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**Brief Report**

# Human Touch via Touchscreen: Rural Nurses' Experiential Perspectives on Telehealth Use in Pediatric Hospice Care



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**Abstract**

**Context.** Telemedicine has the potential to extend care reach and access to home-based hospice services for children. Few studies have explored nurse perspectives regarding this communication modality for rural pediatric cohorts.

**Objectives.** The objective of this qualitative study was to learn from the experiences of rural hospice nurses caring for children at the end of life using telehealth modalities to inform palliative communication.

**Methods.** Voice-recorded qualitative interviews with rural hospice nurse telehealth users inquiring on nurse experiences with telehealth. Semantic content analysis was used.

**Results.** About 15 hospice nurses representing nine rural hospice agencies were interviewed. Nurses participated in an average of eight telehealth visits in the three months prior. Nurses were female with a mean age of 38 years and an average of seven years of hospice nursing experience. Five themes about telehealth emerged: accessible support, participant inclusion, timely communication, informed and trusted planning, and familiarity fostered. Each theme had both benefits and cautions associated as well as telehealth suggestions. Nurses recommended individualizing communication, pacing content, fostering human connection, and developing relationships even with technology use.

**Conclusion.** The experiences of nurses who use telehealth in their care for children receiving end-of-life care in rural regions may enable palliative care teams to understand both the benefits and challenges of telehealth use. Nurse insights on telehealth may help palliative care teams better honor the communication needs of patients and families while striving to improve care access. *J Pain Symptom Manage* 2020;60:1027–1033. © 2020 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

**Key Words**

*Telehealth, telemedicine, hospice care, palliative care, pediatric palliative care, communication, coronavirus*

**Key Message**

This article describes the telehealth experiences of nurses in caring for children receiving hospice care in rural regions. Although telehealth fosters accessibility, there are communication cautions related to this modality. Nurse interviewees' recommend

engaging in creative forms of human connection and fostering therapeutic relationships across screens.

**Introduction**

Patients in rural regions experience geographic barriers to accessing palliative or hospice teams, with certain zip codes lacking access to home-based end-

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of-life care,<sup>1–3</sup> a problem that is especially pronounced for pediatric populations.<sup>4–6</sup> This crisis in access, heightened by an increasing number of pediatric patients and families choosing end-of-life care at home,<sup>7</sup> warrant the innovative leveraging of telehealth platforms.<sup>8,9</sup> Although evidence is limited, research suggests that telemedicine initiatives to expand hospice access in rural settings for adult patients may improve symptom management, benefit communication, and enhance adult patient-reported and caregiver-reported satisfaction, while reducing costs.<sup>10–13</sup> Recent advances in technological platforms and connectivity have fostered a cautious increase in telemedicine uptake in adult hospice cohorts during the past decade.<sup>14,15</sup> This trend has been slower and remains understudied in pediatric palliative care and hospice.<sup>16</sup>

Research highlighting the complex factors shaping the uptake of telehealth in the arena of palliative care and hospice finds that, patients receiving palliative care and their family caregivers have reported mostly positive experiences with the utilization of telehealth,<sup>13,14,17,18</sup> whereas feedback from palliative teams has been less consistently positive.<sup>9</sup> Some research reports hospice staff enthusiasm toward telehealth as an enhancement of care reach,<sup>19–23</sup> whereas other studies report staff discomfort because of equipment logistics and concerns about technology's impact on human relationships.<sup>24,25</sup> Importantly, evidence suggests that medical personnel, particularly nurses and clinicians, function as gatekeepers to the utilization of telehealth services in palliative or hospice care.<sup>12,14,15</sup>

If telehealth is to be implemented in palliative care and hospice, feedback from these gatekeepers must be carefully considered and integrated into program design. Yet, largely missing from the current literature base are reports of the nurse perspective on their experience with telehospice. Our team was not able to identify a study explicitly investigating nurse experiences with the utilization of telehospice in their care for pediatric patients. This qualitative study helps to address this gap by providing experiential perspectives from adult-trained nurses using telehealth to provide home care for children receiving palliative care at end of life in a rural setting.

## Methods

The institutional review board approved the methodology and implementation of this Care Across Locations Longitudinally in Navigation of Goals and Symptoms protocol. This article specifically reports on the qualitative study aim of the protocol, registered as NCT03999957.

Eligibility criteria for this qualitative study included English-speaking hospice nurses who served as the

primary in-home nurse for children admitted to home hospice care in rural regions enrolled in a telehospice program from July 2018 to March 2020. Rural zip code was defined according to the Census Bureau Rural and Urban taxonomy.<sup>26</sup> The nurses were present in the child's home during routine hospice care encounters with inclusion of the pediatric palliative care specialist via telehealth connection. The nurse was present physically with the family, whereas the palliative physician joined the nurse and the family via telehealth.

This study involved voice-recorded phone interviews with 15 adult-trained hospice nurses. The nurses were employed with rural hospices serving primarily adult patients. The study method included interviewing all 15 nurses enrolled in the larger telemedicine acceptance study,<sup>27</sup> regardless of the timing of study theme saturation. One open-ended statement was asked of each nurse at Month 3 of telehealth use or at the conclusion of their care (because of child's reaching end of life): Please describe your experience with telepalliative use. This question was asked verbatim from a one-question interview guide. The nurse response was a mean of 16 minutes per nurse. Trained medical transcriptionists transcribed the interview content verbatim with a minimum of one study team member confirming accuracy.

Responses were analyzed using semantic content analyses.<sup>28</sup> Every phrase spoken by the nurse was entered into qualitative software program (NVivo 12 [QSR International, Doncaster, Australia]). The interviewer created group classifications of phrases from the interview content to develop a code dictionary.<sup>28,29</sup> The interviewer and another team member then used this grouped-specific codebook to review the content of the interview data. Team members further grouped the codes with overlapping meaning and co-occurrence into themes. The frequency of each theme was calculated by these three team members. Difference in code or theme perspective was resolved with discussion and consensus. A conceptual definition was then developed for each theme based on the interviewee's verbiage and the assessed meaning of the described theme according to benefit or caution relevant to telehealth use. For the final validation step, three rural hospice nurse study participants reviewed the article and shared consensus opinion that the content was comprehensively representative.

## Results

All approached 15 nurses for the 15 children enrolled in the Care Across Locations Longitudinally in Navigation of Goals and Symptoms study consented to participate. Nurses were female with a mean age of 38 years (range 31–62). Nurse participants,

representing nine rural hospice agencies in one mid-Western state, averaged seven years in hospice nursing (range 1–18) but were largely new to both pediatric populations and to telehealth. One nurse had prior telehealth experience with adult patients. Three had cared for a pediatric-age patient in the prior two years; otherwise, 13 (87%) nurses reported the child to be their first pediatric-age hospice patient in 24 months.

Study saturation was reached at the 13th interview with new participants no longer eliciting novel themes not raised by the previous participants. Inter-rater coding reliability ranged from 86% to 100% for each theme.

Five themes emerged from the interviews (Table 1): accessible support, participant inclusion, timely communication, informed and trusted planning, and familiarity fostered. Each theme was noted to contain a benefit paired with a caution.

Every interviewed nurse mentioned accessible support as a benefit (15 of 15) with a primary mention of accessibility for symptom management and the immediacy of communication regarding medical changes. This was balanced with a caution that the screen format bypassed the organic unfolding of symptom review, which feels more natural in in-person format (5 of 15). Nurses cautioned that telehealth conversations carried a certain immediacy less paced than in-person full symptom assessment, sharing caution to pace the cadence of symptom review.

Most nurses acknowledged that telehealth allowed for participant inclusion with a wider support network included for palliative care encounters (14 of 15). The multiface screen function allowed for coparents or grandparents or other relatives, local pediatricians, and interdisciplinary palliative care team members to join. With this inclusion came a caution of creating a mass presence while missing the intimate, personal touch each family deserves. This sense of personal touch was not only depicted as physical hand-holding or hugging but also expanded to the deeper personal touch of attentiveness and healing presence for each individual in the room. Although the screen fostered a community gathering, this risked missing moments of attending to each participant's personal needs. Nurses recommended finding ways to check in with each person who had been present at the telehealth visit after the visit, as one would in person. Although this is a time commitment, this sense of personalized care was notably essential when using a less personal communication format.

Although timely communication (11 of 15) represented a strength for goals-of-care discussions to include advance care planning, the nurse sitting next to the family depicted a sense of awareness of energy and emotion difficult for providers to capture on

screen (4 of 10). One nurse described: Her [mom's] hands were just trembling, trembling and I was so glad that I was there to hold her hands and steady them. She knew we had to talk about how the dyspnea was going to turn more agonal but it was so hard a topic for her to imagine the breathing even getting worse. She could hear the care through the computer. But, me sitting there next to her allowed me to help pace the conversation across the screen so that we could talk through it but I knew to pace it by how her hands were trembling. They couldn't see her hands below the video camera. Nurses recommended specifically checking in on family readiness and pacing with clear communication cues as nonverbal gestures were more challenging to notice by screen.

Nurses valued that telehealth not only fostered an informed and trusted plan with clarity in messaging across providers (10 of 15) but also expressed concern that the family confidence in the expertise of the telehealth team may inadvertently minimize the family's sense of confidence in their own family caregiver intuition (4 of 15). The screen offered the security of an external voice of validation but perhaps risks minimizing the family's own intuition or awareness: Like it was safer for them to ask a screen than to hear their own sense of it and so I like when we said, "what is your heart telling you?" on the screen. Like, you know, you are in the room and so you tell us what you sense being as you are right there and we are all in this together. Nurses recommended strategic and purposeful inquiries about family perception, family intuition, and family experience as part of telehealth.

Telehealth fostered familiarity (9 of 15), which the interviewed nurses recognized as important for professional presence. The hospice nurses also recognized that a screen relationship can feel more superficial or less deeply trusting, as there remains a sense of still being a bit on the outside, you know, distant. One nurse phrased this as the family may not be yet fully trusting of the technology and then there is a provider who they do not yet personally trust so there needs to be that extra commitment to building trust through caring communication. The nurses voiced that therapeutic relationships and personal trust felt a little longer to really enter into with the screen. Taking a moment for relational content and thoughtful pauses may form as a way to foster relationship, asking about the pet in the room or just asking about hobbies or pleasures is extra important to make the place feel more personal.

## Discussion

Telehealth, through its utilization of technology to connect medical professionals with patients and family caregivers, has been recognized as one potential

Table 1  
Benefits and Challenges of Pediatric Telehealth Care According to Nurse Participants

Benefit Themes ( <i>n</i> = 5)	Benefit Description	Participant Reporting Benefit and Caution	Exemplary Quotes
	<i>Caution Mentioned</i>	<i>n</i> = ___/15 (%)	
Accessible support	Enabled the family and nurse to access immediate support for symptom management or medical changes <i>Risks overutilization</i>	Benefit = <i>n</i> = 15 (100%); challenge = <i>n</i> = 5 (33%)	Benefit quotes: When he had a seizure, I felt most supported being able to call in real-time with an update and the family felt supported by the ready access. Discussing the pain plan together helped me to feel confident about our options and helped [the family] feel supported. Caution quote: Sometimes [child's mom] wanted me to call the doc at the start of every visit before I even did my symptom assessment because she felt like the screen made the doc available any time even if there was not really a question to ask yet.
Participant inclusion	Inclusion of additional team and family members <i>Risks missing a personal touch for the participants</i>	Benefit = 14 (93%); challenge = 8 (53%)	Benefit quotes: We were able to include both parents and grandparents and that would not have worked for their work schedules otherwise to all be together at one time. Our social worker could join in even though the commute time from her last home visit would have made it not possible otherwise. Challenge quote: More people can maybe access it but there still is something about a hug or a hand held. You know, that physical and actual presence which is hard to create unless there ... Beyond a screen, the hands-on is part of the experience for them and also for me in my nursing touch.
Timely communication	Allowed for timely goals-of-care communication <i>Risks rushing content without reading the room</i>	Benefit = 11 (73%); challenge = 4 (27%)	Benefit quotes: I did not know how to really talk about death with him [adolescent] and so having someone who does this type of conversation with teenagers right there on the screen helped and [adolescent] was good with the technology and that made the conversation easier and better for all of us. The mom was acting like we were home health. So, the doctor being there on the screen talking about the benefits of hospice at the first couple visits helped us be able to talk right then more openly about the bigger goals and hospice-specific goals. Challenge quote: Being in the room, I can feel the body language and the general readiness of the parents to really get into these goals but I think from the side of the screen it probably feels like we are all ready at that moment. The mom may be actually giving off a subtle nervous vibe that is hard to see across a computer and can really only be felt sitting next to her on the sofa.

(Continued)

Table 1  
Continued

Benefit Themes (n = 5)	Benefit Description	Participant Reporting Benefit and Caution	Exemplary Quotes
	<i>Caution Mentioned</i>	n = ___/15 (%)	
Informed and trusted plan	Fostered clarity of care plan together with larger medical team; built trust in communication and care <i>Risks family's trust in their own intuition or the prior messaging</i>	Benefit = 10 (67%); challenge = 4 (27%)	Benefit quotes: Sitting together with the team on the screen gave [relative] a sense of confidence that this dose increase was worth the possible side effects. The telehealth times helped him trust and validated the care We were able to together come up with clear plans for terminal dyspnea. We discussed options and what to do in various scenarios and they knew that the entire medical team knew since we were all there on the screen right before he died. Challenge quote: The family knew how long she had left by their own intuition but seemed like they wanted the safety of the screen instead of the power of their own intuition.
Familiarity fostered	Included team members already familiar to the patient and family <i>Risks delaying development of new relationships</i>	Benefit = 9 (60%); challenge = 7 (47%)	Benefit quotes: In telehealth, she was talking about how [the patient] did not historically respond to certain meds which are usually our first-line on formulary. [Parent] seemed relieved that their child's history was known and shared in front of them on the screen. The fact that we knew the name of her favorite stuffed animal did seem to help on the screen to have a bit of "being known already" to help the screen be more personal. Challenge quotes: Professional validation was immediate because of the more familiar telehealth visits but a personal relationship took longer. The knowledge is immediate but the relationship and rapport are slower by screen.

solution to address critical access issues in hospice care<sup>30</sup> and is now set to turn into an essential tool in the face of the coronavirus pandemic.<sup>31</sup> As the coronavirus disease 2019 pandemic has necessitated the rapid incorporation of screen modalities into palliative care, that suddenness warrants pause to consider the baseline barriers or discomforts with telehealth, particularly as they relate to the provision of palliative or hospice care. Prior studies have revealed reasons for palliative care providers' tangible concerns about telehealth: lack of training and lack of incentives,<sup>24</sup> lack of equipment availability or lack of perceived ease of equipment use,<sup>25</sup> concern about technology functionality,<sup>21</sup> and uncertainty about patient eligibility criteria for telehealth.<sup>25</sup> User-friendly, reliable, accessible, secure technologies, and clear connectivity are

well-established requirements for successful telehealth, as is provider training.<sup>15,32,33</sup>

The deeper concern with telemedicine use in palliative and hospice care is the concern with whether this communication modality is a facilitator or a barrier for the relationality so core to the profession. A fear about virtual interaction is whether the communication format depersonalizes the team or family experience, particularly when discussing the sensitive topics relevant to pediatric end-of-life care. Palliative and hospice teams have shared concerns about the way telehealth impacts professional roles: telehealth's impact to professional autonomy,<sup>21</sup> fear of decay in the quality of care provided,<sup>23</sup> and concern for risk of not being present to assist the patient such as in adverse medication reactions.<sup>23</sup>



Few studies have explicitly explored palliative or hospice nurse experiences with telehealth, although nurse perspectives on telehealth use should inform practice. In focus groups with nurses involved in piloting a multidimensional telehospice program in Australia, Collier et al.<sup>16</sup> found that nurses view themselves as central to successful implementation of telehealth programs, citing the potential for technology to enhance patient relationships and undermine trust when technical difficulties arise. A study of video consults for rural pediatric hospice patients found a lower acceptance of telehealth by home hospice nurses than by family caregivers, but note that nurse attitudes toward telehealth improved after their first virtual meeting, including their acceptance of telehealth as a suitable way to receive palliative care services.<sup>27</sup> In a study on video consults for elderly rural patients, nurse experience with the program revealed nurse comfort and nurse perception that the encounter address patient needs as well as an in-person appointment, with most agreeing that they would use telehealth for similar situations in the future.<sup>34</sup>

Nurses in our study were able to accept and use the new approach to pediatric palliative care, could report the benefits, and yet were also able to share insightful cautions. The positives about telehealth seem to point toward benefits for overall care and specifically for the family (inclusion) and the patient (support for symptom management). The cautions related to the prioritization of the nurse-family trust relationship and the worry that this could be slowed, interrupted, or altered in some way with the use of telehealth. The nurses emphasized the need to support the primacy of the care relationship even with the use of technology. Each caution provides opportunity to consider purposeful attentiveness for recognizing the challenges introduced by technology use although striving to still offer quality care. A limitation of our study was that the methods included a nurse present physically in the room with the child and family while the physician joined by screen; thus, the findings cannot be extrapolated to a strict telehealth-only model.

Importantly, studies almost universally caution that telehealth should function as a *supplement to*, rather than an entire *replacement of*, in-person care, and that issues related to training and technical problems need to be considered before implementation.<sup>14,22,34,35</sup> In a video consult setup, there may be benefits associated with having a nurse in the home with a patient during the telehealth consult to help to navigate communication and technical issues as well as to benefit from important insight from the clinician on care planning.<sup>27,34</sup> Some evidence also points to telehealth visits being more appropriate for follow-up visits than for initial appointments.<sup>27,34</sup> Further telehealth research warrants after the

experience during a longer period to learn more about communication, symptom burden, quality of life, and relationships longitudinally.

Technology impacts the relational and affective component of communication.<sup>35</sup> Telehealth has triggered historic concerns about shifts in working patterns including the way people relate to each other.<sup>35</sup> Prior discomfort with telehealth in palliative care emphasized risk of being an impersonal modality<sup>36,37</sup> with worry that telehealth minimized the importance of the actual touch so core to our field.<sup>36,38–40</sup> As we creatively offer palliative care in rural and underserved settings, telehealth may serve as a modality to foster relationships and togetherness although this does require special attentiveness to communication values. One of our interviewed nurses stated: I find myself touching the screen, even if it is not a touchscreen. I just lean in and touch the screen. I need them to know I am reaching out. With everything I have, I am reaching out. We remain connected.

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