“It gives you hope”. How Support Groups Promote Social Support In Mothers With Children Born With A Cleft Lip And/ Or Palate.

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Abstract

Cleft Lip And/ Or Palate is the most common craniofacial condition in the UK with 1 in 700 being affected. The cleft journey a mother and her child have is emotionally distressing, leading to many mothers accessing support groups. Support groups can offer support, guidance, and information to mothers throughout their cleft journey. However, little research has been conducted solely on mothers with cleft affected children and how support groups have promoted social support in all aspects of their life. This study uses the Solomon et al's. (2001) framework which identifies 3 functioning domains promoting social support. The aim was to investigate how support groups promote social support in mothers with children born with a cleft. Mothers (N=7) with cleft affected children who had accessed a support group session were purposively sampled to take part in a semi-structured qualitative interview. Four main themes were generated: The Unknown, Shared Experiences, Life Changes and Friendship, all of which helped promote social support for mothers in all aspects of their life. These results have novel findings in relation to the normalisation of emotions, the abortion offer at the prenatal scan and how a support group helped mothers have increased social support in these areas. Future directions of these findings are discussed as well as future research opportunities such as investigating both parents of the child. Applications include raising awareness and emphasising the importance of support groups.

Introduction

Congenital anomalies include a wide range of body structure abnormalities and functions which are present from birth or recognised from a prenatal scan, (CDC, 2020). In 2019, 13,306 babies were born with one or more congenital anomaly in the UK, (National Congenital Anomaly and Rare Disease Registration Service, 2019). The most common type of congenital anomaly is a Cleft Lip and/ or Palate (CLAP), defined as either a gap or a split in the roof of the mouth (palate) which can also extend into the upper lip towards the nasal passage (NHS, 2022). A CLAP occurs due to bones in the foetus' face not fusing together during pregnancy therefore causing a gap (NHS, 2022). CLAPA. (n.d.) adds that the split of the upper lip, can be either unilateral (one side) or bilateral (both sides) occurring in 1 in 700 live births, making it the most common birth defect in the UK, (Mossey & Catilla, 2003).

A cleft lip can be identified in the mid pregnancy anomaly scan conducted between week 18 and 21 of pregnancy (NHS, 2022). Not all cleft lips can be diagnosed, it’s even harder to diagnose a cleft palate on an ultrasound scan, therefore some parents will not be aware their child is affected until after their baby is born (NHS, 2022). Diagnosis can be a difficult time for parents and many mothers think they caused the malformation (Drotar et al., 1975) with the birth being an emotionally distressing time (Davalbhakta & Hall, 2000). Parents and the child are likely to face multiple struggles in their cleft journey psychologically, with their speech, hearing, appearance, surgeries, and social integration, (Mossey et al., 2009). Whilst extensive research into the cause of clefts has been conducted, no direct cause has been found for this craniofacial condition (NHS, 2022).

CLAP has widespread impacts throughout the journey for cleft affected individual’s and family members (Rich, 2003; Baker et al., 2009; Sischo et al., 2015; Breuning et al., 2021; Razera et al., 2017). Literature on carers of cleft children has identified a common underlying theme of worry for the child's life experiences and anxiety surrounding surgeries, aftercare, and financial burden (Drotar et al., 1975; Clifford & Crocker, 1971; Niinomi et al., 2022; Kramer et al., 2007; Sischo et al., 2016; Agnew et al., 2020). Parents struggle with anxiety around feeding issues and the realisation their child will have a visual abnormality (Nitta, 2012). Knowing their child's life experiences are going to be different to a 'normal' child's can be distressing, specifically worries around the baby's malformation and the grief journey (Tisza & Grumpertz, 1962). These studies have all been conducted within the last 60 years which documents the plight of children with CLAPS in the age of modern medicine and the NHS. However, they neglect to address life before this time for cleft patients, who were undoubtedly impacted differently due to the lack of updated treatment. A more recent study by Aslan et al. (2018) found that parents with children without clefts have better quality of life than parents with cleft affected children in physical and psychological subsets than in the cleft parent group when their child was aged 13-18. Additionally, social and psychological fields of life quality were lower in cleft parents compared to the non-cleft group. However, using questionnaires does not provide an in-depth understanding of the emotions of the parents nor does it allow the participants to elaborate on their definition of quality of life, reducing the validity of the findings in this study.

Support groups are self-help or peer discussion groups offering people with shared experiences the opportunity to connect with one another and share their knowledge and emotions without criticism (Zordan et al., 2010). Benefits of attending a support group meeting are improvements in quality of life (Cunningham & Tocco, 1989), enhanced management (Fawzy et al., 1990) and psychological wellbeing (Montazeri et al., 2001). An abundance of variation in existing literature for the definition of a support group uses phrases such as self-help and treatment group alternately (Scheidlinger, 2004; Schopler & Galinsky, 1993). Support groups play an integral role in establishing social networks by a person building an identity based on their social ties with others (Mason et al., 2005). Yet there are several barriers affecting members attendance in person such as mobility-reducing physical issues, time constraints, distance to the meeting, financial difficulties and caring for others (Galinsky et al., 1997). Since the COVID-19 pandemic, many support groups moved online (Tollow et al., 2023). Research has found benefits of online support groups helped users be able to develop their responses in their own time, fewer geographic and travel barriers, and people with disabilities being able to participate with ease (Finn, 2014; Madara, 1997).

A notable change in society which is important in terms of support groups is the use of social media by parents affected by CLAP (Cinar & Boztepe, 2020). Social media platforms such as Facebook are a growing international socioeconomic phenomenon (Chang, Woo & Cederna, 2015), with the potential to reach people from across the world and connect more people than ever before (Khouri, McCheyne & Morrison, 2018). Accessing support groups has become more common, especially Facebook for accessing support around feeding issues (Huang, 2022). People join a group to get advice and information from people in the same position as themselves (Barak et al., 2008).

Support groups are important for families affected by CLAP to help navigate the uncertain world of the cleft journey. Increasing a sense of power and belonging as well as improved skill and providing a greater social network for people to support each other (Law et al., 2002). When a parent receives a cleft diagnosis there is a lot of new information handed to them, yet Kuttenberger, Ohmer and Polska. (2010) found that 80% of parents request more information related to surgeries from their cleft teams. Support groups can act as a vital source of information in an informal setting, often ahead of contact from a medical professional.

Blame and guilt are common emotions mothers have about their child exacerbated by courtesy stigma experienced from both their friends and the public (Hlongwa & Rispel, 2018). The concept of courtesy stigma was introduced by Goffman. (2009) as public disapproval elicited because of the child's cleft. Hlongwa & Rispel. (2018) reported that courtesy stigma was expressed by staring, gossiping and excessive questioning which in turn made mother's feel ashamed. Support groups aid mothers in managing their emotions and can foster their well-being while giving them a sense of control and boosting their self-confidence (Heaperman & Andrews, 2020). Helping mothers to feel more independent and have a greater feeling of personal empowerment. (Barak et al., 2008).

Support groups for caregivers of children with CLAP found outcomes after accessing a support group for mothers were improved coping, resilience, parenting skills, diagnosis information and self-care, which all fostered a feeling of greater social support (Johns et al., 2018). However, little research has been conducted surrounding specifically mother’s experiences of support groups with children born with a cleft and whether it promoted their confidence in raising their child.

Solomon et al. (2001) specifically investigated the benefits of mutual support groups run for parents with children who have disabilities. Feelings of grief, loss and guilt were common emotions of the parents such as the previous literature on parents of cleft affected children. This paper identified how little research has been conducted to investigate the benefits of mutual support groups (Solomon et al., 2001; Gottlieb, 1982). Maton. (1988) found two categories of variables which were associated with the user’s wellbeing and benefits of the group: social support and organisational characteristics. However, this study failed to apply the findings to parents of children with disabilities. Another study which highlights failings in research in this area found that women were intimidated by their doctors and sought information from the support groups instead (Linder, 1970). However, there were significant shortcomings in the describing and assessing mothers after they accessed the support group to understand what the effect was.

The aim of Solomon et al’s. (2001) framework was to investigate what parents of disabled children find helpful about mutual support groups. They found support groups to be helpful in three domains, the first being the socio-political, such as developing a sense of control in the outside world. The second domain was the interpersonal which describes their sense of belonging to a community. Lastly, the intraindividual domain which is their self-change. This can be adopted in the study of support groups for mothers with children born with a cleft as these three concepts combined could increase social support.

Research shows the importance of support groups in helping parent’s gain more confidence in themselves, their child's medical experiences and their emotional wellbeing throughout the CLAP journey. However, while previous studies show how support groups have helped parents, many studies fail to solely investigate mothers of cleft affected children’s experiences. Additionally, they use quantitative methods to investigate only one of the domains proposed by Solomon et al. (2001) and therefore do not give a well-rounded insight into increased social support. It is vital that this study is conducted to gain an understanding of this specific group of people and how support groups have helped mothers gain social support. Therefore, this study aims to investigate how support groups have promoted socio-political, interpersonal and intraindividual functioning in parents of a child born with a cleft.

Methodology

Participants

Seven participants were recruited using purposive sampling through social media and the CLAPA website. The inclusion criteria included, participants had to be mothers of a child who was born with a cleft lip and/or palate who had attended at least one or more support group sessions prior to the interview taking place. They had to be over the age of 18 and proficient in English as an ability as well as proficiency using Zoom to conduct the interview. The average age of the participants was 37 years old with the average age of their child being eight. Only one participant had prior knowledge to CLAP before their child’s diagnosis. See Table 1 for Participant information. All participants identified as a biological female mother with a cleft affected child.

Table 1: Participant information

Respondent	Respondent Age	Respondent child's age	Cleft type	Cleft team	Spousal status	Prior knowledge of cleft	Other children
R1: Mrs A	36 years old	6 months	Cleft Lip	Birmingham Children's Cleft Team	Married	No	Yes
R2: Mrs B	51 years old	16 years old	Bilateral cleft lip and palate	Salisbury Cleft Team	Married	Yes	Yes
R3: Mrs C	34 years old	1.5 years old	Cleft lip and palate	Birmingham Children's Cleft Team	Married	No	Yes
R4: Mrs D	44 years old	11 years old	Cleft palate	Nottingham Trent Cleft Team	Married	No	Yes

R5: Mrs E	33 years old	3.5 years old	Undiagnosed cleft palate	Nottingham Trent Cleft Team	Partner	No	No
R6: Mrs F	33 years old	11 years old	Cleft lip and palate	Nottingham Trent Cleft Team	Married	No	Yes
R7: Mrs G	32 years old	15 years old	Bilateral cleft lip and palate	South Thames Cleft Team	Not at the time	No	No

The interview

Seven semi-structured, online interviews were conducted lasting between 25 and 45 minutes, which were audio recorded. The interviews were transcribed by a company (Devon Transcripts) and anonymised before being returned. Participants were interviewed in-depth about being a mother of a cleft-affected child, their feelings of social support and the role the support group had in facilitating this. An open chronological and retrospective approach was used to trace their feelings from specific events in their life since their child was born. Questions focused on how the support group helped to promote social support within the mothers. Highlighting specifically socio-political, interpersonal and intraindividual functioning.

Section A of the interview gathered demographic information about the mother and their child. This was important as cleft care differs from each cleft team therefore participants could be at different stages of their journey. Additionally, it was important to note when the mother was born as it helps to understand more about their life and about their views from society's ideologies from when they were younger. Section B gained an understanding of the mother's life before their child was born, helping to understand their social networks and day to day life to discover how their child having a cleft lead them to support groups. Section C highlighted the diagnosis of their child with a cleft and what life was like around that time. This was important to understand their thoughts and emotions but also if support was offered, what type and if they opted to accept the support or not. Section D asked the participant to speak about their life now, the ways the support group helped them and what life looks like with a child affected by cleft. Lastly, section E ended the interview by positively asking participants to give advice for other mothers in their situation and whether they think support groups helped them increase their feelings of social support. See Appendix C for full list of questions posed to participants.

Method of analysis

A constructivist grounded theory approach was applied to analyse the interview transcripts. This theory was used as an investigative method to read through the interviews and conduct coding (Bennet & Vidal-Hall, 2000). Firstly, the researcher read through each interview as a whole to gain a contextualised understanding of the participants' experiences. Every interview was coded line-by-line to pinpoint open ended codes which then created specific categories. Finally, themes were formed from these categories across the transcripts. (See Appendix H and I). This approach is reflexive, allowing identification of emergent themes which allows for re-coding to take place. Coding for social support did not happen at this stage. The transcripts were downloaded and coded using the NVivo application. The researcher theoretically sampled until reaching theme saturation. (Charmaz, 2014). There were 7 interviews conducted due to the time constraints of the PSYC340 module. An 8th participant had to be excluded due to not meeting the inclusion criteria.

After this, the researcher linked the types of support being offered by the support group to the following criteria from the Solomon et al. (2001) framework:

i. Socio-political functioning which entails developing a sense of control in the outside world
ii. Interpersonal functioning which entails a sense of belonging to a community

iii. Intraindividual functioning which encapsulates self-change.

Ethical consideration

The study received ethical approval from the University of Liverpool Research Governance Committee. (See Appendix F). Approval was completed once a committee meeting had taken place to find out more about the study and amendments had been made. Some of the amendments added to the application were due to suggestions from CLAPA such as clarifying that children can be any age of the mother and refining the definition of a support group in the information sheets given to the participants. Lastly, CLAPA suggested changing the wording on the information sheet for charities which offer support upon completion of the study. Some changes suggested by the Ethics Committee were completed but a recommendation to use more up-to-date research was not actioned due to the unsuitable use of derogatory language, for instance referring to a cleft as a harelip. Other modifications made were to change wording in the participant information sheet and the consent form to make the information consistent. See appendix A and B.

Results

There were 4 main themes generated; The unknown, Shared experiences, Life changes and Friendship, which are discussed below and mapped into the Solomon et al. (2001) framework. The themes inter-relate as when faced with the unknown, the participants accessed the support group and found people with shared experiences which helped build connections and make friends which contributed to their life changing.

The unknown

Lack of information (Socio-political functioning)

Many of the participants spoke about the fear of the unknown due to the lack of information given throughout their cleft journey. The support group helped answer questions quickly and efficiently which the cleft team were unable to provide.

This can be identified when Mrs G stated:

> *you could just pop a question in and you'd get a few answers and go oh, cool, I feel better.* (Mrs G)

After accessing a support group Mrs G joined a Facebook chat where she could get information quickly which in turn helped reduce her worries around her daughter's surgery. Additionally, due to the lack of information of clefts Mrs D identified that she didn't know people in the UK had the condition.

Furthermore, an interesting finding is that some women spoke about not wanting to search for information on 'Google' due to misinformation online, while others found Google powerful enough to find CLAPA, this can be seen when Mrs B stated:

> *Like the power of Google we found CLAPA.*

In contrast to Mrs B, Mrs C commented:

> *We didn't want to go Googling things because we didn't want to just frighten ourselves.*

It is clear that around diagnosis and the early years of their cleft journey, there is a lack of information which instils fear and worry in the mothers' minds. Not knowing anything about the journey they are going to be on or anything about the condition itself can be difficult to navigate, the mothers expressed this clearly and identified how the support group helped them gain answers to questions they had. This is an example of socio-political functioning as the mothers can develop a sense of control in the outside world through gaining information and understanding more about their child's prognosis.

Diagnosis and possible abortion (Socio-political functioning)

Many women spoke about the offer of an abortion given to them and the mental struggle they had in coming to a decision within a few weeks post diagnosis. Mrs G expressed this clearly when she stated that:

> *A lot of people said I should have done it but I just didn't want to*

Additionally, Mrs F strengthened this point by saying:

> *I could take another course of action, if I wanted to…. which shocked me, I don't really know a lot about this so I don't know why you're suggesting this.*

The offer of an abortion came as a shock for many of the women as expressed above and once finding out more information from the group decided not to go through with it. This is another example of socio-political functioning as the mothers were able to develop control over their body and what happened to their baby as well as controlling the decisions made around their treatment once more information was accessed from the support group.

Shared experiences

Similar experiences (Interpersonal)

In total 4 of the mothers commented on the shared experiences from the support group sessions and that hearing similar experiences helped them feel more ‘normal’. Mrs D conveys this clearly when she says:

> *You can’t get that unless you’ve been through it* as well as *Nothing like personal experience that somebody has been through it.*

It is evident here that the women in the support groups understand the complexities of cleft treatment and have higher baseline of knowledge than the average population. This is valuable in increasing social support as mothers are able to speak to women just like them with the same experiences and offer advice and help. This is a clear example of inter-personal functioning as the women feel they belong to the cleft community through their shared experiences. Having the same problems as other mothers and talking about it helped them feel a bond to one another which through the support group helped them find a community of people on a similar cleft journey.

Normalisation and validation of emotions (Interpersonal)

Some of the women spoke about the importance of validating their emotions and normalising their feelings in their cleft journey. Knowing other women have the same worries and emotions helped reassure Mrs A she wasn’t crazy which in turn made her feel less alone and part of the cleft community. This is identified when Mrs A stated:

> *I wasn’t the only one having the same thoughts as I was* as well as *That really helped me go, okay I’m not crazy to think like this…I’m not the only one thinking them, I’m not the only one having these thoughts.* (Mrs A)

Furthermore, Mrs D spoke about the worries women were having about not loving their baby and commented:

> *I'm like it's totally normal that you're worried that you won't love them. It's totally normal if you look at pictures of a child and go, god I hope mine doesn't look like that. That's all okay.* (Mrs D)

Another important part of normalising emotions was the grief journey which many participants spoke about during and after diagnosis. Mrs A spoke about her grief journey and stated:

> *We had to grieve at diagnosis, the baby we thought we were having.*

Mrs A went on to talk about grieving twice as she had to grieve the cleft smile (unrepaired lip) after her baby's lip repair:

> *Now I've had to grieve that. That's not my child's smile. I think we had to grieve twice.*

Finding people who had also gone on this specialised grief journey helped to normalise the feelings the mothers were having and feel part of the community. It is important for the mothers to find a community where they can share their emotions and feel they are validated and shared among the group members as this helps them feel less alone. This is an example of interpersonal functioning as the mothers find a community they belong to and people who have the same emotions to validate and resonate with.

What you need when you need it (Socio-political)

An important message many of the mothers touched on was the support group availability even if they weren’t ready for the support. A cleft journey is a long 18+ years therefore mothers will dip in and out of support as and when they need it as well as the type of support they want. This can be seen when Mrs G stated:

> *It’s there and it’s accessed when I need it. What I did and didn’t need.*

Mrs B supports this by saying:

> *Whenever we’ve needed support, either they’ve offered it or we’ve asked for it.*

It is evident that mothers feel they can take ownership of the support they want and access it when they need it in order to not overwhelm themselves too quickly. This is an example of socio-political functioning as they are able to control the outside world by accessing the support when they need to even though it’s always accessible. Mothers expressed knowing when they needed support and note that if they had accessed it earlier it would have been too much.

Life changes

Awareness of comments (Intraindividual)

Many women spoke about one major life change being their awareness of comments and their worries of judgement and bullying in the future. This is depicted well by Mrs F when she said that she must:

> *Deal with other people, Other people judging you.*

Mrs A also comments on her experience of comments said to her and stated:

> *An off-the-cut comment that you think is helpful is actually quite damaging.*

It is clear here that having common ground with other cleft women in the support group helped them not feel judged or worried what other people were going to say. This in turn helped them feel more supported in their lives and more able to respond to comments confidently.

Some women talked about their worries for the future and their children experiencing this first hand. Mrs E stated:

> *Our next child could have the cleft lip and palate….it could be a bigger cleft palate so that's just, unfortunately put us off.*

Additionally, Mrs G talked about her daughter's cleft and said she wish she could:

> *Change it for her daughter's sake for the things that she's had to go through.*

It is evident how much comments can affect these women to the point of not having any more children and is a big life change for many mothers in their cleft journey which is expressed as intraindividual functioning. This self-change described in Solomon et al's. (2001) framework, is an important part of a cleft journey as mothers expressed how their views and opinions changed within themselves as well as how they are more conscious of what they say to people than before their cleft journey started.

Becoming a volunteer (Intraindividual)

Becoming a cleft mother opened a door for some of the women to become volunteers for CLAPA who they received support and guidance from. Evidence of this can be seen when Mrs A commented she is now a volunteer for CLAPA. Furthermore, it's evident this was not just one mother as Mrs C stated:

> *Something that I never thought I'd be able to do, which was to step into a role where I can help advise other people as well.*

It is clear here that becoming a volunteer was important to some of the mothers as they wanted to give back to the community they became a part of and who helped them when they needed it. Becoming a volunteer is another example of intraindividual functioning as there is an element of self-change; the mothers take on a new role in their life and a new responsibility in themselves to help other women.

Friendship

Making friends (Interpersonal)

From these support groups some of the mothers commented that they were able to make lasting friendships which helped them in their cleft journey. Which in turn helped promote their social support. This can be seen when Mrs E stated:

> *I've got (Name) to fall back on and it's nice.*

She goes on to say:

> *I'm in the WhatsApp group with I would say randomers, and now they're friends.* (Mrs E)

Mrs D started her own support group after attending a session in her local area and realising it wasn't helpful, and through this group she has been able to make her own friends.

Through the support group it is evident these mothers can make lasting friendships for themselves. Knowing other people with a cleft who understand the journey is already an easy way to become friends as they have a common understanding for each other. This is an example of interpersonal functioning as they developed a sense of belonging in the cleft community by making friends who hey now see and keep in contact with.

Physical and emotional support (Interpersonal)

The physical and emotional support that comes from the support group is something a lot of the mothers mentioned. This is evident when Mrs C talked about how you can feel very isolated. She goes on to talk about how the support group helped by:

> *Seeing other parents as well and seeing that they're just normal, nice, down-to-earth people just like we are….it stops you from feeling so alienated.* (Mrs C)

Finally, she stated:

> *It was more that they helped me with the realisation of, kind of, how far I'd come from those dark days just after the diagnosis to where we are now.* (Mrs C)

Additionally, Mrs E talked about how the support group helps you check in with yourself beyond being a mother of a cleft child:

> *We ask how each other are, self-care and that kind of thing.*

It is evident that mothers value the emotional support offered by the support group to check in and help them along their cleft journey but also to go beyond cleft care and act as a check in for all aspects of life.

Physical support the mothers mentioned was the ability to meet up in person and see each other, this is conveyed when Mrs E commented that it is better to speak in person as you can give each other advice. Mrs D supports this by commenting that being in a room and making bonds with people is important as they share the same experiences. She goes on to say:

> *I just think for me, particularly meeting people and physically seeing a baby that's got a cleft or seeing a baby that's had a cleft and you can't tell, helps more than anything else really.* (Mrs D)

It is clear here that the physical and emotional support gained from the support groups help the mothers immensely in their cleft journey, in processing their emotions and being with people who understand the struggles they face. This fits into interpersonal functioning as the mother's felt they belonged to the community gaining both emotional and physical help which they can offer in return to other mothers who need help.

Discussion

Seven participants were interviewed about how support groups promoted social support as mothers of children born with a cleft. Four themes were generated: The Unknown, Shared Experiences, Life Changes and Friendship. All of which were mapped into the Solomon et al. (2001) framework and its 3 functioning domains; socio-political, interpersonal and intraindividual.

Socio-political functioning, described as expanding a sense of control in the outside environment (Solomon et al., 2001) was found to be significant in 3 results subthemes: lack of information, diagnosis and possible abortion and what you need when you need it. Mothers spoke about their ability to develop a sense of control in their care, the information they encountered and accessing support when they want to. This is consistent with previous literature, describing that people access support groups to gain information (Barak et al., 2008) as there is a lack of information at diagnosis (Kuttenberger et al., 2010) and the enhanced management gained from the support group (Fawzy et al., 1990). These findings are also significant with Johns et al. (2018) finding that participating in support groups fostered feelings of resilience; parents gained information around diagnosis and other skills. A sense of control over the information mothers were exposed to was not identified in pre-existing literature. Additionally, there was little research literature on the offer of abortions to women pregnant with a baby affected by cleft and accessing a support group to help manage the emotions which accompany the procedure; therefore, this theme is relatively novel in its field.

Interpersonal functioning is described as a sense of belonging to a community (Solomon et al., 2001) and was significant in 4 results subthemes. Mothers spoke about how the support groups helped them to make friends with whom they were able to share similar experiences which in turn helped to normalise their emotions. Another subtheme significant with this functioning domain was the physical and emotional support gained from the support group. The subtheme of friendship and building a support network which helps mothers have a greater feeling of belonging to a community was significant in the results and within previous literature. Mothers spoke about the ability to create social ties with others in the support group, notable within pre-existing literature such as Mason et al. (2005). Furthermore, Law et al. (2002) identified how support groups increase a sense of power and belonging participants and create a greater social network, allowing people to support one another. This is significant with the physical and emotional support subtheme as well as similar experiences which many of the mothers spoke about throughout their interviews. Interestingly normalisation of emotions was not noted in previous literature however, it’s implicitly suggested throughout similar experiences research.

Lastly, intraindividual functioning domain described as self-change in the Solomon et al. (2001) framework was significant with 2 subthemes: becoming a volunteer and awareness of comments. Mothers spoke about how since starting their cleft parent journey they wanted to give back to other mothers experiencing the same emotions. Additionally, their awareness of comments towards them and the way their child looks became elevated along with the way they now speak to expecting mothers before their prenatal scans and once their baby is born. This is consistent with other previous literature talking about the awareness of comments and staring (Goffman, 2009; Hlongwa & Rispel, 2018). Furthermore, accessing a support group has been found to help self-care and resilience in parents (Johns et al., 2018) which one could argue would be the self-change in becoming more resilient to comments from the public.

The main strength of this research is the use of qualitative interviews giving in-depth and well-rounded information about the investigative question. Furthermore, due to my lived and professional experience in a cleft journey the reading and analysis of the data is more robust enriching the study further. However, there were limitations to the current study hindering its standing in literature in this field. Firstly, the sample was biased due to the gender and ethnicity of the participants hindering the population validity and therefore the generalisability to the general population. Future research could be conducted investigating both parents and widening the study accessibility. Another limitation reducing the external validity is the sampling method used to gain participants, using purposive sampling only allowed for participants who took an active role in seeking the advert and participating in taking part in the interview to be included. This excludes women who do not have knowledge of the online page on CLAPA and women who are not part of the Facebook group where the advert was posted. However, women who did not reach out to take part may have done so due to their reluctance to talk about their journey. Additionally, social desirability is a limitation as participants answered positively about their experiences of accessing a support group and did not answer questions unfavourably. This was aided through the questions asked as they all had a positive undertone causing the participants to unconsciously answer positively. However, a cleft journey can be emotionally challenging therefore highlighting the positive moments within their experience and reflecting on the bad was a more positive way to lead the interview for the participants. Future research could be done investigating positive and negative experiences of a support group to get a more rounded insight into their efficacy. Additionally, there needs to be further research into support groups and the difference in efficacy between face to face and online due to groups staying online since the COVID-19 pandemic.

There are multiple applications of this study’s findings which can be disseminated into the wider world. Firstly, on an intraindividual level, this study can be used by cleft teams to understand the importance of promoting CLAPA and their supportive community to enhance social support in mothers. On a sociopolitical level, this study can be used by health professionals more widely to understand the importance of sensitivity at diagnosis and how to approach the conversation around a possible abortion and knowing how to promote support groups during this time. On an interpersonal level, some mothers participated because they had a desire to give back to the community, therefore the findings benefit other parents going through the shared experiences and are not in receipt of support. This helps raise awareness of CLAP and elevates its ability to become a more well-known condition.

Overall, this study aimed to investigate how support groups promoted social support in mothers with cleft affected children using the Solomon et al. (2001) framework. Seven mothers participated in semi-structured interviews generating four overall themes; The Unknown, Shared Experiences, Life Changes and Friendship. These four themes identify that support groups did help promote the social support in mothers. These findings can be used by CLAPA, Cleft Teams in hospitals and the government to support families affected by CLAP, increasing confidence of CLAP affected people and helping to decrease stigma around the condition.

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Appendix

Appendix A
Participant consent form

Version number & date: , 30/07/2022
Research ethics approval number:
Title of the research project: How do support groups promote social support in mothers with children born with a cleft
Name of researcher(s): Dr Warren Donnellan, Benjamin Hunt, Claudia Pieczka

Please initial box

1. I confirm that I have read and have understood the information sheet dated 30/07/2022 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that taking part in the study involves taking part in an interview about my child, and answering the questions. ☐

3. I understand that I may be randomly allocated to a group that is required to access some educational materials every day for seven days. ☐

4. I understand that my participation is voluntary and that I will be able to withdraw from the study, at any time, either immediately before, or during the interview, without being asked to give my reason for doing so. ☐

5. I understand that I can ask for access to the information I provide, and I can request the destruction of that information if I wish at any time prior to anonymisation. I understand that following this I will no longer be able to request access to or withdrawal of the information I provide. ☐

6. I understand that signed consent forms and data collected from my participation will be retained for 10 years from the completion of the study and only the principal investigator and student investigators will have access to them. Both forms and data will be kept on University of Liverpool premises, on a password-protected network drive. ☐

7. I agree to take part in the above study. ☐

______________________________ ___________ _________________________

Participant name Date Signature

______________________________ ___________ _________________________

Name of person taking consent Date Signature

Principal Investigator
Warren Donnellan
School of Psychology – The University of Liverpool
Eleanor Rathbone Building
Bedford Street South Liverpool
L69 7ZA

Student Investigator
Claudia Pieczka
hlcpiecz@Liverpool.ac.uk

Appendix B
Participant information sheet

PARTICIPANT INFORMATION SHEET (ver. 6.0 – 30/07/2022)

Study Title:

How do support groups promote social support in mothers with children born with a cleft

Researchers: Mr Warren Donnellan, Mr Benjamin Hunt, Claudia Pieczka

We would like to invite you to take part in a research study, but before you decide, we would like to provide you with some information about why the research is being done and what it would involve. We hope this information sheet will help you decide whether you would like to take part, but if you have any further questions, someone from the research team can answer these for you. You may also wish to discuss this information with friends or family before deciding whether to take part. We would like to stress that you do not have to accept this invitation and should only agree to take part if you want to. You will need access to zoom or teams.

What is the purpose of the study?

We want to understand how support groups helped to promote social support in mothers with children who have a cleft lip and/ or palate. Going through cleft treatment as a parent is a journey and we want to investigate if mothers feel more support and resilient after accessing a support group.

Why have I been chosen to take part?

For the purposes of the present study, we are inviting for participation mothers, who have used a support group to gain advice, and have a child born with a cleft lip and/or palate. You need to have access to zoom or teams.

Do I have to take part?

It is up to you to decide whether or not to join the study. You can go through this information sheet and ask any questions you may have. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw from the study up to 2 weeks after the interview after which it will be anonymised. You do not need to give a reason for withdrawing.

If you decide to take part you will be invited to carry out an interview, remotely on teams or zoom. Having answered some basic questions such as your age and where you are in the cleft treatment timeline you will be asked a series of questions. You can take your time to answer each question and you can choose to not answer if you don’t feel comfortable. The whole interview should take approximately 1 hour to complete. After the interview you will be given a debrief form with information and contact details if you wish to get in contact again.

How will my data be used?

The University of Liverpool processes personal data as part of its research and teaching activities in accordance with the lawful basis of ‘public task’, and in accordance with the University’s purpose of “advancing education, learning and research for the public benefit.

Under UK data protection legislation, the University of Liverpool acts as the Data Controller for personal data collected as part of the University's research. The Principal Investigator acts as the Data Processor for this study, and any queries relating to the handling of your personal data can be sent to the Principal Investigator (contact details provided below).

Further information on how your data will be used can be found in the table below.

How will my data be collected?	You will be asked to take part in an interview which will be recorded using the zoom audio recording.
How will my data be stored? What measures are in place to protect the security and confidentiality of my data?	Upon completion of the study, all data related to you will be identified by a number, rather than your name. During the study, only the research team will have access to your identifying data. Data will be stored on a secure network drive, managed by the University of Liverpool.
How long will my data be stored for? How will my data be destroyed?	All data will be destroyed, 10 years after study completion, using software designed for safe data removal.

Will my data be anonymised?	Your data will be anonymised after 2 weeks of completing the study.
How will my data be used?	Your data will not be used individually, but only together with those collected from the remaining participants. All data will be analysed in aggregate form.
Who will have access to my data?	The principle investigator and the student researcher.
Will my data be archived for use in other research projects in the future?	No.

Are there any risks in taking part?

No major risk is expected to derive from participating in this study. Some of the questions are sensitive in the event that you become upset, please inform the researchers immediately. Having discussed your discomfort with the researcher, if no way is found to mitigate it please feel free to withdraw from the study.

Support contact details

Mind.org.uk

For general mental wellbeing advice please navigate to mind.org.uk

The Cleft Lip and Palate Association

For further information on infants and parents affected by cleft lip and/ or palate visit www.clapa.com

Are there any benefits in taking part?

There are no direct benefits to taking part however many participants benefit from the opportunity to speak frankly and openly about their experiences. However, the research will provide us with information on how support groups can help parents become more supported when raising a child with a cleft which in turn could be used to advise other parents.

What will happen to the results of the study?

The findings from this study will be written up as part of an undergraduate student's dissertation. None of the participants will be identifiable from any information that is published or disseminated. Participants may receive a summary of the results from the study, upon request.

What will happen if I want to stop taking part?

If you decide to take part, but then change your mind, you can withdraw from the study at any time up to two weeks after the study, without the need to give a reason. You can withdraw your data up until 2 weeks after the interview after which it will be anonymised and it will not be possible to destroy the data. Otherwise you may request that the data are destroyed, and no further use is made of them. Please let the principal investigator (contact details below) know about your intention to withdraw.

What if I am unhappy or if there is a problem?

If you are unhappy at any point in the study, or if there is a problem with the study, please contact the principal investigator at the address provided below and we will try to help. If you remain unhappy or have a complaint which you feel you cannot come to us with, then you should contact the Research Ethics and Integrity Office at ethics@liv.ac.uk. When contacting the Research Ethics and Integrity Office, please provide details of the name or description of the study (so that it can be identified), the researcher(s) involved, and the details of the complaint you wish to make. The University strives to maintain the highest standards of rigour in the processing of your data. However, if you have any concerns about the way in which the University processes your personal data, it is important that you are aware of your right to lodge a complaint with the Information Commissioner's Office by calling 0303 123 1113.

Who can I contact if I have further questions?

Principal Investigator:

Warren Donnellan

School of Psychology - The University of Liverpool

Eleanor Rathbone Building

Bedford Street South

Liverpool

L69 7ZA

email: ps0u9265@liverpool.ac.uk

Appendix C
Interview schedule

Thank you for agreeing to talk about your experience of accessing a support group and being a mother with a child born with a cleft. I am interested in your own experiences which may be different from other people's, so tell me what it has been like for you. I would like to record the conversation with your permission. We will be able to arrange an opportunity for you to hear the recording if you would like. Should you wish to stop the interview at any time, or take a break, please tell me. Because the topic of our discussions is sensitive I can assure you that it will remain confidential.

I would like first of all to ask you half a dozen factual questions and then ask you some more open questions about your experiences.

Section A

1. Can I please take a note of when you were born?
2. When was your child born?
3. Which cleft team oversees your child's care?
4. How old is your child now?
5. Do you have any other children?
6. Do you have a job?

Section B

I would now like to ask you a little about before your child was born

7. What was life like?

8. A. Did you have any hobbies? Prompt: Work? Sports?

   B. Describe a typical weekend

9. A. What was your relationship with your spouse like?

   B. Did you feel supported in everyday life?

Section C

I would now like to ask you to think about the weeks after they were diagnosed with their cleft. I know this might be painful, so we can take it slowly and we can stop if you like.

10. A. How did you feel? Prompts: How did you react? What was your mood like? What happened as the days passed? What kind of support was made available?

    B. How did your roles and responsibilities in your family change following the diagnosis? Prompt: Think about housework, cooking, cleaning, your spouse relationship

    C. Did you have anyone to talk to at this stage? Prompt: If not, would do you think you would have benefitted from?

    D. Did you access a support group? Prompt: If so how did it help, If not looking back would you have done now?

Section D

I would like to ask you about since your child has been born

11. How has your life changed?

12. A. What is a typical week for you now?

    B. How do you feel about that? Prompt: How are you with other people? What is your mood like?

C. Do you feel more supported in your cleft journey now than you did before accessing the group?

D. Do you feel more confident raising your child now?

E. What has changed the most from when your child was first diagnosed with their cleft?

13. A. Some people say ‘Everything gets easier with time’. What do you think? Has that been your own experience?

B. Was it a gradual process?

Section E

I would now like to return to our earlier interview and ask your some more general questions

14. A What advice would you give someone in the same situation as yourself?

B. What would make life easier for you?

C. Do you think support groups are helpful for gaining support in mothers?

Appendix D
Advert

UNIVERSITY OF LIVERPOOL

PSYCHOLOGY STUDY INVESTIGATING:

How support groups promote social support in mothers with children born with a cleft

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Participants are required for an online or in person study assessing how support groups promote social support in mothers with children born with a cleft

Take part in an interview where mothers will be asked questions about their experiences

The interview lasts around 60 minutes

CRITERIA:

You must be a mother with a child born with a cleft lip and/ or palate

You must have accessed a support group

For more information or to sign up to the study please contact Claudia Pieczka, the lead student investigator
hlcpiecz@liverpool.ac.uk

Appendix E
Debrief sheet

PARTICIPANT DEBRIEFING FORM

Version 2.0,30th July 2022

Title of Research Project:	How do support groups promote social support in mothers with children born with a cleft
Researchers:	Mr Warren Donnellan, Mr Benjamin Hunt, Claudia Pieczka

Thank you for taking part in this study. We hope that you have found this experience enjoyable. Please take as long as you need to read this debrief sheet.

What did we want to find out?

Our aim was to investigate how support groups promote social support in mothers whose child is born with a cleft lip and/or palate. We expected

Why was I able to take part?

You were chosen to take part because you said you are a parent to an infant born with a cleft lip and/or palate. If you require any more information about this study, and if you would like to receive a copy of its final report (or a summary of its findings) when it is completed, please feel free to contact the principal investigator: Warren Donnellan (ps0u9265@liverpool.ac.uk).

What if I am unhappy or there was a problem?

If you are unhappy, or if there is a problem, please feel free to contact the chief investigator, Mr Warren Donnellan by email: ps0u9265@liverpool.ac.uk. You may also contact the student investigator, Claudia Pieczka, by email: hlcpiecz@liverpool.ac.uk. If you have any questions or problems with this study you can contact the University's Research Governance Committee at integrity@liverpool.ac.uk

Can I still withdraw?

You can withdraw your information at any time, up until completion of the study (upon completion your information will be anonymised up to 2 weeks after the interview date and we will not be able to determine which data is yours). If, at any point in the study, you decide you no longer wish to take part, then we will include the information you have given us up until the point you withdraw, if you are happy for us to do this. If you would prefer for your information to be destroyed, then no further use will be made of the information you have given us. In either case, please let us know by contacting either the student investigator: Claudia Pieczka (hlcpiecz@liverpool.ac.uk) or the principal investigator: Mr Warren Donnellan (ps0u9265@liverpool.ac.uk) and no further use of your data will be made.

Will my data/ information be kept anonymous?

Participants will be made anonymous after the interview has been conducted.

How will we use information about you?

The anonymous information that you have given will only be known by the research team involved in this study and will be kept safe and secure. Once we have finished the study, we will analyse the results and write up reports about what we find. These reports may be published in academic journals and discussed at conferences. Your anonymous information will also be made available via open access publishing and data sharing. No one will be able to tell who you are from the information you have given us. Electronically stored information will be kept for 10 years when the study is finished, to meet the University of Liverpool's data protection policy, and will then be destroyed

Are there any benefits to taking part?

There are no direct benefits to taking part in this study. Some of the questions are sensitive in the event that you become upset, please inform the researchers immediately. Having discussed your discomfort with the researcher, if no way is found to mitigate it please feel free to withdraw from the study.

Further support and advice

In the unfortunate event that you feel affected negatively by this study, please see below for some charities. For any medical problems, please contact your GP in the first instance.

Support contact details

Mind.org.uk

For general mental wellbeing advice please navigate to mind.org.uk

The Cleft Lip and Palate Association

For further information on infants and parents affected by cleft lip and/ or palate visit

www.clapa.com

Appendix F
Ethics approval letter

Central
University
Research Ethics
Committee C

14 December 2022

Dear Dr Donnellan

I am pleased to inform you that your application for research ethics approval has been approved. Application details and conditions of approval can be found below. Appendix A contains a list of documents approved by the Committee.

Application Details

Reference: 11502
Project Title: PSYC340 How do support groups promote social support in mothers with children born with a cleft?
Principal Investigator/Supervisor: Dr Warren Donnellan
Co-Investigator(s): Miss Claudia Pieczka, Mr Benjamin Hunt
Lead Student Investigator: -
Department: Psychology
Approval Date: 14/12/2022
Approval Expiry Date: Five years from the approval date listed above

The application was **APPROVED** subject to the following conditions:

Conditions of approval

- All serious adverse events must be reported to the Committee (ethics@liverpool.ac.uk) in accordance with the procedure for reporting adverse events.
- If you wish to extend the duration of the study beyond the research ethics

approval expiry date listed above, a new application should be submitted.

- If you wish to make an amendment to the study, please create and submit an amendment form using the research ethics system. If the named Principal Investigator or Supervisor changes, or leaves the employment of the University during the course of this approval, the approval will lapse. Therefore it will be necessary to create and submit an amendment form within the research ethics system.
- It is the responsibility of the Principal Investigator/Supervisor to inform all the investigators of the terms of the approval.

Kind regards,

Central University
Research Ethics
Committee C
CUREC-C
(ethics@liverpool
.ac.uk)

Appendix - Approved Documents

(Relevant only to amendments involving changes to the study documentation) The final document set reviewed and approved by the committee is listed below:

Document Type	File Name	Date	Version
Research Tools	ETHICS - Distress protocol V1 2018	12/09/2022	1
Interview Schedule	Interview transcript	12/09/2022	1
Participant Information Sheet	Participant information sheet	08/11/2022	2
Participant Consent Form	Participant consent form	08/11/2022	2
Debriefing Material	Participant debrief form	08/11/2022	2
Advertisement	ADVERT3	08/11/2022	2
Research Tools	Ethics comments	11/11/2022	1

Appendix G

Reflective log

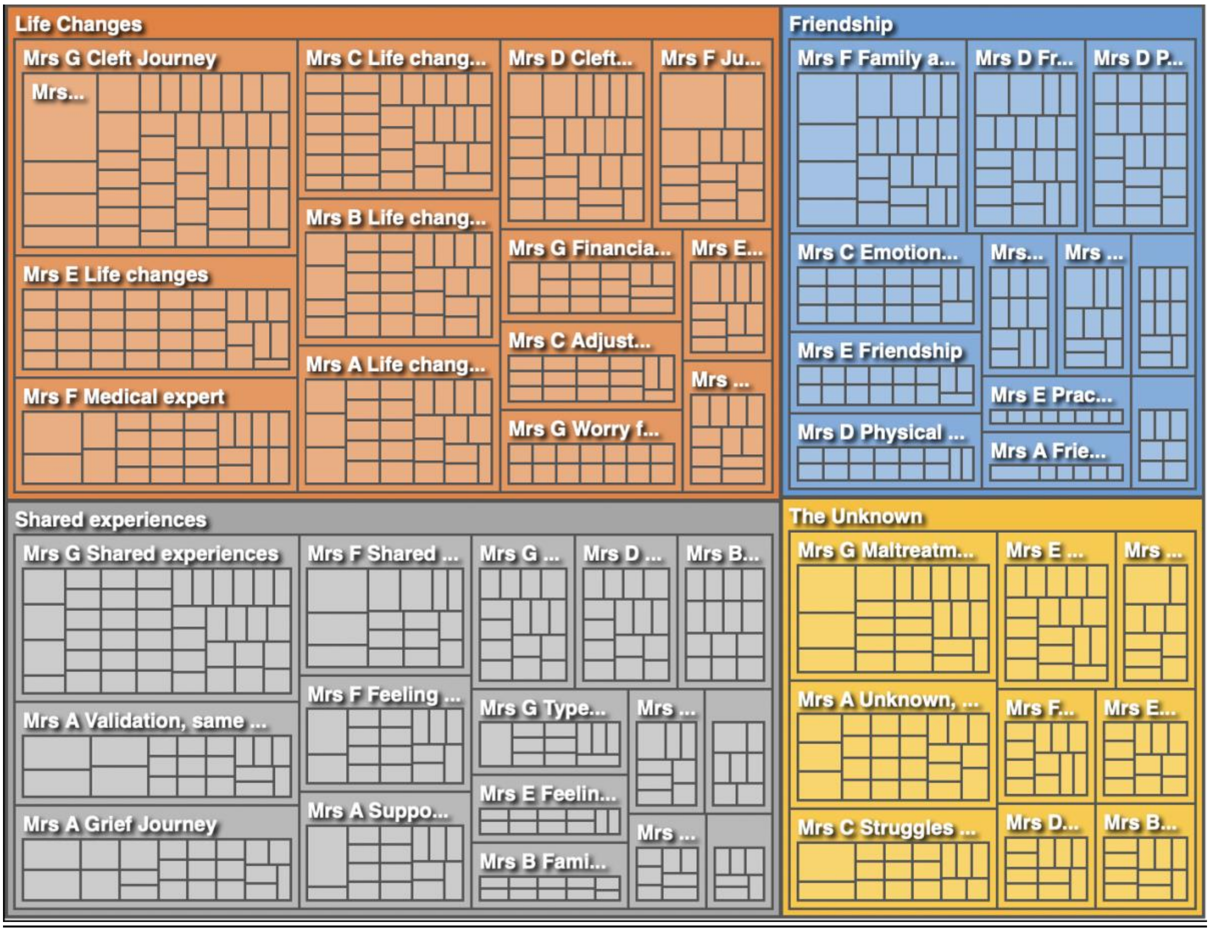
Reflective log initial thoughts

Being born with a unilateral cleft lip and palate and working with CLAPA for 9 years I felt I had a unique perspective on this study which instigated me wanting to carry it out. With prior knowledge in my family of cleft lip and palate with my father, we were lucky to have some understanding of what the condition is and what it entails. I found it inspiring listening to these mothers' stories and gave me a whole new perspective to draw on in my volunteering role. I reflected after each interview and conducted an overall reflection at the end of the results write up. My reflections and thoughts changed throughout the process and differed due to the personal experience of the interviewee. I also reflected with my mother and her experiences of raising me to see if any of the themes were significant with herself.

Overall reflections

Reflecting with my mum on her thoughts about the findings she had interesting comments which I though were worthy of including. She too resonated with one of the participants having a partner with a cleft and the prior knowledge alleviating the unknown worries at diagnosis. I found it interesting how my mum spoke about the disappointments at diagnosis as she knew the journey I was going to be on. Just like another participant my mum started a support group in her local area because she wanted to meet like minded people with a cleft. My mum spoke about how cleft creates a bond between people which links them together. At the time I was born Facebook was not really a thing but my mum said how useful she would have found it and wishes it was available back then. Another interesting comment was on the support the cleft nurse gave which was invaluable, just like other participants commented. My mum was offered an abortion at 24 weeks pregnant with me, she did not think this was appropriate and was disgusted that it was offered as an option. From my point of view this study has opened my eyes to the struggles cleft mums face and how much the journey affects them as well. I can take all of these findings with me in my volunteering roles at CLAPA to better support and help mothers who come with worries and anxieties and hope they leave feeling more confident in their abilities. It has been an honour to hear these women’s stories and I hope I can help the cleft community in some way by carrying out research like this.

Appendix H
Hierarchy chart



Appendix I
Nvivo Codebook

Nodes

Name	Files	References
Friendship	0	0
Mrs A Friends for life	0	0
Mrs A Cleft mum's understand on deeper level	1	1
Mrs A Gives you hope	1	1
Mrs A Have other cleft people for life	1	1
Mrs A In cleft bubble for life	1	1
Mrs A Lots of support around	1	1
Mrs A Made good friends from support group	1	3
Mrs B Proximity and Friendship	0	0
Mrs B Cleft team support	1	1
Mrs B Continuity of staff	1	2
Mrs B Hospital close for help	1	1
Mrs B Local CLAPA support group once born	1	1
Mrs B Meet ups for mums with cleft kids	1	1
Mrs B Met in the middle of distance	1	1
Mrs B Met up with family in same position	1	1
Mrs B Stayed in contact with some mums	1	1

Name	Files	References
Mrs B Support groups vital	1	1
Mrs D Friendship	0	0
Mrs D 130 people show up to christmas party	1	1
Mrs D Asked cleft nurse to meet another cleft parent	1	1
Mrs D Because of cleft meet so many other people	1	2
Mrs D Because of group, met so many families	1	1
Mrs D Child made friends to go to school with	1	1
Mrs D Christmas party event of the year	1	1
Mrs D Different perspective to cleft nurse	1	1
Mrs D Excited as child with identical cleft to her son	1	1
Mrs D Great to know cleft parents	1	1
Mrs D Know other cleft children through group	1	1
Mrs D Knows lots of people with cleft now	1	1
Mrs D Met people from all walks of life	1	1
Mrs D Met so many families through group	1	1
Mrs D Met so many people and made a difference	1	1
Mrs D Really helped knowing other people	1	1

Name	Files	References
Mrs D Residential focused on child, not much for parents	1	1
Mrs D Some from support group became good friends	1	2
Mrs D Support group helped child too	1	1
Mrs D Wanted her child to grow up knowing other cleft children	1	1
Mrs D Worried about surgery and could text a friend from the group	1	1
Mrs E Friendship	0	0
Mrs E Forever grateful for friends from support group	1	1
Mrs E Friends with other cleft mums	1	1
Mrs E Got friends from support group to fall back on	1	1
Mrs E Group chat with cleft mums with cleft kids of all ages	1	1
Mrs E Lost college and school friends	1	1
Mrs E Lots of friends and family helped with moving	1	1
Mrs E Made a friend through their child having a cleft	1	1
Mrs E Met the friends off the group	1	1
Mrs E Now look out for cleft lip and or palate	1	1

Name	Files	References
Mrs E People in support group are now friends	1	1
Mrs E Sharing knowledge	1	1
Mrs E Support group becomes support network	1	1
Mrs E Support group can share knowledge	1	1
Mrs E Support groups you can meet people in same boat	1	1
Mrs E Want to make friends with local groups as lack of support network	1	1
Mrs F Family and Friends	0	0
Mrs F Can rely on family	1	1
Mrs F Chilling out together	1	1
Mrs F Cleft Hereditary	1	1
Mrs F Didn't know cleft was in family	1	1
Mrs F Difficult relationship with husband	1	2
Mrs F Doing a lot together	1	3
Mrs F Evicted from previous house	1	1
Mrs F Family member familiar with cleft	1	1
Mrs F Going out, social life	1	2
Mrs F Good Family + Friend support	1	1
Mrs F Good friends and family	1	1

Name	Files	References
Mrs F Got new job	1	1
Mrs F House chores	1	1
Mrs F Important Family bond	1	4
Mrs F Living with mum	1	1
Mrs F Physical exercise	1	1
Mrs F Relationship with husband	1	2
Mrs F School run	1	1
Mrs F See Grandma	1	1
Mrs F Spending time with family	1	3
Mrs F Too Busy Now	1	1
Mrs F Unkown Cleft in family discovered	1	1
Mrs F Used To Live with work friend	1	1
Life Changes	0	0
Mrs A Comments awareness	0	0
Mrs A Bringing up child proud of cleft	1	1
Mrs A Callie cleft book	1	1
Mrs A Comments can be damaging	1	1
Mrs A Documented cleft journey	1	1
Mrs A Emotional documentation	1	1
Mrs A Flippant comments to try to help	1	1
Mrs A Helped to let go of feelings and write down	1	1
Mrs A More aware of comments	1	1

Name	Files	References
Mrs A More aware on what she says	1	1
Mrs A Proud of cleft	1	1
Mrs A Write feelings down	1	1
Mrs A Life changes	0	0
Mrs A Baby just had surgery	1	1
Mrs A Baby needed constant care	1	1
Mrs A Being mum to previous child	1	1
Mrs A Didn't plan baby coming premature	1	1
Mrs A Doing house chores	1	1
Mrs A Enjoys reading	1	1
Mrs A Enjoys watching tv	1	2
Mrs A Family are close	1	1
Mrs A Family became closer	1	1
Mrs A Family good at supporting	1	1
Mrs A Going out shopping	1	1
Mrs A Going out with friends	1	1
Mrs A Hard to do life chores	1	2
Mrs A Looking after other child too	1	1
Mrs A Looking to move house	1	1
Mrs A More stressful life	1	2
Mrs A Not first child	1	1
Mrs A Now volunteer for CLAPA	1	1

Name	Files	References
Mrs A Passionate about raising awarness	1	1
Mrs A Planning wedding before child	1	1
Mrs A See mother a lot	1	1
Mrs A Spouse shared caring for baby	1	1
Mrs A Supported by family and friends	1	1
Mrs A Without group, would not have these friends	1	1
Mrs A Would love to raise more awarness	1	1
Mrs B Life changes	0	0
Mrs B Almost at end of journey	1	1
Mrs B Around people less	1	1
Mrs B Big life change	1	1
Mrs B Child had other complications	1	1
Mrs B Child's life can begin after end of journey	1	1
Mrs B Childcare cost too much	1	1
Mrs B Constant appointments	1	1
Mrs B Constant issues	1	1
Mrs B Didn't have own time	1	1
Mrs B DIY house project	1	1
Mrs B Gave job up to have children	1	2
Mrs B Going out with friends	1	1
Mrs B Got married to husband	1	1

Name	Files	References
Mrs B Had a good job	1	1
Mrs B Kept off work due to cleft child	1	1
Mrs B Left work	1	1
Mrs B Life impacted due to cleft	1	1
Mrs B Long journey	1	1
Mrs B Long road and journey	1	1
Mrs B Lots of surgeries and appointments	1	1
Mrs B Mum wasn't supportive	1	1
Mrs B Nearly at end of cleft journey	1	1
Mrs B Need one final surgery to end	1	1
Mrs B Not easy path	1	2
Mrs B Not only child	1	1
Mrs B Wont need appointments anymore	1	1
Mrs C Adjustment to new life	0	0
Mrs C Cleft journey up and down due to constant changes	1	1
Mrs C Couldn't have managed without support groups	1	1
Mrs C Had lots of support	1	1
Mrs C Had to go through process on her own	1	1
Mrs C Knew nothing about cleft	1	1
Mrs C Lots of appointments	1	1
Mrs C Lots of support	1	1

Name	Files	References
Mrs C Made peace with not knowing cause	1	1
Mrs C Nothing can make it easier	1	1
Mrs C Now helps others in same situation	1	1
Mrs C Now proud to volunteer for CLAPA	1	1
Mrs C Now volunteer with free time	1	1
Mrs C Still in early surgery time	1	1
Mrs C The feelings are valid	1	1
Mrs C Wouldn't change journey	1	1
Mrs C Life changes	0	0
Mrs C All new when daughter was born	1	1
Mrs C Also normal baby experiences to anchor you	1	1
Mrs C Always enjoyed baking	1	1
Mrs C Become more accepting of other children differences	1	1
Mrs C Big circle of friends of all ages	1	1
Mrs C Brother and sister's never argue	1	1
Mrs C Enjoyed ballet	1	1
Mrs C Felt like parent before duaghter born due to step sons	1	1
Mrs C Going out with friends	1	1

Name	Files	References
Mrs C Husband at same workplace	1	1
Mrs C Husband close with her family	1	1
Mrs C Known husband for long time	1	1
Mrs C Learning to play drums	1	1
Mrs C Lie in on Saturday	1	1
Mrs C Life has changed by becoming a parent	1	1
Mrs C Not just cleft parents	1	1
Mrs C Now part time job	1	1
Mrs C Perfer part time over full time work	1	1
Mrs C Really close to family	1	1
Mrs C really close with family and friends	1	1
Mrs C Spend a lot of time with family	1	1
Mrs C Still get out and do activities	1	1
Mrs C Stopped ballet before pregnant	1	1
Mrs C Take baby to soft play	1	1
Mrs C Take step sons out to do activities	1	1
Mrs C Try to go for meals with family and baby	1	1
Mrs C Two step sons prior to own baby	1	1
Mrs C Used to go for drinks with friends	1	1

Name	Files	References
Mrs C Used to travel with husband	1	1
Mrs C Went back to work part time	1	1
Mrs D Cleft journey struggles	0	0
Mrs D Angry he had to change	1	2
Mrs D Baby most beautiful thing she had ever seen	1	1
Mrs D Baby was him he was perfect	1	1
Mrs D Baby was perfect	1	1
Mrs D Baby was perfect once born	1	1
Mrs D Before birth busy with other child	1	1
Mrs D Cleft can be fixed	1	1
Mrs D Couldn't enjoy pregnancy due to worries	1	1
Mrs D Couldn't focus on anything else but cleft	1	1
Mrs D Found surgeries as a baby really difficult	1	1
Mrs D Found surgery really hard	1	1
Mrs D Friends and family got them through	1	1
Mrs D Friends and family offered support	1	1
Mrs D Got older child	1	1
Mrs D Hoped her baby wouldn't look as bad	1	1

Name	Files	References
Mrs D It will be okay	1	1
Mrs D It's a journey	1	1
Mrs D Monthly meeting with cleft nurse and cleft team	1	1
Mrs D Overall cleft journey has been positive	1	2
Mrs D Part-time job	1	1
Mrs D Reassuring you can't tell baby had surgery	1	1
Mrs D Surgeons forget about parents	1	1
Mrs D Worried baby was going to look like other cleft baby	1	1
Mrs D Worried she woulnd't love baby as looks different	1	1
Mrs D You get obsessed with the cleft	1	1
Mrs E Expensive	0	0
Mrs E Feeding bottles are conversation starter	1	1
Mrs E Feeding bottles expensive	1	1
Mrs E Hospital had lots of good support	1	1
Mrs E Hospital supportive	1	1
Mrs E It's expensive	1	1
Mrs E Likes to give knowledge and advice and start conversations from feeding bottles	1	1
Mrs E Physical support from doctor was helpful	1	1

Name	Files	References
Mrs E Special feeding bottles expensive	1	2
Mrs E Used to have money to go out with friends	1	1
Mrs E Used to nap from long days at work	1	1
Mrs E Life changes	0	0
Mrs E 20 person friendship group	1	1
Mrs E After surgery don't hear from cleft team	1	1
Mrs E Always got to be checking for any changes	1	1
Mrs E Always out with friends or family	1	1
Mrs E And partner don't go out now	1	1
Mrs E Best friends came round to help	1	1
Mrs E Can't do spur of the moment activities	1	1
Mrs E Don't go out as much	1	1
Mrs E Don't want another child as risk of bigger cleft	1	1
Mrs E Experience of working with kids, but not easier with own	1	1
Mrs E Go out with friends to pub and clubbing	1	1
Mrs E Life used to be more sociable	1	1
Mrs E Like to let loose and go to spas	1	1

Name	Files	References
Mrs E Lost friends because of baby and no time	1	1
Mrs E Moved house, further away from friends and family	1	1
Mrs E Moved when 9 months pregnant	1	1
Mrs E Only has one child	1	1
Mrs E People from all over UK in group	1	1
Mrs E Rely on family	1	1
Mrs E Short relationship before pregnancy	1	1
Mrs E Some posts on facebook can be hard	1	1
Mrs E Surgery delayed due to COVID	1	1
Mrs E Take child to activities	1	1
Mrs E Used to go clubbing	1	1
Mrs E Used to go on holidays	1	1
Mrs E Used to have wider net of friends and family	1	1
Mrs E Used to live with parents	1	1
Mrs E Went to a few normal baby groups but COVID stopped them	1	1
Mrs E Went to family fun days	1	1
Mrs E When moving had lots of people to help	1	1

Name	Files	References
Mrs E Works in care home	1	1
Mrs E Wouldn't change cleft or journey for the world	1	1
Mrs F Judgement and bullying	0	0
Mrs F Become normal to stare	1	1
Mrs F Can't imagine child without cleft	1	3
Mrs F Cleft child resilient	1	1
Mrs F Cleft journey unique to everyone	1	1
Mrs F Cleft photo album	1	1
Mrs F Don't talk about cleft	1	1
Mrs F Fighting a battle with people	1	1
Mrs F Life chaged for better since cleft	1	1
Mrs F Life changed since cleft	1	1
Mrs F Life changed with people's opinions	1	1
Mrs F Loves child with their cleft	1	5
Mrs F Other people judging	1	2
Mrs F Questioned a lot	1	1
Mrs F Worry about bullying	1	1
Mrs F Medical expert	0	0
Mrs F Always something wrong	1	1
Mrs F Baby in Neonatal	1	1
Mrs F Become medical expert	1	3

Name	Files	References
Mrs F Cleft birth events	1	1
Mrs F Cleft child had other complications	1	2
Mrs F Cleft Nurse explained timeline	1	1
Mrs F Cleft nurse supportive	1	4
Mrs F Cleft team support good	1	1
Mrs F Cleft team support not immediate	1	1
Mrs F Cleft team supportive good	1	1
Mrs F Continual stages with problems	1	1
Mrs F Dental hygiene important	1	1
Mrs F Different stages to normal baby	1	1
Mrs F First surgery first stage	1	1
Mrs F Get used to new feeding	1	1
Mrs F Good cleft repair	1	1
Mrs F Hard to feed baby	1	2
Mrs F Just review with team	1	1
Mrs F Knew something was wrong	1	1
Mrs F Lots going on	1	1
Mrs F Palate surgery second stage	1	1
Mrs F Struggle after surgery	1	1
Mrs F Understanding toothpaste	1	1
Mrs F Used to care for grandma	1	1

Name	Files	References
Mrs G Cleft Journey	0	0
Mrs G Appointments become identity	1	1
Mrs G Bad cleft repair on other person	1	1
Mrs G Cleft nurse asked what she wanted	1	2
Mrs G Cleft nurse at house for long time	1	1
Mrs G Cleft Nurse positive	1	1
Mrs G Cleft nurse support too soon	1	1
Mrs G Cleft nurse went to house	1	3
Mrs G Cleft team amazing support	1	1
Mrs G Cleft team is amazing	1	1
Mrs G Cleft team know you	1	1
Mrs G Confidence came with time	1	1
Mrs G Confident in telling medical professionals off	1	1
Mrs G Don't know any different	1	2
Mrs G Easier with time but not change	1	1
Mrs G Every cleft is different	1	1
Mrs G Every cleft journey different	1	1
Mrs G Extra support vital	1	1
Mrs G Felt sad	1	1
Mrs G Going to hospital is regular	1	1

Name	Files	References
Mrs G Going to hospital normal	1	1
Mrs G Good friendship relationships before	1	1
Mrs G Got best outcome	1	1
Mrs G Had to become independent	1	1
Mrs G Had to become resilient quickly	1	1
Mrs G Helpless as parent	1	2
Mrs G Importance of CLAPA support	1	8
Mrs G Instant support after birth	1	1
Mrs G Lived at home for a while	1	1
Mrs G Lost friends, doing different things	1	1
Mrs G Met spouse after birth	1	1
Mrs G Nothing different immediately after birth	1	1
Mrs G Only one child	1	1
Mrs G Only that to compare to	1	1
Mrs G Physical support from mum	1	1
Mrs G Referral to specialist hospital	1	1
Mrs G Same cleft team since birth	1	1
Mrs G Saw cleft nurse asap	1	1
Mrs G Single parent whole pregnancy	1	3
Mrs G Still bad info even knowing cleft	1	1

Name	Files	References
Mrs G Support group help with surgery questions	1	1
Mrs G Unique experience	1	1
Mrs G Unique journey	1	1
Mrs G Wasn't happy	1	1
Mrs G Financial burden	0	0
Mrs G Can't buy normal bottles	1	1
Mrs G Changed career	1	1
Mrs G Could breastfeed using pump	1	1
Mrs G Couldn't have breastfed without hospital equipment	1	2
Mrs G Financial struggles with cleft equipment	1	1
Mrs G Focus on own dreams	1	1
Mrs G Full time Job now	1	1
Mrs G Got job worked around appointments	1	1
Mrs G Had to quit job for appointments	1	1
Mrs G Learnt how to feed her	1	1
Mrs G Less appointments now	1	1
Mrs G Life got less busy	1	1
Mrs G Normal life now	1	1
Mrs G Normal preparation things	1	1
Mrs G Stopped her career	1	1
Mrs G Worry for child	0	0

Name	Files	References
Mrs G Change clef for daughter sake	1	1
Mrs G Child is resilient	1	1
Mrs G Hard to watch as parent	1	1
Mrs G Have to get on with it	1	1
Mrs G More constant worries before	1	1
Mrs G Scared for child	1	1
Mrs G Support child	1	1
Mrs G Want to protect your child	1	1
Mrs G Wanted to support her child	1	1
Mrs G Went to counselling	1	1
Mrs G Worried about other people comments	1	1
Mrs G Worried for child's experiences	1	1
Mrs G Would swap places in heartbeat	1	1
Mrs G Wouldn't change anything	1	1
Shared experiences	0	0
Mrs A Grief Journey	0	0
Mrs A Additional diagnosis	1	1
Mrs A Devestated at diagnosis	1	1
Mrs A Didn't get to say goodbye to cleft smile	1	2
Mrs A Didn't know what to do	1	1
Mrs A Doesn't get easier with time	1	1
Mrs A Gireve at diagnosis	1	2

Name	Files	References
Mrs A Grieve cleft smile	1	1
Mrs A Grieve cleft smile loss	1	1
Mrs A Had to grieve twice	1	1
Mrs A Hard at begining	1	3
Mrs A In shock	1	1
Mrs A Learn to accept long journey	1	1
Mrs A Limited support at diagnosis	1	1
Mrs A Loved cleft smile	1	3
Mrs A Never not miss cleft smile	1	1
Mrs A NICU baby	1	1
Mrs A No Cleft nurse at diagnosis	1	1
Mrs A See new smile behind a curtain	1	2
Mrs A Spouse and her crying	1	1
Mrs A Spouse and her devestated	1	1
Mrs A Upset	1	1
Mrs A Validation, same emotions	0	0
Mrs A Baby struggling after surgery	1	1
Mrs A Cleft nurse helped	1	1
Mrs A Clingy baby	1	1
Mrs A Constantly something in cleft journey	1	4
Mrs A Didn't feel embarrassed	1	1

Name	Files	References
Mrs A Difficult pregnancy	1	3
Mrs A Don't understand until you have cleft baby	1	1
Mrs A Everyone in same situation	1	1
Mrs A Got to speak to people who got it	1	1
Mrs A Managing baby's pain	1	1
Mrs A Other mums in group	1	1
Mrs A Say goodbye to child	1	1
Mrs A Some support from nurses	1	3
Mrs A Support group friends for life	1	1
Mrs A Support group just understand	1	1
Mrs A Validated thoughts and emotions	1	3
Mrs A Validation from group helped most	1	1
Mrs A Walking away from baby	1	1
Mrs A Worrying about surgery	1	1
Mrs B Family prior knowledge	0	0
Mrs B Divorced parents	1	1
Mrs B Husband family close	1	1
Mrs B Husband has cleft	1	1
Mrs B Mother-in-law experience with cleft	1	1

Name	Files	References
Mrs B Mother-in-law helpful	1	1
Mrs B Mother-in-law reliving cleft again	1	1
Mrs B Mother-in-law supportive	1	1
Mrs B Prior knowledge to cleft	1	1
Mrs B Shock to mother-in-law	1	1
Mrs B Traumatic for mother-in-law	1	1
Mrs B Shared experience	0	0
Mrs B CLAPA gave support	1	1
Mrs B Coffee mornings	1	1
Mrs B Didn't know anyone else with cleft	1	1
Mrs B Don't feel traumatised as shared with people	1	1
Mrs B Felt supported by group	1	1
Mrs B Good support	1	1
Mrs B Good support group younger	1	1
Mrs B Isolated	1	1
Mrs B Non cleft mums not on same journey	1	1
Mrs B Shared experiences	1	1
Mrs B Shared worries and thoughts	1	1
Mrs B Similar anxieties	1	1
Mrs B Went through everything together	1	1
Mrs B Worries never go away	1	1
Mrs D Normalise feelings	0	0

Name	Files	References
Mrs D Encourage other mums to take lots of photos	1	1
Mrs D Encourage people to come before birth	1	1
Mrs D Helps to realise you didn't do anything wrong	1	1
Mrs D Normalising feelings	1	1
Mrs D Share the same feelings	1	2
Mrs D The worry went quite quickly	1	1
Mrs D Validating each other's feelings	1	1
Mrs D Your feelings are normal	1	1
Mrs D Shared experiences	0	0
Mrs D Become more aware and accepting	1	1
Mrs D Don't understand unless you have been through it	1	1
Mrs D Good to have option to speak to other people	1	1
Mrs D Have to be careful to not give out wrong information	1	1
Mrs D Hope she has made a difference	1	1
Mrs D Most people feel positive after group	1	1
Mrs D Nothing beats personal experience	1	1
Mrs D Nothing replaces that	1	1

Name	Files	References
Mrs D Pros and cons of groups	1	1
Mrs D She was happy when baby was in recovery	1	1
Mrs D Show each other photos	1	1
Mrs D Speaking to cleft mum really helped	1	1
Mrs D Struggle to connect with non cleft mums in pregnancy	1	1
Mrs D Support group is invaluable	1	1
Mrs D Support groups massively important	1	1
Mrs E Feeling less alone	0	0
Mrs E Charity helped realise baby was unique	1	1
Mrs E If didn't have any support she would be beside herself	1	1
Mrs E In person support group, now go to girl with experience	1	1
Mrs E Jealous of other parent's to take kids out to restaurants and eat whatever	1	1
Mrs E Not met just cleft palate	1	1
Mrs E Stressful times	1	1
Mrs E Without support group feel alone and unsupprted, worry about mental health	1	1
Mrs E Without support would be more stressed	1	1
Mrs E Without support would feel lonely and	1	1

Name	Files	References
worry about mental health		
Mrs E You need support groups	1	1
Mrs F Feeling lonely	0	0
Mrs F Be lost without support group	1	1
Mrs F Cleft baby comes first over work	1	1
Mrs F Had to leave work	1	1
Mrs F Lost Friends	1	1
Mrs F No support around diagnosis stage	1	1
Mrs F No support when cleft child older	1	1
Mrs F Not Good friend post diagnosis	1	1
Mrs F On her own, lonely	1	1
Mrs F People staring	1	2
Mrs F What will people say to child worry	1	1
Mrs F Sad when find out you aren't working hard enough	1	1
Mrs F Support group would have been useful earlier	1	1
Mrs F Work didn't understand surgery time off	1	1
Mrs F work life balance	1	1
Mrs F Work unsupportive	1	1
Mrs F Working Full time	1	1
Mrs F You have to reach out for help	1	2

Name	Files	References
Mrs F Shared experience	0	0
Mrs F Can turn to support group for help	1	3
Mrs F Cleft Knowledge	1	1
Mrs F Cleft people information only way	1	1
Mrs F Didn't know anyone with cleft	1	1
Mrs F Didn't want to Google	1	1
Mrs F No Previous Cleft Knowledge	1	2
Mrs F Pregnancy cleft monitoring	1	1
Mrs F Shared experiences	1	4
Mrs F Spoke to people with cleft	1	1
Mrs F Struggle to bond with baby	1	1
Mrs F Support group help older as well	1	1
Mrs F Support groups important	1	1
Mrs F Support when cleft baby lots	1	2
Mrs F Tried to find out more	1	1
Mrs F Would have no one to turn to	1	2
Mrs G Normalise feelings	0	0
Mrs G Grief at beginning	1	1
Mrs G Hard to look at photos straight after diagnosis	1	1
Mrs G Hearing other people the same	1	1
Mrs G Helps normalise feelings	1	1

Name	Files	References
Mrs G Info more helpful for the supporters around	1	1
Mrs G Jealous of other friends	1	1
Mrs G One foot infront of the other	1	1
Mrs G Part of life now	1	1
Mrs G Scary and new	1	1
Mrs G Still emotional days	1	1
Mrs G Support group positive	1	1
Mrs G Support group uplifting	1	1
Mrs G Support is hands on	1	1
Mrs G Unfair	1	1
Mrs G You want someone to validate feelings	1	1
Mrs G Shared experiences	0	0
Mrs G Alone early in pregnancy	1	1
Mrs G Always ran in her life	1	1
Mrs G Bad home life	1	1
Mrs G Building support community	1	1
Mrs G Busy life	1	1
Mrs G Cleft people share and are open	1	1
Mrs G Depends on person	1	1
Mrs G Did DOE award	1	1
Mrs G Didn't give anything up for parenthood	1	1

Name	Files	References
Mrs G Enjoyed running	1	1
Mrs G Falling pregnant good thing	1	1
Mrs G Getting older and knowing less people same age	1	1
Mrs G Give each other support	1	1
Mrs G Homeschooled	1	1
Mrs G Importance of shared experiences	1	1
Mrs G In school before pregnancy	1	1
Mrs G Lack of love from father	1	2
Mrs G Life had purpose after birth	1	1
Mrs G Listen to you and understand shared experiences	1	1
Mrs G Looked for people same cleft	1	1
Mrs G Make friends through cleft	1	1
Mrs G Meet other children in same positions	1	1
Mrs G Meeting up in person with other clefties	1	1
Mrs G Messing up future	1	1
Mrs G More aware to support others	1	1
Mrs G Mum knew cleft person	1	1
Mrs G Mum shared experience of young mum	1	2

Name	Files	References
Mrs G Mums all having children	1	1
Mrs G Naughty teenager	1	1
Mrs G Normal teenager things	1	2
Mrs G Not long education	1	1
Mrs G Parents pulled her out of school	1	1
Mrs G Pregnancy was good for her	1	1
Mrs G Shared cleft experiences	1	1
Mrs G short teen years due to birth	1	1
Mrs G Struggled in teen years	1	1
Mrs G The older the harder	1	1
Mrs G The unknown	1	1
Mrs G Took part in school running	1	1
Mrs G Tried to find same people	1	1
Mrs G Use before and after photos	1	1
Mrs G Young mum	1	1
The Unknown	0	0
Mrs A Unknown, Lack of info	0	0
Mrs A Annoying lack of information	1	1
Mrs A Anxiety from unknown	1	2
Mrs A Cleft does not have enough awarness	1	1
Mrs A Cleft nurses don't know	1	1

Name	Files	References
Mrs A Couldn't answer questions	1	1
Mrs A Didn't know about support group	1	1
Mrs A Didn't want to Google	1	2
Mrs A Difficult for cleft nurse if haven't been through it	1	1
Mrs A Don't google	1	1
Mrs A Given leaflet of information	1	1
Mrs A Got to be another cleft baby	1	1
Mrs A Idea of what baby will look like would be useful	1	1
Mrs A Knowing all informaiton would have been good	1	1
Mrs A Lean on people in support group	1	1
Mrs A Limited information given	1	2
Mrs A No one cleft related to support	1	1
Mrs A Posted photos of new smile	1	1
Mrs A Reduce amount of unkowns	1	1
Mrs A Struggle to support with lack of information	1	1
Mrs A The unknown, asking questions	1	1
Mrs A Unkown before birth	1	1
Mrs A Wanted to explain to family's kids	1	1

Name	Files	References
Mrs A Would have accessed group earlier	1	1
Mrs B Diagnosis	0	0
Mrs B Big shock at diagnosis	1	1
Mrs B Diagnosis was shock	1	1
Mrs B Difficult period	1	1
Mrs B Difficult to visualise cleft life	1	1
Mrs B Fear and anxiety at diagnosis	1	1
Mrs B Fear of unknown	1	1
Mrs B Info before birth would have been too overwhelming	1	1
Mrs B Long time from diagnosis to meeting baby	1	1
Mrs B Support at diagnosis would have been too overwhelming	1	1
Mrs B Wern't expecting cleft due to prior children	1	1
Mrs C Struggles of diagnosis	0	0
Mrs C Both in pieces at diagnosis	1	1
Mrs C Couldn't have waited any longer for scan	1	1
Mrs C Cried at diagnosis	1	1
Mrs C Days moved so slowly	1	1
Mrs C Didn't know what to do after diagnosis	1	1

Name	Files	References
Mrs C Feeling angry at diagnosis	1	4
Mrs C From diagnosis everyone rallied round	1	1
Mrs C Diagnosis feelings of disbelief	1	1
Mrs C Hard because it was a planned baby	1	1
Mrs C Never think it will be you	1	1
Mrs C People tried not to make a fuss	1	1
Mrs C Questioning why her	1	1
Mrs C Sonographer left the room	1	1
Mrs C Special scan done quickly	1	1
Mrs C Waiting was excruciating	1	1
Mrs C Waitng was agonising	1	1
Mrs D Didn't want baby to change with surgery	1	1
Mrs D Cleft team	0	0
Mrs D Care from cleft team at diagnosis was brilliant	1	1
Mrs D Cleft nurse from diagnosis	1	1
Mrs D Cleft nurse was incredible	1	1
Mrs D Cleft team support group too	1	1
Mrs D Devestated at diagnosis	1	3
Mrs D Diagnosed at 20 week scan	1	1
Mrs D Hated diagnosis	1	1

Name	Files	References
Mrs D Lack of support from cleft team as you get older	1	1
Mrs D Lots of support from cleft team at diagnosis	1	1
Mrs D Parental support great but fine line with cleft team	1	1
Mrs D Unknown	0	0
Mrs D Completely unknown	1	1
Mrs D Didn't know anything about clefts	1	1
Mrs D Didn't know what it meant	1	1
Mrs D Didn't matter baby was different she was proud of him	1	1
Mrs D Didn't realise people in UK had clefts	1	1
Mrs D No history of cleft in family	1	1
Mrs D So many unknowns	1	1
Mrs D The worries of the unknown	1	1
Mrs D Wanted to know as much info as possible at diagnosis	1	1
Mrs D Wish somebody could have told her sooner	1	1
Mrs E Emotions at diagnosis	0	0
Mrs E Angry at midwife for not checking	1	1
Mrs E Angry at undiagnosis	1	1

Name	Files	References
Mrs E At diagnosis just leaflets and random local baby groups	1	1
Mrs E Cleft nurse was only support at diagnosis	1	1
Mrs E Diagnosis only support was health visitor	1	1
Mrs E Doctors did their checks days later and found cleft	1	1
Mrs E In shock at diagnosis	1	1
Mrs E It's a shock at diagnosis	1	1
Mrs E Partner cried at diagnosis	1	1
Mrs E Phoned family asap after diagnosis	1	1
Mrs E Undiagnosed cleft	1	1
Mrs E Unknown and future worries	0	0
Mrs E Completley new	1	1
Mrs E Complications after birth, life threatening	1	1
Mrs E Didn't know anything about it	1	1
Mrs E Didn't know what a cleft was	1	1
Mrs E Don't know what future holds	1	1
Mrs E Everyday there is something new	1	1
Mrs E Excited for future	1	1
Mrs E Had to learn a lot of medical terminology	1	1

Name	Files	References
Mrs E Had to teach how to feed cleft baby to family	1	1
Mrs E Health visitor didn't know much about cleft	1	1
Mrs E Learning curve for everyone	1	1
Mrs E Repeating information to different friends	1	1
Mrs E Scared for attendance drop in school for appointments	1	1
Mrs E Seen cleft adverts on TV	1	1
Mrs E Take each day as it comes	1	1
Mrs E Worried about future for child	1	1
Mrs E Worried about the future	1	1
Mrs E You have so many questions	1	1
Mrs F Abortion offer emotions	0	0
Mrs F Confused At Diagnosis time	1	1
Mrs F Confused why abortion option	1	1
Mrs F Diagnosis family offered support	1	1
Mrs F Difficult to ask for help	1	1
Mrs F Doctor acting weird at diagnosis	1	1
Mrs F Doctor Explain scan	1	1
Mrs F Feeling annoyed at asking for help	1	1

Name	Files	References
Mrs F Initial Diagnosis feeling	1	1
Mrs F More regular scans	1	1
Mrs F Offered an abortion	1	1
Mrs F Shock at abortion comment	1	1
Mrs G Maltreatment from medical staff	0	0
Mrs G Age so treated her like child	1	1
Mrs G Awful information given at start	1	1
Mrs G Bad other people's reactions	1	1
Mrs G Devestated at diagnosis	1	1
Mrs G Didn't know purpose of 2nd scan	1	1
Mrs G Didn't like doctor attitude	1	2
Mrs G Doctor google cleft not charity info	1	1
Mrs G Doctors say mean things	1	1
Mrs G Encouraged to have abortion	1	1
Mrs G Given false information	1	1
Mrs G Given printed info from Google	1	1
Mrs G Given worst case senarios	1	1
Mrs G Had job while pregnant	1	2
Mrs G No support from hospital at diagnosis	1	1

Name	Files	References
Mrs G Not prepared for going wrong	1	1
Mrs G Offered abortion	1	1
Mrs G Panphlets too much at beginning	1	1
Mrs G Quesiton choice for keeping her	1	4
Mrs G Shocked at diagnosis abortion comments	1	3
Mrs G Thought she had to go alone	1	1
Mrs G Upset about abortion thoughts	1	1
Mrs G Went to diagnosis scan alone	1	1
Mrs G Wish abortion as other people comment	1	1
Typology of support	0	0
Mrs A Support when you need	0	0
Mra A Cleft nurse got in contact	1	1
Mrs A Access group when you are ready	1	1
Mrs A Can get the support you need	1	1
Mrs A Cleft nurse visited	1	1
Mrs A Cleft wasn't her fault	1	1
Mrs A Definitely access support group	1	1
Mrs A Have as much support as you want	1	1
Mrs A Joined pre baby classes by CLAPA	1	1

Name	Files	References
Mrs A Knowing group available would be good	1	1
Mrs A Really helpful group	1	1
Mrs A Support group would have been good	1	1
Mrs A Support groups helpful	1	4
Mrs A Take time to process it	1	1
Mrs A Take your time	1	1
Mrs A Takes time to get used to it	1	1
Mrs A Time to come to terms with it	1	1
Mrs B Evolution of support	0	0
Mrs B Cleft people capable of anything	1	1
Mrs B Harder when younger	1	1
Mrs B More comfortable approaching	1	1
Mrs B No online support available then	1	1
Mrs B Support always there	1	1
Mrs B Support group more info	1	1
Mrs B Will get through it	1	1
Mrs C Emotional support	0	0
Mrs C Can feel isolated	1	1
Mrs C Can't skip the hard emotions	1	1
Mrs C Confusing due to TV adverts in other countries	1	1

Name	Files	References
Mrs C Connected with baby inside kicking	1	1
Mrs C Didn't want to Google	1	1
Mrs C Easy to frighten yourself with internet	1	1
Mrs C Feel everything you need to feel	1	1
Mrs C Meeting other cleft parents the same helps feel less lonely	1	1
Mrs C Parent's aren't their only identity	1	1
Mrs C Parents more worried	1	1
Mrs C Reminding herself she loved her baby	1	1
Mrs C Support group helped realise how far she had come	1	1
Mrs C Support groups helped from diagnosis dark days	1	1
Mrs C Support offered by CLAPA	1	1
Mrs C Too much easily accesible info on internet	1	1
Mrs C Took a while to believe baby will be perfect	1	1
Mrs C Worried about future for baby	1	1
Mrs C Worried she caused it	1	1
Mrs C Practical support	0	0
Mrs C Cleft nurse in touch quickly	1	1

Name	Files	References
Mrs C Cleft team and foetal medicine in touch quickly	1	1
Mrs C Hospital support invaluable	1	1
Mrs C Peer support everyone is normal	1	1
Mrs C Peer supporter from CLAPA got in touch	1	1
Mrs C Support groups gave practical information	1	1
Mrs C Wern't treated any differently	1	1
Mrs C Timing, Processing	0	0
Mrs C Didn't want someone that early	1	1
Mrs C Husband spoke to CLAPA but she wasn't ready	1	1
Mrs C Need time to process alone	1	2
Mrs C Needed to be at stage to seek out group alone	1	1
Mrs C Struggle to accept help from a charity	1	1
Mrs C Took time to process it	1	1
Mrs C Wasn't ready to talk about it after diagnosis	1	1
Mrs D Emotional support	0	0
Mrs D Didn't contact peer supporter until longer in pregnancy	1	1
Mrs D Didn't feel positive before child was born	1	1

Name	Files	References
Mrs D Emotional for parents	1	1
Mrs D Emotional thinking about birth	1	1
Mrs D Everyone has same feelings	1	1
Mrs D Friends and family can offer emotional support	1	1
Mrs D Had a number for weeks but didn't phone	1	1
Mrs D Hard before you are in that headspace	1	1
Mrs D People are vulnerable at that point	1	1
Mrs D Physical support from group	0	0
Mrs D Be in a room and make bonds with people	1	1
Mrs D Because they couldn't meet it pushed them more to now	1	1
Mrs D Due to COVID families couldn't meet anyone	1	1
Mrs D Great to be in room sharing photos	1	1
Mrs D In a room with people who share same journey	1	1
Mrs D Looking at pictures of cleft babys	1	1
Mrs D Loves getting photos out and sharing	1	1
Mrs D Parents love sharing journey and sharing stories	1	1
Mrs D Peer supporter really helpful	1	1

Name	Files	References
Mrs D Physically meeting people helps more	1	1
Mrs D Physically meeting was good	1	1
Mrs D There is a demand from people that want to meet	1	1
Mrs D Wanted to give cleft mother's experience to meet others	1	1
Mrs D Went on to set up own support group	1	1
Mrs D Practical support	0	0
Mrs D Attended Happy Faces group	1	1
Mrs D Didn't get what they wanted from HF group	1	1
Mrs D Family has changed as started a support group	1	1
Mrs D Family life important	1	1
Mrs D Friends and family can offer practical support	1	1
Mrs D Going out for walks in the park with the dogs	1	1
Mrs D If not for the group they set up, there would be nothing	1	1
Mrs D Lots of pictures in house	1	1
Mrs D Need nerve to go to group	1	1
Mrs D No local support group at the time	1	1

Name	Files	References
Mrs D Not everyone is in the right headspace	1	1
Mrs D Opportunity to speak with cleft mum at diagnosis	1	1
Mrs D People cope differently	1	1
Mrs D Pointed in direction of CLAPA	1	1
Mrs D Saw family on weekends	1	1
Mrs D Set up own group	1	1
Mrs D Some people can cope with more than others	1	1
Mrs D Some people didn't go to group it's hard to walk into room	1	1
Mrs D Spoke at a conference because of group	1	1
Mrs D When set up group it was for parental support	1	1
Mrs E Emotional support	0	0
Mrs E Attended support group christmas party	1	1
Mrs E Check in on each other in self care aspect too	1	1
Mrs E Don't know what would have done	1	1
Mrs E First surgery major milestone as had more use of mouth	1	1
Mrs E Found middle point for everyone and did a meet up	1	1

Name	Files	References
Mrs E Give views and advice on kids growing up	1	1
Mrs E In person emotional support	1	1
Mrs E Social aspect of going to the groups is nice	1	1
Mrs E Support group if she ever needs advise	1	1
Mrs E Used Facebook support group	1	1
Mrs E Practical advice	0	0
Mrs E Better to meet in person and give each other as much advice	1	1
Mrs E Can ask group chats tips for hospital and surgery	1	1
Mrs E Can give practical advice about oral health at support group	1	1
Mrs E Don't Google	1	1
Mrs E Got cleft nurse number in case	1	1
Mrs E No physical family support because live too far away	1	1
Mrs E Offer help to other cleft mums	1	1
Mrs E Told other cleft parents to join group	1	1
Mrs F Proximity	0	0
Mrs F Families come back to support group	1	1
Mrs F Families travel far to join	1	1
Mrs F Lack of support groups	1	1

Name	Files	References
Mrs F Lack of support groups near area	1	1
Mrs F Never lost family post diagnosis	1	1
Mrs F Support groups stop COVID-19	1	1
Mrs G Type of support and when	0	0
Mrs G Accessed help when needed	1	1
Mrs G Change in support type	1	1
Mrs G Coffee morning online	1	1
Mrs G Early on need empathy	1	1
Mrs G Information available when ready	1	1
Mrs G Need different things at different times	1	1
Mrs G Need time to process alone	1	1
Mrs G Online support groups quick and useful	1	1
Mrs G Support was available	1	3
Mrs G Used what was useful	1	1
Mrs G Would give compassion	1	1