# 1 Experiences and Support Needs of Grandparents of Children Born with Cleft Lip

## 2 and/or Palate

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#### 4 Abstract

- 5 *Objective:* The birth of a child with a cleft lip and/or palate (CL/P) can have a significant emotional
- 6 and social impact on parents. Yet, the impact on the wider family is rarely investigated. Grandparents
- 7 are becoming increasingly involved in the care of their grandchildren, and may therefore have support
- 8 needs of their own. The aim of the current study was to explore the experiences and support needs of
- 9 grandparents of children born with CL/P.
- 10 Design: Individual semi-structured telephone interviews were carried out with 12 grandparents of
- 11 children born with CL/P, and were analysed using inductive thematic analysis.
- 12 Results: Five themes were identified 1) Emotional Impact of CL/P on Grandparents 2) Grandparents'
- 13 Social Experiences 3) Grandparents' Involvement 4) Grandparents' Information Needs 5)
- 14 Grandparents' Support Needs. Participants experienced difficult emotions around the time of
- 15 diagnosis, and were concerned about the child's treatment and future experiences. Participants played
- 16 a significant role in supporting the whole family, but received little information or support themselves.
- 17 Conclusions: Grandparents reported experiences comparable to published literature on parents.
- 18 Clinicians and charitable organisations could consider how existing resources could be made more
- 19 accessible to and/or adapted for wider family members, including grandparents.

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- 21 Key words: cleft lip and palate, family, psychological adjustment, support, grandparents, qualitative
- 22 analysis.

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### 26 Introduction

Increasingly, grandparents are becoming more involved in the upbringing of their grandchildren 27 (Dunifon and Bajracharya, 2012); providing support to both their grandchildren and the 28 grandchildren's parents. This has been attributed to a range of factors, such as a rise in the number of 29 single parents, and an increase in the number of women returning to work following the birth of a 30 child (Bol and Kalmijn, 2016; Dunifon and Bajracharya, 2012; Mitchell, 2007). Furthermore, life 31 expectancy in the UK continues to increase (Public Health England, 2017), meaning that grandparentgrandchild relationships are often sustained for many years (Moorman and Stokes, 2014). In fact, 33 Smith (2005) suggests that some may be grandparents for as much as a third of their lifetime. 34 Grandparenting is associated with many personal benefits, including increased happiness, personal 35 satisfaction, and keeping physically and mentally active (Powdthavee, 2011; Sands, Goldberg-Glen, 36 and Thornton, 2005; Seligman, 2002). These factors enable grandparents to maintain their sense of 37 autonomy (Sands et al., 2005), and can lead to personal growth, resilience, and greater life fulfilment 38 (Findler, 2016; Sands et al., 2005). 39 Cleft lip and/or palate (CL/P) is one of the most common congenital conditions worldwide (World 40 Health Organisation, 2016). In addition to those who are born with the condition, CL/P can have a 41 significant psychosocial impact on those around them. While these impacts have been explored in 42 parents of children born with CL/P (Nelson et al., 2012) little research has looked into the impact on 43 wider family members. Studies investigating psychosocial wellbeing in parents suggests that 44 emotional experiences, such as worry, and feelings of bereavement are common at the time of 45 diagnosis (Cadogan et al., 2009; Chuacharoen et al., 2009). Parents may also find it difficult to adjust 46 to the implications of their child's condition, and report symptoms of depression and anxiety (Nelson 47 et al., 2012); particularly in relation to the extensive surgical treatment that their child must undergo 48 (Klein et al., 2006). Additionally, parents often recount negative social experiences, such as upsetting 49 reactions from friends, family, and members of the public (Nelson et al., 2012), and commonly report 50 concerns about their child's future in relation to making friends, potential experiences of bullying, 51

and attending school (Klein et al., 2006). Conversely, some research finds that having a child with CL/P is also associated with unique positive experiences, such as the condition brining the family 53 closer together, increasing a sense of community, and finding inner strength at a time of adversity 54 (Eiserman, 2001; Klein et al., 2006; Nelson et al., 2012). Consequently, many parents benefit from 55 CL/P-related information and psychological support, in order to minimise distress and increase 56 resilience. 57 Given the known psychosocial impact that having a child with CL/P can have on a parent, and the 58 broader evidence that grandparents play an increasingly significant role in the upbringing of their 59 grandchildren, it is possible that grandparents may have support needs of their own. One recent study 60 investigated the psychosocial impact of CL/P on unaffected siblings, and reported a range of positive 61 and negative impacts of CL/P on this often overlooked population (Stock et al., 2016). Further, the 62 study called for an inclusive approach to healthcare encompassing all members of the family in order 63 to optimise outcomes. In the wider chronic illness and disability literature, Mitchell (2007) also 64 proposed that future research should specifically explore the support needs of grandparents, and 65 consider how support may best be offered to grandparents of a child with a disability. Gaining insight 66 into the experiences and support needs of grandparents could thus enable existing resources to be 67 expanded and/or specific support to be developed, in addition to providing us with a better 68 understanding of how to promote personal growth and holistic family care. The aim of the current 69 study was to explore the experiences and support needs of grandparents of children born with CL/P 70 using a qualitative approach, in order better understand the psychosocial impact of CL/P on wider 71 family members, and to inform future service provision. 72

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### 74 Method

#### 75 Design

- 76 This study was conducted as part of a national evaluation of the support services provided by the
- 77 Cleft Lip and Palate Association (CLAPA), known as the Regional Coordinators Project (manuscript

in press). Further information about this project is available at <a href="https://www.clapa.com/about-us/what-">https://www.clapa.com/about-us/what-</a>
we-do/regional-coordinator-project. An inductive qualitative approach was employed to address the aims of the study. Qualitative methodology enables detailed insight to be gained in areas that are understudied, or in cases where a topic is being explored from a new perspective (Morse and Richards, 2002). Individual, semi-structured telephone interviews were conducted over the telephone, to eradicate travel costs and geographical barriers.

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#### Ethical Considerations

Prior to data collection, the study gained ethical approval from the Faculty Research Ethics
Committee at (*university*). Additionally, CLAPA's project Advisory Group, consisting of CLAPA
staff, researchers, clinicians, and patient and parent representatives reviewed the study design and
protocol before recruitment took place. The code of conduct of the (*society*) was adhered to at each
stage of the study.

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#### 92 **Procedure**

The Regional Coordinators Project was partially funded through charitable organisations based in 93 (country). For the present study, participants were therefore eligible to participate if they were living 94 in (country) at the time of interview. Participants were self-selecting. CLAPA advertised the study 95 through their official social media pages, and through direct e-newsletters to their (country) 96 membership. Those who expressed an interest in the study were sent a Participant Information Sheet, 97 outlining the purpose of the study, what they would be asked to do, and what would happen to any 98 information that they provided. It was made clear to participants that they had the right to withdraw 99 100 from the study prior to the completion of data analysis. Additionally, participants were sent a copy of the Consent Form. On the day of each interview, the researcher read through the consent form with 101 the participant and gave them time to ask any questions prior to the interview commencing. 102 Participants then provided verbal consent to participate. Interviews were conducted over a period of 103

three months, between 01/04/2017 and 30/06/2017. The researcher followed a semi-structured interview schedule, consisting of open-ended questions relating to the grandparents' experiences and support needs in relation to having a grandchild with CL/P. Specifically, this included questions relating to their grandchild's diagnosis and treatment, grandparents' support needs, and access to services. In addition, participants were asked to provide some basic demographic information for the purpose of describing the sample. Interviews lasted 45 minutes on average.

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### 111 Participants

Twelve grandparents (11 female) who had a grandchild born with CL/P and who were living in (country) at the time of interview took part in the current study. Participants' ages ranged from 53 to 79 years (M=64.2). All participants reported their ethnicity to be White British or White Scottish. Of

the sample, only one participant reported having a family history of CL/P.

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## 117 Data Analysis

The interviews were audio-recorded, transcribed verbatim, and analysed using inductive thematic 118 analysis (Braun and Clarke, 2006). Thematic analysis is a widely used method of qualitative data 119 analysis, which involves identifying and organising key themes within qualitative datasets (Braun 120 and Clarke, 2006). An inductive, data-driven approach was employed (e.g. Fishman, 1999), following 121 Braun and Clarke's (2006) six steps of thematic analysis: 1) Familiarisation with the data, 2) 122 Generating initial codes, 3) Searching for themes, 4) Reviewing themes, 5) Defining and naming 123 themes, 6) Producing the report. Analysis was seen as a recursive process, and detailed notes were 124 written throughout. Themes were subsequently chosen for their prevalence and/or their importance 125 126 (or "keyness") in relation to the research question (Braun and Clarke, 2006). Each transcript was analysed independently by the first and second authors. These analyses were then compared, and 127 overall findings were discussed with the third author until full agreement was reached. 128

TOT IZEQUITS	131	Results
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Thematic analysis identified five key themes relating to the experiences and support needs of grandparents whose grandchild was born with CL/P. These were 1) Emotional Impact of CL/P on Grandparents 2) Grandparents' Social Experiences 3) Grandparents' Involvement 4) Grandparents' Information Needs 5) Grandparents' Support Needs. In the following section, each theme is presented with direct quotes to illustrate the findings. All participants have been given pseudonyms to preserve

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## 139 Theme 1: Emotional Impact of CL/P on Grandparents

- 140 The first theme relates to the emotional impact associated with having a grandchild with CL/P.
- 141 Participants recounted experiencing a range of negative emotions following the news of their
- 142 grandchild's diagnosis:

anonymity.

- 143 "It was a shock" (Rachel).
- "I suppose the initial reaction was a bit disappointed" (Katie).
- 145 Perhaps unsurprisingly, many participants had experienced concern for both their grandchild, and the
- 146 grandchild's parents:
- "But the initial, it was a worry... Was [my grandchild] going to be badly disfigured and would
- she be called names?" (Katie).
- "I felt for my son and his wife really, more than anything else..." (Cath).
- 150 Participants also spoke of how their grandchild's treatment had affected them emotionally. Again,
- 151 this included feeling worried about future procedures that their grandchild had to undergo:
- "You worry about what is going to happen in the operation theatre" (Sophie).
- "I worry he has to have, at some point, a bone implant into his gum, and that's another huge
- operation" (Rachel).

155	Participants also expressed concern for their grandchild's future in relation to speech and language
156	difficulties, and the child's social interactions at school:
157	"I think my main concern is whether he'll have any speech problems in the future There
158	could be bullying down the line, which is another thing possibly to worry about" (Cath).
159	Conversely, and despite experiencing a range of challenging emotions, participants also reported that
160	having a grandchild with CL/P had a positive impact on their emotional wellbeing. This included
161	increased feelings of gratitude, and improved family functioning:
162	"It makes you appreciate how skilled the medical professionals are" (Rachel).
163	"Having never had anybody in the family who's had anything like that, it makes you realise
164	how lucky you are" (Cath).
165	"I suppose, a positive is it draws family members together" (Rachel).
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<ul><li>167</li><li>168</li><li>169</li><li>170</li><li>171</li><li>172</li></ul>	The second theme relates to participants' discussions around their social experiences. Some participants recalled negative encounters with members of the public:  "[It] was quite difficult when you were out and about because people stared" (Rachel).  "The reactions of some people, like "oh a new baby", and then "oh" drawing back as if there
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167 168 169 170 171 172 173	The second theme relates to participants' discussions around their social experiences. Some participants recalled negative encounters with members of the public:  "[It] was quite difficult when you were out and about because people stared" (Rachel).  "The reactions of some people, like "oh a new baby", and then "oh" drawing back as if there was some kind of monster in the pram" (Elaine).  Interestingly, participants felt that having a grandchild with CL/P had enabled them to have novel

Participants also discussed how having a grandchild with CL/P had enabled them to support other affected families, which was described as a highly rewarding social experience:

"...We were out for a meal and there was a family who came into the restaurant and the baby had a cleft lip...and I said "go across and just show these people what can be done'... By being in a position to do that and also encourage them, I think that was rewarding for us and I'm sure it was helpful and rewarding for the [other] family" (Sam).

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## Theme 3: Grandparents' Involvement

- The third theme focuses on participants' perceptions of the role they adopted in relation to their grandchild being born with CL/P. First, participants recounted visiting their grandchildren in hospital and attending other medical appointments:
- ''I certainly attended quite a few of the initial meetings with the surgeon, the dental institute,

  the speech therapist, and the endocrine department" (Rachel).
- 191 Additionally, they referenced their role in providing practical and emotional support to their 192 grandchild's parents:
- "I was involved in quite a lot. Most days helping out, even if it was just doing washing or cleaning" (Elaine).
- "Support for his mum while she was in hospital...and taking turns to watch the baby so she had a chance to get a cup of tea and shower" (Claudia).
- 197 Finally, participants had provided support by taking care of their grandchild's siblings during CL/P
  198 treatment:
- "I was helping out with a sibling my granddaughter's brother" (Susan).
- 200 "I looked after her baby sister" (Katie).

## 2 Theme 4: Grandparents' Information Needs

- 203 The fourth theme centres on discussions of grandparents' access to CL/P-related information. Some
- 204 participants did not feel that they had received enough information about their grandchild's condition:
- "I wasn't given any information. Other than he had been born with a cleft lip and palate"
- 206 (*Sam*).
- 207 Participants reported that their grandchild's parents had been their main source of information, from
- 208 the initial point of diagnosis and throughout treatment:
- "I would ask my daughter about treatment and she would tell me what was happening, and
- 210 *anything further down the line" (Annabel).*
- 211 However, participants had not found this source of information to always be reliable:
- "We couldn't really get that much information out of my daughter because she was distraught
- 213 really" (Sophie).
- 214 Participants also reported using the internet to gain information about the condition:
- 215 "Most information I got was basically online" (Sam).
- 216 A smaller proportion of participants had also received information from CLAPA and the specialist
- 217 cleft teams:
- "[The cleft team] explained things so it was a big help...and being able to...contact them ...if
- 219 *you've got a question or something that's worrying you" (Claudia).*
- "We got all the information we needed CLAPA, the cleft team, everybody...so it was really
- 221 good" (Elaine).
- 222 In contrast, participants felt that non-specialist health professionals, including midwives, lacked
- 223 understanding of CL/P:
- "It felt as if you were constantly explaining what [the cleft] was and what [the specialists]
- were doing" (Claudia).

"Even something as simple as a leaflet...because not everyone is as internet savvy or would 227 know where to look... It would be good to have a leaflet that could...point in the direction of 228 real time support" (Sophie). 229 230 Theme 5: Grandparents' Support Needs 231 The final theme describes the sources of support that participants drew upon, and any additional 232 CL/P-related support needs. 233 234 In all cases, grandparents had looked to their friends and family for support: "I have a sister and she was very helpful .... I got support from my friends ... Also I have a son 235 236 who...is a dentist and he was great help" (Annabel). A small number of participants spoke of gaining support from health professionals: 237 "You get good support from the nursing staff... There to hold your arm and, you know, tell 238 239 you everything's alright" (Elaine). In contrast, the majority of participants had not had the opportunity to engage with the health professionals involved in their grandchild's care: "I never really had any direct contact with them" (Alex). 242 Similarly, only a few participants had benefitted from the services offered by CLAPA: 243 "We didn't have contact with any support group at all... [CLAPA] is more just for the parents 244 from what I can make out" (Rachel). 245 Interestingly, many participants felt that additional support for grandparents wasn't necessary, so long 246 as the other members of the family were well cared for: 247 "I don't honestly think that we need anything" (Julia). 248 "As long as my daughter got support that was enough" (Susan). 249

Some participants felt that additional sources of information for grandparents would be helpful:

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Nonetheless, participants reflected on the types of support that grandparents might benefit from. This included increased contact with health professionals, advice about how to best support the family, practical help with feeding, and access to peer support:

"I think it would have been nice to be approached by somebody...probably when the baby was born...so you knew that there were people there" (Rachel).

"Even something as simple as a leaflet so you know how you as grandparents can support the process" (Sophie).

"We've left it to my son and his wife to do all the feeding....whereas, maybe if you'd been shown yourself, had some support in that, you'd have been confident to do it. So a meeting would have been nice to be told how to do things" (Alex).

"It would be nice to have a grandparents meeting sometime. You know, get together and share experiences" (Cath).

### Discussion

The findings of this study provide novel insight into the experiences of an under-explored population in the context of CL/P. Grandparents who participated in this study reported similar experiences and support needs as has previously been identified in parents, suggesting a need to expand existing resources to encompass members of the wider family.

# Grandparents' Information and Support Needs

The reported social and emotional consequences of having a grandchild born with CL/P included shock, sadness, uncomfortable encounters with members of the public, and concern for their grandchild's future. These findings are highly comparable to those reported by parents of children with CL/P (Nelson et al., 2012), suggesting that grandparents must also come to terms with 'losing' the grandchild they were expecting, and the long-term implications of the condition (Hastings, 1997;

275 Mitchell, 2007). In order to better cope with these concerns, participants emphasised the value of accurate and reliable information, engagement with specialist health professionals, and access to peer 276 support. These types of effective support are already offered to parents, via the specialist cleft teams 277 278 and/or through charitable organisations such as CLAPA (manuscript in press; Hodgkinson et al. (2005), and could therefore potentially be expanded to also encompass grandparents. Nonetheless, 279 only a few of the participants in the current study had engaged with the support services that are 280 currently available. While some participants commented that they felt they had all the support they 281 needed, others had the misconception that support was exclusively aimed at parents. Additional 282 efforts to promote existing resources to those outside of the immediate family may therefore be 283 necessary. One potential route could be to identify grandparents who may be able to offer peer support 284 to others, since this can provide psychosocial benefits for both those providing and receiving the 285 286 support (Shilling et al., 2013). Further to this, participants reported additional concerns for the wellbeing of their grandchild's 287 parents, which has also been identified in grandparents of children with other chronic conditions (Bol 288 and Kalmijn, 2016). The birth of a grandchild with a health condition such as CL/P may therefore 289 place an additional burden upon grandparents, particularly given the increasing role that they play in 290 the upbringing of their grandchildren, and in supporting the wellbeing of the family as a whole 291 (Dunifon and Bajracharya, 2012). Previous research has found that this additional responsibility can 292 be stressful for grandparents (Ferguson et al., 2004; Mitchell, 2007), particularly if they do not have 293 a good understanding of the condition (Schilmoeller and Baranowski, 1998), or are struggling to come 294 to terms with the diagnosis themselves. In response to these concerns, participants felt that receiving 295 advice about how they could best support the family, in addition to practical guidance on how to use 296 297 the specialist feeding equipment would be valuable. Grandparents who participated in the current study highlighted several positive experiences that they 298 299 believed they had gained as a result of their grandchild's condition. These included feelings of gratitude for the health system, a greater appreciation for one's own health, and a sense of the family 300

being brought closer together in the face of adversity. Again, similar positive experiences have been reported by parents of children with CL/P, such as closer family relationships, confidence, stress-related growth, and improved coping strategies (Baker et al., 2009; Klein et al., 2006; Nelson et al., 2012). Findings such as this call for an investigation of positive outcomes to be included in research studies, so that more can be learned about how to best promote resilience in all members of the family.

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## Methodological Considerations

A number of methodological issues relevant to the current study should be considered. First, 308 participants were self-selecting, and may therefore have had a particular motivation for participating 309 in this research, which in turn could have biased the findings of the study. Further, participants were 310 primarily recruited online, which could have inadvertently excluded those who are less confident in 311 312 using the internet. In addition, and due to the source of the project funding, recruitment was only possible in (*country*), which may limit generalisability of the findings to other countries and cultures. 313 Finally, the practical and financial limitations of the project reduced the amount of time in which 314 recruitment and data collection could take place. While three authors agreed that data saturation had 315 been achieved, future research should seek to clarify and expand the findings of the current study. 316

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#### Conclusions

This small-scale but novel study provides important insight into the experiences and support needs of grandparents of children born with CL/P. Participants reported experiences comparable to published literature on parents, and played a key supportive role in the upbringing of their grandchild and the wellbeing of the family as a whole. Clinicians and charitable organisations could consider how existing resources could be made more accessible to and/or adapted for wider family members, including grandparents.

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