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Original Paper

QUALITATIVE STUDY ON FAMILY HEALTH-RELATED QUALITY OF LIFE DUE TO PEDIATRIC COVID-19 INFECTION IN LATVIA

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The coronavirus disease (COVID-19) pandemic and ensuing public health policies have immensely affected the lives of billions of people worldwide and been challenging for families. There have been studies exploring mental health of different age groups during a pandemic, but few have focused on family health-related quality of life (HRQoL). This qualitative study investigates the emotional well-being of families while caring for an acutely sick child with COVD-19, using semi-structured in-depth interviews. The results demonstrate that it is one of the most affected components of the family HRQoL.

Keywords: *parents, well-being, HRQoL, COVID-19, qualitative research.*

INTRODUCTION

The severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) pandemic, which commenced in 2019, has immensely affected the lives of billions of people worldwide. The pandemic and successive safety measures implemented by authorities have been unique, unprecedented for the current society, and with emotional, financial, and social impact, which have not been fully evaluated. The role of health-related quality of life (HRQoL) is becoming increasingly acknowledged in one's well-being (McKenna and Hunt, 1994; Thorrington *et al.,* 2014; Haraldstad *et al.,* 2019; Choi *et al.,* 2021). To the best of our knowledge, the available research reports have been focused on the epidemiology of coronavirus disease (COVID-19), its clinical symptoms, treatment, and prophylaxis options, as well as mental health (Cusinato *et al.,* 2020; Deolmi and Pisani, 2020; Singh *et al.,* 2020; Kim *et al.,* 2021) of children during the pandemic, rather than well-being of the family while caring for acutely sick child. Although several studies on health-related quality of life HRQoL regarding COVID-19 have been published (Cusinato *et al.,* 2020; Choi *et al.,* 2021; Corsi *et al.,* 2021; Mastorci *et al.,* 2021a; 2021b; Ravens-Sieberer *et al.,* 2021) there is limited data available on family HRQoL due to COVID-19 (Di Giorgio *et al.,* 2016; Patrick *et al.,* 2020; Stars *et al.,* 2021). The objective of the study was to assess the family functioning and familial HRQoL in a sample of children diagnosed with severe SARS-CoV-2 infection and to identify the difficulties of family functioning they faced. The acute symptoms and the course of the COVD-19 in children implies certain analogies to other known acute diseases (McKenna and Hunt, 1994; Thorrington *et al.,* 2014; Laizane *et al.,* 2018), however, the "novelty factor" of the SARS-CoV-2 is distinctive.

National Institutes of Health define emotional wellbeing as the ability to successfully handle life's stresses and adapt to change and difficult times.

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Family HRQoL has been described as the capacity of parents and families to adjust to a child's health status (Wallander and Varni, 1998).

MATERIALS AND METHODS

Study design. The applied qualitative study was carried out from September 2020 to October 2021. The study was a part of the State Research Programme on eliminating consequences of the COVID-19 in Latvia, VPP-COVID-2020/1-0011.

Participants and data collection. The Children's Clinical University Hospital set up a designated follow-up programme for children (< 18 years old) who had tested positive for SARS-CoV-2. The programme was promoted on social media, by inviting parents who had concerns about their children's health 1 to 3 months post COVID-19 to sign up their children to the programme and have them evaluated by a paediatrician. During the visit, qualitative on-site semi-structured, in-depth interviews with 15 parents of altogether 20 underaged (1 month – 15 years) COVID-19 patients were conducted (Table 1). The number of infected children in families varied from 1 to 3. The parents of 12 girls and 8 boys were interviewed. To comply with the hospital's infection control policy, the interviews were conducted with only one parent, all 15 of them being a mother. Written informed consent was obtained from all mothers. The interviews covered questions on parental perception of the diagnosis and child's symptoms, health care provided, families' emotional reactions to the child's disease, and the impact of paediatric COVID-19 on the parents' social and economic situation.

Interviews were recorded and transcribed for the analysis. Inductive thematic analysis was used for data processing — the transcribed data were explored; recurring words and patterns were identified, and subsequently they were combined into common themes and interpreted.

Table 1. Characteristics of the study participants

Characteristic	n	%
Participants	15	100
Participants' relation to the child		
Mother	15	100
Number of children with COVID-19 in family		
1	11	73
2	3	20
3	1	7
Family status		
Single parent	2	13
Both parents (in the household)	13	87
Gender of the child		
Girls	12	60
Boys	8	40
Child admitted to the hospital		
Yes	3	15
No	17	85
Child's age		
< 1	6	30
1–11	10	50
12–18	4	20

RESULTS

The main themes repeatedly coming up throughout all interviews were emotions in different aspects, which affected family well-being. Five dominant aspects are described in this article.

When asked to recall the first emotions felt upon learning the child's positive SARS-CoV-2 test result, a sense of powerlessness was mentioned, as parents emphasised all measures of epidemiological safety had been taken within the household and outside. Other emotions mentioned were disbelief, shock, anger, fear, and guilt of not being able to protect their child from contracting the virus. The negative emotions were mostly reported from families where the child was the first one to become SARS-CoV-2 positive. Some of the families had anticipated the laboratory confirmation, as someone else the child had recently contacted in the family, friend circle or school/day-care already had COVID-19. A mother of three children confessed: "I felt guilty that maybe we did not follow the restrictions 100% and thus could not avoid my children catching COVID-19."

The second aspect was ignorance of how to communicate the diagnosis to the child and feeling fear of upsetting him/her, considering the vast amount of negative information in media about the increasing mortality due to COVID-19. This was not an issue for parents with very young children. The youngest child who was informed about the positive laboratory test result was five-years old. One mother recalled telling her daughter without going into detail: "You have the disease that everyone is talking about".

The third aspect coming up during the interviews was fear that other family members, specifically younger children, or persons with chronic conditions, would get sick. One illustration of the concerns expressed by a mother is: "We were very cautious about the other child to not get COVID-19 as he has bronchial asthma".

Quite early in the pandemic, one of the main COVID-19 symptoms recognised was extreme fatigue, and therefore, the families expressed fear of being unable to take care of their sick child/children. Another concern parents felt regarding their ability to look after their children was the possibility of having severe COVID-19 symptoms themselves or even needing to be admitted to the hospital. This frustration was powered by the stream of information on social media seemingly focused on the devastating number of hospitalised patients and deceased due to COVID-19. Quoting one of the mothers, "I had extreme anxiety about becoming

sick and being unable to care for my children, or even getting to the hospital myself".

One more aspect affecting familial emotional well-being was the unpredictability of this new disease. Insufficient information on the course of COVID-19, treatment options, the short-term and long-term outcomes was available at the time. This concern was more expressed by mothers of very young children (< 1 year) and by a mother who decided to isolate her teen-age daughter in a distant apartment to avoid transmitting the infection to other family members. As mothers reminisced, "Our middle child was afraid to die", and "I spent some sleepless nights making sure several times that my children were fine".

DISCUSSION

The study was targeting to explore familial HRQoL while having to care for children with acute COVID-19. As anticipated, our data revealed the families' well-being was significantly affected by the COVID-19 pandemic, in line with previous similar studies (Cusinato *et al.,* 2020; Choi *et al.,* 2021). The new disease with many unknowns raised a myriad of negative emotions, leading parents to increased levels of fear, helplessness, anger, which in turn might trigger anxiety, depression, and post-traumatic stress disorder (Di Giorgio *et al.,* 2016; Corsi *et al.,* 2021; Demaria and Vicari, 2021; Orsini *et al.,* 2021; Viola and Nunes, 2022).

The role of a parent is challenging *per se*, but facing child's acute illness, even if its course is mild, especially within the previously unfamiliar situation of a pandemic and necessity to obey safety measures of a lockdown, can become debilitating. This result is consistent with other studies (McKenna and Hunt, 1994; Di Giorgio *et al.,* 2016 Laizane *et al.,* 2018; Demaria and Vicari, 2021).

According to our results and literature, parents of younger children and predominantly single parents were more likely to experience higher stress levels and frustration when being exposed to their child's illness (Cusinato *et al.,*2020; Patrick *et al.,* 2020; Ravens-Sieberer *et al.,* 2021; Viola and Nunes, 2022). Single parents had no possibility to share the burden of childcare, especially if they were SARS-CoV-2 positive. Parents of younger children were more likely to feel helpless if an infant became acutely ill with COVID-19, as with other febrile infections.

Our study illustrates the incredible dilemma the parents had to face — to isolate the child with COVID-19 symptoms in a separate residence or risk their own health by caring for the sick child in the same household.

The main limitation of the study is that the results cannot be generalised, as only mothers were interviewed and their perception of familial HRQoL was represented. Other limitations may include questions that did not perfectly catch the parents' perception or that the answers were affected by the interviewer's presence.

CONCLUSIONS

Emotional well-being is one of the most affected components of the family health-related quality of life due to paediatric COVID-19 infection in Latvia. The findings indicate the need of a better understanding and dedicated support and mental health care services in the country as well as highlight the need for improvements in health communication.

ETHICS

Ethical approvals (No. 6-1/05/20 and No. 6-1/07/35) for this study were obtained from the Ethical Committee of Rīga Stradiņš University.

CONFLICT OF INTEREST

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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REFERENCES

Choi, E. P. H., Hui, B. P. H., Wan, E. Y. F., Kwok, J. Y. Y., Tam, T. H. L., Wu, C. (2021). COVID-19 and health-related quality of life: A community-based online survey in Hong Kong. *Int. J. Environ. Res. Public Health*, **18** (6), 3228. DOI: 10.3390/ijerph18063228. PMID: 33804725; PMCID: PMC8003940.

Corsi, M., Orsini, A., Pedrinelli, V., Santangelo, A., Bertelloni, C. A., Carli, N., Buselli, R., Peroni, D., Striano, P., Dell'Osso, L., Carmassi, C. (2021). PTSD in parents of children with severe diseases: A systematic review to face COVID-19 impact. *Ital. J. Pediatr*., **47** (1), 8. DOI: 10.1186/s13052-021-00957-1. PMID: 33446246; PMCID: PMC7807213.

Cusinato, M., Iannattone, S., Spoto, A., Poli, M., Moretti, C., Gatta, M., Miscioscia, M. (2020). Stress, resilience, and well-being in Italian children and their parents during the COVID-19 pandemic. *Int. J. Environ. Res. Public Health*, **17** (22), 8297. DOI: 10.3390/ijerph17228297. PMID: 33182661; PMCID: PMC7696524.

Demaria, F., Vicari, S. (2021). COVID-19 quarantine: Psychological impact and support for children and parents. *Ital. J. Pediatr*., **47** (1), 58. DOI: 10.1186/s13052-021-01005-8. PMID: 33750452; PMCID: PMC7941406.

Deolmi, M., Pisani, F. (2020). Psychological and psychiatric impact of COVID-19 pandemic among children and adolescents. *Acta Biomed*., **91** (4), e2020149. DOI: 10.23750/abm.v91i4.10870. PMID: 33525229; PMCID: PMC7927507.

Di Giorgio, E., Di Riso, D., Mioni, G., Cellini, N. (2012). The interplay between mothers' and children behavioral and psychological factors during COVID-19: An Italian study. *Eur. Child Adolesc. Psychiatry*, **30** (9), 1401–1412. DOI: 10.1007/s00787-020-01631-3. PMID: 32865654; PMCID: PMC7456665.

Haraldstad, K., Wahl, A., Andenæs, R., Andersen, J. R., Andersen, M. H., Beisland, E., Borge, C. R., Engebretsen, E., Eisemann, M., Halvorsrud, L., *et al*. (2019). A systematic review of quality of life research in medicine and health sciences. *Qual. Life Res*., **28** (10), 2641–2650. DOI: 10.1007/s11136-019-02214-9. PMID: 31187410; PMCID: PMC6761255.

Kim, S. J., Lee, S., Han, H., Jung, J., Yang, S. J., Shin, Y. (2021). Parental mental health and children's behaviors and media usage during COVID-19-related school closures. *J. Korean Med. Sci*., **36** (25), e184. DOI: 10.3346/jkms.2021.36.e184. PMID: 34184439; PMCID: PMC8239422.

Laizane, G., Kivite, A., Stars, I., Cikovska, M., Grope, I., Gardovska, D. (2018). Health-related quality of life of the parents of children hospitalized due to acute rotavirus infection: A cross-sectional study in Latvia. *BMC Pediatr*., **18** (1), 114. DOI: 10.1186/s12887-018-1086-y. PMID: 29544465; PMCID: PMC5856199.

Mastorci, F., Bastiani, L., Trivellini, G., Doveri, C., Casu, A., Pozzi, M., Marinaro, I., Vassalle, C., Pingitore, A. (2021a). Well-being perception during COVID-19 pandemic in healthy adolescents: From the Avatar study. *Int. J. Environ. Res. Publ. Health*, **18** (12), 6388. DOI: 10.3390/ijerph18126388. PMID: 34204811; PMCID: PMC8296203.

Mastorci, F., Piaggi, P., Doveri, C., Trivellini, G., Casu, A., Pozzi, M., Vassalle, C., Pingitore, A. (2021b). Health-related quality of life in Italian adolescents during COVID-19 outbreak. *Front Pediatr*., **9,** 611136. DOI: 10.3389/fped.2021.611136. PMID: 33996676; PMCID: PMC8116526.

McKenna, S. P., Hunt, S. M. (1994). A measure of family disruption for use in chickenpox and other childhood illnesses. *Soc. Sci. Med*., **38** (5), 725–731. DOI: 10.1016/0277-9536(94)90463-4. PMID: 8171351.

Orsini, A., Corsi, M., Pedrinelli, V., Santangelo, A., Bertelloni, C., Dell'Oste, V., Cordelli, D., Perrone, A., Parini, L., Lanari, M., *et al*. (2021). Post-traumatic stress, anxiety, and depressive symptoms in caregivers of children tested for COVID-19 in the acute phase of the Italian outbreak. *J. Psychiatr. Res*., **135**, 256–263. DOI: 10.1016/j.jpsychires.2021.01.024. PMID: 33508545; PMCID: PMC7825987.

Patrick, S. W., Henkhaus, L. E., Zickafoose, J. S., Lovell, K., Halvorson, A., Loch, S., Letterie, M., Davis, M. M. (2020). Well-being of parents and children during the COVID-19 pandemic: A national survey. *Pediatrics*, **146** (4), e2020016824. DOI: 10.1542/peds.2020-016824. PMID: 32709738.

Ravens-Sieberer, U., Kaman, A., Erhart, M., Otto, C., Devine, J., Löffler, C., Hurrelmann, K., Bullinger, M., Barkmann, C., Siegel, N. A., *et al.* (2021). Quality of life and mental health in children and adolescents during the first year of the COVID-19 pandemic: Results of a two-wave nationwide population-based study. *Eur. Child Adolesc. Psychiatry*, **12**, 1–14. DOI: 10.1007/s00787-021-01889-1. PMID: 34636964; PMCID: PMC8506100.

Singh, S., Roy, D., Sinha, K., Parveen, S., Sharma, G., Joshi, G. (2020). Impact of COVID-19 and lockdown on mental health of children and adolescents: A narrative review with recommendations. *Psychiatry Res*., **293**, 113429. DOI: 10.1016/j.psychres.2020.113429. PMID: 32882598; PMCID: PMC7444649.

Stars, I., Smane, L., Pucuka, Z., Roge, I., Pavare, J. (2021). Impact of pediatric COVID-19 on family health-related quality of life: A qualitative study from Latvia. *Glob. Pediatr. Health.,* **8**, 2333794X211012394. DOI: 10.1177/2333794X211012394. PMID: 33997124; PMCID: PMC8072840.

Thorrington, D., Ramsay, M., van Hoek, A. J., Edmunds, W. J., Vivancos, R., Bukasa, A., Eames, K. (2014). The effect of measles on health-related quality of life: A patient-based survey. *PLoS One*, **9** (9), e105153. DOI: 10.1371/journal.pone.0105153. PMID: 25202905; PMCID: PMC4159135.

Viola, T. W., Nunes, M. L. (2022). Social and environmental effects of the COVID-19 pandemic on children. *J. Pediatr.* (Rio J.), **98** (Suppl 1), S4–S12. DOI: 10.1016/j.jped.2021.08.003. PMID: 34571018; PMCID: PMC8463108.

Wallander, J. L., Varni, J. W. (1998). Effects of pediatric chronic physical disorders on child and family adjustment. *J. Child Psychol. Psychiatry*, **39** (1), 29-46. PMID: 9534085.

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KVALITATĪVS PĒTĪJUMS PAR BĒRNU COVID-19 INFEKCIJAS IETEKMI UZ ĢIMEŅU AR VESELĪBU SAISTĪTO DZĪVES KVALITĀTI

Koronavīrusa izraisītās saslimšanas (Covid-19) pandēmija un sekojošie epidemioloģiskie ierobežojumi dramatiski ietekmēja miljardiem cilvēku dzīves. Ir pieejami pētījumi par dažādu vecuma grupu mentālo veselību pandēmijas laikā, bet tikai dažos no tiem pētīta ģimeņu ar veselību saistītā dzīves kvalitāte. Šajā pētījumā izmantotas daļēji strukturētas intervijas, lai noskaidrotu ģimeņu labbūtību pandēmijas laikā, rūpējoties par akūti saslimušu bērnu. Rezultāti rāda, ka no vairākiem dzīves kvalitātes parametriem tieši emocionālā labbūtība tika ietekmēta visvairāk.