

Determining Post-Discharge Needs of South African Parents with Premature Infants

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Determining the Post-discharge Needs of South African Parents with Premature Infants**Abstract**

This study explored the information and support needs of South African parents with premature infants after the initial discharge home from the hospital setting. Asynchronous online focus groups on the Facebook platform were utilized to identify the caregiving needs expressed by 25 South African parents with premature infants and to inform a parent support program in South Africa. The findings concluded that South African parents have unfulfilled information and support needs regarding their caregiving for their premature infants and their overall well-being.

Key words: *Facebook, focus groups, infant caregiving, information, parents, premature infants, post-discharge, South Africa, support*

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Introduction

Despite the fact that South Africa is classified as an upper-middle-income country (World Bank, 2019), health disparities and economic factors continue to make a negative impact on the country. This includes an increased rate of premature births (Coovadia et al., 2009). In fact, the World Health Organization (WHO, 2012) and Save the Children (2012) reported 1,050,000 live births in South Africa of whom approximately 84,800 (0.8%) were born premature.

Premature infants in South Africa are often discharged with unresolved medical issues, thus resulting in extensive types of resources and additional support being needed once they are sent home (Van der Westhuyzen & Kenner, 2013). This often coincides with a wide range of challenges such as discrepancies and inequalities in healthcare, health disparities, human resource incompetence, and a general lack of awareness surrounding premature births (Mayosi & Benatar, 2014; Shrivastava et al., 2016). Because of limited resources and inadequate social support systems available to them, the health and developmental needs of premature infants and their parents may continue to go unmet (Ataguba & Alaba, 2012; Ataguba et al., 2015).

There are few studies that explore the self-reported perceived information and support needs regarding the caregiving of their premature infants after the initial discharge home from the hospital (Adama et al., 2016; Griffin & Pickler, 2011; Whittingham et al., 2014). Very limited published literature is available regarding the needs of parents with premature infants in South Africa. To date, there is no literature found concerning South African parents with self-reported perceived information and support needs in the caregiving of their premature infants after the discharge home from a hospital. Research, however, shows that there is an immense need to implement equitable and sustainable early childhood interventions (ECI) for vulnerable

South African families such as those associated with the premature birth population (Coovadia et al., 2009; Galeano & Carvajal, 2016).

There is no clear direction about who is responsible for the social and professional support of the parents in South African communities when their use of healthcare services post-discharge is planned (Benatar, 2013; Mmusi-Phetoe, 2016). Nonetheless, South Africans need the equitable implementation of significant early interventions to support parents and premature infants (Chola et al., 2015; Galeano & Carvajal, 2016). A first step would be to gain an understanding of the parents' information and support needs regarding their caregiving for their premature infants and how to best support these parents in the home environment once discharged from the hospital. Therefore, the aim of this research was to explore the information and support needs of South African parents in the caregiving for their premature infants after the initial discharge home from the hospital.

Method

The study employed a qualitative descriptive design (Bradshaw et al., 2017; Creswell & Poth, 2017; Maxwell, 2014) and utilized four asynchronous online focus groups that were conducted on the Facebook platform. Through this design, the study was able to describe the phenomenon of the parenting of premature infants in South Africa in a framework that could in future add to the existing knowledge of the healthcare profession when developing interventions or programs to support these parents.

Participants

Twenty-five parent participants who met the specified criteria were recruited to participate in the focus groups. Participants had to be South African and biological parents (18 years or older) of premature infants who had been admitted and discharged from a South African hospital. Their

premature infants should have been admitted and discharged within the last five years at the time of data collection and must have been born between 28-37 weeks' gestation.

Table 1 provides a summary of the participants' demographic information. All participants were mothers with ages ranged from 22 to 47 years ($M=32.3$ years) with the majority ranging from 30-34 years of age. The majority (76%) of the were married while one participant (0.4%) were in a customary marriage. In an African customary marriage, there is an arrangement between families where *lobolo* (bride wealth) was seen as a token of gratitude for the upbringing of the daughter, as well as a step to guarantee that she was treated appropriately by her husband and his family (Rautenbach & Du Plessis, 2012). The customary marriage was a formal, though unwritten, arrangement between two families. In 2000, the Recognition Act recognized customary marriages as valid marriages. Participants' educational level ranged from Grade 10 to a master's degree with 80% who had a post matric qualification. The majority (64%) participants were employed full time outside of the home during the time of data collection, while six (24%) stayed at home full time and two (12%) participants stated they were employed part-time outside of the home. Although their first languages differed, all the participants had command of their knowledge and understanding of English.

Table 1

Demographic Variables of Parent Participants in Focus Groups (N=25)

Variable	N=25	n (%)
Race	White	17 (68%)
	Black	3 (12%)
	Coloured (mixed race)	3 (12%)
	Indian	2 (8%)
Age	20-24	1 (4%)
	25-29	7 (28%)
	30-34	10 (40%)
	35-39	4 (16%)

	40-44	2 (8%)
	45-49	1 (4%)
First Language	English	12 (48%)
	Afrikaans	11 (44%)
	Zulu	1 (4%)
	Tswana	1 (4%)
Relationship Status	Married	17 (76%)
	In relationship	3 (12%)
	Single	2 (8%)
	Customary Marriage	1 (4%)
Level of Education	Grade 10	1 (4%)
	Grade 12	4 (16%)
	Certificate	1 (4%)
	Diploma	7 (28%)
	Bachelors	7 (28%)
	Honours	4 (16%)
	Masters	1 (4%)
Employment Status	Full time	17 (64%)
	Part time	2 (12%)
	Stay at home	6 (24%)
Monthly Household Income	R20,000 and below	3 (12%)
	R20,001-30,000	4 (16%)
	R30,001-40,000	6 (24%)
	R40,001-50,000	2 (8%)
	R50,000 and above	10 (40%)
Note: R=Rand (South African currency)		

Data Collection

During their stay in the neonatal intensive care unit (NICU), parents are often unable to immediately take care of their premature infants because of the latter's medical condition. These parents may consequently experience higher levels of stress and be susceptible to greater emotional challenges than the parents of full-term newborns (Clotney & Dillard, 2013; Ionio et al., 2019). Therefore, it was appropriate to go beyond the scope of the hospital settings that typically offer services and support to parents and premature infants to recruit potential parent participants in the study.

The Facebook platform is the most widely used social media platform in South Africa, with 16.9 million active users at the end 2019 (Clement, 2020). It was selected as the best method to recruit, enroll and collect data from South African parents who had premature infants discharged from hospital within the last five years. This time frame was chosen because it not only allows for transition to home life from the hospital discharge, but also provides an adequate duration of time for parents to become their infants' primary caregivers (Kusters et al., 2013). The first author had to ensure that the procedures used in the online focus groups would be confidential, reliable, and valid for collecting data. When creating a group on Facebook, the administrator or moderator has a choice of three privacy settings: public, closed or secret ([facebook.com/help](https://www.facebook.com/help)). All groups require member approval by either an administrator or group member, depending on the group's settings. However, in this research, the 'secret' group setting was chosen for conducting the online focus groups because it is the most private and confidential group setting on the Facebook platform.

The materials developed for data collection included a parent invitation to participate in the study, a parent biographical questionnaire, the focus group questions, and a facilitation script that was used during the focus group discussions. Because South Africa has a diversified population in terms of language, culture and religious beliefs, care was taken to ensure the developed materials were appropriate within the South African context. There had to be no cultural mismatch or any misunderstanding of the written language where parents could get confused or lost in an attempt to read and respond to the questionnaire (Abdoola, 2015; Kanjee, 2005; Peña, 2007). Details of the procedures that were followed throughout the data collection process, as well as a description of how it was implemented, are explained in Table 2.

Table 2

Detailed procedures followed during data collection process

Procedures / Actions (Creswell & Creswell, 2017; Maxwell, 2014)	Implementation for the current study
<ul style="list-style-type: none"> Stipulated the qualitative research question(s) and decided upon the qualitative approach. 	<p>Qualitative research question: What would a parent support program entail that focuses on the information and support needs of parents related to the caregiving for their premature infant after their initial discharge home from the hospital?</p>
<ul style="list-style-type: none"> Obtained permission to conduct the research. 	<p>Ethic approval was granted by the Ethical Committee of the Faculty of Humanities, University of Pretoria (# GW20181129HS). Permission was obtained from the parents to participate in the focus groups and from Early Childhood Intervention (ECI) professionals to assist with the development of the parent biographical questionnaire and focus group questions.</p>
<ul style="list-style-type: none"> Identified the qualitative sample. 	<p>Non-probability sampling using the purposive, convenience and snowball methods (Maree & Pietersen, 2016) were utilized to select parent participants for the study. A convenience sample of 25 parents were subsequently selected (McMillan & Schumacher, 2014). All parents who gave their consent and met the selection criteria were selected to participate. Purposive sampling (Maree & Pietersen, 2016) was utilized to recruit three (3) ECI professionals. Their task was to review and critically analyze the parent biographical questionnaire and the online focus group questions to confirm applicability to the South African context.</p>
<ul style="list-style-type: none"> Collected open-ended qualitative data from four online focus groups. 	<p>Each parent was asked two questions in the focus group discussions: (1) What made it easier for you to take care of your baby after your discharge home from the hospital? (2) As a parent, what do you regard as necessary to include in a support program for South African parents? When necessary, the first author posted prompting questions if parents did not provide clear (rich) answers to the question.</p>
<ul style="list-style-type: none"> Captured and organized qualitative data from focus group discussions. 	<p>Using Microsoft’s snipping tool, the first author was able to capture or screenshot the conversations in the focus groups and print out the conversations in their entirety, which ensured that a more accurate record was kept of each post in the group. By capturing the conversations in the focus group, the first author was able to organize, accurately reflect, document and identify themes from the data collected.</p>
<ul style="list-style-type: none"> Analyzed the qualitative data by using thematic analysis specific to answering the research question to determine the information needed for the next phase of the study. 	<p>The first and second author utilized thematic analysis to generate subthemes and themes for the data collected from the online focus groups. Member checking was done to ensure rigor and validity of the interpretation of results. Data triangulation occurred in the final phase of data analysis. The results of triangulation were the basis for initiating the next phase, which outlined the steps that informed and provided recommendations for a parent support program for South African parents with premature infants.</p>

Data Analysis

Thematic analysis was used to assist the authors to analyze the focus group data and create straightforward, insightful, thick and trustworthy findings when exploring the direct perspectives

of the parent participants and for summarizing the data from the parents' posts (Braun et al., 2019; Nowell et al., 2017). The two coders (first and second authors) familiarized themselves with the focus group data over an extended period in order to identify codes (Nowell et al., 2017). A codebook – with 46 pre-developed codes from an integrative review by the same authors (Davis-Strauss et al., 2020) on the information and support needs of parents with premature infants that had been stored in ATLAS. Ti.8, a Computer-Assisted Qualitative Data Analysis software (CAQDAS) – was utilized to deductively analyze the focus group data (Braun & Clarke, 2006; Friese et al., 2018). New codes that were not included in the pre-developed code book were coded in the “other” category. The two coders then generated new codes for this “other” category in an iterative way and repeated the process until a mutual agreement was reached, and no new codes emerged. The newly adapted codebook was then accepted to be a valid representation of the focus group data (Roberts et al., 2019).

The initial codes from the focus groups were identified on a semantic level with surface-level meanings (Braun et al., 2019). Having independently coded the data, the two coders together went through the process of re-reading the remaining coded words or phrases. They renamed, split and merged codes, which resulted in 40 generated content codes. Codes were then listed from the highest to the lowest number of times grounded (mentioned) by the participants. The codes and the number of times the codes were grounded are illustrated in Table 3. Codes that were mentioned twice or less by the parent participants are not reflected in the table.

Table 3

Content codes and number of times grounded

#	Codes	Grounded
1.	How much to feed infant	25
2.	Breastfeeding	25
3.	Supplemental milk feeding	20

4.	Lack of support from HCPs	19
5.	Infant illnesses/infections	18
6.	Infant digestion	16
7.	Schedules and routines	16
8.	Feelings of stress or anxiety	16
9.	Feelings associated with fear	14
10.	Being misunderstood by others	12
11.	Expected behaviors of premature infants	12
12.	Sleep/awake patterns for premature infants	11
13.	Infant weight gain	11
14.	Developmental milestones/adjusted age	10
15.	Lack of support received from work	10
16.	Feelings of guilt	9
17.	Bathing/skin care/soaps/creams	9
18.	Dressing/keeping infant warm	8
19.	Home environment/temperature	8
20.	Giving infant medication	7
21.	Infant colic/being gassy	7
22.	Infant breathing	7
23.	Learning CPR/First aid	7
24.	Feelings of being depressed	7
25.	Lack of support from family and friends	6
26.	Sleep deprivation	5
27.	Initial emotions experienced post-discharge	5
28.	Feelings of being lonely	5
29.	Financial assistance from medical aid schemes	4
30.	Social disruption/isolation	4
31.	Infant holding/swaddling	4
32.	When to begin solids	4
33.	Feelings of worry	4
34.	Using monitors at home	4
35.	Infant crying/fussiness	3
36.	Taking infant outside of home	3
37.	Responding to an emergency	3

38. Getting the Synagis injections	3
39. Vaccinating premature infants	3
40. Spousal/partner relationships	3
Total:	371

The two coders next mutually analyzed and synthesized the 40 generated codes into seven subthemes that captured and described relevant, similar themes connected to the information and support needs stated by the South African parents. The seven categorized subthemes were synthesized into two main themes after mutual agreement by the two coders and the assistance of four independent academic colleagues who had to determine whether the themes were sufficiently clear and comprehensive (Braun et al., 2019; Nowell et al., 2017). The numbered generated codes, as illustrated in Table 3, are listed in parenthesis under each of the generated subthemes, and the two generated main themes are displayed in Figure 1.

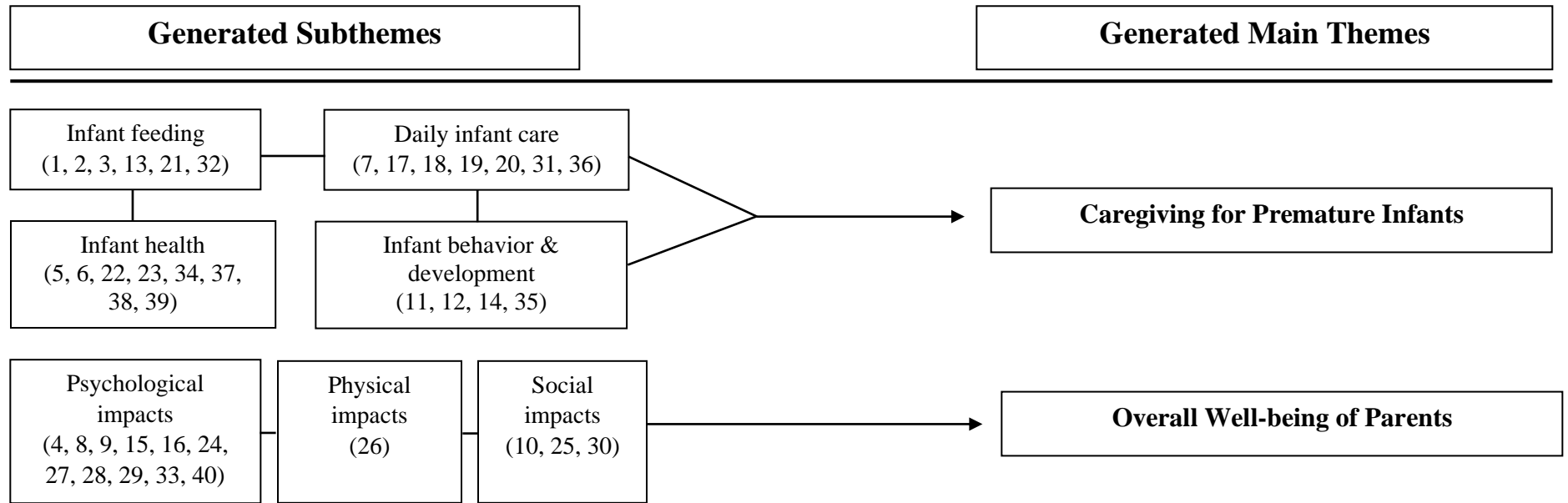


Figure 1. Categorized subthemes and main themes with codes in parenthesis

Member checking was utilized to minimize the potential of any bias. The parent participants were actively involved in checking and approving the findings as an accurate reflection of their perceptions, comments and responses in the online focus group discussions (Birt et al., 2016; Harvey, 2015). The nature of the process of member checking helped to ensure the authenticity of the findings by providing the parent participants an opportunity to edit, clarify, or elaborate on the generated themes and subthemes. An email was sent to each parent individually to request their further participation in the study (Curtin & Fossey, 2007).

Findings

Based on the generated subthemes with the inclusion of the coding (mentioned needs by the parent participants) as illustrated in Figure 1, two main themes were generated. These themes represented the South African parents' information and support needs regarding the caregiving for their premature infants after their initial discharge from hospital: (1) Caregiving for premature infants, and (2) Overall well-being of parents.

Theme 1: Caregiving for premature infants

Four subthemes emerged in respect of the caregiving for premature infants. The first subtheme was concerned with infant feeding and included topics such as how much to feed the infant; breastfeeding; supplemental milk feeding; infant weight gain; infant colic/being gassy; and when to begin solids? The second subtheme concerned daily infant care and focused on topics such as schedules and routines; bathing/skin care/soaps/creams; dressing to keep infant warm; home environment/temperature; giving infant medications; infant holding/swaddling; and taking the infant outside of the home. Infant health as the third subtheme was concerned with infant illness/infections; infant digestion; learning CPR/first aid; using monitors at home;

responding to an emergency; getting the Synagis injections; and vaccinating premature infants.

The fourth subtheme was infant behavior and development and it focused on topics such as expected behaviors of premature infants; sleep/awake patterns for premature infants; developmental milestones/adjusted age; and infant crying/fussiness. Examples of direct quotes from the parent participants related to the caregiving for their premature infants are shown in Table 4.

Table 4
Examples of verbatim quotes from parent participants in respect of Theme 1

Subtheme	Examples of Parents' Posts
Infant Feeding	
How much to feed infant	I was worried whether they got enough milk during breastfeeding because I was so used to exact measurements through a feeding tube. (FG3)
Breastfeeding	My daughter wouldn't latch, so after 2 and half months of expressed milk we moved to formula...expressing was just too much. (FG 1)
Supplemental milk feeding	We were mix feeding when she was in the hospital and then discharged. I needed information on what to do when she does not want to feed, how to increase milk supply and in the meantime also what formula to give, how much to give, changing formulas due to constipation and what the weight gain should be at that age. (FG4)
Infant weight gain	I never knew how much my baby should weigh; is her weight normal for her chronological age or corrected age? (FG3)
Infant colic/being gassy	Definitely colic - constant fear if something was seriously wrong with him or was it was just the colic as he would scream non-stop. (FG4)
When to begin solids	I found myself a bit confused with feedings and when to change to solids or when to start feeding more. (FG3)
Daily Infant Care	
Bathing/skin care/soaps/creams	The first few baths were also very daunting, they are so little that you are afraid of hurting them. (FG3)
Dressing/keeping infant warm	Also, how many layers to put her in; was she too hot or comfortable? (FG3)
Home environment/temperature	How many people were allowed to visit; for how long should we be making people sanitize religiously before touching her; how long was it advisable that she was allowed to be held by others? (FG1)
Giving infant medication	Our babies came home with bags of medicine and vitamins. In the hospital these were given through the NG tubes. All of a sudden, we had to give the meds and we weren't sure. (FG2)
Schedules and routines	How long to let them sleep, when to increase feeding times, for example 3-hourly in the day and 4-hourly at night. (FG1)
Infant holding/swaddling	Were we holding her too much? Were we swaddling her the right way? (FG1)
Taking infant outside of home	We were told not to take him out for the first few months, but I have since learned that it was fine to take him out. I wish we had been given guidelines on that. (FG1)
Infant Health	
Using monitors at home	All the monitors made me more paranoid. I now only used the angel care. (FG2)

Learning CPR/First aid	I wish I could have taken a course in CPR before she was discharged from the hospital. (FG1)
Infant breathing	I would check on him when he was asleep to make sure he was still breathing. I was so used to the monitors in NICU to feel secure but now I had to do it myself...it was quite scary. (FG2)
Infant illnesses/infections	I was concerned with him getting sick and how I can tell that he isn't feeling well...I didn't know what to look for. (FG2)
Infant digestion	With him being my first child, I always felt unsure when it came to bowel movements and when to worry if your baby has not had a bowel movement, etc. (FG3)
Responding to an emergency	I looked for information regarding emergencies and what to do should a medical emergency happen. (FG2)
Getting the Synagis injections	We were told to get the Synagis injection for our daughter to help her through the winter months, but we weren't given the information we needed to make a decision. My paed was able to calm our fears. (FG4)
Vaccinating premature infants	I wasn't sure what schedule to follow with vaccinating my preemie. Do I follow her corrected age or from the time she was born? (FG4)

Infant Behavior & Development

Developmental milestones/adjusted age	We were always trying to keep up to date with what their corrected milestones were, so we had an app called Wonder Weeks. Also, we wondered about when to start solids, vaccines, etc. on corrected age, as I was scared we were giving normal doses to micro prem babies. (FG3)
Expected behaviors of premature infants	I think every parent of a prem worries about milestones and what to expect and I was just always assured about that and that every baby is different, but there are things to look out for. (FG2)
Sleep/awake patterns for premature infants	Sleeping was also something I sought advice on as she slept so much and I had to wake her for feeds and she would just sleep again, well over her full term date. (FG2)
Infant crying/fussiness	I cried so much when my boys finally got home because they would cry and I just didn't know why they were crying. It took a couple of weeks to figure out their certain cries for being hungry, sleepy, etc. (FG2)

Theme 2: Overall well-being of parents

Three subthemes emerged concerning the impact on the overall well-being of parents: psychological, physical and social. The first subtheme was concerned with psychological impacts such as the lack of support received from healthcare professionals and their employers/co-workers; experiencing initial feelings of stress, anxiety, fear and depression; being lonely; worrying; and negative effects on spousal/partner relationships. The second subtheme involved the physical impact on parents and looked at sleep deprivation and other negative effects. Social impact was the third subtheme and focused on topics such as being misunderstood by others; lack of support from family and friends; and social disruption/isolation. Examples of direct quotes from participants as related to their overall well-being are provided in Table 5.

Table 5
Examples of verbatim quotes from parent participants from Theme 2

Subtheme	Examples of Parents' Posts
Psychological Impacts	
Lack of support from HCPs	I feel like I needed (maybe still need) psychological support. It was a big shock. Feels like I never had a normal and memorable birth and never will. (FG3)
Lack of support received from work	Resigning was not an easy decision and financially not always easy...I had a difficult pregnancy from 20 weeks on. My previous employer was horrible to the extent they wanted me to leave the hospital when I was admitted to come back to work and harassed myself and my doctor. (FG2)
Feelings of stress or anxiety	Leaving the hospital after all the added stress leaves you very emotional, unsettled, horrible things going through your minds. (FG1)
Feelings associated with fear	My worse fear at home was that he would get sick again and I would miss it. Also, the fear that he would stop breathing. (FG1)
Feelings of guilt	Definitely dealing with all the emotions and guilt that come from having a premature baby. (FG4)
Feelings of being depressed	It was extremely lonely and made me feel even more depressed and stress over everything. (FG2)
Spousal/partner relationships	I found myself emotional not knowing what to expect and not knowing how to feel or how to deal with all my emotions and taking care of the smallest baby I have ever seen and trying to make sure he is ok but also focusing on my wellbeing and my marriage. (FG3)
Initial emotions experienced post-discharge	I counted the days to take my boy home and the night before his discharge I couldn't sleep. The reality hit that there will be no more monitors and medical personnel and I was terrified! (FG1)
Feelings of being lonely	Having a premature baby is a very lonely and scary journey. We've never felt so alone and scared and little support. (FG2)
Feelings of worry	I was worried about breathing, feeding, etc. and used a monitor when he was sleeping. (FG1)
Financial assistance from medical aid schemes	I think medical aid should pick up some of the financial strain with the therapy premature babies need like physio. (FG2)
Physical Impacts	
Sleep deprivation	I remember a few times just walking around like I was in a fog because I just couldn't sleep for fear of something happening to him and me not being awake to know. (FG2)
Social Impacts	
Being misunderstood by others	Our families thought we were overreacting and germophobes! (FG2)
Social disruption/isolation	My husband and I just didn't go out anymore because our focus was on keeping him healthy. (FG4)
Lack of support from family and friends	I didn't have a lot of support (friends were working, hubby worked long hours and my mom couldn't help regularly). (FG1)

Discussion

This study aimed to determine the information and support needs of South African parents relating to the caregiving for their premature infant after the initial discharge home from the hospital. Our findings confirmed that the information and support needs of South African parents in the caregiving for their premature infants post-discharge are largely unmet.

Findings from this study are in related literature and indicated that parents often feel unprepared and anxious at the time of the hospital discharge, causing them to question their ability to take care of their premature infant (Aloysius et al., 2018; Jefferies, 2014). Findings from our study, related to the parents' fear of being discharged from the NICU, were also confirmed by a study conducted by Phillips-Pula et al. (2013) whose findings showed that fear and anxiety persisted in some parents for six months after the hospital discharge of their premature infants. These findings are echoed in a study conducted by Nicolaou et al. (2009) where parents expressed mixed feelings such as joy, excitement, nervousness and fear about going home with their premature infants. A study conducted by Boykova (2016) found the initial mixed feelings experienced by parents were associated with having their premature infants hospitalized. The situation altered the parents' perception of their role as a parent, lowered their self-confidence, produced feelings of not being a parent, and decreased their ability to make decisions for their infant's care and health.

Participants contributed their fear of the infant's discharge to the limited interaction they had had with the premature infants while being cared for in the NICU. As a result, they felt not confident about and unsure of how to care for their tiny, fragile infants. Participants' lack of (or limited) opportunities to care for their premature infants while in the NICU left them feeling

fearful, anxious and doubtful about providing the necessary care for their infants once they were in their home environment. The mothers in the study by González and Espitia (2014) reported similar findings and indicated that the separation from their infants during the latter's admission to the NICU, and their lack of opportunity to experience and develop their maternal role, prevented them from assuming this new position with confidence and joy. Instead, it produced doubts, insecurity and fear when they eventually became responsible for the care of their premature infants at home. Similarly, Hemati and colleagues (2017), who aimed at investigating the challenges of mothers after their premature infant's discharge home, also found that parents with inadequate experiences or opportunities of caring for their premature infants in the NICU suffered with intensified fears and stress in caring for their infants post-discharge.

Literature indicates that parents of premature infants have intensified parental needs after the discharge home and often require additional information on infant caregiving, social support and professional healthcare services (Aylward, 2002; Petty et al., 2018). Similar findings were generated from the current study, as several participants stated they were unprepared for the challenges they faced after the discharge home. They also mentioned their need for information relating specific to their premature infant's needs, such as feeding; expected premature infant's behaviors; expected milestones and development of premature infants; and how to recognize when their premature infants were getting ill. These findings coincide with a study by Boykova (2008) where the mothers expressed concerns about issues related to the caregiving for their premature infants, such as feeding; sleep patterns; infants getting ill; the expected development and future care needs of their premature infants.

Findings from the current study were similar to a literature review conducted by Boykova (2016), which involved parents of premature infants in Russia, the USA, Canada, United

Kingdom and Iran. Findings confirmed that parental needs are similar regardless of culture and not influenced by social or geographical settings. Findings from the study in hand and related literature further suggested that the unfulfilled needs of parents demanded continued information and adequate social and professional support after the infant's discharge from hospital.

Limitations and Future Research

Although the current study yielded important findings, it also had several limitations. The study was conducted in English, so participants had to have knowledge and understanding of written and spoken English to participate in the focus groups. South Africa has 11 official languages (Stultz, 2009), so there were many more parents who could have participated if the study had been available in multiple languages. Different perspectives could have been represented by parents who speak other languages, and this could possibly have changed the findings from the focus groups. Also, in utilizing online focus groups, the study may have missed the voices of rural or poor South African parents who did not have Internet access or access to the Facebook parent support groups. The biased selection of a group of participants who had already been involved in the parent support groups should be acknowledged.

The study focused on participants 18 years and older, which implies that younger participants who might have added different perspectives, were excluded. Participants also had to have premature infants born between 28-37 weeks' gestation, which ignores the fact that parents of premature infants born before 28 weeks' gestation may have other needs that were not supported in this study.

Despite these limitations, the current study provides an in-depth summary of the perceptions of South African parents of premature infants, which permitted a greater understanding of their perceived needs during the important early months at home after being

discharged from hospital with their premature infants. The current study highlighted parents need for more supportive experiences of caregiving during their baby's NICU stay. Thus, future research could focus on the prevalence of developmental care in NICUs in South Africa and baby friendly care and the role of NICU nurses in supporting parents in their rightful parenting role. The findings generated from the online focus groups can serve as the foundation for an early intervention design or program that specifically targets the information and support needs of South African parents with premature infants. The program, to be introduced prior to discharge from hospital, should include a component of providing continuity of care by healthcare professionals trained in topics surrounding premature infants to better support South African parents within their own communities. The role of the community and available sources in low-and middle-income countries in supporting parents of premature infants also needs to be investigated in future research.

Conclusion

Our study revealed that South African parents have unfulfilled information and support needs that cause them to struggle with the caregiving for their premature infants after their initial discharge home from hospital. The study further clarifies that South African parents share common information and support needs, regardless of their demographic characteristics. It is therefore hoped that this body of work will help raise awareness of the plight of South African parents with premature infants, as their information and support needs are many and – if they remain unmet – can cause negative short- and long-term consequences for the whole family unit.

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