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Research Paper

Neonatal care during the COVID-19 pandemic - a global survey of parents' experiences regarding infant and family-centred developmental care

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ARTICLE INFO

Article History: Received 21 May 2021 Revised 13 July 2021 Accepted 15 July 2021 Available online xxx

Keywords:
Preterm Birth
Newborn Infant
Neonatal Intensive Care Unit
Parents
Covid-19
SARS-CoV-2
Pandemic
Low Birth Weight
Kangaroo Mother Care
Infant and Family-Centred Developmental
Care
Survey

ABSTRACT

Background: The COVID-19 pandemic restrictions affect provision and quality of neonatal care. This global study explores parents' experiences regarding the impact of the restrictions on key characteristics of infant and family-centred developmental care (IFCDC) during the first year of the pandemic.

Methods: For this cross-sectional study, a pre-tested online survey with 52 questions and translated into 23 languages was used to collect data between August and November 2020. Parents of sick or preterm infants born during the pandemic and receiving special/intensive care were eligible for participation. Data analysis included descriptive statistics and statistical testing based on different levels of restrictive measures.

Findings: In total, 2103 participants from 56 countries provided interpretable data. Fifty-two percent of respondents were not allowed to have another person present during birth. Percentages increased with the extent of restrictions in the respondents' country of residence (p = 0.002). Twenty-one percent of total respondents indicated that no-one was allowed to be present with the infant receiving special/intensive care. The frequency (p < 0.001) and duration (p = 0.001) of permitted presence largely depended on the extent of restrictions. The more restrictive the policy measures were, the more the respondents worried about the pandemic situation during pregnancy and after birth.

Interpretation: COVID-19 related restrictions severely challenged evidence-based cornerstones of IFCDC, such as separating parents/ legal guardians and their newborns. Our findings must therefore be considered by public health experts and policy makers alike to reduce unnecessary suffering, calling for a zero separation policy.

Funding: EFCNI received an earmarked donation by Novartis Pharma AG in support of this study.

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1. Introduction

Preterm birth is the leading cause of death under five years of age. Worldwide, more than one in ten infants, an estimated 15 million, are born preterm every year [1,2]. Together with sick and low birthweight infants, these newborns require specialised care to prevent mortality, support adequate growth and development, and to reduce the risk of morbidities in later life. Yet, their needs have not been considered adequately during the COVID-19 pandemic, which has created exceptional challenges and disrupted healthcare provision across the globe even more [3–6]. Several measures were put in place to reduce social interaction and the risk for virus transmission,

especially in hospital settings including maternity and newborn care units [7]. In neonatal intensive care units (NICUs), measures were implemented aiming to stem transmission which had immediate adverse consequences on the care of the most vulnerable groups of patients — sick, preterm and low birthweight infants.

Recent research demonstrates that the COVID-19 pandemic and related restrictions are affecting both provision and quality of neonatal care [4] with a severe impact on infant and family-centred developmental care (IFCDC) [6,8]. Few studies have been conducted focusing on how the mother's presence with the newborn, frequency of parental presence, and developmental care practices have been influenced [5,9,10], or mothers' experiences on receiving support for breastfeeding during lockdown [11]. Studies are highlighting that implemented measures have resulted in a limitation of some of the core elements of IFCDC, such as parental presence and family access for infants admitted to NICUs, as parents were routinely separated from their newborn [5,12,13]. Within a developmental care

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Research in context

Evidence before this study

The COVID-19 pandemic and the associated restrictions affect both provision and quality of neonatal care. Recent findings indicate that the implemented restrictive measures have resulted in limited parental and family presence for infants admitted to neonatal intensive care units (NICUs). Moreover, a reduction in care-seeking by parents, lack of guidelines regarding preterm newborns and infants with low birthweight, and discontinued or discouraged kangaroo mother care (KMC) due to restrictions on parental presence during the pandemic have been observed.

Added value of this study

This global online survey explored parents' experiences on key characteristics of infant and family-centred developmental care (IFCDC) during the first year of the COVID-19 pandemic concerning the related restrictions across 56 countries. An alarming rate of parents (>20%) were not permitted to be present with their newborn receiving special/intensive care, which means that the infant did not have the opportunity to experience and benefit from the closeness of the parent/s, neither in form of skin-to-skin contact, KMC or simply in terms of hearing the parents' voice and smelling their scent. The parents' role in the care of their newborn is of paramount importance, and their experiences provide unique insights to the challenges of IFCDC during the COVID-19 pandemic.

Implications of all the available evidence

While COVID-19 related restrictions are generally necessary to stem transmission, disregarding evidence-based cornerstones of IFCDC increases the risk of morbidity and mortality of vulnerable infants across the globe. Based on the results of this study and pre-existing evidence on the benefits of IFCDC and KMC, we call for a zero separation policy of parents and infants to avoid unnecessary suffering of the youngest and most vulnerable members of society.

framework, parents, however, provide an essential initial platform for early communication and interaction with the newborn [14]. Recent findings indicate that the use of personal protective equipment, including face masks in neonatal care, as well as separation from the parents, alters parents' as well as the healthcare professionals' ability to communicate with the infant, potentially impacting the development of speech, language and communication [14-16]. Moreover, restricted parental presence increases feelings of sadness, anger, fear and distress in parents [9], and a general strain on mental health, increasing the risk for posttraumatic stress syndrome and postnatal depression [10]. In addition, some women have reportedly stopped breastfeeding earlier than they had planned, e.g. due to lack of support and safety concerns for the newborn [11]. An online survey conducted among healthcare professionals - mainly from low- and middle-income countries – furthermore revealed high levels of stress on healthcare staff, disruption of newborn care practices due to compromised workforce, a reduction in care-seeking by parents, discontinued or discouraged kangaroo mother care (KMC), and lack of guidelines regarding preterm newborns and infants with low birthweight [4]. A recent systematic review of more than 800 articles confirms these findings on a global level. The results show that hospital restrictions had adverse effects on care delivery and health outcomes

for newborns, their families and healthcare professionals. The review also identified the impact on professionals, including lack of personal protective equipment, staff shortages and staff concerns about the lack of parental presence in the NICU, which led to high level of stress and anxiety [8]. Given the disruption of neonatal health services. recent research highlights that the positive impact on survival of KMC – involving close contact between infant and a parent (usually the mother) – far outweighs the small risk of death due to the virus infection [17]. Ensuring close contact between infants and their parents is hence crucial, as the separation puts these vulnerable infants at additional risk of death and long-term complications [17]. Applying an IFCDC approach is considered essential for the provision of good-quality neonatal care, including the use of human milk and early breastfeeding, skin-to-skin care and KMC, parental presence and involvement in the care, shared decision making, and managing stress and pain control etc., as supported by many authorities including the World Health Organization [18].

As this pandemic is an unprecedented challenge for healthcare professionals and parents alike, there is a paucity of scientific evidence on how to best respond to emergency situations in general and to the current pandemic in particular, making this research ever more important. Initiated by the European Foundation for the Care of Newborn Infants (EFCNI) – the first pan-European organization and network to represent the interests of preterm and newborn infants and their families – this is to our best knowledge the first worldwide study to focus exclusively on the experience of parents with infants in need of special/intensive care during the first year of the COVID-19 pandemic. The parents' role regarding the care of their newborn is of paramount importance [19], and their experiences provide unique insights to healthcare provision and neonatal care. Conducting this global online survey, we aimed to explore parents' experiences regarding the impact of restrictions, in particular during an ongoing pandemic, on key characteristics of IFCDC around the world.

2. Methods

2.1. Study design and population

This cross-sectional study was conducted through an online, webbased, open-link survey. The study targeted parents of sick, preterm, or low birthweight infants who were born during the COVID-19 pandemic (as of 1st of December 2019) and who were receiving special or intensive care (inclusion criteria). The term "parent" was broadly defined, covering biological and/or social parents, allowing for self-defining as either "mother", "father" or "other parent". Respondents who did not identify themselves as parent of a sick, preterm, or low birthweight infant in need of special/intensive care and/or whose child was not born during the COVID-19 pandemic were excluded from the analysis (exclusion criteria). The study was performed and reported in line with the Checklist for Reporting Results of Internet E-Surveys (CHERRIES; Supplement S1) [20].

Participants were recruited through social media, newsletter, and website outreach by EFCNI and its initiative, the Global Alliance of Newborn Care (GLANCE). Additionally, the established network of national parent organizations across the globe, as well as the partnering professional healthcare societies — the Council of International Neonatal Nurses (COINN), the European Society for Paediatric Research (ESPR), the Newborn Individualized Developmental Care and Assessment Program (NIDCAP), and the Union of European Neonatal and Perinatal Societies (UENPS) — all supported the dissemination of the survey link, by promoting the study in their networks and their social media channels. EFCNI provided the above-mentioned stakeholders a communication toolkit, in advance, to support the dissemination of the link.

2.2. Questionnaire

The survey was developed by researchers in the scientific affairs department of EFCNI in collaboration with specialised medical professionals and parent representatives who critically reviewed the English version. Prior to data collection, a pre-test of the survey was performed among parents who matched the target group criteria (n = 8) with the option for them to provide written feedback on this draft questionnaire. No further changes were made to the questionnaire following the pilot study. The final version was translated into 23 languages with the help of parent representatives in the international parent network of EFCNI (Bulgarian, Chinese, Czech, Dutch, English, Finnish, French, German, Greek, Hungarian, Italian, Japanese, Macedonian, Norwegian, Polish, Portuguese, Romanian, Russian, Slovakian, Swedish, Spanish, Turkish and Ukrainian). Every translation was reviewed by a native medical expert and revised if needed, prior to being transferred into an open online format.

The questionnaire consisted of 52 questions (prespecified answers with single and multiple response answer options) covering categories of IFCDC [21]. Data was collected on the respondents, the infant, and COVID-19 related topics. These topics included: (1) background information (on the participants), (2) COVID-19 testing and measures in the respective country/region, (3) access to perinatal care, (4) presence with the newborn receiving special/intensive care, (5) breastfeeding/infant nutrition, (6) health communication, and (7) mental health and support. Prior to participation, respondents read the introduction text which provided information about the survey, data collection process and privacy. Informed consent was then confirmed by checking a confirmation box. For those persons who declined participation, the web-interface was terminated. No financial or other incentives were offered to participants of this survey. The English questionnaire is provided in Supplement S2.

2.3. Data collection, processing and statistical analysis

Data were collected between August and November 2020 through an online survey tool (SurveyMonkey®), and were available to the main authors of this article. Not fulfilling the inclusion criteria provoked a termination of the online survey. Eligible for analysis were all respondents that fulfilled the inclusion criteria (defined as 'total set') irrespective of whether they completed all questions in the survey. All data collected was anonymous. Data analysis for the total set was performed as an exploratory approach providing descriptive statistics (relative frequencies and percentages (n (%)). Multiple response questions were analyzed as sum of answers per answer option (n (%)) and thus can exceed 100%.

Subgroup analyses aimed to further elucidate how specific restrictive measures influenced the perceived problems of perinatal and neonatal care. For this purpose, question 14, which asked for the current situation around the time of birth in the respondent's country/ region, was used to group participants into categories according to the respective measures. Indicating answer option (1) 'there was no major concern about Coronavirus/COVID-19 in the country/region in which I live' was defined as 'no major concern', option (2) 'people were advised to take precautions (e.g. hand washing) but day-to-day life continued as usual' as 'precautions', option (3) 'social distancing was strongly encouraged (e.g. keeping a distance, avoiding public gatherings) but no lockdowns were in place' as 'social distancing', option (4) 'lockdown had been implemented (e.g. advised to stay home except for essential activities; schools, restaurants and nonessential businesses were closed)' as 'lockdown', and (5) 'quarantine was implemented and/or people were fined for leaving their homes without authorization' as 'quarantine'. Due to some missing data in question 14, the total number of participants in subgroup analyses ('total subgroup') is lower compared to the total set.

Subgroup analyses investigated the effect of these five categories of restrictive measures on the items of the remaining questions in a descriptive approach (i.e. frequencies and percentages). Chi-square tests were used to explore significant differences between the subcategories. For all analyses, p-values of p < 0.05 were considered as statistically significant. No adjustment was made for multiple comparisons. All analyses were performed using SPSS software (IBM SPSS Statistics for Windows, version 27-0, IBM Corp, Armonk, New York).

2.4. Ethics and privacy

A study protocol was submitted to the Ethics Committee of Maastricht UMC+ which officially waived the need for ethics approval for this survey (METC 2020–1336). Data collection, processing and storage was conducted in accordance with the General Data Protection Regulation and the Declaration of Helsinki. Respondents were made aware that some of the questions might cause distressing reactions considering their personal situation and experience and that they had the opportunity to stop participation at any time.

2.5. Role of funding source

This study was financially supported by Novartis Pharma AG in form of an earmarked donation. The study was independently conducted by the authors of this paper. The donor had no role in any step of the research process.

3. Results

The results of this survey are categorized into different themes of IFCDC, following the structure of the online questionnaire.

3.1. Participation rate and baseline characteristics

In total, n = 2978 participants started the questionnaire. Among them, n = 23 declined participation, and n = 852 either did not provide details on or did not meet the inclusion criteria and were excluded from the total set. The total set consisted of n = 2103 participants from 56 countries (Fig. 1; Supplementary Table S1), with most of them being the mother of the infant (n = 2004; 95%; father n = 99; 5%). The total subgroup set for the analysis of restrictive measures consisted of n = 1987 participants.

Baseline characteristics of participants in the total set (n = 2103)are shown in Table 1. The majority of participants were between 30 and 39 years old (57%) and were a parent of a very preterm (28-< 32 weeks of gestation; 33%) or moderate to late preterm (32-< 37 weeks gestation; 38%) infant. Most infants were born via caesarean section (68%). While 9% of newborns received special/ intensive care for less than a week, 46% required special/intensive care for more than five weeks at the time of responding to the questionnaire. Overall, 44% of respondents faced lockdown measures in their country around the time of birth, followed by measures that encouraged social distancing (28%). 12% of the respondents were advised to take precautions such as handwashing, and 12% had an implemented quarantine in their country/region at the time of birth. A minority of respondents (4%) were located in countries/regions where COVID-19 was no concern. Less than 5% of respondents, their partner or newborn have tested positive for COVID-19 before participating in the survey (Supplementary Table S2). Duration of special/ intensive care and frequency of single or multiple pregnancy differed significantly across subgroups stratified by restrictive measures (Supplementary Table S3). Additional analysis revealed that there were no significant differences in baseline characteristics and COVID-19related characteristics between participants of the total subgroup set and those who were not included in subgroup analyses due to missing information on the respective policy (data not shown).

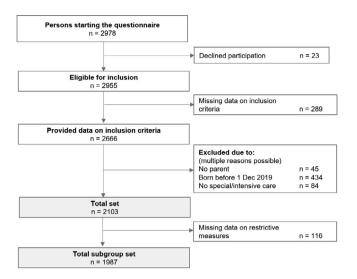


Fig. 1. Flow-chart of questionnaire respondents.

3.2. Access to perinatal care

In total, 49% of respondents indicated that the timing of pregnancy-related appointments was not affected by COVID-19 related measures; 33% mentioned that fewer appointments took place than usual, and for 6% of respondents no pregnancy-related appointments took place. Restrictive COVID-19 related measures significantly influenced the timing of pregnancy-related appointments (p < 0.000; Table 2). Overall, 42% of respondents were not allowed to be

Table 1Baseline characteristics of participants.

	n (%)
Age of respondent (years) (n (%))	n = 2097
<20	13 (1%)
20–29	748 (36%)
30–39	1200 (57%)
>40	136 (7%)
Gestational age at birth (weeks) (n (%))	n = 2023
Early preterm: <28	381 (24%)
Very preterm: 28-<32	664 (33%)
Moderate to late preterm: 32-<37	769 (38%)
Term: 37-42	109 (5%)
Multiple pregnancy (n (%))	n = 2030
Yes	309 (15%)
No	1721 (85%)
Birth mode (n (%))	n = 2027
Vaginal birth	632 (31%)
C-section	1381 (68%)
Both (e.g. in case of multiple pregnancy)	14 (1%)
Birth weight of the baby (grams) (n (%))	n = 2028
<1000	514 (25%)
1000-1500	621 (31%)
>1500-2500	698 (34%)
>2500	193 (10%)
Don't know the birth weight	2 (0%)
Duration of special/intensive care (weeks) (n (%))	n = 2029
<1	172 (9%)
1–3	474 (23%)
>3-5	454 (22%)
>5	929 (46%)
COVID-19 situation in country/region around time of baby's	n = 1987
birth	
No major concern	85 (4%)
Precautions	228 (12%)
Social distancing	551 (28%)
Lockdown	871 (44%)
Quarantine	234 (12%)

Note: percentages may not total 100% due to rounding.

accompanied by another person to their pregnancy-related appointments during the ongoing pandemic. This was indicated by 20% of the participants in the 'no major concern' group, and 31% of the participants in the 'precautions' group. For the other subgroups, the percentages were 43% ('lockdown') and 46% ('quarantine') with significant evidence of statistical between-group differences (p = 0.004; Table 2).

During birth, 52% of all respondents were not permitted to have a support person present. Subgroup analyses revealed that 61% of the participants from the 'quarantine' group were not allowed to have an accompanying person present, in contrast to 50% of the no concerngroup, showing a significant gradient depending on the extent of restrictive measure (p = 0.002). Among the respondents who were allowed to have another person present with them during birth, 76% of the accompanying persons could stay for the entire labour; however, for 24% of the respondents the other person was allowed to be present with them for only a part of it. These results were not statistically different between subgroups (p = 0.347).

Only ten percent of respondents reported that skin-to-skin contact was initiated immediately after birth, while 46% of respondents indicated that skin-to-skin contact was initiated during the first week. Twenty-one percent of participants indicated that skin-to-skin contact was not initiated at all during the time of the hospital stay, with more than half of participants (56%) reporting that this happened after the first week, following discharge or not at all, at the time of data collection (Table 2). Overall, 30% of respondents stated that they were allowed to have skin-to-skin contact as often as they wanted. Further information on the timing of initiating skin-to-skin contact (including KMC) is shown in Table 2. Subgroup analyses revealed significant differences according to the extent of implemented COVID-19 related measures with a considerable difference in the answer option of initiating skin-to-skin contact 'not so far' or 'not during the time of the hospital stay' (p < 0.001; Table 2).

Overall, 79% of the respondents were permitted to touch the newborn in the incubator or bed, but only just over half (53%) of them as often as they desired. While there was no statistical difference in being allowed to touch the newborn in the incubator between subgroups (p = 0.610), the frequency of skin contact in the incubator differed significantly between subgroups based on restrictive measures (p = 0.006; Table 2).

3.3. Presence with the newborn receiving special/intensive care

In total, 83% of respondents experienced restrictions on the policy level of the facility (Table 3), with highest rates exhibited in the 'quarantine' subgroup (93%; p < 0.000). While 74% of participants indicated that the mother was allowed to be present with the newborn receiving special/intensive care, only 56% reported this for the father/partner. While 21% of the total sample stated that nobody was allowed to be present with the newborn, this percentage was highest in the 'quarantine' subgroup. In 63% of the total set, no more than one person could be present at the same time, which was significantly associated with the level of restrictions (Table 3).

The majority of respondents (55%) indicated that they could be present with the newborn all the time or multiple times per day, whereas 15% were not allowed to be present at all. While 41% obtained unlimited access, 30% were only permitted to be with the infant for up to one hour. The frequency and duration of being allowed to be present and the duration significantly differed depending on the extent of the restrictive measure (Table 3).

Most of the participants felt that the measures implemented due to the COVID-19 pandemic, made it more difficult for them to be present (71%) or interactive (e.g. KMC) (62%) with their newborn, with significant differences between the subgroups (Table 3). Respondents perceived that neither they themselves (28%) nor their partner (49%) were involved in the care. For 52% of the participants,

Table 2Access to perinatal care in the total sample and in subgroups according to restrictive measures.

			COVID-19 related restrictions in country/region around the time of baby's birth							
	Total	Total Subgroup	No major concern	Precautions	Social distancing	Lockdown	Quarantine	p-value		
How was the timing of pregnancy-related appoint- ments affected, if at all, by Coronavirus/Covid- 19?	n = 1913	n = 1892	n = 81	n = 217	n = 531	n = 836	n = 227	.000**		
It was done as usual	937 (49%)	927 (49%)	52 (64%)	133 (61%)	275 (52%)	372 (44%)	95 (42%)			
No appointments took place	105 (6%)	105 (6%)	7 (9%)	14 (6%)	21 (4%)	39 (5%)	24 (11%)			
Fewer appointments took place	634 (33%)	627 (33%)	11 (14%)	53 (24%)	163 (31%)	317 (38%)	83 (37%)			
Other	237 (12%)	233 (12%)	11 (14%)	17 (8%)	72 (14%)	108 (13%)	25 (11%)			
Was another person permitted to accompany you to pregnancy-related appointments during the	n = 1911	n = 1890	n = 82	n = 217	n = 530	n = 835	n = 226	.004**		
Coronavirus/COVID-19 phase?										
Yes	396 (21%)	391 (21%)	29 (35%)	71 (33%)	89 (17%)	153 (18%)	49 (22%)			
Not to all appointments	531 (28%)	528 (28%)	16 (20%)	56 (26%)	180 (34%)	226 (27%)	50 (22%)			
No, never	793 (42%)	783 (41%)	16 (20%)	67 (31%)	236 (45%)	361 (43%)	103 (46%)			
Don't know/NA	191 (9%)	188 (10%)	21 (26%)	23 (11%)	25 (5%)	95 (11%)	24 (11%)			
Were you permitted to have another person present with you during birth (e.g. partner)?	n = 1914	n = 1892	n = 82	n = 217	n = 531	n = 836	n = 226	.002**		
Yes	926 (48%)	917 (48%)	41 (50%)	105 (48%)	290 (55%)	392 (47%)	89 (39%)			
No	988 (52%)	975 (52%)	41 (50%)	112 (52%)	241 (45%)	444 (53%)	137 (61%)			
If yes, for how long was this person permitted to stay with you?	n = 979	n = 971	n = 48	n = 110	n = 306	n = 415	n = 92	-347		
For the entire labour	745 (76%)	739 (76%)	39 (81%)	84 (76%)	243 (79%)	304 (73%)	69 (75%)			
	234 (24%)		, ,		, ,					
For a part of it	, ,	232 (24%)	9 (19%)	26 (24%)	63 (21%)	111 (27%)	23 (25%)	000**		
When was skin-to-skin contact with your baby and one of the parents initiated (e.g. holding the baby on the chest, kangaroo mother care)?		n = 1890	n = 82	n = 217	n = 530	n = 835	n = 226	.000**		
Immediately after birth	183 (10%)	182 (10%)	8 (10%)	17 (8%)	61 (12%)	77 (9%)	19 (8%)			
On the first day	220 (12%)	218 (12%)	6 (7%)	21 (10%)	81 (15%)	89 (11%)	21 (9%)			
After the first day but during the first week	451 (24%)	447 (24%)	16 (20%)	42 (19%)	140 (26%)	196 (23%)	53 (23%)			
After the first week	448 (24%)	442 (23%)	29 (35%)	42 (19%)	103 (19%)	219 (26%)	49 (22%)			
Not so far (If you are still in the hospital with your baby)	204 (11%)	201 (11%)	16 (20%)	53 (24%)	57 (11%)	61 (7%)	14 (6%)			
Not during the time in the hospital (if you are already at home with your baby)	404 (21%)	400 (21%)	7 (9%)	42 (19%)	88 (17%)	193 (23%)	70 (31%)			
How often were you permitted to have skin-to- skin contact (kangaroo mother care) with your baby?	n = 1909	n = 1888	n = 82	n = 219	n = 529	n = 832	n = 226	.001**		
As often as I wanted	578 (30%)	569 (30%)	27 (33%)	54 (25%)	201 (38%)	216 (26%)	71 (31%)			
At least once per day	518 (27%)	517 (27%)	15 (18%)	44 (20%)	136 (26%)	270 (32%)	52 (23%)			
At least once per week	124 (7%)	121 (6%)	8 (10%)	11 (5%)	29 (5%)	57 (7%)	16 (7%)			
Less than once per week	166 (9%)	164 (9%)	10 (12%)	20 (9%)	35 (7%)	76 (9%)	23 (10%)			
Not so far	523 (27%)	517 (27%)	22 (27%)	90 (41%)	128 (24%)	213 (26%)	64 (28%)			
Were you permitted to touch your baby in the incubator or bed?	n = 1916	n = 1895	n = 82	n = 219	n = 531	n = 836	n = 227	-610		
Yes	1509 (79%)	1493 (79%)	58 (71%)	150 (68%)	443 (83%)	674 (81%)	168 (74%)			
No	407 (21%)	402 (21%)	24 (29%)	69 (32%)	88 (17%)	162 (19%)	59 (26%)			
How often were you permitted to touch your baby	n = 1913	n = 1892	n = 82	n = 218	n = 530	n = 834	n = 228	.006**		
in the incubator or bed?	n - 1913	n - 1032	11 - 02	11-210	n - 330	11 - 034	11 - 220	.000		
As often as I wanted	1012 (53%)	1003 (53%)	38 (46%)	93 (43%)	329 (62%)	434 (52%)	109 (48%)			
	, ,	, ,	, ,	, ,	` ,	, ,	, ,			
At least once per day	372 (19%)	367 (19%)	16 (20%)	39 (18%)	81 (15%)	182 (22%)	49 (21%)			
At least once per week	75 (4%)	74 (4%)	2 (2%)	8 (4%)	24 (5%)	31 (4%)	9 (4%)			
Less than once per week	114 (6%)	112 (6%)	4 (5%)	15 (7%)	20 (4%)	54 (6%)	19 (8%)			
Not so far	340 (18%)	336 (18%)	22 (27%)	63 (29%)	76 (14%)	133 (16%)	42 (18%)			

^{*}p<0.05; **p<0.01.

Note: percentages may not total 100% due to rounding.

no alternatives (e.g. photos, videos) to being present with the newborn receiving special/intensive care were offered.

3.4. Breastfeeding/nutrition

The initiation of breastfeeding as indicated by the total set and all participants included in the subgroup analyses was 'highly' or 'somewhat' encouraged by medical/nursing staff in 77% of participants (Supplementary Table S4). More than 85% of the respondents' infants were partly or exclusively breastfed or fed with their mother's own pumped or expressed milk in the first weeks after birth. The initiation of breastfeeding/provision of mother's own pumped or expressed milk took place mostly on 'the first day' or after 'the first day but during the first week after birth'. Over 70% of the respondents from all

subgroups confirmed they could bring expressed milk, except for participants from countries/regions in which quarantine was in place (62%; p = 0.019; Supplementary Table S4).

3.5. Health communication

Information on general communication with staff during neonatal care is shown in Supplementary Table S5. Overall, more than 85% of the respondents in the total set felt that they received adequate general health information about the newborn during the hospital stay to 'some' or a 'high degree'. Forty-nine percent received information at least once per day. More than 30% of the participants from the 'social distancing' and 'lockdown' subgroups received information multiple times per day.

 Table 3

 Presence with the newborn receiving special/intensive care in the total sample and in subgroups according to restrictive measures.

		COVID-19	COVID-19 related restrictions in country/region around the time of bab					
Total	Total Subgi	roup No major concern	Precautio		l Lo	ckdown	Quarantine	p-value
Do you know if the Coronavirus/COVID-19 situation $n=1$ affected the facility policy around your ability to be present with the baby receiving special/intensive care?	813 n = 1792	n = 77	n = 203	n = 5	00 n	= 794	n = 218	.000**
There were no changes 145 (8%) 142 (8%) (83%) 1494 (83%)	15 (19%) 53 (69%)	24 (12%) 153 (75%	,	•		4 (2%) 203 (93%)	
I don't know if there were changes 157 (, , , , ,	9 (12%)	26 (13%)			, ,	11 (5%)	
Who was allowed to be present with your baby receiving special/intensive care? (multiple answers possible)	814 n = 1793	n = 77	n = 203	n = 5	01 n	= 794	n = 218	
Sum of multiple answers	2856 (157%)	2827 (158%)	138 (179%)	324 (160%)	851 (170%)	1197 (151%	6) 317 (145%)
Mother	1343 (74%)	1327 (74%)	54 (70%)	137 (68%)	379 (76%)	614 (77%)	143 (66%)	.006*
Father/partner	1020 (56%)	1011 (56%)	52 (68%)	113 (56%)	330 (66%)	405 (51%)	111 (51%)	.000*
Sibling/s	52 (3%)	52 (3%)	3 (4%)	8 (4%)	27 (5%)	12 (2%)	2 (1%)	.000*
Other family members	42 (2%)	41 (2%)	7 (9%)	8 (4%)	15 /3%)	11 (1%)	0 (0%)	·000*
Friends No one	13 (1%) 376 (21%)	13 (1%)	3 (4%)	3 (2%)	7 (1%)	0 (0%)	0 (0%) 60 (28%)	·000* ·023*
No one I don't know	376 (21%) 10 (1%)	373 (21%) 10 (1%)	16 (21%) 3 (4%)	51 (25%) 4 (2%)	91 (18%) 1 (0%)	154 (19%) 1 (0%)	1 (1%)	023 000*
Could more than one person be present with the baby at the same time?	n = 1813	n = 1792	n = 77	n = 203	n = 501	n = 794	n = 217	.000*
Yes	664 (32%)	658 (37%)	38 (49%)	82 (40%)	248 (50%)	234 (29%)	56 (26%)	
No	1149 (63%)	1134 (63%)	39 (51%)	121 (60%)	253 (50%)	560 (71%)	161 (74%)	
How often were you allowed to see your baby receiving special intensive care?	•	n = 1792	n = 76	n = 203	n = 502	n = 793	n = 218	-000*
All the time, (24/7)	668 (37%)	663 (37%)	30 (39%)	64 (32%)	236 (47%)	270 (34%)	63 (29%)	
Multiple times per day	326 (18%)	320 (18%)	6 (8%)	29 (14%)	72 (14%)	175 (22%)	38 (17%)	
Once per day	351 (19%)	346 (19%)	16 (21%)	40 (20%)	82 (16%)	154 (19%)	54 (25%)	
Multiple times per week Once per week	76 (4%) 66 (4%)	75 (4%) 66 (4%)	0 (0%) 2 (3%)	11 (5%) 8 (4%)	23 (5%) 17 (3%)	32 (4%) 26 (3%)	9 (4%) 13 (6%)	
Less than once per week	57 (3%)	57 (3%)	4 (5%)	7 (3%)	12 (2%)	28 (4%)	6 (3%)	
Never	268 (15%)	265 (15%)	18 (24%)	44 (22%)	60 (12%)	108 (14%)	35 (16%)	
How long were you allowed to see your baby per visit?	n = 1810	n = 1789	n = 77	n = 203	n = 500	n = 791	n = 218	.001*
Up to an hour	551 (30%)	541 (30%)	21 (27%)	68 (33%)	136 (27%)	243 (31%)	73 (33%)	
More than one hour, up to three hours	133 (7%)	130 (7%)	5 (6%)	11 (5%)	29 (6%)	68 (9%)	17 (8%)	
More than three hours, but not unlimited	122 (7%)	122 (7%)	2 (3%)	11 (5%)	25 (5%)	67 (8%)	17 (8%)	
Unlimited	746 (41%)	741 (41%)	32 (42%)	68 (33%)	249 (50%)	317 (40%)	75 (34%)	
Not at all	258 (14%)	255 (14%)	17 (22%)	45 (22%)	61 (12%)	96 (12%)	36 (17%)	
Were sleeping facilities provided so you could stay with the baby (24/7)?	n = 1807	n = 1786	n = 75	n = 200	n = 500	n = 793	n = 218	.003*
Yes, sleeping facilities were provided next to my baby in the unit Yes, sleeping facilities were provided outside the unit (e.g. in an apartment house nearby, in another unit)	t 363 (20%) 269 (15%)	359 (20%) 269 (15%)	16 (21%) 7 (9%)	38 (19%) 26 (13%)	126 (25%) 93 (19%)	140 (18%) 116 (15%)	39 (18%) 27 (12%)	
No, sleeping facilities were not provided	1175 (65%)	1158 (65%)	52 (69%)	136 (68%)	281 (56%)	537 (68%)	152 (70%)	
Which alternatives to being present were provided with your	n = 1796	n = 1775	n = 74	n = 201	n = 496	n = 786	n = 218	
baby receiving special/intensive care? (multiple answers possible)								
Sum of multiple answers	2136 (119%)	2114 (119%)	86 (116%)	232 (115%)	591 (119%)	939 (120%)) 266 (122%)	
Photos	598 (33%)	592 (33%)	22 (30%)	59 (29%)	167 (34%)	274 (35%)	70 (32%)	488
Livestream	139 (8%)	137 (8%)	5 (7%)	14 (7%)	45 (9%)	64 (8%)	9 (4%)	255
Recorded video	169 (9%)	167 (9%)	4 (5%)	13 (7%)	44 (9%)	83 (11%)	23 (11%)	216
Video calls	125 (7%)	125 (7%)	4 (5%)	13 (7%)	42 (9%)	51 (7%)	15 (7%)	661
None	932 (52%)	923 (52%)	42 (57%)	113 (56%)	244 (49%)	396 (50%)	128 (59%)	066
Other	173 (10%)	170 (10%)	9 (12%)	20 (10%)	49 (10%)	71 (9%)	21 (10%)	.944
Do you feel that the measures that were implemented due to Coronavirus/COVID-19 (e.g. restrictions by hospital management) made it more difficult for you to be present with you baby?	ge-	n = 1791	n = 76	n = 202	n = 501	n = 794	n = 218	.000**
Yes	1294 (71%)	1278 (71%)	42 (55%)	144 (71%)	309 (62%)	599 (75%)	184 (84%)	
No, not more difficult	372 (21%)	369 (21%)	16 (21%)	38 (19%)	143 (29%)	145 (18%)	27 (12%)	
No, there were no restrictive measures in place	100 (6%)	99 (6%)	10 (13%)	13 (6%)	39 (8%)	34 (4%)	3 (1%)	
Don't know	46 (3%)	45 (3%)	8 (11%)	7 (3%)	10 (2%)	16 (2%)	4 (2%)	000**
Do you feel that the measures that were implemented due to Coronavirus/COVID-19 (e.g. restrictions by hospital management) made it more difficult for you to be interactive with your baby (e.g. skin-to-skin contact or being involved in the care of your baby)?	ge- 1	n = 1789	n = 77	n = 201	n = 499	n = 794	n = 218	·000**

(continued)

Table 3 (Continued)

Sum of multiple answers	2136 (119%)	2114 (119%)	86 (116%)	232 (115%)	591 (119%)	939 (120%)	266 (122%)	
Yes	1114 (62%)	1099 (61%)	43 (56%)	125 (62%)	256 (51%)	520 (65%)	155 (71%)	
No, not more difficult	499 (28%)	497 (28%)	19 (25%)	48 (24%)	175 (35%)	203 (26%)	52 (24%)	
No, there were no restrictive measures in place	155 (9%)	152 (8%)	9 (12%)	21 (10%)	56 (11%)	58 (7%)	8 (4%)	
Don't know	42 (2%)	41 (2%)	6 (8%)	7 (3%)	12 (2%)	13 (2%)	3 (1%)	
Did medical/nursing staff involve you in the care of your baby	n = 1810	n = 1789	n = 77	n = 202	n = 501	n = 792	n = 217	455
(e.g. nappy changing, feeding, temperature taking)?								
Yes, to a high degree	912 (50%)	901 (50%)	35 (45%)	83 (41%)	281 (56%)	395 (50%)	107 (49%)	
Yes, to some degree	391 (22%)	387 (22%)	13 (17%)	37 (18%)	112 (22%)	178 (22%)	47 (22%)	
No, not at all	497 (28%)	492 (28%)	29 (38%)	79 (39%)	105 (21%)	216 (27%)	63 (29%)	
Don't know	10 (1%)	9 (1%)	0 (0%)	3 (1%)	3 (1%)	3 (0%)	0 (0%)	
Did medical/nursing staff involve your partner in the care of	n = 1812	n = 1790	n = 77	n = 202	n = 500	n = 793	n = 218	.000**
your baby?								
Yes, to a high degree	573 (32%)	568 (32%)	29 (38%)	57 (28%)	212 (42%)	209 (26%)	61 (28%)	
Yes, to some degree	311 (17%)	309 (17%)	11 (14%)	35 (17%)	83 (17%)	144 (18%)	36 (17%)	
No, not at all	886 (49%)	871 (49%)	35 (45%)	106 (52%)	192 (38%)	422 (53%)	116 (53%)	
Don't know	24 (1%)	24 (1%)	2 (3%)	3 (1%)	8 (2%)	6 (1%)	5 (2%)	
I don't have a partner	18 (1%)	18 (1%)	0 (0%)	1 (0%)	5 (1%)	12 (2%)	0 (0%)	

^{*}p<0.05; **p<0.01.

Note: percentages may not total 100% due to rounding.

The majority of participants (69%) indicated that they received adequate information about protection from COVID-19 transmission for themselves and their newborn during the hospital stay; 18% responded that they did not feel well informed; 9% did not receive any information. The percentages of respondents not receiving any information and feeling insufficiently informed decreased with increasing extent of restrictive measures (p = 0.003). Forty percent of respondents stated not having received 'adequate information' or 'no information at all' on COVID-19 protective measures when being discharged from the hospital (p < 0.000; Supplementary Table S5).

3.6. Mental health and support

Information on respondents' mental health status during the COVID-19 pandemic and accompanying implemented restrictions is shown in Supplementary Table S6. Overall, 78% of respondents worried 'to a high degree' or 'to some degree' about the COVID-19 situation during pregnancy, and 92% worried about the situation after birth. With increasing extent of restrictive measures, the frequency of respondents worrying about the COVID-19 situation during pregnancy and after the birth increased (p < 0.000 respectively). Overall, 53% of participants reported that they 'did not feel adequately informed' or that there was 'no mental health support' (e.g. counseling, self-help/parent group). Subgroup analyses revealed that this frequency was highest in the 'quarantine' subgroup (61%; (p = 0.008); Supplementary Table S6).

4. Discussion

The COVID-19 pandemic is an unprecedented challenge for both healthcare professionals and parents, with a lack of scientific evidence on how to best respond to this emergency situation. With this multi-national online survey, we explored parents' subjective experiences during the pandemic in relation to pre- and neonatal care, considering the impact of local COVID-19 related policy measures. We were able to gather responses from a large study sample of 2103 parents, who were living with different degrees of pandemic-related restrictive policy measures (ranging from general precautions to quarantine) and with different implications for infant and family-centerd developmental care (IFCDC), a concept which has been both acknowledged for its impact and therefore gradually introduced in neonatal units around the world [21–24].

Given that the application of IFCDC benefits and positively influences developmental outcomes of particularly vulnerable infants [25,26], it is essential that its practical implementation remains

ensured despite the ongoing COVID-19 pandemic and in other similar future situations. However, the results of this study indicate significant influence of restrictions on several aspects of IFCDC approaches. We found particular evidence for implications on the timing of pregnancy-related appointments, the permission to be accompanied by support persons during care appointments and birth, and the presence and interaction with the newborn receiving special/intensive care (e.g. skin-to-skin, KMC) depended on the severity of related local policy restrictions, which we will now explore.

COVID-19 related restrictions had severe implications for the presence and involvement of parents during the pre- and postnatal period. During the ongoing pandemic, more than one third of respondents of this study were not allowed to be accompanied by their partner or another support person during pregnancy-related appointments and about half of them during the actual birth. This is especially problematic during birth, as the availability of a partner or other support person provides the mother with emotional, informational and practical support and facilitates non-pharmacological pain relief [27]. The inclusion of the partner by health professionals may furthermore enable bonding and also contributes to the well-being of the mother [28]. In turn, excluding the partner prevents the parent from playing an active part in the process and sharing emotions, potentially with life-long implications [28]. Moreover, our study identified an alarming rate of parents who were not permitted to be present with their newborn receiving special/intensive care during the pandemic, as noted by more than 20% of respondents indicating that absolutely no family member (including the parents) or carer were allowed to be present with their newborn. This means that in one of every five cases, the infant did not have the opportunity to experience and benefit from the closeness of their parent/s, neither in the form of skin-to-skin contact, KMC or simply in terms of hearing the parents' voice, or smelling their scent, potentially influencing bonding and attachment, as well as the newborn's neurobehavioral development [29–31]. Furthermore, almost one in ten parents were only allowed to have skin-to-skin contact (e.g. KMC) with their child less than once per week, and for a quarter of the respondents the first skin-to-skin contact was only initiated after the first week following

Our results support the findings of similar research. A smaller study of 231 parents with infants hospitalized in NICUs in the UK and the USA showed that a large percentage (41%) reported to be unable to bond and only 37% were able to be present with their infant as often as desired [10]. Comparisons of the pre- and pandemic status in one NICU clearly link limited parental presence abilities to the COVID-19 pandemic [5]; and a large global survey of 1120 neonatal

care providers, from 62 countries, concluded that restrictions during the pandemic have led to a general separation between the mother-infant dyads [4], which was also suggested for the entire family [6]. Our results confirm this limited ability to be present with the hospitalized newborn now on a global level and show the magnitude of the impact of implemented restrictions.

We argue that the approach of separating vulnerable infants and their parents in general and due to COVID-19 related restrictions in particular cannot be justified with the potential risk of transmission from the parents, as confirmed by recent studies [8,17,32]. Researchers in the UK analyzed incidence, transmission and severity of SARS-CoV-2 cases in newborn babies receiving hospital care. Their study revealed that newborns are unlikely to contract the virus from infected mothers, and if they do, the symptoms are mild [32]. Recent research also indicates that in most of the cases, infections in newborns came from healthcare professionals rather than the parents in the NICUs [8]. The World Health Organization and UK guidance are therefore advocating to keep newborns with their mothers as it is important for breastfeeding, bonding and development of the infant. The separation of parents and their newborn has been proven to impair developmental outcomes [32]. Furthermore, the consequences are ever so alarming as a recent two-scenarios-analysis - weighing the risk of not implementing KMC among newborns with neonatal deaths from COVID-19 - shows: in particular KMC has substantial benefits for the development of preterm, sick, and low birthweight infants, which far outweighs the risk of death due to COVID-19 [17].

Mental health and related support are themes stemming from our results that we want to highlight. It is noteworthy that a large majority of the participating parents in our survey were either very or somewhat worried during the pre- and postnatal period because of the COVID-19 situation. It is important to mention at this point that these parents are already under immense stress due to the fragile health state of their newborn. The pandemic situation is an additional stress factor for parents and the limited ability to be present during hospitalization constitutes an even greater additional emotional burden. An important issue to consider is that pre- and perinatal stress are strong risk factors for maternal postpartum depression which can negatively influence the mother-infant relationship and thus the long-term development of the infant [33]. Additionally, we also identified a need for more adequate information about how to protect oneself and one's newborn from COVID-19 transmission while being hospitalised and following discharge. Thorough information is not only important to stem virus transmission but also to support parents' mental health under these challenging and stressful circumstances, which is ultimately relevant for both the infant's and parent's well-being in the long-run.

However, there are some limitations of this study that must be acknowledged. Conducting surveys in an online format carries the risk of selection bias [34], and might have affected the representativeness of respondents in some countries, as well as those who live in very remote or rural areas with limited internet access. Based on this online format, we were unable to provide the response rate and are aware that data from non-responders and persons who declined participation might be of particular value. Surveys with lengthy selfadministered questionnaires frequently have the challenge of participants not completing the survey [35], which we also observed in our study. Furthermore, the respondents completed the questionnaire at different phases of hospitalization, meaning some answered while the infant was still in the hospital, and some after discharge which may have impacted the parents' perceived experiences. In addition, we must highlight that the study drew from a range of contexts – different countries, cultures and settings with different capacities and health systems – pre-COVID and during the pandemic – carrying the risk of confounding bias. Another factor contributing to confounding bias is the account for different countries' contribution to the full sample. A country comparison will therefore be conducted in

addition to this study to better explore country specific differences and their accounts to the full sample. Moreover, we acknowledge that the provision of IFCDC differs across countries and regions, with disruptions also before the COVID-19 pandemic [36]. Due to missing demographics on neonates requiring special/intensive care in the respective countries, we could not assess the representativeness of the sample. Possible participation bias needs to be noted as parents experiencing stronger restrictions may have felt a greater need to respond. In addition, 'first time' parents may have found it challenging to evaluate as to whether restrictions were in place at all (and the degree to which), as well as to categorize the government restrictions in force in their area/country at the time of response. Given the timely context of the pandemic, the collected data does not allow for detailed comparisons with pre-pandemic situations although we sought to at least investigate the effect of different restrictions on IFCDC. However, we need to acknowledge that there was already wide variation between settings for newborn care, and quality of care together with restrictions on parental access may not be exclusively due to the pandemic. Due to some missing information on implemented restrictive measures in the respective country/region, the total number of participants in subgroup analyses ('total subgroup') is slightly lower compared to the total set; however, further analysis revealed that missing information was independent from participant characteristics and COVID-19-related information. We are aware that applying chi-square tests for categorical variables does not indicate the strength of the difference or association between the respective variables which has extensively been described elsewhere [37,38]; and might imply a greater chance for significant findings [39]. Thus, using chi-square test as statistical measure in the underlying study has some limitations that must be acknowledged. Correspondingly, significant results should be interpreted with caution. Finally, we are aware of some inconsistencies related to the extent of restriction, explained by the limitations mentioned above. Hence, we acknowledge that there is not always a linear gradient indicating that the more restrictive the measure, the more severe the implication for neonatal care.

Notwithstanding, there are several strengths that merit particular attention. Based on this global survey, which as noted earlier included an extensive outreach and data collection across 56 countries, we were able to comprehensively describe the parents' experiences regarding several degrees of policy restrictions on IFCDC during the COVID-19 pandemic. A thorough pre-testing of the questionnaire in the specific target group enabled us to minimise methodological inaccuracies and to collect data in a sensitive and parent-friendly manner. Our findings provide unique insights from a parents' perspective, and give valuable insights for future emergency situations/pandemics.

In conclusion, while we acknowledge that COVID-19 related restrictions are mostly inevitable to prevent and reduce transmission of the virus, disregarding evidence-based cornerstones of IFCDC will increase the risk of morbidity and mortality of vulnerable infants across the world. As we see from the results of this study – the implementation of a holistic approach has been left behind in order to minimise personal contacts and thus the spread of COVID-19. The parents' role regarding the care of their newborn is, however, of paramount importance and separation cannot be justified considering the available evidence and risk of transmission and could even be harmful [40]. This study should therefore provide a strong impetus for public health experts, and policy makers to advocate and ensure that parents and their newborns remain together in accordance with the Charter of the European Association for Children in Hospital (EACH) [41] and the United Nations Convention on the Rights of the Child [42]. In line with the WHO Baby Friendly Hospital Initiative [36] and the UNICEF Mother Friendly Hospital Initiative [43], we recommend that breastfeeding, rooming in 24/7 and skin-to-skin care are protected to give every child the best possible start in life [36] and that these should not be disregarded in times of crisis. Applied measures to prevent virus transmission in NICUs while ensuring optimal neonatal care must urgently be reconsidered in light of a continuation of the pandemic and for future emergency situations. Finally, implementing a zero separation policy is essential to avoid unnecessary suffering among the youngest and most vulnerable members of our society.

Funding

The European Foundation for the Care of Newborn Infants received an earmarked donation by Novartis Pharma AG in support of this study. The study was independently conducted by the authors with absolutely no influence by the donor. The content of this study is solely the responsibility of the authors and does not necessarily represent the official views of the institutions with whom the authors are affiliated.

Data sharing statement

Additional datasets used and analyzed during the current study are available from the corresponding author on reasonable request.

Declaration of Competing Interest

All authors report an earmarked donation from Novartis Pharma AG, during the conduct of the study.

Acknowledgment

We would like to express our gratitude to all respondents and highly appreciate their time and commitment to participate in this study. We further warmly thank all representatives of national parent organisations and experts across the world, who have translated the questionnaire and have promoted dissemination of the survey. Without their support, this study would not have been possible.

Supplementary materials

Supplementary material associated with this article can be found in the online version at doi:10.1016/j.eclinm.2021.101056.

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