social networks are those constituted by very close and quality relationships. A social network is composed of relationships that vary in their structures, functions, and bonds, in addition to influencing coping with adverse situations, as well as resilience.[10]

The study was developed in a municipality in the interior of São Paulo, Brazil, with 254,857 inhabitants, with a premature birth rate of 10.2%. The specific field was a high-risk maternal and child outpatient clinic. Approximately 500 families living in the municipalities of the health region served were monitored in 2021. The inclusion criteria for participants were: being a mother of a child(ren) born preterm; being monitored for the health of this child in the service studied; having elapsed up to 120 days since the birth of this/these child(ren). The exclusion criteria were: pregnancy resulting from sexual violence; women in psychological distress and/or with severe cognitive deficit. All participants in the selection process met the inclusion criteria.

Recruitment and invitation occurred as follows: the outpatient clinic professionals presented the research objectives to the women who attended the service and met the selection criteria; once the woman demonstrated interest, the professionals contacted the first author, informing her of the day and time of the next appointment; at the next appointment, the researcher made the official invitation and presented the Informed Consent Form (ICF) and/or the Informed Assent Form (IAF); in turn, the day and time for the remote interview were scheduled.

After obtaining consent from each participant and before the scheduled interview date, the researchers read the outpatient records to collect data on sociodemographic characteristics and prenatal, labor, and birth conditions of their child(ren), following a previously established script. The questions for constructing the Minimum Map of the Personal Social Network (MMPSN) were presented[10] on the day and time scheduled for the individual interview (Figure 1). To this end, the first author invited the mothers to report on people and services that had been part of their lives since the preterm child's birth (Remember the time since the birth of (child's name) and tell us about the people who were with you, who you consider to be important, who supported you or still support you). The quality of each of the relationships mentioned was then explored (Did you mention (name of person or service), tell us about your relationship with him/her), what was that relationship like? – repeating for each of the people/services mentioned). Specific information was also sought about each 'field' of the MMPSN (Thinking about your family and friends, do you think there were other people who could have supported you? Tell me about this: Thinking about your community, the services you know and use, do you think any of them could have supported you? Tell me about this.). Finally, the focus was on child care (What has it been like caring for [child's name]? Who and which support service has collaborated in this care?).

Before data collection began, the lead researcher instructed the women to seek a private space to ensure privacy, and that they could interrupt the interviews whenever they wanted and/or needed to. The interviews were conducted throughout the months of April and May 2021, in a virtual environment, with the support of the WhatsApp® application (version 2.23.20.76, 2023, WhatsApp LLC, USA), through audio messages, lasting 20 to 30 minutes. The audio recordings were transcribed using the Transkriptor® program (Version 1.0.17, 2023, USA). Fictitious names were used for the participants to ensure anonymity.

The researchers then created the maps based on each participant's responses, and sent the finalized version to each of them. The interviewees were asked to send an audio recording confirming the map drawn and/or making suggestions for adjustments. All participants confirmed that the maps adequately represented their social networks. These audios were also transcribed and analyzed.

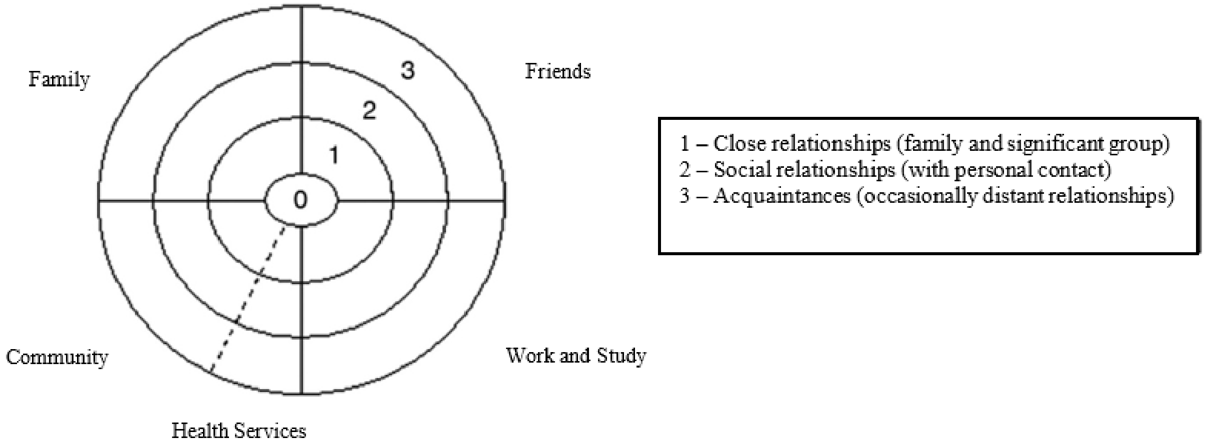

Figure 1 – Minimum Personal Social Network Map. Adapted from Sluzki[10]

The decision was made to seek saturation of meanings, which corresponds to a deeper, more detailed and complex discussion with the findings to ensure understanding of the phenomenon of interest.[13] Data collection was concluded when this saturation was reached in the 11th participant; a new mother was included to validate the process, making 12. A total of 21 mothers were initially indicated, none of whom were excluded.

The study took place during the indication of social restrictions due to the COVID-19 pandemic, therefore all measures to minimize transmission of the virus were adopted when the researchers were present at the service. However, the use of non-face-to-face strategies predominated for developing the study.

The Consolidated Criteria for Reporting Qualitative Research (COREQ) guided development of the report.[14] The research team was composed of people with experience in qualitative approaches. The members initiated in this approach received training on the topic and role-played interviews with the team to increase their competence and ease in the interviews.

The participants were characterized using descriptive statistics. The maps were analyzed using the criteria proposed by Sluzki,[10] and comprised the qualitative data set. The criteria are: size (number of institutional/personal ties established, with the network being classified as reduced, medium or expanded); density (quality of the ties observed in relation to the map lines); distribution/composition (number of people or institutions located in each quadrant); dispersion (geographic distance between members and institutions); homogeneous or heterogeneous (characteristics of the members and institutions, in order to verify the diversity and similarities which compose the network). It is important to note that these criteria are linked to the participants' own perception of their networks.

The data set was analyzed inductively using the Reflective Thematic Analysis technique. This analysis is considered a reflective, creative, subjective and deliberative process.[15] It brings a systematic and rigorous approach to coding and creating themes, which is both fluid and recursive. The following steps were followed: familiarization with the data collected from the studies through exhaustive readings of the transcripts and descriptions of the maps; coding, producing the intermediate codes: "Lack of support", “Premature birth”, “Insecurity”, “Family”, “Difficulties”, “Loneliness”, and “Social isolation”; search for themes in the articulation between the codes; review of themes; definition and naming of themes - “Challenges of adaptations in a fragile social support context” and “Restriction in social relations in facing COVID-19”; and final writing.

The following steps were included for data reliability: return of transcripts and maps to participants so that they could add or correct information; construction of the analysis of maps and interviews by two researchers, with the inclusion of a third, if necessary, for consensus. No participant wished to add data or perceptions.

The study followed the recommendations of Resolutions No. 466/2012 and 510/2016 on research involving human beings, and was approved by the Human Research Ethics Committee (CAAE: 42675521.4.0000.5504). The service authorized data collection, and each person had access to the written and oral consent form to ask questions before signing it. It is worth noting that, as demonstrated below, the health service also served adolescents under 18 years of age, and because it understood that their experiences are relevant to the theme of this study, the sample included adolescent mothers. In these cases, the participants signed the IAF, and their guardians signed the ICF.

Results

A total of 12 women participated, aged between 14 and 40 years old, one of whom was in the job market. All had single pregnancies, three were primiparous and nine were multiparous; the children (n=12) required hospitalization in a neonatal unit. Moreover, HELLP syndrome (n=2), COVID-19 (n=2), gestational syphilis (n=2) and eclampsia (n=2) were identified regarding gestational complications, while one child was diagnosed with fetal distress. Half of the participants had fewer than 6 prenatal consultations.

The maps constructed with the participants showed small social networks, with the main source of support being found in the Family quadrant of the MMPSN. Significant family ties ranged from one to five people, some of whom had daily home contact. These people played the roles of partner/spouse, mother, father, sister, mother-in-law, father-in-law and older children of these women.

In contrast, fragile and/or occasional relationships prevailed in the other MMPSN quadrants. Two participants mentioned a significant friendship relationship in the Friends quadrant. The bonds in the Community quadrant were mostly characterized as fragile and occasional, and the maximum number of institutions mentioned was three (3). The Church was repeatedly mentioned among these, sometimes being characterized as a significant bond. Health Services, when present, were characterized as fragile and dispersed. Finally, the School/Work sector remained empty for 11 women, and only one of them declared a social bond with music, college and language studies.

The maps of Janaína (33 years old) and Magda (40 years old) are representative of the group of participants.

Figure 2 – Social Network Maps of Janaína and Magda, São Carlos, São Paulo, Brazil, 2023

Legend: Significant bonds are represented by solid black lines; weakened bonds are represented by black dashed lines; broken and/or non-existent bonds are represented by gray dotted lines. Lines ending in space 1 represent close relationships; lines ending in space 2 represent social relationships; and lines ending in space 3 represent occasional relationships.

The thematic analysis identified two themes with regard to the social network, entitled “Challenges of adaptations in a fragile social support context” and “Restriction in social relations in facing COVID-19”.

Challenges of adaptations in a fragile social support context

Insertion into the prematurity context was described as sudden, with unprecedented and challenging demands, managed with fragile social support that diminished over time. Premature birth and the hospitalization of the child in a neonatal unit were experienced as sudden, out of control, bringing feelings of insecurity, helplessness and frustration, as described by three participants:

> *It was al unplanned, he didn't have a baby shower, he didn't have anything [...]. (Bernadete, 17 years old)*
>
> *They were trying to keep him a few more days due to the prematurity, he was very small, low weight [...] then it was necessary to do a cesarean [...] everything was so sudden, I was upset and lost with everything. (Magda, 40 years old)*
>
> *It was very rushed, emergency situation, I wasn't expecting it. (Rafaela, 31 years old)*

Adaptations to the daily routines and dynamics of these mothers were required to monitor the child in the neonatal unit and to provide care at home. Regarding this, they highlighted the support of family members, which is more present in the initial stages and later becomes more fragile, culminating in some cases in the absence of in-person help. For primiparous mothers, the fact of being mothers and caring for their child for the first time is also considered challenging, according to the following testimonies:

> *He spent 22 days in the ICU, I came every day to see him [...] my husband, my mother and my mother-in-law helped a lot. (Leticia, 22 years old)*
>
> *My mother came, stayed for a week, my husband helped, he helps me every day, after he completed a month [...] he and my mother left, he works and it was just me and him [baby]. (Bernadete, 17 years old)*
>
> *I had the support of my mother, she lives in Baixada, she came to spend a few days with me here, it was calm, in fact it was a bit of a rush being a first-time mother [...]. (Marilia, 30 years old)*

The arrival of the family home, far from the support of hospital care, required mothers to interpret the child's behavior in order to make decisions about care. It is worth noting that the COVID-19 pandemic and its consequences for the organization of health services resulted in early discharges in some cases. Participants reported feeling little supported during this period, describing the feeling of loneliness in the hospital-home transition, and later:

> *It was a little scary [arriving home with the child], because I was lost, I didn't know what I was going to do, how I was going to manage. (Sonia, 33 years old)*
>
> *[...] Sometimes a different cry and I can't understand, she needs something, that ended up being a little bit new, but the issue of bathing, at first it also makes you a little scared [...]. (Marília, 30 years old)*
>
> *I was adapting [...] I was very scared because when he was born with a breathing problem, I was very scared to take care of him and I had no one to turn to. (Maria, 21 years old)*
>
> *I had difficulty breastfeeding, because he couldn't suck [...] because he was adapted to the tube, to the bottle. It was difficult at first at home. (Bernadete, 17 years old)*

Restriction in social relations in facing COVID-19

The social distancing guidelines to control the COVID-19 pandemic resulted in restricted social ties and networks, resulting from the overlapping fears and insecurities of prematurity and COVID-19. Thus, participants tried to stay at home and expose their children to as little risk as possible. Some mothers mentioned disregarding Primary Healthcare (PHC) service for monitoring their children due to the reduced travel time, the burden on them, and the waiting time at the outpatient service.

> *I don't go out much because of the pandemic, I stay at home more, I only come here [specialized health service] because he needs it. (Janaina, 33 years old)*
>
> *There are my parents, my grandmother, now I am not having much contact because of him [newborn son], before the pandemic the contact was very frequent, but now due to the pandemic I can't. I won't, he is premature. (Magda, 40 years old)*
>
> *The [specialized health unit] did bother me a bit because every month I had to go there [...] knowing that there is a doctor at the clinic [...] it is very tiring, not only for us but also for the children, they get very tired because the waiting time is too long. (Bernadete, 17 years old)*

Despite social distancing, participants expressed movements to maintain significant social ties, in this case associated with spirituality and hobbies, demonstrating a high level of social resources and skills:

> *The church is usually closed, online worship is available. (Tábata, 33 years old)*
>
> *I'm a Christian, I have online worship [...] I also take online music classes. (Magda, 40 years old)*

In view of this, despite the challenges, mothers presented creative repertoires which could be experienced in the pandemic context to reduce social isolation, even with physical distancing.

Discussion

The social networks of mothers of premature babies were small and not very dense (less than three significant ties per participant). Relationships were mainly concentrated in family relationships, which also showed a tendency to reduce and weaken over time.

Relationships with children's parents and grandparents were considered essential for mothers' support. The literature has argued that paternal presence and participation, from prenatal care onwards, are conducive to a very positive family dynamic of care for the child, with the possibility of establishing greater emotional stability, income, support in domestic activities, care and emotional bonding.[16-17]

Regarding grandmothers, intergenerationality and female figures stand out in the care of children.[18] Therefore, it is urgent to consider inclusion and support of the paternal figure and grandmothers in healthcare from prenatal care, especially in high-risk cases, as well as after the child's birth. This can favor bonding between family members, as well as mitigate the tendency towards loneliness and withdrawal from the significant network in support of the woman.

Expansion and support to increase the density of significant social relationships influence and impact better functionality in the care of premature babies. A study showed that the fewer the bonds in the maternal network, the greater the chance of postpartum depression,[19] while in contrast the presence of social support reduces the maternal overload with household tasks[20] and family financial issues.[20-21]

Mothers felt insecure and challenged in the adaptations needed to be present and care for their premature infant. This aspect is in line with a Swiss observational study,[22] which highlighted that the first days after neonatal hospitalization are exhausting, marked by fear, difficulties in organizing themselves to be in the neonatal unit and by the challenges related to caring for the premature infant.[22] In view of this, professionals should talk and provide guidance on adaptations that mothers of premature infants face, starting from the hospitalization time in the neonatal unit. This may include discussion about their own social networks, the role that relationships can play in this period, and the use of the MMPSN can be an efficient and illustrative resource.

Relational incipiencies were described in the “Community” quadrant of the MMPSN, which involves health services and their professionals. The measures to contain the COVID-19 pandemic had a negative impact on the social network for home care for premature children. It is common knowledge that adaptations in work processes were required, however the issue of travel, attachment and long waiting times are elements which are recurrently pointed out as areas that require improvement in qualifying care for children born at risk. In this case, they need to be taken into consideration with the aim of improving the follow-up care of these children.[22]

It is worth highlighting here the physical distance of the Specialized Care Service for Premature Babies, which made it difficult to connect with families and to identify strategies to rethink territorial services. In this regard, telecare in Nursing for longitudinal actions and health education in the follow-up of premature children enhances supportive practices.[4] Accordingly, the online strategy was an alternative found for the socialization of participants, which corroborates the results of this study.[16,19,23-24]

That said, the particularities of growth and development of premature infants require careful consideration based on comprehensiveness and support and assistance from health professionals.[22] Nursing occupies a privileged position to act in these situations, whether in the hospital, outpatient or PHC setting.[9] This action should include planning discharge to home, referral to the care network and promoting home visits with priority for premature infants and their families.[4,9,20] Furthermore, the use of resources such as the social network map or ecomap can be therapeutic strategies to be used with the premature infant’s family.

A disconnected care network for premature babies and their families, which is a common problem in Brazil, involves numerous factors which have been intensified by COVID-19.[4,25] The participants' testimonies demonstrated a lack of support and connection with these services, which is also observed in other studies with mothers of premature children.[4,9,25] The complexity of the pandemic context in child care in the literature went beyond merely biological care, and as the German study pointed out, there are impacts on economic issues and issues related to services.[11] Consequently, monitoring throughout child growth and development is suggested for children born before the gestational age.[11]

The pandemic has increased the isolation of mothers of premature babies, resulting in a feeling of helplessness and doing little to strengthen women in caring for their children,[8] and heightening feelings of fear and insecurity. Social networks can alleviate these feelings and contribute to knowledge and adaptations for caring for children. It has been observed that a strengthened social network can contribute to reducing difficulties and insecurities in establishing care and the emotional overload of these women.

Furthermore, it has been understood that the social network of mothers of premature babies is influenced by the quality of relationships, determined by multifactorial issues related to complex sociocultural and historical issues.[17] Addressing the fragility of this network should start from this premise, with interventions that consider the individual, family, community and political levels, including guidance from the health professional team.

Home care for a premature newborn requires assistance, knowledge, and emotional, social, and physical support for the family, especially the mothers. In this context, the study has implications for nursing know-how, such as ensuring that skills are built during in-hospital care to bring the family closer to the caregiver; not only strengthening caregivers in terms of technical skills, but also in their relationship with the child; fostering and articulating a formal and informal care and support network that is strengthened between services and intersectorally; and monitoring the growth and child development of premature children born during the COVID-19 pandemic in the long term. It is worth reiterating that although this study was conducted during the pandemic, it presents contemporary trends and challenges that deserve to be illuminated.

The quadrants related to friends and work/study reveal inequities and suggest a distancing of social relationships, with indications that they should be explored in future studies in the context of premature birth. Finally, the Social Network Map stands out as a powerful tool for guiding healthcare, especially for nurses, providing a visual and practical representation of caregivers' relationships and potential. On the other hand, the Social Map can identify weaknesses that need to be overcome, with a view to expanding significant social networks and facilitating coping with the adaptive challenges arising from premature birth.

The limitations of this study were related to remote data collection, which, to a certain extent, interferes with establishing relationships when compared to face-to-face meetings. In addition, the particularities of family configurations, which may influence perception and access to networks, were not addressed. Lastly, like all qualitative studies, its results do not intend to generalize, but contribute evidence to discuss advances in healthcare.

Conclusion

In response to the initial objective, the family was identified as the main and significant bond for the woman/mother who needs to care for her prematurely born child. In contrast, health services were represented as mostly absent, in addition to being physically distant. Prematurity was seen as unexpected, permeated by adaptations to care for the child, with such experiences being exacerbated by COVID-19.

Healthcare for prematurely born children and their families requires considering the social network of women/mothers, with efforts to implement intersectoral and territorial and community-based care. It is essential to give autonomy and support to these women, which requires actions that reinforce significant bonds and qualify the others.

It is necessary to continue exploring the relationship between parenting in the context of preterm birth and social network. The findings point to innovative aspects, such as the tendency to reduce the intensity and quality of family support; the lack of mentions of friendship and study/work relationships as being significant; as well as research and intervention using the MMPSN by health professionals and its effect on the appreciation and intervention of the social network of women/mothers of premature children. The lack of progress in theoretical and practical issues related to social network and social support promotes permanence in healthcare that opposes coping and resilience in the context of becoming a mother/father of premature babies.

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