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COVID-19 in pediatric palliative care: what can we learn from the pandemic and possible future directions

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Abstract

Introduction. Patients in pediatric palliative care (PPC) live with multiple comorbidities which represent a risk factor for severe form of COVID-19.

Methods. This monocentric retrospective study was performed at the PPC Center of Padua (Italy). Testing methodology, prevention strategies and infection characteristics were documented and compared during the first and second peak of SARS-CoV-2 infection.

Results. Between April-June 2020 a population swab screening was performed and a strong reduction of the habitual family support was observed. Between November 2020-January 2021 swab testing was limited to specific cases and the support network for families was partially restored. Incidence of COVID-19 was low, resulting in 0.04% of total pediatic cases in the Veneto Region. No severe forms were observed.

Conclusion. The use of adequate preventive measures by families and support networks associated with testing in specific contests is safe, cost effective and has a minor impact on caregiver's care load.

Key words

- SARS-CoV-2
- COVID-19
- Pediatric palliative care
- Home care
- Preventive measures

INTRODUCTION

To date, the pandemic has reached more than 100 million cases globally [1]. The incidence of COVID-19 among children showed an upward trend during this year [2-5]. Although children have a better prognosis compared to adults [6], in Europe 8-10% of infected children developed a severe form of COVID-19 and required intensive care support [7, 8]. The presence of preexisting comorbidities or complex medical needs is a risk factor for developing a severe form of COVID-19 [7, 9]. Moreover, multisystem inflammatory syndrome (MIS-C) has been observed only in children and is associated with an increased need of intensive care support and higher mortality [10].

Children eligible for pediatric palliative care (PPC) have life-threatening and life-limiting diseases. They normally have multiple comorbidities, complex medical needs and the majority of them need life-saving support (60% in our contest). A supportive multi-specialist network (palliative pediatricians, nurses, psychologists, physiotherapists, physiatrists) is crucial for them and their families in order to ensure an adequate quality of life [11].

Consequent to their critical health condition, children who require PPC have a high-risk for severe forms of COVID-19.

The aim of the present retrospective study is to assess the incidence of SARS-COV-2 among children in PPC and to suggest the most safe, helpful and cost-effective management strategy.

MATERIALS AND METHODS

The study was approved by the Ethics Committee of the Padua Hospital (protocol 0037730).

This monocentric retrospective study involves all patients from the PPC Center of Padua (Italy) and their families. A comparison between the first (April-June 2020) and second wave (November 2020-February 2021) was performed to evaluate the screening methodology adopted by our center, the differences in the home care support and the incidence of SARS-CoV-2 infection among children.

From April to June 2020 a population screening was proposed, with previous consent, to all families in charge at our center and nasopharyngeal swab (NPS) for SARS-CoV-2 molecular search was performed at home on PPC patients and all family members in close contact with the child. Results of laboratory analysis

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were collected at the PPC Center of the Department of Women and Children Health at the Padua Hospital (Italy).

From November 2020-February 2021 the NPS for the SARS-CoV-2 molecular search was proposed only to patients and caregiver before hospitalization in the Pediatric Hospice and to symptomatic or close contact patients or caregivers.

In April 2020 and February 2021, we submitted an anonymous online questionnaire (*Appendix 1*) to all the main caregivers of children in charge at our PPC center. The topics analyzed in the questionnaire were: the application of the World Health Organization recommendations for the prevention of infection, the changes of habits to reduce the risk of contagion, the reduction in practical support received from people outside the family (health providers/friends/family), the flu vaccinations status of both patient and family. In February at the same questionnaire was added an additional focus regarding the personal opinion of parents on COVID-19 vaccine.

The quantitative and qualitative analysis of the survey was performed at the PPC Center of the Department of Women and Children of the Padua Hospital.

Our data were compared with the absolute number of COVID-19 infections documented until February 2021 at the Regional Register of SARS-CoV-2 infections of the Veneto Region.

In our observational study variables associated with patients, screening methodology and questionnaire were expressed as absolute value, mean, percentage. No further statistical analysis was performed.

RESULTS

Incidence

From April 2020 to February 2021 the total number of positive children was 13 out of 170 patients followed by our PPC center in February 2021 (8%). The characteristics of this population are resumed in *Table 1*. Two patients (15.4%) had a hospital-acquired infection, six patients (46.2%) had a domestic-acquired infection, three asymptomatic patients (23.1%) resulted positive at the pre-hospitalization screening, in two patients (15.4%) the source of the infection was unknown.

In addition, eight other families reported positive NPS among parents and siblings. Of these, two caregivers were asymptomatic and were identified by the pre-hospitalization screening.

Once identified, positive patients were closely monitored by our medical-nursing team with telemedicine. Specific pathways in case of severe symptoms were previously defined and shared with families.

Four patients (30.7%) were asymptomatic, nine patients (69.2%) presented mild-moderate symptoms as mild respiratory symptoms as flu, worsening of secretion, pneumonia (7/13), fever (4/13), abdominal pain and diarrhea (2/13). Two patients (15.4%) required hospitalization for pneumonia, none required intensive care support or presented MIS-C. All patients had a complete recovery from COVID-19.

Only one caregiver resulted positive in April 2020 and no children contracted the infection during the first wave. Since September 2020 we have observed a higher incidence of the infection among children and caregivers, with a peak between November and February 2021 (11/13).

Table 1
Characteristics of children with documented SARS-CoV-2 infection in PPC up to February 2021

Characteristic	N of patients (%)
Total number of children in PPC	170
Total number of children with SARS-CoV-2 infection	13 (8%)
Number of children with SARS-CoV-2 infection (April-August 2020)	0
Number of children with SARS-CoV-2 infections (September-October 2020)	2 (15%)
Number of children with SARS-CoV-2 infection (November- February 2021)	11 (85%)
Median age (years), range	7.44 (1.3-15.11)
Age group (y):	
<1	0
1-5	6 (46.2%)
6-10	1 (7.6%)
>10	6 (46.2%)
Sex	
Male	6 (46.2%)
Female	7 (53.8%)
Pathology	
Oncologic	2 (15.4%)
Non oncologic	11 (84.6%)
Life support	
Non invasive ventilation	3 (23.1%)
Tracheostomy	2 (15.4%)
Gastrostomy/SNG	7 (53.8%)
Need of frequent access to the hospital (for treatments or follow up)	4 (30.8%)
Need of physiotherapy	7 (53.8%)
Going to school	4 (30.8%)
Origin of infection	
Hospital	2 (15.4%)
Family	6 (46.2%)
Detected by screening	3 (23.1%)
Not known	2 (15.4%)
Main symptoms	
Fever	4 (30.8%)
Flu	2 (15.4%)
Increase of secretions	3 (23.1%)
Pneumonia	2 (15.4%)
Abdominal pain	1 (7.7%)
Diarrhea	1 (7.7%)
Asymptomatic	4 (30.8%)
Need of hospitalization	2 (15.4%)
Need of intense care unit	0

Survey results

The adherence to the questionnaire proposed in April 2020 and February 2021 was respectively 52% and 28%.

In both periods the most adopted prevention measures by the families were: avoiding aggregations (92% *vs* 77%;), ventilation of rooms in the house (70% *vs* 57%) and washing hands (56% *vs* 55%). The use of masks at

home was higher in the first questionnaire (40%) compared to the second (27.5%). The distance of at least 1 meter was respected only in 25% of cases. In February 2021 in case of positive cases in families the use of masks at home and the domestic isolation were the two most adopted measures (respectively 20% and 17.5%).

Since the beginning of the pandemic, we observed an overall reduction in the child's outdoor recreational activity (88% *vs* 77%) and routine medical visits (74% *vs* 55.3%).

In April 2020 families reduced or suspended access of health-care providers to their home in 65.4% of cases and those of external people who normally assist the child in 100% of cases for friends or relatives and 57% for other professional care providers (babysitters, educators). In February 2021, the access at home of health care providers was reduced or suspended in only 39.2 % of patients and that of external people who normally assist the child was reduced in 36.8% for professional care providers and in 97.5% for friends or family members.

In April 68% of parents changed their work habits to reduce their outings whereas in February 64.1% of parents referred not to have any variation in work activities.

The use of telehealth consultation was higher in April 2020 (54%) compared to February 2021 (37.5%).

Evaluating the flu vaccination status, we observed in both periods a non-adherence to the flu vaccination in 40% of families. Moreover, in February 2021 40% of caregivers were still doubting about the SARS-CoV-2 vaccination.

Screening strategies

Between April-June 2020, 163 children were followed by our PPC center, of which 146 (89.6%) agreed to be screened for the SARS-CoV-2 infection. A total of 401 NPS were performed:103 children (71%) and 298 family members (63%), with an overall cost of approximately 25,500 euro (64€/swab). 43 patients and 3 families were not tested for the SARS-CoV-2 infection due to organizational reasons.

Between November 2020-January 2021, 68 families were tested for a total of 169 NPS: 104 as pre-hospitalization screening (61.5%) and 65 in 16 symptomatic families (38.5%). The cost was approximately 10,820 euro (64€/swab).

DISCUSSION

Several reports assessed how the presence of pre-existing comorbidities represents an important risk factor for developing severe forms of COVID-19 [7, 9]. Most patients in PPC present multiple comorbidities, making this population especially at risk.

The analysis of data collected at the Padua PPC center suggests a different picture.

The overall incidence of COVID-19 among children in our region reached 4.2% of the total pediatric population, according to the Veneto Regional Register. Children in PPC represented 0.04% of total positive pediatric cases in Veneto (13/35,504) and no severe forms of the infection were observed. During the first observational period, from the screening performed on the pediatric population in charge of PPC, a zero-incidence rate of COVID-19 emerged. It is likely that the immediate strict adherence to preventive measures adopted by the family had a positive impact on this finding. In fact, the COVID-19 prevention measures that these families adopt every year during the winter season only increased. Furthermore, the caregivers of children eligible for PPC are subjects who normally live in social isolation and the COVID-19 pediatric rates were not that high during the first wave in our region as during the second one. The survey showed that during the first observation period the major change was the reduction of the support from the health network normally guaranteed at home by the pediatrician, the physiotherapist or nurses, as well as that of other family members or friends who concretely help the family in the child's daily management. This implies a major work for the caregivers that already have an important daily care load [12] with a consequent greater burden [13], which deserves further investigation on the quality of life impact in a medium long term perspective.

During the second observational period, the decision of not repeating any population screening was consequent to the very low incidence of infection during the previous observational period. Moreover, seeing the strong impact of the isolation on the caregiver care load and family burden, preventive strategies were still adopted but with the resumption of the clinical and social network that normally helped the families at home. As a result, the second survey showed that in almost 50% of families the support at home from pediatricians or other health care providers was restored.

The reduction of social restriction compared to the first wave, can partially justify the increased number of SARS-CoV-2 infections observed among children in the second wave, which was also in line with the overall increased incidence of SARS-CoV-2 infections among children during the second spread of COVID-19. The origin of the infection was mostly secondary to other family members (46,2%) and only two cases (15,4%) were secondary to an inhospital spread of the infection.

A considerable number of asymptomatic cases (30.8% among children) were observed justifying the need of keeping the pre-hospitalization screening in order to maintain the Pediatric Hospice COVID-free.

The aim of PPC is the global quality of life of children and family [11]. For this reason, considering the minor impact of COVID-19 in this population and the negative effect of isolation on family's burden, we assume it to be a priority to restore the health-related support network at home. As a consequence of this, specific precautions and screening strategies are needed.

Prevention strategies were continuously used by the families based on WHO's recommendations as shown in the surveys. In terms of screening, using NPS for pre-hospitalisation and in case of symptoms or close contact together with the maintenance of home care (if feasible) were the most safe and cost-effective strategies.

Limitations

This study has potential limitations related to the heterogeneity of the sample and the data collection based on caregiver's evaluations. Moreover, other pos-

sible contributing factors may have caused the increase of incidence of COVID-19 during the second wave. A case-control study comparing our population to the general pediatric population would have helped to evaluate those factors related to the increased incidence of COVID-19.

CONCLUSION

In conclusion, considering the minor impact of COVID-19 in our population, we highlight the importance of preserving the family support network, with an adequate use of preventive measures and NPS. These tools resulted safe, cost-effective and helpful for the caregivers. Moreover, the pandemic has not induced a major awareness among families on vaccinations, with the need in the next future to intensify educational campaigns.

Conflict of interest statement

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors. Authors have nothing to disclose.

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Appendix 1. Questionnaire

The questionnaire was submitted to the main caregiver in Italian as an e-CRF using surveymonkey in April 2020. The same questionnaire, with the exception for the first and last question was proposed in February 2021.

1. How important is for you the opportunity to be screened for SARS-CoV-2? (only in April 2020)
   Likert scale from 1 to 5 (1= not at all; 5= very much)

2. At home do you follow these preventive measures (using a Likert scale 1-5 where 1 was no and 5 was always):
   - ☐ Frequently wash hands with soap or alcohol-based hand sanitizer
   - ☐ Avoid touching your eyes, nose or mouth with unwashed hands
   - ☐ Cough or sneeze into a tissue or on your elbow
   - ☐ Keep safe distance from other people (1 meter)
   - ☐ Disinfect surfaces
   - ☐ Avoid aggregation or crowded place
   - ☐ Keep your home well ventilated
   - ☐ Use of masks

3. Do you use other kind of precautions? (open answer)

4. If anyone in family presented possible symptoms of COVID-19, how did you behave? (multiple choice)
   - ☐ Use of mask at home
   - ☐ Domestic isolation of the sick person
   - ☐ Quarantine of the sick person in another home
   - ☐ None
   - ☐ No one presented symptoms

5. How did your life change in this period? (Likert scale 1-5; 1= for nothing, 5= very much)
   - ☐ Reduction of health-related outside activities
   - ☐ Reduction of recreational outside activities
   - ☐ Reduction of work activity
   - ☐ Reduction of mere necessity activities (i.e., grocery shopping)
   - ☐ Reduction of help from friends and family member at home
   - ☐ Increased use of web/call for communication with the child support network
   - ☐ Sharing of the care load with other member of the family

6. In this period how did it change the support from the health care network normally involved in the care of your son at home?
   (Scale 1-4; 1= unchanged, 2= reduced, 3= stopped, 4= never used)
   - ☐ From the pediatrician
   - ☐ From other health-care providers (physiotherapist, psychologist, nurse...)
   - ☐ From other non-professional figures (baby-sitters, educators, volunteers)
   - ☐ Other

7. Is your son regularly vaccinated?
   - ☐ Yes
   - ☐ No
   - ☐ Never been vaccinated

8. Are you and your son vaccinated for flu?
   - ☐ Both
   - ☐ Only my son
   - ☐ Only parents
   - ☐ No one

9. Would you like to be vaccinated for COVID-19? (question added in February 2021)
   - ☐ Yes
   - ☐ No
   - ☐ I don't know

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