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# Parental Perceptions toward Digital Imaging and Telemedicine for Retinopathy of Prematurity Management

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# Abstract

**Background:** Telemedicine is an emerging technology with potential to improve retinopathy of prematurity (ROP) care. This study evaluates parental perceptions about digital imaging and telemedicine for ROP care.

**Methods:** During a one-year period, one parent of each infant who underwent wide-field retinal imaging for ROP was given a questionnaire designed to evaluate parental perceptions using a 5-point Likert scale. Five items assessed perceptions toward digital retinal imaging, and 10 items assessed attitudes toward telemedicine. Construct validity of the questionnaire was examined using factor analysis. Responses were summarized using descriptive and correlational statistics.

**Results:** Forty-two parents participated. Factor analysis extracted two factors explaining 79% of the total variance in digital retinal imaging items (Cronbach's alpha=0.843), and three factors explaining 63% of the total variance in telemedicine items (Cronbach's alpha=0.631). Among digital imaging items, the highest mean ( $\pm$ SD) score was for "digital pictures of my child's retinopathy should be included in the permanent medical record" (4.4 $\pm$ 0.6), and the lowest was for "digital cameras and computers are reliable" (3.8 $\pm$ 0.8). Among telemedicine items, the highest mean ( $\pm$ SD) score was for "technology will improve the quality of medical care for my child" (4.3 $\pm$ 0.6), and the lowest was for "technology will make it harder for a patient and doctor to establish a good relationship" (2.6 $\pm$ 1.1).

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**Conclusions:** Parents reported positive perceptions about telemedical ROP diagnosis, but expressed some preference for face-to-face care. Telemedicine has potential to alter the nature of the patient-physician relationship.

#### Keywords

retinopathy of prematurity; retina; pediatric ophthalmology; telemedicine; medical informatics; survey

Retinopathy of prematurity (ROP) is a proliferative vitreoretinal disease affecting low birthweight infants. Significant progress has occurred in development of treatment criteria and creation of an international disease classification system.<sup>1-2</sup> However, ROP continues to be a major cause of childhood blindness in the United States and throughout the world.<sup>3-4</sup> Important limitations persist with the current strategy for ROP care: (1) Diagnosis often requires extensive travel and coordination, which is logistically-difficult for ophthalmologists and neonatal staff. (2) The number of infants who require ROP surveillance continues to grow. The rate of premature births has increased approximately 30% in the United States since 1981,<sup>5</sup> and the incidence of ROP has risen worldwide as neonatal survival rates improve.<sup>6</sup> (3) At the same time, the availability of ophthalmologists who perform ROP examinations is decreasing.<sup>7</sup>

Telemedicine is an emerging technology in which medical data and images are captured, and subsequently interpreted by a remote expert.<sup>8</sup> This has potential to address many of the existing limitations of ROP care, and has become more realistic with the increasing availability of wide-angle digital retinal imaging devices. Using these cameras, telemedicine has been shown to have high accuracy and reliability for ROP diagnosis,<sup>9-17</sup> and to be more cost-effective than standard ophthalmoscopy for disease management.<sup>18-19</sup> However, no previous research to our knowledge has formally examined the acceptability of telemedicine to infants' families. This is an important gap in knowledge because large-scale adoption of telemedicine for ROP diagnosis in neonatal intensive care units (NICUs) would likely require the support of both parents and caretakers.<sup>20-23</sup>

The study was designed to examine the attitudes of parents of premature infants toward digital retinal imaging and telemedicine for ROP management. Existing, validated telemedicine questionnaire instruments were adapted for use in the study. All participating infants underwent both dilated ophthalmoscopy and wide-angle retinal imaging examinations.

### METHODS

This study was approved by the Institutional Review Board at Columbia University Medical Center, and was conducted in compliance with Health Insurance Portability and Accountability Act (HIPAA) guidelines regarding patient privacy and security.

#### **Study Population**

From November 1, 2005 to October 31, 2006, one parent of each infant at the Columbia University NICU who met existing ROP examination guidelines<sup>24</sup> was eligible for inclusion.

Parents were given the opportunity to provide informed consent for wide-field retinal imaging (RetCam-II; Clarity Medical Systems, Pleasanton, CA) for a study involving telemedical ROP diagnosis.<sup>11,12</sup> In addition, parents were given the opportunity to provide separate informed consent for this questionnaire survey. Parents were permitted to consent for retinal imaging but not the questionnaire, and vice-versa.

#### **Development and Validation of Survey Instrument**

To maximize content validity, the survey developed for this study was based on existing psychometric instruments used for evaluation of telemedicine satisfaction.<sup>25-26</sup> Items in existing instruments were adapted to measure parental attitudes by 15 question items using a 5-point Likert-type scale (1=strongly disagree, 2=disagree, 3=neutral, 4=agree, 5=strongly agree). There were a total of 15 survey items, consisting of 5 items which assessed attitudes toward digital retinal imaging, and 10 items which assessed attitudes toward telemedicine. Certified translation of the questionnaire into Spanish was performed by the Hispanic Recruitment and Retention Center at Columbia University Medical Center, and subjects were allowed to select their language.

Characteristics of study subjects were asked at the beginning of the survey. Demographic questions included age, gender, race/ethnicity, and level of education. Additional background information was obtained from questions about level of computer experience (none, limited, casual, comfortable, expert); whether the subject had previously used the Internet to search for health care information (yes, no); whether the subject had previously heard of telemedicine (yes, no); and whether the subject had watched their infant receive ophthalmoscopic and/or imaging examinations at the NICU bedside (yes, no).

To examine construct validity of the questionnaire, factor analysis was used to identify subdomains that represented disparate underlying concepts. Because of sample size limitations, this was done separately within the telemedicine items, and within the digital retinal imaging items. The principal component extraction and Varimax rotation methods were used. Internal consistencies of the items and sub-domains were calculated with Cronbach's alpha.

#### Analysis of Responses

Descriptive statistics were used to summarize responses to questionnaire items. To examine relationships between responses and continuous or ordinal participant characteristics, such as age and computer experience, the nonparametric Spearman coefficient was used to evaluate correlation. This was defined as strong (0.60), moderate (0.30-0.59), or weak (0.10-0.29). In cases where the participant characteristics were binary or categorical, such as race/ethnicity and whether the subject has ever heard of telemedicine, the nonparametric Wilcoxon rank-sum or Kruskal-Wallis tests were used to identify differences in responses among different subgroups. To draw conclusions regarding multiple post-hoc pair-wise comparisons, the Bonferroni criterion was applied.

Data analysis was performed using statistical software (SPSS13.0; SPSS, Inc., Chicago, IL). Statistical significance was considered to be two-sided p-value <0.05.

# RESULTS

#### **Study Subjects**

118 unique infants from 92 families received ROP examinations during the study period. Among these 92 families, 61 (66.3%) were approached by study personnel, and 56 (60.9%) consented to participate in the study. One parent from 42 (45.6%) families returned a completed questionnaire. Baseline characteristics of these 42 subjects are summarized in Table 1. Among the 42 subjects, 34 (81.0%) had previously used the Internet to search for health care information and 12 (28.6%) had previously heard of telemedicine. Infants underwent standard ophthalmoscopic examinations as well as digital imaging examinations for the telemedicine study. Ophthalmoscopic examinations were observed by 23 (54.8%) of parents, whereas digital retinal imaging examinations were observed by 16 (38.1%) of parents.

#### Validation and Psychometric Analysis

Among the digital retinal imaging items, the overall Cronbach's alpha was 0.843 after appropriate adjustments to word the tone of each item positively. Principal components factor analysis extracted two components ("quality and utility of digital images" and "attitudes toward digital retinal imaging") explaining 79% of the total variance (Table 2).

Among the 10 telemedicine questionnaire items, the overall Cronbach's alpha was 0.631 after appropriate adjustments to word the tone of each item positively. Principal components factor analysis extracted three components ("data communication and privacy," "accessibility and trust," and "quality of care") explaining 63% of the total variance (Table 3).

#### Survey Responses

Table 2 summarizes responses to the digital retinal imaging items. The lowest mean ( $\pm$ SD) score was for the item "digital cameras and computers are reliable" (3.8 $\pm$ 0.8). The highest scores were for the items "digital pictures of my child's retinopathy should be included in the permanent medical record" (4.4  $\pm$  0.6), "digital pictures of my child's eye findings will help me better understand his/her disease condition" (4.2  $\pm$  0.6), and "digital pictures of my child's eye findings will improve the quality of care from his/her doctor" (4.2  $\pm$  0.8).

Table 3 summarizes responses to the 10 questionnaire items involving telemedicine for ROP care. The lowest mean ( $\pm$  SD) scores were for the items "I am worried sending these pictures electronically will create risks for the privacy of my child's medical information" (2.6  $\pm$  1.1), "overall, technology will make it harder for a patient and doctor to establish a good relationship" (2.6  $\pm$  1.1), "I am worried that a computer may not send the pictures correctly" (2.7  $\pm$  1.1), and "the quality of care from diagnosis by far-away medical experts is better than the care from face-to-face medicine" (2.7  $\pm$  0.9). The highest mean ( $\pm$  SD) scores were for the items "overall, technology will improve the quality of medical care for my child" (4.3  $\pm$  0.6), and "it is essential to meet face-to-face with my child's doctor" (4.3  $\pm$  0.8).

#### **Relationships between Parental Characteristics and Responses**

Table 4 summarizes cases in which there were statistically-significant relationships between parental characteristics and questionnaire responses. For example, parents with higher educational background tended to provide higher scores for the item "the potential benefits of telemedicine are worth risks for the privacy of my child's medical record," and parents with higher levels of computer experience tended to provide lower scores for the item "it is essential to meet face-to-face with my doctor."

Parents who had previously searched the Internet for health care information tended to provide higher scores for the items "the potential benefits of sending these pictures electronically are worth the privacy risks" (p=0.004), and lower scores for "I am worried that a computer may not send the pictures correctly" (p=0.012). Those who had previously heard of telemedicine tended to provide higher scores for the telemedicine "quality of care" factor (p=0.041). There were no statistically-significant responses between questionnaire responses and parental gender, or whether parents had observed ophthalmoscopic or digital retinal imaging examinations.

There were statistically-significant differences in responses to several items based on parental race and ethnicity. Black non-Hispanic parents had lower mean scores compared to other parents for the items "digital pictures of my child's retinopathy should be included in the permanent medical record" (p=0.023), "digital pictures of my child's eye findings could diagnose disease as accurate as an actual eye exam" (p=0.013), and "digital cameras and computers are reliable" (p=0.023); and for the digital retinal imaging factor "parental opinions about digital retinal imaging" (p=0.006).

#### DISCUSSION

This is the first study to our knowledge that formally evaluated parental attitudes toward telemedicine and digital imaging technologies for ROP care. The key findings are that: (1) Parental acceptance of digital retinal imaging and telemedicine is promising; (2) Main areas of parental concern include safety and accuracy of digital image capture and transmission, privacy of protected health information, and perceived lack of face-to-face communication with physicians; and (3) Parental perceptions may differ based on characteristics including education and computer experience.

Only a small fraction of studies involving telemedicine satisfaction have reported the reliability and validity of the instrument used to measure satisfaction. The questionnaire in this study was based on previously-validated instruments for measuring telemedicine satisfaction. During psychometric analysis, a three-factor solution was developed for the telemedicine items, and a two-factor solution was developed for the digital retinal imaging items. Internal consistency reliability was good, with Cronbach's alpha of 0.696-0.706 for the three telemedicine factors and 0.661-0.889 for the two digital retinal imaging factors. These findings support the construct validity of the instrument used in this study.

Our findings indicate that parental perceptions toward digital retinal imaging were positive. Parents agreed with statements that digital imaging offered benefits such as permanent

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documentation of retinal findings, improved understanding of underlying disease conditions, and improved quality of care. From a medical perspective, retinal imaging may become important because published studies have demonstrated that the accuracy and consistency of plus disease diagnosis are imperfect, even when performed by recognized experts.<sup>27-28</sup> Previous studies have demonstrated that agreement between ophthalmoscopic and telemedical ROP examination modalities is high, even when images are captured by a trained neonatal nurse, and that telemedicine may actually be more accurate in some cases. <sup>9-17</sup> Therefore, from a medicolegal perspective, imaging may become important as a mechanism for objective documentation of examination findings.

Parents felt that telemedicine may provide improved accessibility to the best possible health care, but had neutral feelings or concerns regarding data privacy, technical errors, and impact on the patient-doctor relationship. Patient confidentiality has become a growing concern as medical data is increasingly stored electronically and transmitted for auxiliary purposes such as research, quality assurance, and public health.<sup>29</sup> Although legislation such as HIPAA has been enacted to protect privacy and security of medical data, technological methods and policy approaches for ensuring the protection of medical privacy are continuing to evolve. <sup>30-31</sup> In addition, preventable medical errors have received increasing attention, particularly after publication of an Institute of Medicine report which estimated that they cause up to 98,000 annual deaths in the United States.<sup>32</sup> Information technology has been proposed as a mechanism for decreasing the incidence of medical errors by detecting adverse events. offering automated decision support to physicians, and improving communication among providers.<sup>33</sup> Published studies have shown mixed results regarding the impact of these systems.<sup>22,34</sup> Finally, participants felt that face-to-face contact with physicians is essential. In general, reliance on information technology may threaten to interfere with development of rapport and communication with between patients and physicians. At the same time, these technologies offer potential to increase patient-doctor interactions through novel electronic mechanisms.<sup>23,35</sup> These are potential barriers to telemedicine for ROP care, and should be addressed before large-scale implementation of these systems.

Parents with higher levels of education and computer expertise tended to be less concerned about perceived problems with telemedicine such as privacy and face-to-face communication with physicians (Table 4). This is not surprising, given that experienced computer users might be expected to be more comfortable integrating these technologies into their lives. A recent large-scale study found that up 40% of adult Internet users have used online tools to search for health care information, while 6% used email to communicate with a medical provider.<sup>36</sup> Growing numbers of patients are communicating with physicians through secure messaging protocols, and several third-party payers have begun reimbursing for electronic consultations.<sup>23</sup> These trends suggest that the continuing dissemination of computer and information technologies may be associated with increasing acceptance of telemedicine for diseases such as ROP. Of note, parents with greater computer experience tended to feel that digital cameras and computers are reliable, and further studies may be warranted to explain this finding. We also note that 41.5% of subjects did not consider themselves to be "comfortable" or "expert" computer users. Strategies must be developed for introducing these emerging technologies to patients with limited computer accessibility.

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There are several additional limitations of this study: (1) Because it was a small study involving only 42 parents from a single site, the generalizability may be limited. However, we note that this study included a large proportion of eligible parents (42/92 [45.6%]) during a one-year recruitment period, and that the study center was an academic referral center within a large metropolitan area. (2) Because nearly all subjects also provided informed consent to receive digital imaging examinations for a telemedicine study, these participants may not represent typical parents. This study was designed to assess parental perceptions toward emerging technologies which are unfamiliar to many parents. Therefore, it was felt that inclusion of parents with no knowledge of telemedicine or digital retinal imaging would not be meaningful, and that subjects should have had some minimal exposure to these technologies. (3) Similarly, the study infants received both ophthalmoscopic and telemedicine examinations. This study is therefore somewhat hypothetical, because parents were not relying on telemedicine to obtain real-world access to expert care. It is unclear whether any systematic biases would result from this study design. One possibility is that parents in rural areas or developing nations might be pleased about the opportunity to receive improved access to specialized ROP care through telemedicine. Future studies involving a larger cohort of subjects from multiple institutions may be informative.

Digital imaging and telemedicine provide opportunities to improve the quality and delivery of ophthalmic care for infants with ROP, and to improve access to care for infants in medically underserved regions. This study suggests that parental acceptance of these technologies is promising. However, telemedicine has potential to alter the nature of the patient-physician relationship, and parents expressed the importance of face-to-face contact with caretakers. Attention to data privacy, technical quality, and preservation of the patient-doctor relationship will support parental acceptance of telemedicine strategies for ROP management.

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# Table 1.

Baseline characteristics of 42 parents who responded to study questionnaire of telemedicine and digital retinal imaging for ROP diagnosis.

	l l
Characteristic	Value
Age in years (mean $\pm$ SD)	$31.1 \pm 5.7$
Gender (n (%))	
Male	5 (11.9%)
Female	37 (88.1%)
Race/ethnicity (n (%))	
White, non-Hispanic	10 (23.8%)
Black, non-Hispanic	8 (19.0%)
Hispanic	19 (45.2%)
Other	5 (11.9%)
Level of education (n (%))	
High school graduate or less	9 (21.4%)
Some college	13 (31.0%)
College graduate or above	20 (47.6%)
Computer experience (n (%))	
None or limited	6 (14.3%)
Casual	10 (23.8%)
Comfortable	21 (50.0%)
Expert	4 (9.5%)
No response	1 (2.4%)

	Response	nse
5 digital retinal imaging items (Cronbach's alpha 0.843, 79% variance explained)	Mean ± SD Range	Range
Factor 1. Quality and utility of digital retinal images (Cronbach's alpha 0.889, 62% variance explained)		
a. Digital pictures of my child's eye findings will improve the quality of care from his/her doctor.	$4.2\pm0.8$	2 - 5
b. Digital pictures of my child's eye findings will help me better understanding his/her disease condition.	$4.2\pm0.6$	3 - 5
c. Digital pictures of my child's eye findings could diagnose disease as accurately as an actual eye exam.	$4.0\pm0.8$	3 - 5
Factor 2. Parental opinions about digital retinal imaging (Cronbach's alpha 0.661, 17% variance explained)		
a. Digital pictures of my child's retinopathy should be included in the permanent medical record.	$4.4\pm0.6$	3 - 5
d. Digital cameras and computers are reliable.	$3.8\pm0.8$	2 - 5

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Table 2.

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# Table 3.

Parental responses to 10 questionnaire items involving telemedicine for ROP, which were scored on a 5-point Likert-type scale (1=strongly disagree, 2=disagree, 3=neutral, 4=agree, 5=strongly agree).

*·····································	Response	nse
10 telemedicine items (Cronbach's alpha 0.031, 03% variance explained)	Mean±SD Range	Range
Factor 1. Data communication and privacy risk (Cronbach's alpha 0.706, 27% variance explained)		
a. I am worried sending these pictures electronically will create risks for the privacy of my child's medical information.	$2.6\pm1.1$	1 - 5
b. The potential benefits of sending these pictures electronically are worth the privacy risks.	$3.4 \pm 1.2$	1 - 5
c. I am worried that a computer may not send the pictures correctly.	$2.7 \pm 1.1$	1 - 5
d. Overall, technology will make it harder for a patient and doctor to establish a good relationship.	$2.6 \pm 1.1$	1-5
Factor 2. Accessibility and trust (Cronbach's alpha 0.696, 23% variance explained)		
a. Diagnosis by far-away medical expert will make it easier to get the best possible health care for my child.	$3.7 \pm 0.9$	2 - 5
b. I could not trust a doctor that I did not personally meet.	$3.0 \pm 1.0$	1 - 5
Factor 3. Quality of care (Cronbach's alpha 0.697, 13% variance explained)		
a. Overall, technology will improve the quality of medical care for my child.	$4.3\pm0.6$	3 - 5
b. The quality of care from diagnosis by far-away medical experts is as good as the care from face-to-face medicine.	$3.1 \pm 0.9$	1-5
c. The quality of care from diagnosis by far-away medical experts is better than the care from face-to-face medicine.	$2.7 \pm 0.9$	1 - 5
d. It is essential to meet face-to-face with my child's doctor.	$4.3 \pm 0.8$	2 - 5

Items are organized based on results of principal components factor analysis. Cronbach's alpha and percentage of variance explained are displayed for all 10 items, as well as for each of 3 factors identified.

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Nonparametric correlation coefficients between parental characteristics and questionnaire responses. All items with statistically-significant relationships are displayed.

Subject characteristic	Questionnaire item	Correlation coefficient	p-value
Education	The potential benefits of sending these pictures electronically are worth the privacy risks.	0.38	0.017
Education	I am worried that a computer may not send the pictures correctly.	-0.44	0.003
Computer experience	Computer experience Digital cameras and computers are reliable.	-0.35	0.026
Computer experience	Computer experience It is essential to meet face-to-face with my child's doctor.	-0.39	0.011