

Impact of Pediatric COVID-19 on Family Health-Related Quality of Life: A Qualitative Study from Latvia

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Inese Stars¹, Liene Smane^{1,2}, Zanda Pucuka^{1,2}, Ieva Roge², and Jana Pavare^{1,2}

Abstract

Information on family health-related quality of life (FHRQoL) among families of children with the coronavirus disease 2019 (COVID-19) is limited. This qualitative study explores the impact of pediatric COVID-19 on FHRQoL from the parents' perspective. Semi-structured interviews were conducted with parents ($n=20$) whose children had tested positive for the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2). Inductive thematic analysis revealed the following 10 themes that represented parents' perception of FHRQoL while taking care of a child with COVID-19: pediatric COVID-19 as a disease with many unknowns; emotional saturation; internal family relationships in the context of "a new experience"; routine household activities and daily regimen while family is in lockdown; plenty of free time; a wide social support network; social stigma associated with COVID-19; different options for work; savings and debts; challenges with family housing and transport availability. Our results show that parents experience multiple effects of pediatric COVID-19 with regard to FHRQoL.

Keywords

child(ren), parents, family health-related quality of life, COVID-19, qualitative approach

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Introduction

Caring for a child with an acute infectious disease can be challenging due to the abrupt onset and rapid development of the disease.^{1,2} As a result, parents may experience distress, disruption of the routine functioning of the family, worsened economic circumstances, and negative effects on their physical and emotional wellbeing.²⁻⁶ Although the incidence of coronavirus disease 2019 (COVID-19) is lower and the disease is generally milder in children, with fewer critical cases than in adults,^{7,8} caring for children with COVID-19 through to their recovery is essential.⁹ Several studies on health-related quality of life in the context of COVID-19 have been published^{10,11}; however, there is limited information on the impact of pediatric COVID-19 on children's families.¹²

The concept of pediatric infectious disease burdens on parental and family health-related quality of life (HRQoL) is grounded in the perspective that pediatric diseases, whether acute or chronic, are far more than

biological processes, and that such illnesses affect the functioning families holistically.^{13,14}

The concept of parental and family HRQoL has been described as the capacity of parents and families to adjust to a child's health status, especially with respect to chronic conditions.¹³ The measurement of parent and family HRQoL includes indicators of parent functioning (physical, emotional, social, cognitive, communication, worry) and family functioning (daily activities, family relationships)¹⁵; domains of emotional, social and economic/financial impact of a child's disease on a family²; parental opinion on the child's symptoms²; parents'

¹Riga Stradins University, Riga, Latvia

²Children's Clinical University Hospital, Riga, Latvia

Corresponding Author:

Inese Stars, Department of Public Health and Epidemiology, Riga Stradins University, Kronvalda Boulevard 9, Riga LV-1010, Latvia.
Email: Inese.Stars@rsu.lv



interaction with the medical system⁵; impact on leisure time, education and work¹⁶; and social isolation.⁵

The hypothesis that a family is affected by a child's chronic illness has been widely researched,^{13,16,17} and it has been shown that chronic, recurring, or life-threatening health conditions are associated with reduced parental HRQoL and family functioning.¹⁸⁻²¹ Minor illnesses and infections can also disrupt the parents' and family's routines, but these have received less attention from researchers.¹⁻³ Nevertheless, several studies have assessed the effects of infectious pediatric diseases on parents' quality of life and family functioning. These include studies on chickenpox,¹ rotavirus gastroenteritis,^{2,3} influenza,²² influenza-like illness,^{5,22} acute otitis media,⁴ pneumonia,²³ and ear, nose, and throat infections.²⁴

Given the novelty of COVID-19, it is important to gain greater insight on parental and familial functioning during the period of illness due to COVID-19 in children. Further studies will provide a better understanding of how families adjust to children having COVID-19 and how best to mitigate its negative impacts on these families.

In this study, the concept of family health-related quality of life (FHRQoL) is predominantly used, as in the study on FHRQoL in pediatric cyclic vomiting syndrome.²⁰ Despite problems with the conceptualization of FHRQoL,¹⁴ we have used it as an inclusive concept, that is, it includes parents and allows for a more in-depth understanding of how a child's illness affects the functioning of the family unit.¹⁴ The concept of "family" can also lead to confusion due to problems surrounding its definition. In this study, we used the approach presented by Golics et al¹⁶ in a review of the impact of diseases on families, where "a broad view of the term family"¹⁶ (p. 400) was accepted.

The aim of our study was to explore the impact of pediatric COVID-19 on FHRQoL through qualitative interviews with parents.

Methods

This study is a component of a larger study on the impact of COVID-19 on the pediatric health care system in Latvia.

Study Design

This was a descriptive qualitative research study based on the interpretive research paradigm, thus allowing us to understand people's subjective perceptions of phenomena within health contexts.²⁵

Participants

Participants were selected through purposeful sampling. They included parents of children (aged <18) living in Latvia and diagnosed with a laboratory-confirmed case of the severe acute respiratory syndrome coronavirus (SARS-CoV-2).

Researchers distributed an official letter of invitation to potential participants via family physicians who were asked to inform the parents of children with COVID-19 about the study. Twenty parents agreed to participate in the qualitative part of the study. Table 1 presents the demographic data and characteristics of the study participants and their children.

Separation of children with COVID-19 from other household members is important to minimize the risk of COVID-19 transmission. However, it may not be possible to separate such children from their parents due to factors such as age.²⁶ In this study, 5 adolescents over the age of 14 were isolated (2 of the adolescents were accommodated in a separate apartment and 3 in a separate part of an apartment, away from everyone else in the household).

Data Collection

Semi-structured interviews were conducted to obtain qualitative data on parents' perceptions of FHRQoL in the context of pediatric COVID-19. An interview guide was developed based on a literature review on similar issues.^{1,3,5,15,27-30} The interview guide included questions on parental perception of the child's symptoms and health care services received, parents' emotional reactions to the child's disease, and the impact of pediatric COVID-19 on the parents' social life and family's financial situation.

The interview questions were piloted before the official interviews began. The interviews took place at the Children's Clinical University Hospital (Riga, Latvia), where a separate room, suitable for the interview process, was allocated. Data were collected between July 2020 and September 2020. All participants (n=20) were interviewed individually by the first author. The interviews were conducted 2 to 6 weeks after the child's recovery in order to minimize recall bias.

Participation in the study was voluntary and written informed consent was obtained from each participant. Participants were informed that they had the right to withdraw from the interview at any time for any reason. Interviews lasted between 25 and 70 minutes. With the participants' permission, interviews were audio-recorded and then transcribed verbatim in preparation for the analysis.

Table 1. Demographic Characteristics of the Research Participants (n = 20) and Their Children (n = 30).

Characteristic	n	%
Participants	20	–
<i>Participants' link to the child</i>		
Mother	13	65
Father	6	30
Grandmother	1	5
<i>Participants' age (years)</i>		
31-40	8	40
41-50	8	40
51-60	3	15
61-70	1	5
<i>Participants' level of education</i>		
Higher	13	65
College	3	15
Vocational secondary	4	20
<i>Number of children infected with COVID-19 in the family</i>		
1	12	60
2	6	30
3	2	10
Participants' children	30	–
<i>Child's age in years</i>		
0-9	14	46.7
10-19	16	53.3
<i>Manifestation^a of pediatric COVID-19</i>		
Asymptomatic	5	16.7
Symptomatic	25	83.3
<i>Child's hospitalization</i>		
Yes	3	10
No	27	90

^aAsymptomatic or symptomatic manifestation of pediatric COVID-19 is based on parents' reports.

Data Analysis

Interviews were analyzed manually using an inductive thematic analysis approach. The choice of inductive thematic analysis was based on the underpinning that little is known about the effects of pediatric COVID-19 on FHRQoL. This fits well with the assumption that the data are analyzed in a “bottom-up” manner in inductive thematic analysis. This allows themes to emerge from the data without being introduced through a pre-selected coding framework and avoiding rigidity, which are risks of a deductive approach.³¹ Thematic analysis was carried out using the following 6-step method: getting familiarized with the data, generating initial codes, looking for themes, reviewing themes, defining themes, and producing the report.³¹

Research rigor was established through careful documentation that provided transparency of the research process and through a rich description of the

phenomenon under investigation. Two researchers (IS & ZP) independently analyzed the transcriptions independently analyzed the transcriptions. A research team approach was used to identify the main themes and their interpretations.

Ethics

The Ethical Committee of Riga Stradins University granted ethical approval (Nr.6-1/07/35) for this study.

Results

Ten core themes were established as a result of the thematic analysis. Each of the themes highlights a specific domain of FHRQoL (Figure 1).

Domain “Parental Evaluation of the Disease, the Child's Symptoms and Health Care”

Theme 1: Pediatric COVID-19 as a disease with many unknowns. Comparing pediatric COVID-19 to other infectious diseases in children that the families have experienced, many parents described COVID-19 as a disease with many unknowns regarding its course, treatment, and effects on the children's future health.

Some parents admitted that knowing that children are not a high-risk group made them feel calmer. At the same time, parents whose children experienced severe symptoms felt extremely worried about high body temperature, fever, cough, febrile seizure, and breathing difficulties.

“From the beginning it was clear that this cough was not a usual cough. He was coughing constantly, breathless. It looked horrible.” (Mother, higher education, aged 36)

COVID-19 in their children made it necessary for parents to communicate with several health care specialists, mainly epidemiologists and family physicians/pediatricians. Mostly, parents were satisfied with the healthcare received from the responsible public health institutions. However, parents' views regarding family physicians' performance were contradictory. While many parents acknowledged that their family physician was knowledgeable and supportive, others stated that they had not received the necessary professional support from their family physician.

The parents of hospitalized children expressed satisfaction with the medical care they received.

Pediatric COVID-19 created challenges on parental health literacy as parents searched for information about COVID-19 on internet sites and received information

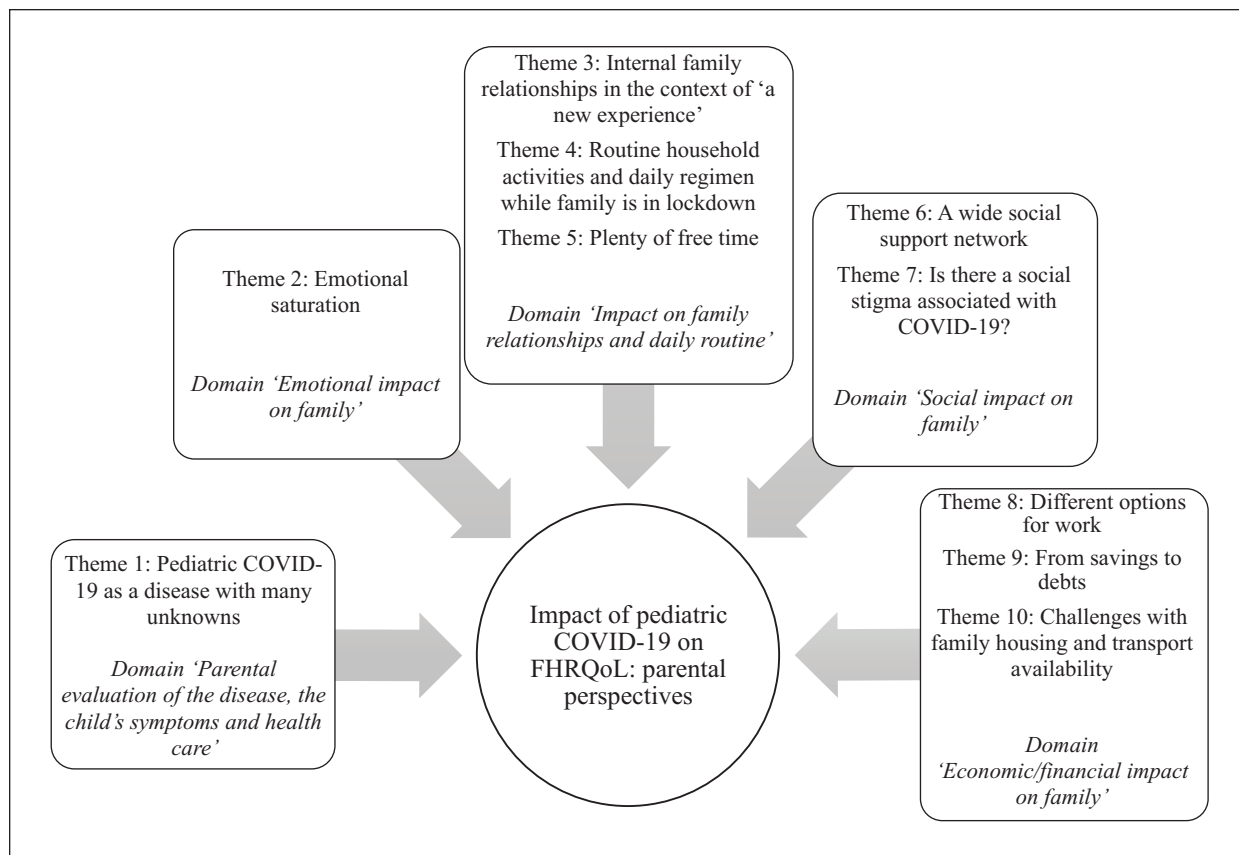


Figure 1. Thematic map: relevance of the themes to the domains of FHRQoL.

from family, friends, healthcare specialists, and television. The parents concluded that the information was extensive, but changeable. They found it difficult to assess the reliability of the information.

Domain "Emotional Impact on Family"

Theme 2: Emotional saturation. Pediatric COVID-19 provoked vivid emotional reactions in parents.

The parents' initial reactions to their child's positive SARS-CoV-2 test result were divided into the following 2 response groups: (1) the event was unexpected (here, parents experienced fear, surprise, confusion, disbelief, and a feeling of unpreparedness); (2) the event was expected because there was already a case of COVID-19 in the family (here, parents responded more calmly and felt morally prepared for the diagnosis).

In general, parents considered the situation of pediatric COVID-19 in their family as an emotionally demanding situation. When describing their emotions, the parents mentioned uncertainty, worry, distress, despair, helplessness, panic, insecurity, guilt, anger, waiting, imprisonment,

psychological fatigue, inability to manage stress, intolerance, and boredom. Two families noted a fear of the "infected" child because she/he was perceived to be a possible transmitter of COVID-19 to the family.

However, positive emotions and feelings (love, trust, optimism, compassion, gratitude, closeness, togetherness, and safeness) were also experienced.

While some parents perceived the disease to be frightening because of its sudden onset and severe course, other parents felt suspicious about the absence of symptoms.

"There was uncertainty. . . Waiting whether and when the disease would start to manifest any symptoms." (Mother, higher education, aged 37)

Mostly, parents felt that their worry eased with the relief of the child's symptoms.

"My daughter had fever for a day. After that there was nothing to worry about. Other diseases have been much more frightening." (Father, college education, aged 50)

Meanwhile, parents who had isolated their children in separate housing or in another part of the home felt an additional responsibility towards the child's socialization and psychological wellbeing.

Domain "Impact on Family Relationships and Daily Routine"

Theme 3: Internal family relationships in the context of "a new experience." Parents described their physical isolation from the "outside world" due to pediatric COVID-19 as "a new experience."

"It was something new. A child being ill and the family forced into lockdown. No other disease has seen the whole family quarantined." (Father, higher education, aged 37)

When asked on how respondents perceived their time spent in quarantine, the dominant response was "together." They spent a long time together in one place as a family. However, the "all together" situation caused mixed feelings. On one side, parents described quarantine as enjoyable because the family experienced togetherness, and they acknowledged that their relationships had improved. Conversely, "all together" also challenged the limits of personal space. As a result, several parents reported a lack of private time and space for both themselves and their children. This, in turn, resulted in a sense of tension, annoyance, intolerance, and minor arguments. However, no family reported a significant deterioration in relationships during quarantine.

Furthermore, families in which the infected child was isolated, or, in which one of the members was isolated to avoid being infected, did this by physical separation in external housing or in another part of the home, which led to division of the family unit.

Theme 4: Routine household activities and daily regimen while family is in lockdown. Daily household chores did not create major problems for families of children with COVID-19. Mostly, parents acknowledged that they were able to deal with routine tasks on their own. Some duties were provided by other people or via the internet. Few parents reported the need for additional household duties such as regular disinfection of rooms, frequent changes of bed linen, monitoring their children's health, and cooking more healthy meals. Parents whose children were isolated in separate housing found that supplying the child with all the necessary things required good logistics.

Families' daily regimens changed significantly. Parental views on their daily family regimen during quarantine could be classified into 4 categories: daily

regimen as planned; chaotic daily regimen; daily regimen different to usual; life on hold.

Theme 5: Plenty of free time. Many parents indicated that they had a lot of free time during the family's lockdown. Both children's and parents' health conditions affected ways of spending leisure time. Parents cited board games, digital games, movie nights, online chatting, using the internet, watching TV, cooking, reading books, engaging in creative activities, working in the garden, sports, and "doing nothing" as the most common leisure activities.

When asked what activity the family lacked, physical activities in the outdoors were the most commonly mentioned. This was particularly true for families who were quarantined in an apartment compared to those living in houses with private yards.

Domain "Social Impact on Family"

Theme 6: A wide social support network. Parents found that the social support available to the family was sufficient and extensive. It was provided by grandparents, relatives, friends, colleagues, and neighbors. The support required was varied. Some families needed more practical support, while others emphasized the need for emotional support. The possibility of talking to someone who had COVID-19 seemed important to several parents as they considered it to be a form of social support.

Theme 7: Is there a social stigma associated with COVID-19? Four families experienced COVID-19-related social stigma. This was manifested in the form of negative attitudes (anger, suspicion, avoidance, threat, rejection, and disinformation) from neighbors, colleagues, friends, and parents of other children. The label "COVID family" was attached to one family, although other families did not experience such attitudes.

Domain "Economic/Financial Impact on Family"

Theme 8: Different options for work. Employed parents experienced different options for work, including working remotely from home, taking sick leave, or combining sick leave with periodic remote working.

Some families used other options. If possible, one of the parents moved to another apartment or, if the child was old enough, she/he isolated in a separate apartment so that the parents could continue to work (after self-quarantine, if the parent has been exposed to the child with COVID-19).

While several parents experienced workdays lost, they also reported that their employment relationship had not been affected significantly. Two parents, whose work required being physically present, indicated that they experienced negative consequences related to their quality of work. Some parents found working from home while their children were ill tough and less productive.

Theme 9: From savings to debts. When asked about how pediatric COVID-19 influenced the family's financial situation, parents' experiences fell into 2 categories: (1) the majority of parents acknowledged that the family's financial situation may have improved because they were unable to do routine social activities due to quarantine; and (2) the family's finances worsened and, in some cases, fast loans were needed.

Unexpected expenses related to the child's illness were rarely indicated. The main reasons for unexpected expenses were medical examinations for the child after COVID-19, medication, vitamins, and an increased amount of healthy food.

Theme 10: Challenges with family housing and transport availability. Available housing resources became thematic in families with children with COVID-19. Single family homes with yards provided better facilities for isolation, as well as the opportunity to spend time outdoors. However, families who spent quarantine in apartments experienced the "four wall phenomenon."

"Our daughter was COVID positive for over a month. We literally sat between four walls and gazed at the summer outside our window." (Mother, higher education, aged 44)

If the family had several properties, they had the opportunity of isolating the child or another family member in them.

Availability of vehicles was also essential since a private car was needed to reach the laboratory for a COVID-19 test. For parents whose children were isolated elsewhere, a vehicle was also necessary to supply the children with necessities.

Several parents stated that a social safety net is needed to help parents navigate such a situation.

Discussion

The findings of the current study explored the FHRQoL from the perspective of parents whose children had COVID-19. The study revealed that pediatric COVID-19 can impact the functioning of families in multiple domains of quality of life.

The child's symptoms that worried parents the most were increased body temperature and fever, as these may indicate the disease is progressing. In Latvia, fever phobia among parents has been previously proven,³² and parents believe that fever can lead to dangerous complications.³⁰ Parents were also worried about their children's respiratory symptoms. Similarly, in Ingram et al's³³ study, a child's persistent cough was perceived by parents as a disturbing symptom that required a physician's attention. In our study, some parents, whose children had an asymptomatic or mild case of the illness, felt suspicious as they expected more severe symptoms. However, when symptoms were reduced or remained unnoticed, parental worry decreased.

Family physicians or pediatricians were the most common sources of care for children with COVID-19. Parents valued regular communication with physicians for professional advice and emotional support. Some parents concluded that the physician's role in the care of children with COVID-19 was insufficient. Dual parental experiences regarding the performance of family physicians were also revealed in a study of children's primary care in cases of lower respiratory tract infections.³⁴

Parents experienced health literacy challenges while taking care of children with COVID-19. Parents reported that although they searched for additional information on COVID-19, they felt overwhelmed by the information. The reliability of information was also reported as a concern. Similar studies have indicated that parents obtain information about children's acute health issues from multiple sources, including laypersons and professional people, the internet, smartphone apps, magazines, books, and leaflets.^{33,35}

The majority of parents acknowledged the effects of a child's illness on their emotional well-being. Parents experienced a vivid and variable spectrum of emotions, varying from unpleasant to positive. Many parents also reported feelings of uncertainty, which stemmed from the novelty of COVID-19. As shown in previous studies, acute infectious diseases in children reduce parental emotional wellbeing,²² resulting in worry, frustration, and anxiety.^{2,3,24,30}

Parents characterized dealing with pediatric COVID-19 as a "new experience" for their family. Many parents experienced a pleasant feeling of connectedness among family members while quarantined in one place. However, sheltering in one place for a long period of time led to a lack of privacy for some parents and children, leading to strained relationships among family members. Signs of relationship changes have been reported in other studies on the impact of infectious diseases on FHRQoL.^{1,5,24} Furthermore, a unique "new experience" was reported by families in which a sick

child was separated from the rest of the family to avoid infecting them. It remained the parents' responsibility to provide their children with various types of support.

Similar studies exploring the impact of children's acute infectious diseases on their families discovered a reduced parental capacity to cope with routine household tasks.^{1,3,5} Interestingly, in our study, parents reported that routine household activities did not cause major problems. However, practical and emotional support from relatives, friends, neighbors, and colleagues helped to cope with quarantine restrictions and maintain a daily routine. Families also experienced changes to their daily regimen, and more free time.

Researchers have previously emphasized the social stigma associated with COVID-19.^{36,37} In this study, 4 families experienced COVID-19-related stigma.

Previous findings indicate that acute infectious diseases in children have a negative effect on parental employment.^{2,3,5,6,23} The current study discovered that many parents had the opportunity to switch to remote work, but paid sick leave was also a common choice; however, it led to missed working days.

Interestingly, most families' financial situation did not deteriorate, and, in some cases, it even improved as they saved money when the family was forced into lockdown with limited opportunities to spend money. Although some families experienced an economic burden, it was not possible to identify whether this occurred because of the child's illness or due to the economic consequences of COVID-19 in Latvia.

The availability of housing and transport were topical for families experiencing pediatric COVID-19. A social safety net should be provided for parents if support with housing, transport or other resources is needed.

Based on our qualitative results, we were able to identify and characterize major FHRQoL issues in the context of pediatric COVID-19.

Limitations

This study has some limitations. Firstly, the state of emergency declared over the COVID-19 pandemic, and other epidemiological safety rules affected the daily life of citizens.³⁸ Consequently, it was difficult to determine precisely whether the FHRQoL was affected exclusively by a child's illness or by the wider conditions caused by COVID-19.

Secondly, we included families with one or more SARS-CoV-2 positive children. During the course of the study, it was found that in several cases, one or both parents were also infected. Consequently, it is possible that the FHRQoL was affected not only by the child's illness but also by that of the parents. To avoid such potential

bias, it would be advisable to use more specific sampling criteria in future studies.

Conclusion

The current study explored the parents' views on the impact of pediatric COVID-19 on FHRQoL. Parents experienced multiple effects of pediatric COVID-19 on domains of FHRQoL, which led to a considerable burden on families during the child's illness.

Author Contributions

IS developed the interview protocol, participated in data collection, analyzed data, wrote the results and prepared the manuscript. IS, LS, JP contributed to the conception and design of the study. LS, ZP and IR were responsible for parent involvement. IS, ZP and JP participated in theme development. JP was the project manager and supervisor.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Ethical Approval

The Ethical Committee of Riga Stradins University granted ethical approval (Nr.6-1/07/35) for this study.

ORCID iD

Inese Stars  <https://orcid.org/0000-0003-3519-0396>

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