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Access to highly specialized care perceived by parents caring for their child at home - supported by e-health

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Conclusion: Parents supported by eHealth after advanced in-hospital care of their child generally experienced a high access to the highly specialized pediatric surgery and neonatology. Still, sending sensitive information about their child, in a not so comprehensible eHealth cyber space, raised security uncertainties. This needs considerations before full implementation of eHealth in advanced pediatric healthcare can be done.

eHealth and its impact on access to highly specialised pediatric medical care, such as advanced pediatric surgery and prematurity care, has not been explored.

Therefore, **the aim** of the study was to analyze dimensions of access to health care, as experienced by parents after specialized pediatric surgery supported by eHealth in transition from hospital to home

Method: Twenty-five parents who went home with their child following hospitalization and received conventional care supported by eHealth (a tablet) were interviewed in this qualitative study. Directed content analysis was used, guided by a framework for dimensions of access previously described as: approachability, acceptability, affordability, appropriateness, and availability.

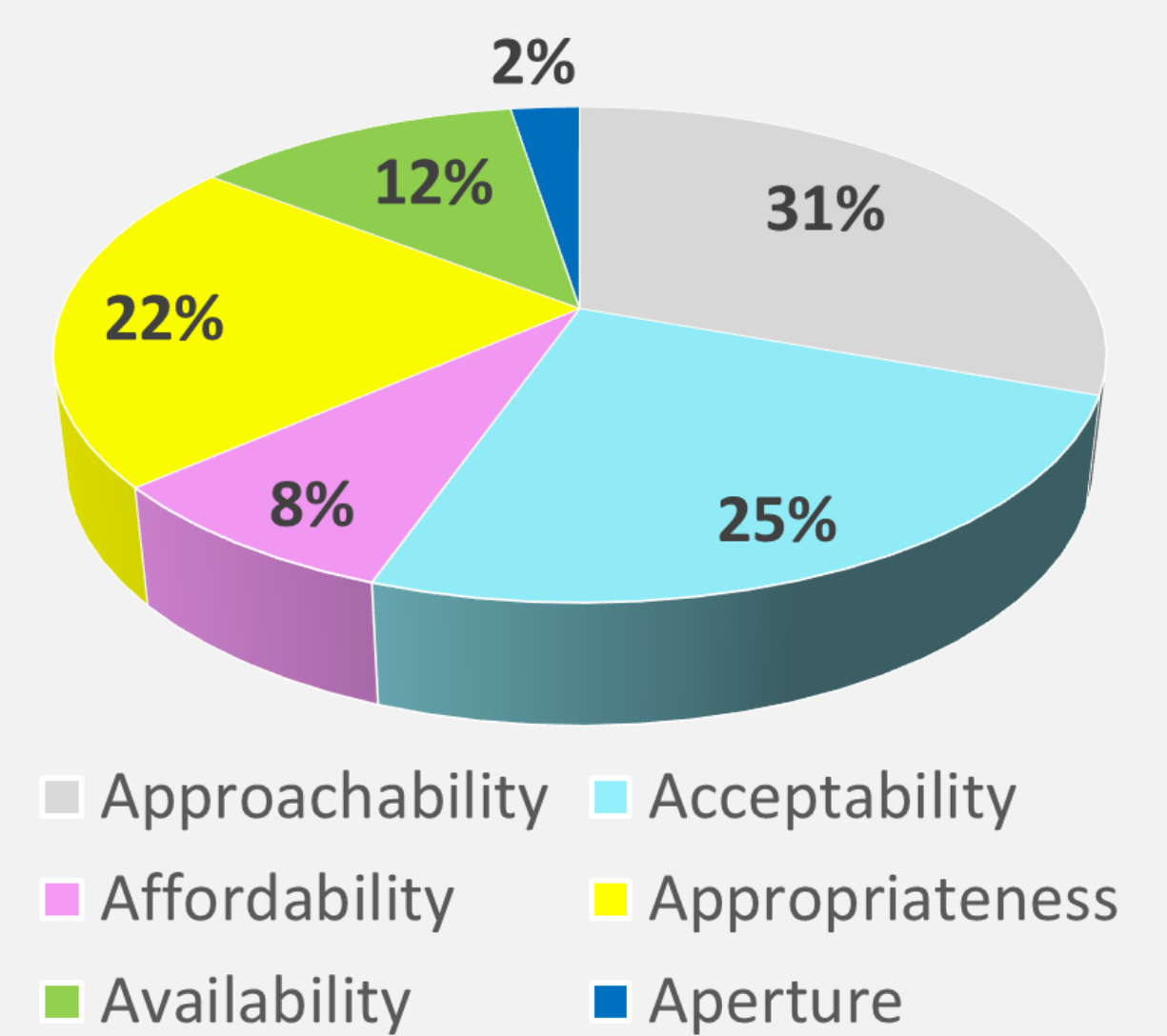
Results: All dimensions of access to healthcare as described in the framework were identified in the analyzed material, as presented in the figure. In general the parents were positive being able to go home with their child and felt supported by the tablet.

Also, a new dimension – Aperture - was introduced described as an uncertainty of security regarding eHealth solutions, affecting trustworthy access to healthcare.

The dimensional framework of access is recommended when evaluating eHealth in the future.



The research program eChild Health



DIMENSIONS	DESCRIPTION	QUOTES
Approachability	Parents experienced it as positive to be able to contact the healthcare professionals familiar to them through the tablet. The chat function was especially appreciated as a good communication solution.	<i>So, I think I got answers, well I probably learned a lot through it (feed-back). Because as soon as I thought of something, I could ask. And that was really good.</i>
Acceptability	The opportunity to stay at home with their fragile or ill child following hospitalization was welcomed. The tablet provided security and helped them take care of their child's day-to-day needs.	<i>I belong to the generation that is used to tablets, cellphones, and the like. So this was nothing new or strange. I just thought it was super.</i>
Affordability	Compared with conventional health care, the tablet saved resources, effort and time when communicating and when receiving services on behalf of their child.	<i>Instead of driving all the way if we don't need the physical contact, we could use the tablet or phone.</i>
Appropriateness	The tablet provided the parents with sufficient, needed information. Also, it gathered structured follow-up information which was used as a form of diary, keeping track of progress.	<i>Because it felt like they wanted to keep, how do you put it, the communication. So that you felt some form of... support and safety, I would say.</i>
Availability	Having to transport the child for follow-up appointments at the hospital was described as challenging. Travelling was described as burdensome and not beneficial to the child – contact over the tablet was then preferred.	<i>We had a newborn child and so it wasn't ideal having to drive three times for four hours for a checkup. Especially in his condition. Since he needed a lot of stops to rest.</i>
Aperture	Messages sent through electronic media were sometimes described as being sent into a vacuum. This led to uncertainties regarding the possibility of trustworthy access to care.	<i>I do not want for my child that there should be pictures of my child that are not suitable for anything other than a hospital.</i>

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