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Gender equality in caregiver attendance for children with chronic diseases: a Swedish longitudinal observational study

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ABSTRACT

Objectives In countries at the forefront of gender equality policy, mothers still play a more pronounced role than fathers in the provision of parental care for their children. This study aimed to explore gender equality in attendance at doctor's appointments among caregivers of children with chronic diseases before and after the introduction of video conference visits.

Methods Children aged 0–17 years diagnosed with cystic fibrosis, inflammatory bowel disease, diabetes or a chronic neurological disease at Gothenburg's and Lund's paediatric hospitals were included. Data on caregiver attendance from 2019 to 2022 were retrospectively collected from medical records. Doctors' appointments were categorised as in-person, telephone or video conference visits. Using mixed-effects models, we evaluated trends in parental attendance and assessed the associations between different types of appointments and gender equality in healthcare.

Results A total of 347 participants were included between 2019 and 2022, resulting in 6134 appointments. Overall attendance rates were 74% for mothers and 44% for fathers, corresponding to a difference of 30%-points (95% CI 27% to 32%-points, p<0.001). Mothers had consistently higher attendance rates across all types of appointments (all p<0.05). The attendance gap between mothers and fathers remained similar over time, except for video conference visits where an increase in maternal attendance was observed (p<0.001) while paternal attendance remained constant (p=0.90). Video conference visits had higher joint attendance rates than in-person and telephone appointments (both p<0.001).

Conclusion Mothers attended paediatric outpatient visits more frequently than fathers across all appointment types. The gender gap in attendance remained unchanged after the introduction of video conference visits, while the joint attendance increased. Future interventions should explore structural strategies to enhance gender equality in caregiver attendance.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Gender equality is one of the United Nations' 17 global goals for a sustainable future. However, women worldwide bear a greater responsibility than men for the care of their children. Gender equality among caregivers of children with chronic diseases remains a relatively unstudied area.

WHAT THIS STUDY ADDS

⇒ This study presents novel data on trends in gender equality concerning attendance at various types of doctors' appointments among caregivers of children with chronic conditions. It highlights the role of healthcare providers in addressing gender inequality and suggests ways to improve it in healthcare settings.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ This study may enlighten and inspire healthcare professionals about their role in perpetuating the current inequality among caregivers. It underscores the need for healthcare professionals and researchers to map gender equality in their healthcare settings and act towards achieving gender equality.

INTRODUCTION

Today, approximately 20% of all children and adolescents live with a chronic condition or disease that requires regular contact with healthcare professionals.[1–3] Demographically, this encompasses an estimated 15 million children in the USA and 14 million within the European Union, with evidence suggesting that their numbers are increasing over time.[3 4] For these children, active involvement of their caregivers in their healthcare appointments is essential. The caregivers provide emotional support for their child and help to promote a clear communication that facilitate well-informed decision-making, all of which contribute to improved health outcomes for the child.[5–7]

Traditionally, mothers play a more pronounced role than fathers in providing parental care for their children.[8 9] The engagement of both caregivers in their child's health is important and provides several advantages for the child, the caregivers and the family

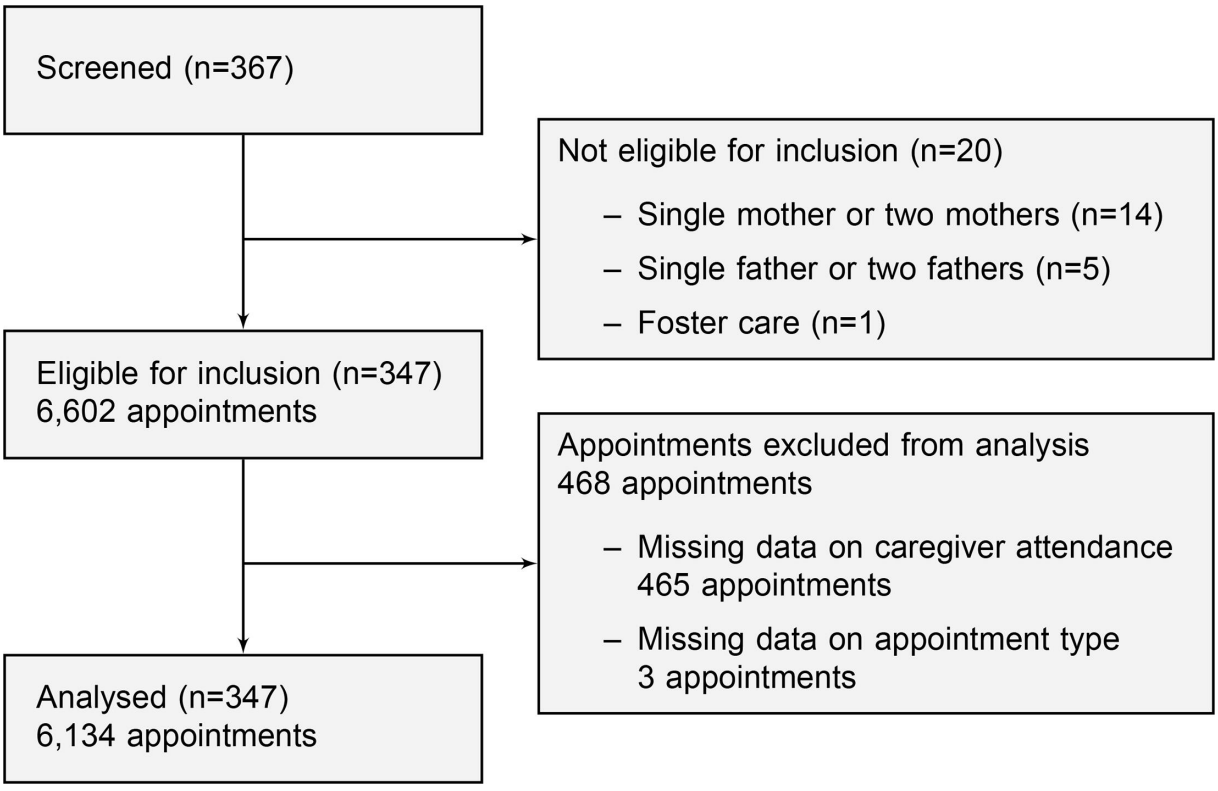

Figure 1 Flowchart of the study cohort, including total number of children and doctors' appointments available, excluded and analysed.

as a whole.[5 10] Equal parental caregiving has positive effects on the child's health and well-being, as well as the development of social and cognitive skills.[5 6] It also helps prevent sick leave, for both mothers and fathers, thereby fortifying positions in the labour market.[11 12]

Sweden has a long tradition of promoting gender equality and is today ranked one of the most gender-equal countries in the world.[9 13] Numerous initiatives have been implemented in Sweden over the last 60 years to foster equality in various societal aspects. Women and men have equal rights under the law, and efforts are made to promote equal opportunities in education, labour market and other societal domains. The Swedish parental insurance system promotes gender equality by encouraging both mothers and fathers to take parental leave and enables parents to take time off from work to care for their sick child. Yet, gender inequality persists in all spheres of social and economic life in Sweden.[13 14] Women do undertake a greater share of unpaid work compared with men are more likely to work part time.[15]

Gender equality is one of the United Nations' 17 global goals for a suitable future; it is promoted by an equal parenthood with shared responsibilities between mothers and fathers for the care of their children.[16] However, gender equality in children's healthcare remains a relatively unstudied field. With the onset of COVID-19, video conference visits were introduced broadly as a complement to in-person and telephone visits. Video conference visits facilitated parental participation in their child's doctor's appointments during the COVID-19 pandemic, even when both parents were physically located at different places.

The primary objective of this study was to examine longitudinal patterns of gender equality in terms of caregiver attendance at doctor's appointments to children with chronic diseases at outpatient clinics in Sweden. We hypothesised that the introduction of video conference visits after the onset of the COVID-19 pandemic would lead to an increased involvement by fathers at doctor's appointments.

METHODS

Study population and study design

This was a longitudinal retrospective observational cohort study. We included children aged 0 to 17 years diagnosed with cystic fibrosis, inflammatory bowel disease, diabetes, chronic hydrocephalus and epilepsy at Gothenburg's paediatric hospital, and cystic fibrosis at Lund's paediatric hospital. Participants were included from 2019 to 2022 and attended a minimum of one routine follow-up visit with a doctor every 6 months. Families consisting of one or two parents of the same sex, or with foster care, were excluded. Prior to the COVID-19 pandemic, a pilot study conducted at Gothenburg's outpatient clinics evaluated the feasibility of video conference visits for cystic fibrosis care. The study, which including two video conference visits with 20 caregivers of children with cystic fibrosis, yielded highly positive results. In the early 2020, the use of video conference visits increased significantly at both

Table 1 Characteristics of the study participants, their caregivers and type of healthcare appointments during the study period

	Year			
	2019	2020	2021	2022
Participant demographics				
Number of participants per year	279	299	322	334
Participants' sex (girls)	128 (45%)	138 (46%)	149 (46%)	156 (47%)
Age of participant (years)	9 (6–12)	10 (6–13)	10 (6–14)	11 (6–14)
Pre-schooler (0–6 years)	63 (23%)	63 (21%)	71 (22%)	67 (20%)
School-aged (7–17 years)	216 (77%)	236 (79%)	251 (78%)	267 (80%)
Study sites				
Cystic Fibrosis Gothenburg	55 (20%)	52 (17%)	64 (20%)	61 (18%)
Cystic Fibrosis Lund	56 (20%)	60 (20%)	62 (19%)	63 (19%)
Neurology Gothenburg	35 (13%)	37 (12%)	43 (13%)	47 (14%)
Gastroenterology Gothenburg	51 (18%)	59 (20%)	59 (18%)	59 (18%)
Endocrinology Gothenburg	82 (29%)	91 (30%)	94 (29%)	104 (31%)
Doctors' appointments				
Total healthcare visits per year	1602	1694	1413	1409
In-person visits	1296 (81%)	935 (55%)	818 (58%)	960 (68%)
Telephone appointments	299 (19%)	396 (23%)	327 (23%)	247 (18%)
Video conference visits	7 (0%)	363 (21%)	266 (19%)	201 (14%)

Data are presented using medians and IQRs for numeric variables and as numbers and percentages for categorical variables.

Gothenburg and Lund's paediatric outpatient clinics in response to the COVID-19 pandemic. Throughout the COVID-19 pandemic, both the Gothenburg and Lund paediatric hospitals implemented a general policy permitting only one caregiver to accompany their child. However, outpatient clinics had the flexibility to make exceptions to this rule.

Outcome measurements

Data on caregiver attendance at doctors' appointments at each outpatient clinic were extracted from the participants' medical records, starting from 1st of January 2019 and ending at 31st of December 2022. Appointments were classified into three categories: in-person visits, telephone appointments and video conference visits. The participants' family constellations were divided into two categories: (A) residing with both a mother and a father or (B) separated mother and father with shared custody.

Patient and public involvement

Neither patients nor their caregivers were involved in this retrospective study. The results regarding caregiver attendance will be shared with the respective patient communities through their social media channels.

Statistical analyses

Descriptive data are presented using medians and IQRs for numeric variables and as numbers and percentages for categorical variables. To evaluate longitudinal patterns in maternal and paternal attendance rates at healthcare appointments, multilevel linear mixed-effects models were used. At each doctor's appointment, the maternal and paternal attendance was modelled as a bivariate binary outcome, with year (categorical), caregiver (mother/father), type of appointment (in-person, telephone or video conference visits) and their interactions as explanatory variables. In-person visits at the outpatient clinic were included as random effects to account for intercluster variations and intracluster correlations. Similar models with time as continuous covariate were considered to evaluate linear trends over time.

Statistical analyses were performed by using SAS/STAT Software, Version 9.4 of the SAS System for Windows (SAS Institute Inc., Cary, NC).

RESULTS

Description of cohort and doctor'S appointments between 2019 to 2022

During the years 2019 to 2022, between 293 and 355 patients were encountered annually. They collectively underwent a total of 6938 doctor's appointments, of which 6480 (93%) had information about the sex of the attending caregiver. Family constellations, such as single-parent households, households with two parents of the same sex or residing in foster homes, were excluded from the analysis. In total, 6134 doctor's appointments were included in the final analysis (figure 1, table 1). The longitudinal composition of in-person visits, telephone

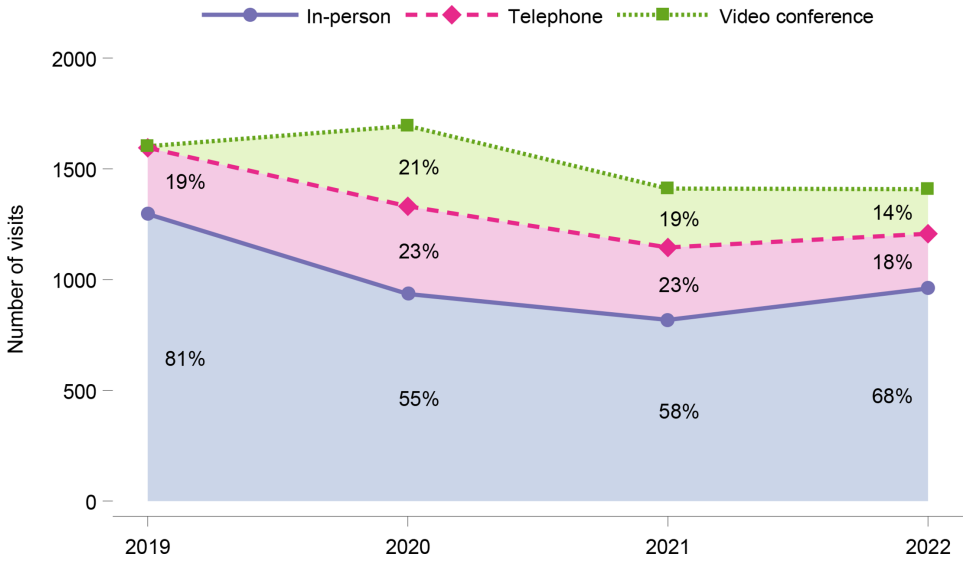

Figure 2 Longitudinal composition of in-person visits, telephone appointments and video conference visits during the study period 1st of January 2019 to 31st of December 2022.

appointments and video conference visits is depicted in figure 2.

Mothers attended their child'S doctor appointments more frequently than fathers

Mothers had consistently higher attendance rates than fathers across at all types of appointments (figure 3, online supplemental table 1). Overall, mothers and fathers attended 74% (95% CI 68% to 80%) and 44% (95% CI 38% to 50%) of the appointments, respectively, with a mean difference of 30%-points (95% CI 27% to 32%-points, p<0.001). The largest difference in attendance rates was observed for telephone appointments, with a mean difference of 45%-points (95% CI 40% to 49%-points, p<0.001; figure 3) between mothers and fathers.

Changes in parental attendance at doctor'S appointment between 2019 to 2022

The overall attendance rates at doctors' appointments declined annually by −1.6%-points (95% CI −2.6% to −0.5%-points, p=0.003) for mothers and by −1.4%-points (95% CI −2.4% to −0.3%-points, p=0.010) for fathers (figure 4, online supplemental table 2). The attendance gap between mothers and fathers remained similar over the study period, with a mean annual decline of 0.2%-points (95% CI −2.0% to 1.6%-points, p=0.83). No significant change was observed among fathers in the attendance rates to video conference visits (p=0.90; figure 4). Conversely, a significant annual increase of 6.9%-points (95% CI 3.2% to 10.7%-points, p<0.001) was observed for mothers, with a corresponding annual increase in

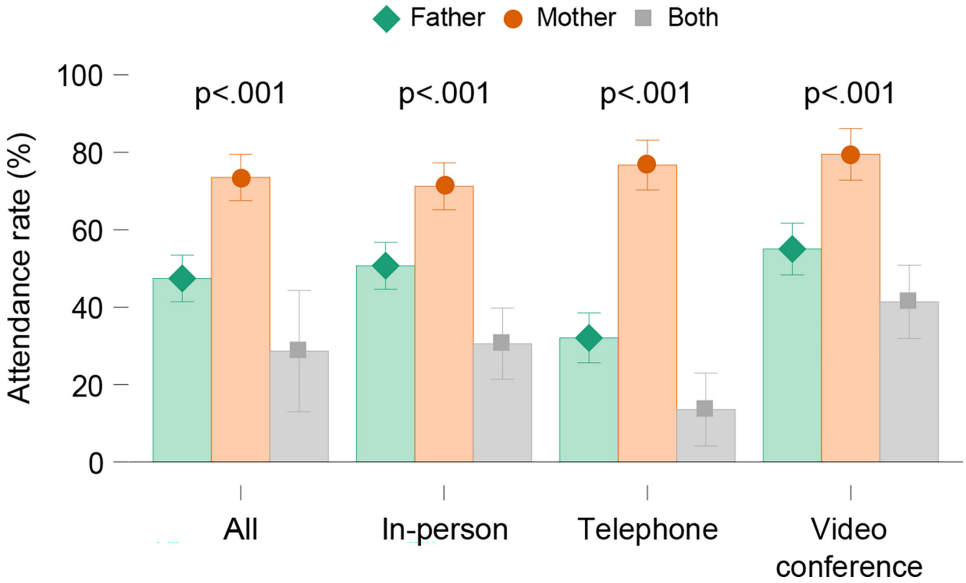

Figure 3 Parental attendance rates at in-person visits, telephone appointments and video conference visits from 2019 to 2022. Mothers consistently had higher attendance rates across all types of doctors' appointments, compared with fathers.

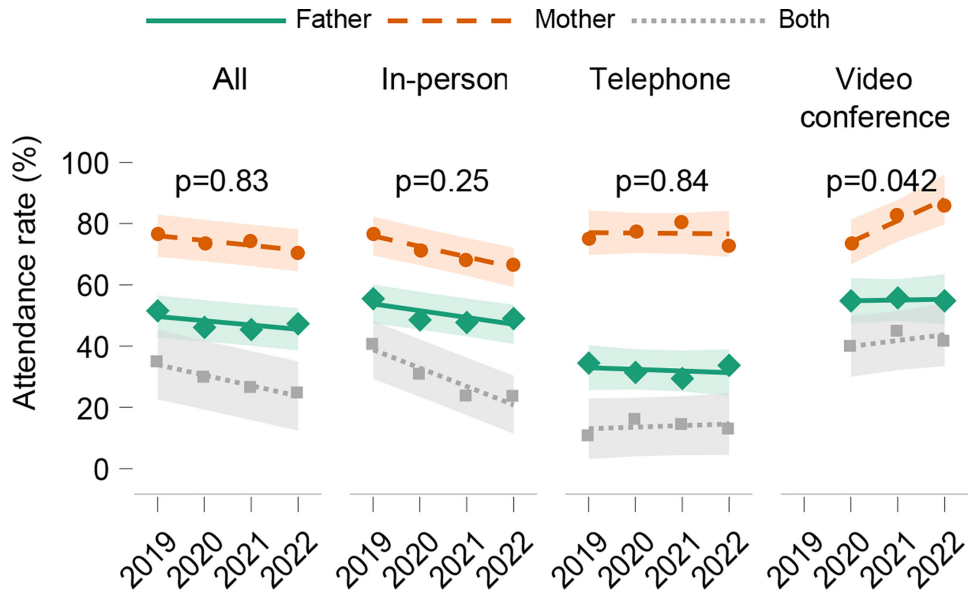

Figure 4 Trends in parental attendance rates for all appointments, in-person visits, telephone appointments and video conference visits during the study period.

attendance gap between mothers and fathers of 6.7%-points per year (95% CI 0.2% to 13.1%-points, p=0.042) for video conference visits.

Video conference visits more frequently involved both Caregivers

Following the COVID-19 pandemic, there was a decline in joint attendance rates of 3.4%-points per year (95% CI 2.6% to 4.3%-points) (figure 4, online supplemental table 3). Overall, the joint attendance rate was 29% (95% CI 13% to 44%) during the study period. Video conference visits had the highest joint attendance, with a rate of 41% (95% CI 32% to 51%) throughout the study period. The corresponding numbers were 13.5% (95% CI 4.1% to 22.9%) and 30.6% (95% CI 21.4% to 39.8%) for telephone and in-person visits, respectively (figure 4 and online supplemental table 3). Furthermore, there was a slight increase in joint attendance during video conference visits 1.9%-points per year (95% CI −1.0% to 4.9%-points) but not for in-person or telephone visits (figure 4, online supplemental table 3).

DISCUSSION

This longitudinal study on caregiver attendance at doctors' appointments for children with chronic diseases identified a significant gender disparity among parents. Mothers had consistently higher attendance rates than fathers across all types of doctors' appointments. This gender gap persisted despite the introduction of video conference visits during the COVID-19 pandemic. Telephone visits demonstrated the lowest joint attendance rate and the largest gender gap in caregiver attendance throughout the study period; whereas, video conference visits emerged with the highest joint attendance rates.

This is, to our knowledge, the first longitudinal study to examine gender equality at doctors' appointments for caregivers. Throughout the study period from 2019 to 2022, mothers were consistently more present than men in in-person visits, telephone appointments and video conference visits. These results align with global traditional social patterns, where women shoulder a greater share of childcare responsibilities.[14 17–19] Childcare encompasses a broad spectrum of interconnected responsibilities, among them healthcare, which is particularly important for families with children facing complex health issues. In our study, fathers attended 44% and mothers 74% of all doctors' appointments. Despite the scarcity of previous studies in this area, research on the well-being of caregivers to children with chronic diseases predominantly features mothers as participants.[20–22] Notably, a recent systematic review on fathers' experiences as caregivers to children with chronic diseases included only 10 papers, of which only one exclusively focused on fathers.[23] A study conducted in Europe, involving caregivers to healthy children, explored the pandemic's impact on caregivers and revealed a consistent gender composition, with over 90% of the participants being mothers.[24] Although comprehensive data on caregiver attendance are lacking, previous research suggests a significant gender gap in caregiver participation at doctor's appointment on a global level. Recognising the significance of both parents in fostering the health of their child, healthcare providers must actively engage and support all family members.[25] Enhancing paternal involvement in families with children with complex health issues can decrease the mental load for mothers as well and impact their work-life balance and career possibilities.[17 22]

Sweden is considered to be in the forefront of modern gender equality policy and was in 2022 ranked as one of the most equal countries in the world.[9 13] Parental leave by fathers in Sweden has gradually increased over the

years. However, with the pace of the last 4 years (2019 to 2022), it will take approximately 70 years until women and men equally share their responsibility for the care of their children.[26] Persistent gender norms and income disparities remain significant barriers to fathers taking on an equal role in childcare.[15 27] Fathers in Sweden now take about 25% of the total parental leave and over 35% of the temporary parental leave for caring for sick children.[27] In our study, fathers participated in almost 50% of all doctors' appointments. We know from earlier studies that paternal leave correlates with greater subsequent involvement in their child's life as well as increased satisfaction with their interactions.[28 29] Parental leave and temporary parental leave are incorporated by law in many Organisation for Economic Co-operation and Development countries but still not in the USA or other well-developed countries. In essence, both parental and temporal leave emerge as essential tools for promoting gender equality within childcare and challenging traditional gender norms within family and society.

With the onset of the COVID-19 pandemic, physical visits to the outpatient clinic were somehow restricted. In response, video conference visits were introduced as a complement to in-person or telephone appointments. We hypothesised that this would increase fathers' participation in doctor's appointments, as video conference visits enabled caregivers to participate regardless of their physical location and typically lasted no longer than 15 to 20 min, making them more compatible with work schedules. However, contrary to our hypothesis, fathers' attendance rates showed a slight decline following the introduction of video conference visits. Video conference visits only accounted for 15% to 20% of all doctor's appointments between 2020 and 2022, which may have affected the results. The widespread implementation of video conference visits in daily clinical practice has proven to be challenging, both due to technical and legal constraints, as well as a lack of guidance and vision for healthcare professionals.[25 30 31] However, in Swedish paediatric care for chronic conditions like cystic fibrosis, video conference visits have proven effective as a complement to in-person care. Caregivers of children with cystic fibrosis rated these virtual consultations as equally effective, with minimal technical issues.[32] Despite concerns and restrictions due to COVID-19, the proportion of in-person visits decreased by only 25 percentage points when comparing 2019 with 2020. This may be attributed to the relatively liberal COVID-19 restrictions in Sweden compared with those in other countries. Regarding video conference visits, no change in the participation rate of fathers was observed. Conversely, there was a significant increase in mothers' engagement in video conference visits during this timeframe, with mothers attending nearly 90% of all video conference visits by 2022. We can only speculate about these results, but just as for men, video conference visits may also facilitate for mother to participate at doctor's appointments. Technical challenges may initially have posed barriers for both men and women, serving as a potential explanation, as women usage of video conference visits increased over time. Throughout the study period, video conference visits consistently exhibited the highest joint attendance rates for all types of doctor's appointments. Telephone appointments had the lowest joint attendance rates. Additionally, telephone appointments exhibited the largest gender gap in caregiver attendance at doctor's appointments, with mothers attending approximately 75% of all telephone appointments throughout the study. The healthcare providers ultimately decide which family member to contact and whether to opt for video conference visits or telephone appointments. Telephone appointments typically involve only one person, but if both caregivers are physically together, as more people were working at home during the COVID-19 pandemic, they could both participate using a loudspeaker function. Conversely, video conference visits offer the option to invite both caregivers to join healthcare appointments, using smartphones, tablets or computers.

This study suggests that outpatient clinics should explore increased utilisation of video conference visits, as a complement to telephone appointments to better engage both caregivers. Video conference visits have proven particularly successful option for caregivers with children who require regular follow-up care from an outpatient clinic.[33] Moreover, video conference visits could serve as an option alongside in-person visits or be integrated as a hybrid model, providing both caregivers with greater flexibility to participate in doctors' appointments. Healthcare providers have a responsibility to create conditions that enable caregivers to be actively involved in their child's healthcare, even though this may be both technically, structurally and financially challenging. Equally important is that healthcare providers do not contribute to creating or perpetuating the existing disparities in care. Paediatricians should be mindful of which caregiver they call in a telephone appointment and how they provide information to both caregivers. Encouraging video conference visits that actively involve all primary caregivers may help address this imbalance. Future research should assess whether structured policies, such as formal invitations to both caregivers and workplace flexibility initiatives, could improve gender balance in paediatric healthcare participation.

Our study provides novel data on gender equality trends over a period of 4 years among caregivers of children with chronic conditions. Data was available for the majority of potential participants, which reduced the risk of selection bias. This was a retrospective study, which comes with its limitations. We lacked information about whether both caregivers were consistently invited to video conference appointments, which may have influenced participation. Additionally, our study did not capture caregivers' work schedules, socioeconomic status or caregiving roles, all of which could have affected attendance patterns in caregiver decisions. The generalisability of our results may be limited; while we have included data from five

different outpatient clinics with various chronic diseases, it is important to note that gender equality in doctor's appointments may vary depending on the specific type of chronic condition and may also differ in caregivers of children without chronic conditions. Additionally, our findings may not be applicable to healthcare settings in other countries. Further studies are needed to explore gender equality among caregivers in various healthcare settings.

This study has revealed gender inequality among caregivers of children with chronic diseases within healthcare settings. Healthcare professionals should actively recognise and comprehend gender equality within their clinics and consider whether video conference visits might be a more suitable option than telephone appointments or in-person visits, to engage both caregivers.

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Contributors LM collected data, drafted the manuscript, and critically reviewed and revised the manuscript. VM, KB and NJ collected and controlled all data, and critically reviewed and revised the manuscript. HI and JM carried out all statistical analyses, and critically reviewed and revised the manuscript. MS conceptualised and designed the study, coordinated and supervised data collection, and critically reviewed and revised the manuscript. MS accepts full responsibility for the finished work and/or the conduct of the study, had access to the data and controlled the decision to publish. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Competing interests None declared.

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Patient consent for publication Not applicable.

Ethics approval The study was approved by the Swedish Ethical Review Authority (diary number: 2022–06 910–01).

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