Telehealth experiences of mothers of hospitalized and discharged preterm infants in Islamic Republic of Iran

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Abstract

Background: The transition to telehealth services for mothers of preterm babies is a challenge in promoting the health of preterm infants, although telehealth allows real-time interaction and support for mothers.

Aim: To compare the experiences of mothers of hospitalized and discharged preterm infants with telehealth services in the Islamic Republic of Iran.

Methods: This qualitative study was conducted from June to October 2021 using a conventional content analysis approach. The study participants included 35 hospitalized and 35 discharged mothers of preterm infants, who received healthcare consultations through WhatsApp and Telegram applications. They were selected using purposive sampling. Data collection was done using in-depth semi-structured interviews and data analysis was performed using Graneheim and Lundman analysis.

Results: Our findings showed request for continuing healthcare support by the mothers as the main category, with 3 subcategories: willingness to connect to telehealth services, more comprehensive education about telehealth services, and opportunities to share experiences. Mothers of hospitalized and discharged preterm infants had conflicting views about the ambiguous role of nurses in telehealth and the use of telehealth as a support system.

Conclusion: Telehealth plays an important role as a supportive method in promoting infant health and boosting the confidence of mothers of preterm infants as they continuously interact with nurses.

Keywords: preterm, infants, telehealth, maternal health, mothers, Iran

Introduction

Continuous follow-up of preterm infants is essential to ensure infants' health during hospitalization and after discharge. The physiological status of preterm infants fluctuates while trying to achieve stability. Respiratory distress, insufficient strength for breast suckling, high incidence of infections, and rehospitalization are the most common threats to infant health. Therefore, it is important to reinforce maternal competency in assessing, performing, and managing the care process (1,2). Mothers have many unanswered questions and concerns that could cause low self-confidence and limit skill to care for premature infants independently. Neonatal intensive care units (NICUs) prepare mothers for the transition from hospital to home care. However, this is only the first step in the process of caring for preterm infants. Mothers must continually interact with caregivers to learn the specialized skills required. For mothers, hospitalization of infants is a time of anxiety, stress, and concern for the future health of their infants, which can prevent them from learning the skills needed to start caring. Support and guidance for this vulnerable group of mothers appears to be neglected because the focus is often on infant rather than maternal care, although mothers are at the centre of the caregiving process (3–6).

Currently, there is a desire among policymakers to transit health service strategies from face-to-face to virtual referrals, and this has been made feasible through the rapid development of telehealth tools. Telemedicine has many advantages, including convenience, safety during infectious disease outbreaks, family connections, reduced health service costs, and preservation of physical health service capacity for urgent cases. The American Telemedicine Association estimates that in 2012, about 10 million people benefited from telehealth services, and 76% of hospitals were equipped with the services (6–8). The Islamic Republic of Iran is among the countries that have started telehealth communication. The dispersed population in remote areas and their difficulty in accessing specialized medical centres during the COVID-19 pandemic were part of the motivation to apply telehealth communications (9).

Mothers of premature infants should be a target group for access to telehealth programmes. Robinson et

al. reported high satisfaction among parents receiving telehealth services (10). Other studies have examined the effectiveness of telehealth for care of premature infants in relation to cost analysis, time consumption, and health providers' satisfaction (11–14). However, no study has adequately focused on caregivers, particularly mothers of preterm infants. This study compared the telehealth experiences of hospitalized and discharged mothers of premature infants, with differences in perceptions about caregiving, geographic setting, and gestational age. Our results provide a different perspective for infant health policymakers to plan telehealth structure based on the perspectives of mothers, who are the main caregivers of infants.

Methods

Study design

This qualitative study with a conventional content analysis approach was conducted using the Graneheim and Lundman analysis (15). The design is usually appropriate when the phenomenon is still unclear and needs to be clarified in different cultural and participant settings. The study compared the telehealth experiences of hospitalized and discharged mothers of premature infants. It was conducted from June to October 2021 at Isfahan University of Medical Sciences, Islamic Republic of Iran.

Study participants

We selected purposively 35 hospitalized and 35 discharged mothers of preterm infants (Table 1) with gestational age of < 34 weeks for preterm hospitalized mothers and > 34 weeks for preterm discharged mothers. The participants received consultation on infant care through WhatsApp and Telegram platforms. They were connected to the virtual groups by nursing managers of 3 main NICUs affiliated with Isfahan University of Medical Sciences (AL Zahra, Shahid Beheshti, and Emam Hossein Hospitals), which provide special care services to the families of preterm infants. There were no age,

ethnicity, or residency restrictions on group enrolment to ensure diversity among participants. The participants lived in different cities, including Isfahan, Sharekord, and Kashan, and were referred to health services in Isfahan. The main aims of the nursing virtual group were consultation, training, and response to mothers' concerns about their infants' health. Services were provided 24 hours a day by 6 experts including 2 neonatal intensive care nurses, 2 hospital nurses, 1 neonatologist, and 1 information manager. The training programme focused on 4 essential elements of care for preterm infants: breastfeeding, enhancement of oral feeding competency, recognition of danger and warning signs in infants, and developmental care. The consultation included a needs assessment to inform the design of a training for the mothers. After 5 months, the mothers were invited to share their experiences with the virtual telehealth group, and all 70 agreed to participate in this process.

Data collection

Data collection was conducted through in-depth semistructured interviews that were performed by telephone. The interviews began with general questions about mothers' experiences, such as: "What was your experience with the telehealth consultative group?". It continued with more in-depth questions, for example, "How do you evaluate telehealth support?"; "How did it help you?"; "What is your opinion about continuing membership in the telehealth group?"; "Have you ever faced challenges?"; "What did you do?"; "Why did you join the group?", "What is your idea about the role of nurses in the group?"; "What is your experience of access to telehealth compared with usual hospital services?"; and "What suggestions do you have to improve group performance?" The analysis was performed after the third interview, simultaneous with the data collection period. The mean duration for the interviews was 25 minutes, depending on the participant's willingness to share their opinions. The interviews continued until data saturation.

Data analysis

Data analysis was performed using Graneheim and Lundman analysis, which focused on context, to highlight the main concepts and explore similarities and differences between participants' viewpoints (15). The interviews were transcribed verbatim in Microsoft Word 2010. According to Graneheim and Lundman analysis, the transcripts were appraised and checked several times, and their meaning units were extracted. The initial codes were labelled, and the main categories and subcategories emerged through further comparison of similarities and differences. To integrate the viewpoints of mothers at home and in hospital, and identify similar experiences, the researchers decided to insert codes with > 50% similarity into 1 subcategory.

Ethical considerations

The study was approved by the Ethics Committee of Isfahan University of Medical Sciences (IR.MUI.

Table 1 Characteristics of the participants

Characteristics	Hospitalized mothers of preterm infants	Discharged mothers of preterm infants
Age, yr		
<25	11 (31.4)	4 (11.4)
25−35	17 (48.5)	12 (34.2)
36−45	7 (20.0)	9 (25.7)
Education		
Under diploma	6 (17.1)	3 (8.5)
Diploma	11 (31.4)	15 (42.8)
Bachelor degree	15 (42.8)	15 (42.8)
Masters degree	3 (8.5)	2 (5.7)
Birth		
Single	28 (80.0)	29 (82.8)
Twins	4 (11.4)	6 (17.1)
Triples	3 (8.5)	0

Results are shown as numbers (%).

NUREMA.REC.1400.055). Oral consent was obtained from all participants for study cooperation and recording of the interviews. We could not obtain written consent because of the COVID-19 pandemic restrictions. The participants were ensured of data confidentiality and the right to withdraw from the study.

Study rigour

Guba and Lincoln's criteria were considered to raise the study's rigor. Constant interaction with mothers during group activities, assignment of adequate time for interviews according to participant requests, and receiving continuous feedback to confirm their narration enhanced the study rigor. Two colleagues with experience in qualitative research analysed ambiguous cases until a consensus was reached. The reliability of the results was ensured by using direct quotations from the participants.

Results

Categories

The interviews of hospitalized and discharged mothers of premature infants generated 3732 codes. Related codes with similar concepts were clustered into 1 main category of requests for continued telehealth support. Three subcategories emerged: willingness to connect to telehealth resources; emphasis on receiving more comprehensive education; and opportunity to share experiences. The findings revealed 2 conflicting categories: (1) ambiguous role of nurses in telehealth (unknown role of consultant nurses as a valid source for mothers); and (2) debate on telehealth as a valid supportive system (controversy on telehealth safety).

Similar concepts and dissimilarities are displayed in Figure 1.

Similarities of viewpoints between hospitalized and discharged mothers of preterm infants (Table 2).

Willingness to connect with telehealth resources

The mothers were interested in maintaining their relationship with health providers through telehealth, and they desired to have a communication link with the health team.

"*I needed to join a group that provided consultation without time restriction. Being linked with nurses gave me peace of mind*" (Mother 6, discharged).

"*I was continually at the ward to learn about essential care. It made me bored, but when I joined the group, I felt okay because I could go home to rest. I was happy to be in contact with nurses that guide me*" (Mother 12, in hospital).

Emphasis on receiving a more comprehensive education

Education is an important ingredient of maternal empowerment. Hospital and telehealth educational programmes had a synergistic effect on learning about maternal care.

"*Different clips and videos about maternal education introduced by nurses on the ward helped me learn better about premature infants*" (Mother 24, in hospital).

"*Virtual learning was a pleasure for me. You are at home and you can have different educational contents on your phone without the need to travel for learning in hospital classes. Also, more subjects are covered in the telehealth groups*" (Mother 11, discharged).

Figure 1 **Similarities and differences in the experiences of telehealth among hospitalized and discharged mothers of preterm infants.**
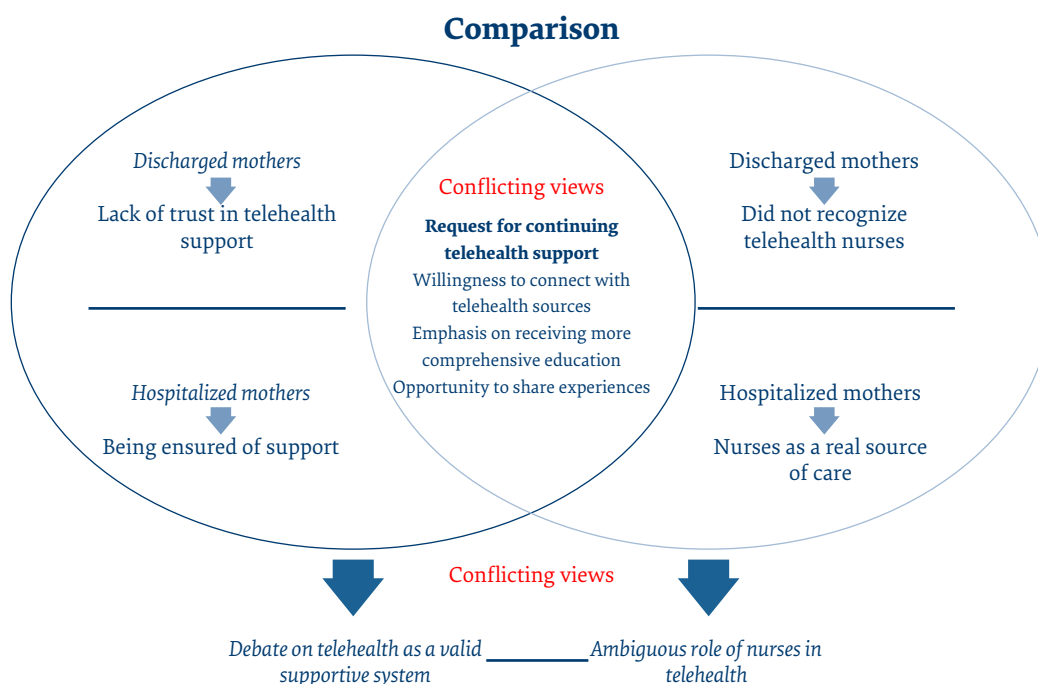
Table 2 Similar experiences of telehealth by hospitalized and discharged mothers of preterm infants

Main category	Subcategories 2	Subcategories 1
Request for continuing telehealth support	**Willingness to connect to telehealth resources**	• Possibility of receiving consultation from health providers • Using educational advice • Being close to nurses and physicians • Possibility of sending messages to health providers • Access to nurses in an emergency • Solving problems with the assistance of health staff
	Emphasis on receiving a more comprehensive education	• Receiving support without restriction • Continued relationship with the health team • Better learning through clips and videos • Receiving breastfeeding education through telehealth • Possibility of continuing education • Access to education at home • Having an enjoyable space for learning • Learning without attending a class • Continuation of hospital education
	Opportunity to share experiences	• Having a listener • Exchanging information • Discussion about concerns • Expressing feelings • Using others' knowledge • Having a new family • Finding new friends • Reduction of maternal stress • Common sense of purpose

Opportunity to share experiences

Telehealth facilitates links between mothers and increases the likelihood of sharing experiences regardless of location.

"My stress decreased a lot because I found many mothers were like me. They shared their concerns and information, and they gave me hope." (Mother 18, in hospital).

"I followed all the messages, explanations, and motherly chats at home. I felt like I was part of a big family with similar problems." (Mother 21, discharged).

Conflicting viewpoints between hospitalized and discharged mothers of preterm infants (Table 3)

Conflicting viewpoints emerged between hospitalized and discharged mothers of preterm infants in relation to the ambiguous role of nurses in telehealth, and the debate about telehealth as a valid supportive system.

The ambiguous role of nurses in telehealth

The hospitalized mothers emphasized the nurses' role as a real healthcare provider in the hospital and trusted their advice, but the virtual world of telehealth led to a lack of awareness among the mothers about the nurses' role in cyberspace. In contrast, discharged mothers understood the nurses' role as a real assistant in the virtual world.

"Telehealth is convenient, but I was able to ask the infant nurse questions directly when I was in the hospital. I feel hospital nurses are more responsive than telehealth nurses." (Mother 10, in hospital).

"When my baby was discharged, I was in shock. I felt lonely and needed to be connected with a valid source to support me and my baby. I called the hospital to receive guidance about my baby's severe reflux, but the nurse was too busy to spend time responding to my request. I spoke with the virtual group, and the nurse made me calm. I think their support helped me to overcome my primary concerns." (Mother 15, discharged).

Debate on telehealth as a valid supportive system

The discharged mothers perceived telehealth as a more supportive system than hospitalized mothers did. The hospitalized mothers appreciated face-to-face interaction.

"I prefer hospital services. There were hospital staff teaching mothers daily about breastfeeding premature infant inhalation, and maternal diet. I prefer contacting the nurses and doctors at the hospital to obtain more information than the telemedicine groups. They knew my baby's history from admission to discharge." (Mother 13, in hospital).

"I had difficulty with the hospital's conventional follow-up. There were no dedicated programmes for follow-up of preterm babies despite their risk. Mothers of preterm infants need to be supported. My husband and I performed all follow-ups by ourselves. The hospital only called us 1 week after the baby's discharge. We could not address each problem of our baby by going to the physician's office. My preference was to access the telehealth group about my concerns and to ask questions instead of constant presence at the hospital" (Mother 6, discharged).

Discussion

This qualitative study focused on the perspectives of hospitalized and discharged mothers of preterm infants

Table 3 Differences in experiences among telehealth of hospitalized and discharged mothers of preterm infants

Hospitalized mothers	Discharged mothers
Nurses as a valid source of care	**Unknown role of telehealth nurses**
• Nurses give assistance • Nurses acting as educators • Primary source of interaction with mother • Gain reassurance about the nurses' care of the infant • Nurses as responsive agents	• Busy nurses • Going out of nurses' attention at discharge • Lack of access to health providers • Weak caring support after discharge • Nurses are nonresponsive after discharge
Hospitals support for follow-up care	**No support for follow-up care**
• Support by health providers • No concern for the infant care process • Follow-up consultation by hospital • Nurses paid attention to mothers' concerns • Responsiveness of the system	• No source of support • Feeling lonely • Obligation to do all infant follow-up • Consequent referral to the physician's office

about telehealth support groups. Our findings revealed that all of the mothers were interested in telehealth. The main finding was a request for continued telehealth support with 3 subcategories of willingness to connect to telehealth resources, emphasis on receiving more comprehensive education, and opportunity to share experiences. Although both groups of mothers expressed a desire to be supported by a telehealth group, other findings indicated some differences in opinion about the telehealth nurses' role and its validity as a supportive source.

Most participants in both groups shared a willingness to connect to telehealth resources and emphasized that telemedicine allows engagement with healthcare providers without time constraints. Continued access to consultation by nurses was a motivation for both groups of mothers to join telehealth groups. Lindberg examined parents' perceptions of video conferencing support. One of the categories was a willingness to try, which indicated that the parents understood telehealth as an opportunity to obtain additional support. Therefore, they requested to have telehealth accompanied by conventional care (16). In the Iranian setting in our study, follow-up services were restricted, therefore a comprehensive follow-up structure was required.

Emphasis on receiving a more comprehensive education was another aspect of telehealth that was important to both groups of mothers. They confirmed that it was necessary to have a continuous learning process through educational videos. The synergistic effect of hospital-based and telehealth learning at home leads to greater competency in the care of preterm infants. Recognizing supervision deficits through constant comparison of maternal activity with the correct method motivates mothers to coordinate the learning process through visual data. Pickard et al. found that telehealth-based education for parents of children with autism significantly improved child care and treatment. (17).

Telehealth as an opportunity to share experiences was also found to be a factor in both groups of mothers. It provided an intimate space for mothers of premature infants as a virtual family that faced similar concerns, and a pleasant atmosphere for mothers who needed to

listen and share their feelings, information, questions, and concerns (18). Similar to our study, Jonsson et al. reported that telephone support provided an opportunity for parents of preterm infants to express their hidden feelings (19).

The dissimilarities in mothers' experiences were around the ambiguous role of nurses in telehealth and the debate about telehealth as a valid supportive system. Mothers of hospitalized preterm infants considered telehealth as complementary to hospital services. They could not accept telehealth nurses as a substitute for face-to-face interaction. Mothers recognized hospital nurses as real nurses because of their direct personal interaction; however, the role of telehealth nurses was ambiguous to them because they were unfamiliar with the virtual space. In contrast, mothers of preterm infants who were discharged from hospital perceived telehealth as a necessary system and fully understood the role of telehealth nurses. They trusted telehealth nurses and considered them to be valid sources of consultation and education for resolving their problems. These findings highlight the need for stakeholders to explain the importance of telehealth nurses to mothers. Fathi et al. focused on the involvement of nurses in telehealth services. They mentioned that the acceptance of telehealth nurses depended on the development of novel roles for nurses in the health system. The transition between traditional and modern methods of consultation needs time to become established in the health culture (20,21).

The relevance of telehealth as a valid supportive system was interpreted differently by hospitalized and discharged mothers. While discharged mothers considered it as an accountable system for contacting healthcare providers, hospitalized mothers' perception of telehealth was as an alternative way to obtain support. The hospitalized mothers of preterm infants were satisfied with receiving support through direct health care at the hospital; however, after discharge, the mothers felt isolated with no system to respond to their concerns. Hägi-Pedersen et al. found that parents' comfort and confidence improved after support through social networks. This implies that the provision of a telehealth service can reduce parental stress, anxiety,

and uncertainty (13,22). Connecting mothers to telehealth resources can positively affect infant health and support mothers during unfamiliar situations, regardless of culture or geography.

Our study had some limitations. First, it did not consider the role of fathers. This is because fathers in Iranian society are forbidden for religious reasons from frequent attendance at NICUs. Second, due to restrictions related to the COVID-19 pandemic, we were unable to meet with mothers in person.

Conclusion

Our results confirmed that mothers of preterm infants need to connect with their healthcare providers via telehealth so they can share experiences, increase learning about infant care, and feel reassured and supported by nurses and other healthcare professionals.

Expériences en matière de télésanté des mères de prématurés hospitalisés et sortis de l'hôpital en République islamique d'Iran

Résumé

Contexte : Le passage aux services de télésanté pour les mères de prématurés représente un défi pour la promotion de la santé de ces derniers, bien que cette discipline permette une interaction pour les mères et leur apporte un soutien en temps réel.

Objectif : Comparer les expériences des mères de prématurés hospitalisés et sortis de l'hôpital avec les services de télésanté en République islamique d'Iran.

Méthodes : La présente étude qualitative a été menée de juin à octobre 2021 à l'aide d'une approche d'analyse de contenu conventionnelle. Les participants à l'étude comprenaient 35 mères de prématurés hospitalisés et 35 mères de prématurés sortis de l'hôpital qui avaient reçu des consultations de santé par le biais des applications WhatsApp et Telegram. Elles ont été sélectionnées sur la base d'un échantillonnage ciblé. La collecte des données a été réalisée à l'aide d'entretiens semi-structurés approfondis et l'analyse des données a été effectuée au moyen de la méthode de Graneheim et de Lundman.

Résultats : Nos résultats ont montré que la demande de soutien continu en matière de soins de santé par les mères était la catégorie principale, avec trois sous-catégories : volonté de se connecter aux services de télésanté, éducation plus complète sur les services de télésanté et possibilités d'échanger des données d'expérience. Les mères des prématurés hospitalisés et sortis de l'hôpital avaient des opinions contradictoires sur le rôle ambigu joué par le personnel infirmier dans la télésanté ainsi que sur l'utilisation de la télésanté comme système de soutien.

Conclusion : La télésanté constitue une méthode d'appui importante pour promouvoir la santé des nourrissons et renforcer la confiance des mères de prématurés dans leurs interactions continues avec le personnel infirmier.

تجارب أمهات الأطفال الخُدَّج الذين تلقوا الرعاية في المستشفيات والذين أُخرجوا منها بشأن توفير الخدمات الصحية عن بُعد في جمهورية إيران الإسلامية

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الخلاصة

الخلفية: يمِثل الانتقال إلى توفير الخدمات الصحية عن بُعد لأمهات الأطفال الخدج تحديًا في تعزيز صحة الأطفال الخدج، على الرغم من أن الخدمات الصحية المقدمة عن بُعد تتيح التفاعل مع الأمهات ودعمهن بصورة فورية.

الهدف: هدفت هذه الدراسة إلى مقارنة تجارب أمهات الأطفال الخدج الذين تلقوا الرعاية في المستشفيات بتجارب أمهات الأطفال الخدج الذين أُخرجوا من المستشفيات بشأن توفير الخدمات الصحية عن بُعد في جمهورية إيران الإسلامية.

طرق البحث: أُجريت هذهِ الدراسة النوعية في المدة من يونيو/ حزيران إلى أكتوبر/ تشرين الأول 2021 باستخدام النهج التقليدي لتحليل المحتوى. وشاركت في الدراسة 35 أمًّا من أمهات الأطفال الخدج الذين تلقوا الرعاية في المستشفيات و35 أمًّا من أمهات الأطفال الخدج الذين أُخرجوا من المستشفيات، ممن تلقين استشارات الرعاية الصحية من خلال تطبيقي واتساب وتيليجرام. وقد اختيرت الأمهات بأسلوب العينة المقصودة. وجُمعت البيانات باستخدام مقابلات متعمقة شبه منظمة، وحُللت البيانات باستخدام تحليل جرانيهايم ولوندمان.

النتائج: أظهرت النتائج التي توصلنا إليها وجود طلب على مواصلة تلقِّي الدعم في مجال الرعاية الصحية باعتباره الفئة الرئيسية، مع 3 فئات فرعية: الرغبة في الاتصال بخدمات الصحة عن بُعد، والتثقيف الأكثر شمولاً بشأن خدمات الصحة عن بُعد، وفرص تبادل الخبرات. وتضاربت آراء أمهات الأطفال الخدج الذين تلقوا الرعاية في المستشفيات مع آراء أمهات الأطفال الخدج الذين أخرجوا من المستشفيات بشأن الدور الغامض لكادر التمريض في مجال توفير الخدمات الصحية عن بُعد، واستخدام الخدمات الصحية المُقدمة عن بُعد بوصفها نظامَ دعم.

الاستنتاج: تؤدي الخدمات الصحية المُقدَّمة عن بُعد دورًا مهمًّا بوصفها وسيلة داعمة للأمهات تؤدي إلى تحسين صحة الرُّضَّع، وتعزيز ثقة أمهات الأطفال الخدج بفضل تفاعلهن المستمر مع كادر التمريض.

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