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Distance support and online intervention to blind and visually impaired children during the pandemic COVID-19

Tiziana Battistin^{a,*}, Elena Mercuriali^a, Vincenzo Zanardo^a, Dario Gregori^b,
Giulia Lorenzoni^b, Laura Nasato^b, Maria Eleonora Reffo^a

^a Robert Hollman Foundation "Consultation and Support for the Development of Visually Impaired Children", Via Siena 1, Padova, Italy

^b Unit of Biostatistics, Epidemiology and Public Health, Department of Cardiac, Thoracic, Vascular Sciences and Public Health, University of Padova, Italy

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ABSTRACT

The COVID-19 pandemic imposed dramatic changes to everyone's daily routines, but especially to children with developmental disabilities. The Robert Hollman Foundation decided not to interrupt its service to all the visually impaired children and initiated a Distance Support Project. It was an online process covering all aspects of support for the children and involving audio-video calls, videos and tailored-made multisensory material created specifically for each child.

A questionnaire, carried out after the 5-month project duration, was created to collect feedback from parents and professionals to understand the impact this project had on everyone involved. Overall both parents and professionals indicated high levels of satisfaction, but in a significant number of questions parents reported consistently higher levels of satisfaction (p-value <0.001).

It was shown that parents felt reassured at this otherwise very difficult time because their children were able to continue their treatment, even if in a very different way. This fact encourages us to consider enriching our existing programmes of support and care, integrating this online approach when necessary. At the same time, it seems clear that the responses of the professionals indicate their belief that the benefits of the traditional ways of working remain of unquestionable importance for children with sight deprivation.

What this paper adds

This paper describes a new approach to supporting the development of blind and visually impaired children. This was developed due to and during the lockdown imposed because of the emergency situation regarding the COVID-19 pandemic. It involves new technologies, such as different e-platforms, which offer the opportunity of working and communicating online. In addition to the novelty of this distance support in this particular population of children with developmental disabilities, the results of a questionnaire, which was given to the children's parents and professionals (psychologists, rehabilitators, educators) alike, show the quite high level of satisfaction with this new approach as well as its strengths and its weaknesses.

* Corresponding author at: Robert Hollman Foundation, Via Siena, 1, 35143 Padova, Italy.

E-mail address: t.battistin@fondazionerobertollman.it (T. Battistin).

1. Introduction

The outbreak of the COVID-19 pandemic (World Health Organization (WHO, 2020), which was widespread in Italy, forced the Central and Regional Italian Governments to immediately adopt very restrictive and severe containment measures, leading to a prolonged lockdown, in order to stop the virus from spreading. During the lockdown, paediatric rehabilitation and support services had to close, as well as all the schools and educational/recreational services. Everyone had to reorganize their daily lives and their daily routines, including all the children. Schools started distance teaching, which was something completely new in Italy both for teachers and pupils. Children with developmental disabilities (DD), including blind and visually impaired children, were the most affected by such dramatic change in both their daily rhythms and ways of learning. It is well known that a severe visual impairment has a strong impact overall on a child's development, delaying the developmental milestones especially in the first years of life (Fazzi et al., 2010); Warner Richter & Lloyd showed how, in the US, developmental delay is the second type of disability among children, affecting 37% of them (Warner-Richter and Lloyd, 2020), underlining the urgency of intervention, even if in a modality alternative to the traditional one.

The Robert Hollman Foundation (RHF) is a private non-profit making organization of Dutch origin which offers free consultation and support for the development of visually impaired children (Battistin et al., 2005; Mercuriali et al., 2016) and which has been working since 1979, in both its centres offering outpatient and residential care to approximately 350 severely visually impaired children (aged 0–14) annually. The care paths offered to the children are tailor-made for them and are limited not only to curing disease, but also involve taking care of the whole child, following his development throughout his formative years and supporting at the same time his caregivers. Of the children 76,2 % are of an early age, which is the ideal period to start a personalised rehabilitative project of the visual functionality, considering the correlation between post-natal development and level of cerebral plasticity (Matsuba and Soul, 2010).

Even though the lockdown interrupted all the programmed activities, the professionals of the RHF, felt it important to continue the therapeutic and rehabilitative activities of support to the child's overall development. The RHF therefore decided to activate and experiment with, through a Distance Support Project (DSP), an online alternative, offering custom-made psychological, educational and rehabilitative treatment, which can be partially compared to that already present in the Australian educational field (Cain and Fanshawe, 2019). The RHF-DSP was created in order to be able to continue offering services and the necessary therapeutic continuity to the children and their families during the lockdown, which was an extremely difficult period for everybody, but especially for children with a DD (Trabacca and Russo, 2020), given that visually impaired children are vulnerable to regressions (Fazzi et al., 2010; Vervloed et al., 2020; Dale and Sonksen, 2002; Waugh et al., 1998) and to developmental risk (Fazzi et al., 2010; Molinaro et al., 2020).

1.1. The pilot project

The RHF-DSP for blind/visually impaired children and their families was implemented through online assessment, treatment and intervention activities, carried out using these modalities:

- audio-video support calls/meetings, rehabilitative treatments with the children and their families in order to:
 - o support the children in their development, by following step by step their stages and highlighting their strengths and potentialities. Postural and environmental facilitations were created by the professionals, explained and shared with the parents and sent to them by email, so that they could help their child daily, favouring not only the development and use of sight but its integration with other senses and with motor, cognitive and affective development
 - o support the parents in the delicate developmental growth of their child, through dedicated online meetings, by listening to their questions and their doubts, by making them feel continuously part of the process in order to help them to overcome any difficulties
- analysis of the videos sent by parents to the professionals in order to answer their questions or doubts regarding the development of their child
- multisensory material dedicated to the children and to their families produced by the professionals, in order to continue achieving certain developmental aims identified before the COVID-19 pandemic

All of the above action was carried out in a supportive distance-learning environment to favour a social-emotional support linked to the child's specific special needs, and as shown in the guidelines given to teachers providing distance learning to students with disabilities (Herburger, 2020). Specific training to professionals regarding online working was initiated, paying particular attention to distance support methodology.

1.2. The satisfaction questionnaire

At the end of July 2020, a satisfaction questionnaire was devised to give to the parents to complete in order to find out what they thought about the distance support and online initiative, to discover if they or their children liked the experience or found it useful and finally if they noticed some positive changes in their children.

A similar questionnaire was given to the professionals of this pilot project, in order to compare their feelings and experiences with those of the families.

Traditionally the therapeutic path itself has a strong emotional impact on the children, because of the relationship between the

child and professional, first and foremost, but also because of the setting and the technical skills, specific to every professional field, which play an important role. The change from the traditional “face to face” or “hands on” therapy to a Distance Support approach, with child and professional relating to each other and working online via a screen, may have influenced both the relationship (Negri et al., 2020), the setting and also technical skills and consequently the feelings both of the child and of the professionals.

Moreover, it is important to consider the “novelty” effect of the distance support method, it being a completely new experience for everybody involved, parents, children and professionals alike. It could have led to different reactions, such as feelings of inadequacy or tendency to react more enthusiastically or desire to learn more and so on.

The twin aims of this questionnaire were to:

- assess the perceived satisfaction with and usefulness of this innovative support method
- contribute to scientific research in the low vision field of children

The results could encourage professionals to use a similar method in the future, particularly if it becomes necessary in similar emergency situations.

2. Materials and methods

This pilot project took place at the RHF, from 12 March 2020 to 31 July 2020, after the lockdown imposed by the Regional and Government Italian regulations for the COVID-19 pandemic and after the approval of the Institutional Board (RHF, Padua, Italy). All parents and professionals gave their informed consent to this project.

2.1. Participants

First sample (N): parents of 106 children, cared for at the RHF were included in this study. Children registering with the RHF solely for eye checks and those with already concluded assessments were not involved in this project.

The majority of the children (85,9%) had a congenital visual impairment and 35,8% had one or more associated disabilities.

According to the WHO classification (World Health Organization (WHO), 2019) of visual impairment, 26,4% of the children were blind (category 4 and 5), 19,8% were blind (category 3), 25,5% were severely visually impaired (category 2), 22,7% were moderately visually impaired (category 1) and finally 6 children (5,6%) resulted with no visual impairment after the online assessment.

The second sample (N₁) involved 34 RHF professionals: 9 psychologists, 13 rehabilitation professionals (physiotherapists, speech therapists, therapists of neuro and psychomotility (TNPEE), orthoptists) and 12 educators.

2.2. Procedure

Structured questionnaires were sent by email via Google Forms to the parents of all the visually impaired children who received online assessment and/or online treatment, and at the same time the questionnaires were sent to their professionals.

The survey was based on the analysis of the responses (N = 106 families; N₁ = 34 operators) to the questions, which were divided into three groups:

- 1 Group 1 composed of 9 questions to both parents and professionals regarding:
 - a the child's perception of the online intervention (3 questions: satisfaction, usefulness and adequacy of the project)
 - b the methods of implementation of the online intervention (3 questions: frequency, contact methods and time dedicated to the intervention)
 - c the possible progress of the children (1 question)
 - d the possible strengths (if any) of the project (1 question)
 - e what are the strengths (if any) (1 question with open response)
- 2 Group 2 composed of 3 questions to parents only regarding:
 - a possible benefits of the RHF-DSP (1 question)
 - b possible reassurances resulting from continuing the treatment/care with this new online modality of support and intervention (1 question)
 - c possible help due to the opportunity to dialogue with and to ask for advice from the professionals (1 question)
- 3 Group 3 composed of 4 questions to the professionals only regarding:
 - a the possible continuation of the online intervention after the emergency period (1 question)
 - b the ease of proposing online intervention (1 question)
 - c the ease of preparing the online intervention activities (materials, planning of the treatment/assessment) (1 question)
 - d the impact of the online communication instrument/device (computer, tablet, telephone/cellular phone) in the way of working and in the relationship with the child (1 question)

At the end of the questionnaire a blank space for comments or suggestions was given.

A Visual Analogue Scale (VAS) (Hayes and Patterson, 1921), from 0 to 10, was used to evaluate the perceptions of parents and of professionals on the various aspects of the project.

A comparison between perceptions of both operators and parents was also undertaken.

The first step in creating the RHF-DSP was to think of a possible way to communicate both with children and their families and at the same time among professionals, having the opportunity to create a DSP and to share thoughts and ideas, as well as materials and data (clinical and non-clinical). Every professional was given a laptop/PC (either personal or supported by the RHF) with access to the customized software for the clinical records of all the children. At the same time, Google Meet was used for team meetings to plan all the activities, while Google Drive was used to create several shared drives on projects, materials, facilitations, research and clinical activities in order to allow data and material sharing among all the professionals. For communication, the RHF-DSP made use of common Video Conferencing Systems (VCS), such as Google Meet, Zoom or Skype, accessible via a computer or tablet connected to the Internet, with no need of special hardware or the installation of special software. The kind of VCS was chosen in agreement with the child's family, according to the ease of access and use. Despite the widespread diffusion of these international VCSs, the project involved professionals and parents in the acquisition of new skills. Training in the use of e-platforms and devices was given to professionals and families who needed it.

The children carried out the activities at home to acquire skills, with the supervision of the professionals and with the support of the parents, using simple and available materials and avoiding the use of sophisticated and special materials, not commonly found at home (Herburger, 2020).

All the materials were customized and created by the professionals for the child and his family to make (for example multisensory toys, such as bottles, dolls etc., simple board games, such as tactile dominoes or auditory memory to then play together with their parents at home).

A cooking group was also organized together with other customized household-based activities (Herburger, 2020).

The parents of the children recently taken into care and those of the new consultancies were invited to participate in the RHF-DSP.

Parents helped the small or the most severely visually impaired children to access the e-platform and they sent material to the professionals, interacting directly with them.

Parents, who needed it, also received online psychological support from psychologists and psychotherapists.

The frequency of these digital calls and meetings was decided within the team and was adapted to the needs of the child and the family. Half of the children in care (50,7 %) received more than one intervention every week.

Calls or meetings lasted from 30–60 min according to the child's age and clinical conditions, in the morning for the youngest and most severely impaired children and in the afternoon for school children, who were following school lessons online in the morning.

The RHF-DSP lasted from March, 12 to July, 31 2020, for a total period of approximately 5 months.

2.3. Statistical analysis

Descriptive statistics were reported as I quartile/Median/III quartile for continuous variables and percentages (absolute numbers) for categorical variables. A Wilcoxon test was performed to compare the distribution of continuous variables between the groups of interest.

Analyses were performed using R software (version 3.6.2) (R Core Team, 2019) within the package rms (F.E.H. Jr, 2019).

3. Results

The survey was completed and returned by 77/106 (72,6%) of the parents and by 34/34 (100%) of the professionals.

The results of the questions of the survey are shown in the following tables.

Table 1 shows the comparison of the responses given by the parents and by the professionals to the Group 1 questions.

The results of this survey show the overall high VAS scores given by parents and professionals in most of the single questions and also overall.

However, the scores given in 7 out of 8 questions were significantly higher in those of the parents compared to those of the professionals (p-value <0.05). Only the final one about the presence of strengths in the RHF-DSP (p-value 0.426) shows no significant difference between the two groups. The response about the presence of strengths was however above the midpoint of the VAS in both

Table 1

comparison of the responses given by parents and those of the professionals in Group 1. The first, second and third quartiles are shown in order.

	N	Parents/Caregivers (N = 77)	Professionals (N1 = 34)	Combined (N2 = 111)	p-value
Satisfaction	104	7/9/10	7/8/9	7/9/10	0.013
Usefulness	105	8/9/10	7/8/8	7/8/10	<0.001
Adequacy	106	8/9/10	6/8/8	8/9/10	<0.001
Frequency	106	8/9/10	7/8/8	7/8/10	<0.001
Contact modality	108	8/9/10	5/7/8	7/9/10	<0.001
Dedicated time	106	8/9/10	6/8/9	8/9/10	<0.001
Progress	103	7/8/9	5/6/7	6/8/9	<0.001
Strengths	103	6/8/9	6/7/8	6/7/9	0.426

groups.

Table 2 shows the results of the responses for parents only (group 2 of questions), with a high response score to all the three questions.

Parents answered very positively to the new RHF-DSP, being involved in it, being reassured by this new opportunity of not interrupting the therapeutic path of their child and by being helped by the continuous support of the professionals.

Table 3 shows the results of the responses to the professionals only (group 3 questions).

Professionals gave generally lower scores than parents; in the first three of four questions, specifically dedicated to them, the score was above average, while in the question about the impact of the new approach in their work and relationship, the score was high, so the impact overall was high.

A comparison of the responses was made also dividing the children, according to the presence of one or more associated disabilities (Table 4) and according to the distinction between blind and visually impaired children (Table 5), but no significant differences (p -value >0.05) were found.

4. Discussion

During the COVID-19 emergency everyone experienced concerns, fears and isolation, as well as changes in social and hygiene behaviour. Nonetheless, the forced inactivity during the lockdown was an ideal opportunity for those able to take advantage of an unexplored range of technological resources to acquire new skills and improve their preparation, promoting resources, tools and innovative online intervention practices.

It is crucial to understand the complex way that a child's mind responds to acute and persistent calamities, by interacting with developmental factors and personality traits. This can manifest itself in various positive and negative phenomena such as creative acts or nightmares (Mastnak, 2020; Secrist et al., 2019). Children with severe visual impairment need on-going and comprehensive support in their development from psychologists, vision rehabilitators, speech therapists, therapists of neuro and psychomotility and other experts in the treatment of their respective specific disorders (Fazzi et al., 2010; Mercuriali et al., 2016).

In the absence of data from experience and literature on distance support and online intervention with visually impaired children, we relied on the comparison of the evaluations of parents and professionals, in testing the pilot RHF-DSP project.

The results of this questionnaire indicate that parents and professionals generally responded with high VAS scores (Table 1); however, the scores in 7 of the 8 questions were statistically higher in parents than in professionals. A consideration of this difference reveals the different position between the two groups with respect to the project. The results indicate that while the parents felt understood, reassured and helped (as indicated in the responses shown in Table 2), the professionals experienced a sense of discomfort. The new communication tool had a strong impact on them. They had to take more time to prepare the necessary materials and they were forced to rethink and create a new way of interacting and working with the children and their families (as indicated by the responses shown in Table 3 and in the section where they were allowed to make additional comments).

Professionals, most of them with many years of face to face experience, had, in fact, to resort to online platforms, to continue their job in giving support to the visually impaired children and to their families. They received specific training in online communication; despite the relatively short training and their limited experience in this field, the pandemic itself forced them to embrace online support, like other professionals in other settings (Alea et al., 2020).

There was also an analysis of the responses of the parents of children with one or more associated disabilities (Table 4) to identify if a higher daily burden relating to the RHF-DSP had had an impact on their perception of the benefit of it, especially for the parents of those children with a neuromotor disability. However, no significant differences (p -value >0.05) in their responses were noted. At the same time, analyses were done comparing the responses of parents of blind children and those of visually impaired children (Table 5), but, even in this case, no significant differences (p -value >0.05) were found. These results show that, despite the type of disability, what was more important and necessary for the child and the family was the opportunity not to interrupt the therapeutic path of individualized care, overall support and treatments.

A prolonged interruption of therapy and other outpatient activities during this COVID-19 emergency could have led to lack of developmental progress (Fazzi et al., 2010; Vervloed et al., 2020), especially in small children where early intervention is crucial (Daelmans et al., 2015; Hadders-Algra, 2014; Purpura and Tinelli, 2020), hence the innovative initiative of RHF to continue on line treatments and assessments using distance support.

There are no similar experiences reported in literature in the field of support given to children with visual impairment, which can be used to compare the methods and results obtained in this questionnaire. The parents' opinion of the RHF-DSP was significantly positive even above that of the professionals. They appreciated the need to avoid a prolonged interruption of therapies, which would have brought with it the risk of causing a loss of pre-acquired skills and a failure to achieve new therapeutic goals, with possible important

Table 2

Responses given by parents to the questions of group 2. The first, second and third quartiles are shown in order.

	N	
Benefit of RHF-DSP	71	8/9/10
Reassurance with RHF-DSP	74	8/9/10
Help given by RHF-DSP by professionals	73	8/10/10

Table 3

responses given by professionals to the questions of the Group 3. The first, second and third quartiles are shown in order.

	N1	
Continuation RHF-DSP	33	5/6/7
Feeling at ease	34	5.0/6.5/8.0
Easiness in preparing online intervention activities	34	5/6/7
Interference of the online device in work and relationship with the child	34	7/8/9

Table 4

comparison between the responses given by parents of children with associated disabilities (AD) and those with no associated disabilities (ND). The first, second and third quartiles are shown in order.

	N	AD (N = 23)	ND (N = 54)	Combined (N = 77)	p-value
Benefit of RHF-DSP	71	6.75/8.50/10.00	8.00/9.00/10.00	8.00/9.00/10.00	0.347
Satisfaction	71	6.00/8.50/9.25	8.00/9.00/10.00	7.00/9.00/10.00	0.082
Usefulness	72	7.0/8.5/9.0	8.0/9.0/10.0	8.0/9.0/10.0	0.078
Adequacy	73	8/9/10	8/9/10	8/9/10	0.411
Frequency	73	7/8/9	8/9/10	8/9/10	0.056
Contact modality	75	8/9/10	8/9/10	8/9/10	0.827
Dedicated time	73	8/9/10	9/10/10	8/9/10	0.458
Progress	72	6.75/8.50/9.00	7.00/8.00/9.00	7.00/8.00/9.00	0.899
Strengths	70	4/6/9	6/8/9	6/8/9	0.22
Reassurance with RHF-DSP	74	8.0/9.0/10.0	8.0/9.5/10.0	8.0/9.0/10.0	0.189
Help given by RHF-DSP by professionals	73	8.0/9.5/10.0	8.0/10.0/10.0	8.0/10.0/10.0	0.857

Table 5

comparison between the responses given by parents of blind, visually impaired children respectively and of 2 children who resulted in having no visual impairment after an online assessment. The first, second and third quartiles are shown in order.

	N	Blind (N = 41)	Visually impaired (N = 34)	No Visual impairment (N = 2)	Combined (N = 77)	p-value
Benefit of RHF-DSP	71	8.00/10.00/10.00	7.25/8.00/10.00	8.50/9.00/9.50	8.00/9.00/10.00	0.223
Satisfaction	71	7.50/9.00/10.00	7.00/8.50/10.00	9.25/9.50/9.75	7.00/9.00/10.00	0.32
Usefulness	72	8.0/9.0/10.0	7.5/9.0/9.5	8.5/9.0/9.5	8.0/9.0/10.0	0.225
Adequacy	73	8.0/9.0/10.0	8.0/9.0/10.0	8.5/9.0/9.5	8.0/9.0/10.0	0.815
Frequency	73	8.0/9.0/10.0	7.5/9.0/10.0	8.5/9.0/9.5	8.0/9.0/10.0	0.339
Contact modality	75	8.0/9.5/10.0	8.0/9.0/10.0	8.5/9.0/9.5	8.0/9.0/10.0	0.558
Dedicated time	73	9/10/10	8/9/10	10/10/10	8/9/10	0.248
Progress	72	7.00/9.00/10.00	7.00/8.00/9.00	5.75/6.50/7.25	7.00/8.00/9.00	0.138
Strengths	70	6.00/8.00/9.00	5.75/7.00/9.00	7.00/8.00/9.00	6.00/8.00/9.00	0.704
Reassurance with RHF-DSP	74	8.75/10.00/10.00	8.00/9.00/9.25	10.00/10.00/10.00	8.00/9.00/10.00	0.009
Help given by RHF-DSP by professionals	73	8.00/10.00/10.00	8.00/9.00/10.0	9.25/9.50/9.75	8.00/10.00/10.00	0.84

damage to neurosensory and comprehensive development of the children (Pfefferbaum et al., 2015). Following the suspension of outpatient activities, the professionals were able to implement online distance support to development and visual on line treatment and assessment, an innovative practice at the RHF, which raised the level of awareness due to new technologies and research. The RHF-DSP made use of different platforms accessible via a computer or tablet connected to the internet and involved, not without the inconvenience of improvisation, professionals and parents in the acquisition of new skills and competences. The RHF-DSP did not consist of merely making a video call or giving suggestions to parents, but it was real, personalised support and therapy, which transferred the activities carried out in the clinic to the child's home where they completed personalized activities and acquired skills, with the supervision of the professionals and with the support of parents where possible. This lacked the direct relationship with children since there was a screen, a computer or a tablet, which divided the user (child and/or parent) from the professional. Specific self-training for the professionals was therefore necessary in order to make communication more empathetic, going beyond the screen and involving the children in online intervention in accordance with the equipment of their families, the autonomy of the children and the parents in managing the IT tool, the age of the children and their cognitive, behavioural, motivational levels (Grolnick et al., 2018).

The main value of this questionnaire on the RHF-DSP was that of having documented the potential of a new auxiliary tool for the support to the child's development, and that it was positively judged in terms of adequacy and effectiveness by parents. The fact that we did not use any validated software for setting up, controlling and remodeling the therapeutic program remotely but basing the project only on the child's skills, abilities and age may have represented a weakness. In addition, the lack of a comparison between the new online method and the traditional method can also be considered a weakness. However, the results of the RHF-DSP lay the foundations for its implementation in future work as an integrative approach in emergency conditions in which the mobility of children in care and/or of professionals is limited.

It is important to be aware that, to be able to offer telehealth as a response to public health emergencies, like the pandemic COVID-19, some barriers exist and must be faced (Zhai, 2020). In fact, barriers like the difficulty in access to the Internet, the stability of the connection, the suitability of the connection for VCS, the need for technology training and the economic and socio-cultural limits of the families must be faced to be able to improve and make distance support optimal.

In conclusion, the RHF undertook a pilot project for distance comprehensive support to assist the development of the visually impaired children, some of them with associated disabilities.

In order for the Distance Support to work, a number of system changes were necessary at the RHF, including adding new software and even hardware, introducing new protocols and working practices, such as weekly online team meetings, flexible scheduling of appointments and so on. Parents were consulted to assess and choose the most reliable communication channel for them and the professionals spent many hours creating and designing a whole series of custom-made activities for each individual child.

The results from the questionnaire given at the end of the 5 month period show positive judgments on the satisfaction perceived by the parents of the children involved, underlining the feasibility of this practice for them. This result encourages the professionals of RHF to contemplate using it again when necessary and in the case of future emergency situations.

At the same time, the responses of the professionals suggest that the benefits of the “hands-on” and “face to face” methodology and the unique characteristics of the traditional way of working still remain unquestionable in their importance, especially in children with sight deprivation.

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CRediT author statement

Tiziana Battistin: Conceptualization, Methodology, Investigation, Writing-Original Draft Preparation, Writing, Review and editing, Visualization. **Elena Mercuriali:** Conceptualization, Methodology, investigation. **Vincenzo Zanardo:** Conceptualization, Methodology, Writing-Original Draft Preparation, Writing, Review and editing. **Dario Gregori:** Formal analysis. **Giulia Lorenzoni:** Formal analysis. **Laura Nasato:** Formal analysis. **Maria Eleonora Reffo:** Conceptualization, Methodology, Resources, Visualization, Supervision and Project administration.

Declaration of Competing Interest

The authors report no declarations of interest.

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