

## Teachers' perspectives on the impact of cleft lip and/or palate during the school years

### Abstract

*Background:* Cleft lip and/or palate (CL/P) poses many challenges for those affected throughout the school years, with recent studies pointing to a trend in poor educational outcomes. Previous research has highlighted the important role that teachers play in supporting young people with chronic health conditions, yet studies in the field of CL/P suggest that teachers may lack knowledge of the condition, and underestimate pupils' academic ability. Qualitative investigation of the impact of CL/P from the teacher's perspective may provide additional insight, as well as potential suggestions for improving the school experience for affected pupils.

*Methods:* Twenty UK pre-school, primary, and secondary school teachers with experience of teaching pupils with CL/P completed an open-ended survey, eliciting qualitative data.

*Results:* Qualitative content analysis was performed. Data were presented under five key headings: Knowledge of CL/P and its effects; Perceived impact of CL/P on education; Teachers' training needs; Delivery of training; and Impact of CL/P on teachers. Teachers were able to identify a number of potential social, emotional and treatment-related challenges within the school setting, yet did not believe that CL/P would have a long-term impact on pupils' educational achievement. Participating teachers reported that cleft-specific training and access to relevant resources would be highly beneficial.

*Conclusions:* Acting as a platform for future research, this exploratory study provides insight into the challenges faced by teachers, and offers suggestions for how to improve teachers' understanding of CL/P, and their confidence in dealing with cleft-related issues.

*Key words:* cleft lip and palate, school, education, achievement, teacher

## Introduction

Growing up with a cleft of the lip and/or the palate (CL/P) poses a number of social and emotional challenges for those affected (see Stock and Feragen, 2016 for a recent review). Despite considerable advances in surgical techniques, medical interventions are unlikely to remove the effects of the cleft entirely, and young people with CL/P may therefore look different to their classmates. A visible difference can invite unwanted questions, comments and teasing, with the potential to compromise emotional wellbeing, particularly during adolescence (Rumsey and Harcourt, 2004). In some cases, young people's speech and hearing can also be affected, impacting on their ability to communicate effectively (Havstam et al., 2011). Regular treatment may also represent a significant burden during the school years (Alansari et al., 2013). Furthermore, a number of previous studies have reported young people with CL/P to perform more poorly in relation to educational achievement than their unaffected peers (Persson et al., 2012; Collett et al., 2014; Wehby et al., 2014; Knight et al., 2015).

Previous research into the impact of chronic health conditions on the school experience has identified teachers' knowledge of the condition, as well as the approach taken by teachers to support affected pupils, to be crucial (Needham et al., 2004). Although dated, quantitative research in the field of CL/P has suggested that teachers may underestimate the intellectual aptitude of young people with congenital anomalies, and have lower expectations of young people's academic ability as a result (Richman, 1978). Research into other health conditions, including congenital health disease, diabetes and epilepsy, has also demonstrated that teachers expect affected pupils to suffer academic difficulties (Olsen et al., 2004). More recently, qualitative studies within the field of CL/P have highlighted a potential lack of understanding and support from teachers, as reported by individuals affected by CL/P and their parents (Stock et al., 2015; Tierney et al., 2015; *paper under review*).

A knowledgeable and supportive school environment is crucial for young people with any kind of health condition, in order to allow them to achieve their full potential (Department for Education, 2015). Teachers play a key role in facilitating young people's adjustment within the school environment, yet their knowledge of the needs of young people with CL/P has not yet been investigated. Qualitative investigation of the impact of CL/P from the teacher's perspective may provide additional insight, as well as potential suggestions for improving the school experience for affected pupils. The aim of the current study was therefore to explore teachers' understanding of CL/P and its effects, as well as any training needs, using a qualitative approach.

## Methods

### *Design*

This study employed an inductive, qualitative approach. Participating teachers completed an open-ended survey eliciting qualitative data, which they returned to the researchers via email. The open-ended survey was

designed and facilitated by the first author, who is trained in qualitative methods. The survey consisted of a broad range of topics, including teachers' experience of working with young people with additional needs, existing school policies, teachers' awareness of CL/P and its potential impact, and their views on relevant training opportunities. Data were collected until 'saturation' had been reached; when no new information emerged.

### *Procedure*

A convenience sample was recruited. Advertisements were widely published on relevant national websites and social media, such as those belonging to the UK-based charity, the Cleft Lip and Palate Association. Via these advertisements, teachers were invited to contact the researchers to participate. In addition, several teachers were approached directly by young people affected by CL/P and/or their parents, who had viewed these advertisements and contacted their schools.

Teachers who expressed an interest in the study were emailed a Participant Information Sheet, containing further details about what participation in the study would entail. Teachers were made aware that completion of the survey would constitute their consent for their anonymised comments to be used for research purposes. Brief demographic information, such as gender, type of school, and number of years working as a qualified teacher was also requested.

### *Participants*

Twenty teachers employed in state schools across the UK participated in this study. Teachers were required to have prior experience of teaching at least one pupil with CL/P to participate. No other inclusion/exclusion criteria were applied. Five participating teachers were male and fifteen were female. On average, teachers reported having fourteen years of teaching experience. Six participants were preschool teachers, seven were state primary school teachers, and seven were state secondary school teachers.

### *Analysis*

Content analysis was carried out on the data, in accordance with the steps described by Hsieh and Shannon (2005). Conventional content analysis is appropriate when the aim of the study is primarily to describe a phenomenon or experience, particularly when existing literature is limited. The first author reviewed the data, searched for common content, identified codes, and defined and named the categories. Findings were then checked and discussed until agreement was reached between all authors. A summary of the findings was also sent to participants to ensure accuracy.

### *Ethical considerations*

Ethical approval was granted by the Faculty Research Ethics Committee at (*university*). The ethical guidelines of (*society*) were followed at all times.

## Results

Data are presented in relation to five key headings: Knowledge of CL/P and its effects; Perceived impact of CL/P on education; Teachers' training needs; Delivery of training; Impact of CL/P on teachers. Findings are summarised in numerical form, and are illustrated with exemplar quotes. While some small differences were observed between the school grades represented, the majority of content was found to be consistent across all grades. Participants have been provided with pseudonyms to protect anonymity.

### Knowledge of CL/P and its effects

While seven teachers who participated in this study reported having some prior knowledge of CL/P and its associated challenges, the remaining thirteen teachers had no knowledge of CL/P prior to meeting a pupil with the condition.

*"I knew what [a cleft] was but I didn't know anything about the effects on the child"* – Jennifer (primary school teacher).

*"I had no knowledge at all of cleft lip and palate prior to teaching this child"* – Mary (pre-school teacher).

Nonetheless, since having a pupil with CL/P in their class, teachers were able to identify some of the challenges that young people with the condition may meet. These challenges included: speech and communication issues ( $n = 14$ ); social exclusion ( $n = 13$ ); low self-confidence ( $n = 10$ ); hearing difficulties ( $n = 5$ ); vulnerability to illness ( $n = 3$ ); problems with eating and drinking ( $n = 2$ ); and problems with literacy ( $n = 2$ ).

During the pre-school and primary school years, challenges were predominantly related to communication and developmental issues.

*"She has a wide vocabulary but only those closest to her can understand the majority of what she says, and even then it can be a guessing game"* - Caitlyn (pre-school teacher).

*"In the early years probably support with eating, then phonics and speech, which could impact on spelling later on"* – Kimberley (primary school teacher).

In contrast, teachers working in secondary schools more frequently identified challenges relating to low self-confidence and unwanted attention from peers.

*"Challenges could include self-esteem, a lack of confidence, feeling worried about their appearance"* – Jason (secondary school teacher).

*"They can receive some negative comments from their peers about the way they look or sound"* – Ruth (secondary school teacher).

### Perceived impact of CL/P on education

Teachers believed that CL/P could impact upon pupil's school work in relation to: time off school due to medical appointments ( $n = 14$ ); emotional distress ( $n = 9$ ); low confidence when speaking in class ( $n = 7$ ); and difficulties hearing in class ( $n = 5$ ). These challenges were more likely to arise in secondary school.

*“Missing school could have a big impact on their learning, whether it is half a day here and there to attend a hospital appointment, or a longer period of absence due to surgery”* – Tanya (secondary school teacher).

*“One child became sort of angry with the world, and his behaviour in class became quite challenging”* - Lisa (secondary school teacher).

*“Anxiety around speaking up in class, sharing answers and fully participating in discussions”* – Phillip (secondary school teacher).

*“If they have hearing problems they don't always hear everything that goes on in a lesson and may miss out on key information”* – Tanya (secondary school teacher).

In spite of this, none of the teachers who participated in this study believed CL/P would have a significant bearing on young people's educational achievement or vocational opportunities.

*“Academically, they are just as capable of achieving great things as any other child”* – Jennifer (primary school teacher).

*“My expectations of their academic ability and career aspirations are the same as for anyone else. All children have needs of some kind. [Cleft] shouldn't be an inhibiting factor”* – Lisa (secondary school teacher).

Concurrently, all participating teachers emphasised that children and young people with CL/P should be given the same opportunities as other pupils.

*“I aim to give my pupil [with cleft] the same learning experiences as every other child in the class”* – Annie (primary school teacher).

*“Students should be given parity regardless of their condition or needs. Every student matters and should be supported in meeting their academic and pastoral potential”* – Jason (secondary school teacher).

### Teachers' training needs

When asked how the school typically approached the care of a child with additional needs, all teachers felt there was a good system in place.

*“The Special Educational Needs Coordinator will meet with the student/parents and outside agencies if applicable... A plan is then formed and all staff are made aware... If the child requires additional support they may have a Teaching Assistant with them”* – Jason (secondary school teacher).

However, all teachers felt that training and resources to deal with issues specifically related to CL/P were lacking.

*“The only information I had was from the child’s mum. She gave me letters from each session he was doing with the speech and language therapist, and I would do my best to carry on the advice”* – Mary (pre-school teacher).

*“I studied some aspects of cleft lip and palate during university for a particular module, but there was nothing at an earlier level”* – Annie (primary school teacher).

*“I have never had any formal or informal training, information or support. To my knowledge this isn’t available in other schools either”* – Phillip (secondary school teacher).

Teachers were asked about the main challenges they had faced in regard to teaching pupils with CL/P. These primarily related to addressing the emotional and social aspects of CL/P ( $n = 13$ ); overcoming communication barriers ( $n = 9$ ); understanding treatment and its implications ( $n = 9$ ), and supporting transitions ( $n = 5$ ).

*“I would like more awareness of the appearance/body image concerns that pupils may have...and how to initiate conversations about this issue”* – Phillip (secondary school teacher).

*“If [the cleft] gets them down it can stop them making friends. As a teacher this can be difficult to spot and doesn’t have an easy solution”* – Ruth (secondary school teacher).

*“How to overcome the communication barrier. Understanding what they are saying when they speak, and how to ensure they can hear everything”* - Russell (pre-school teacher).

*“The treatment and surgeries they are likely to have and how to support them through this”* - Jessica (primary school teacher).

*“How to best liaise with other providers to make sure the transition to secondary school is as good as it can be”* – Kimberley (primary school teacher).

### Delivery of training

All participating teachers expressed an interest in learning more about CL/P and its effects. Ten teachers believed a full ‘Continuing Professional Development’ (CPD) course was necessary. Participants also suggested that direct support from a relevant health professional ( $n = 6$ ); opportunities to meet other children

with CL/P and their teachers ( $n = 4$ ); and written resources ( $n = 4$ ) would be helpful. Two participants also posed the idea of an online support network for teachers, aimed at sharing resources and best practice.

*“A full ‘Continuing Professional Development’ course would have been useful. I also feel that meeting other children with this need and sharing practice with other teachers and professionals outside of my normal setting would have been beneficial, possibly via an online network”* – Tanya (secondary school teacher).

*“Direct liaison with her speech and language therapist would have greatly helped...and practical tools, such as picture flash cards...plus how to operate and insert a hearing aid”* – Caitlyn (pre-school teacher).

*“Written resources describing exercises which would help a cleft palate child, but that could be used in a full class... How to achieve subtle inclusion without drawing attention to their difficulties”* – Debra (primary school teacher).

### Impact of CL/P on teachers

Teachers were asked whether their experience of teaching a pupil with CL/P had impacted on their confidence. The majority of teachers reported that they were somewhat confident ( $n = 12$ ), while six participants responded that they felt confident now that they were more aware of the condition. Two of the participating teachers reported that they did not feel confident.

*“My knowledge of the condition has grown a lot and I have a bank of strategies and resources to help me. However, every child is different and poses different needs. Therefore, if I were to teach another child with a cleft lip and palate, I would not feel as confident”* – Annie (primary school teacher).

*“I suppose I have a little more awareness, but I certainly wouldn’t say I’m confident”* – Jennifer (primary school teacher).

Finally, teachers reported a number of positive impacts resulting from teaching a child with CL/P. These included seeing young people overcoming challenges ( $n = 13$ ), inclusion of difference and acceptance of diversity within schools ( $n = 9$ ), and a better understanding of CL/P ( $n = 6$ ). Six teachers did not believe that teaching a child with CL/P was different to teaching any other child.

*“Inclusion – other children benefitting by seeing that we are all unique. A belief that any form of disability or difference can be dealt with”* – Debra (primary school teacher).

*“I have a better appreciation for the challenges families and professionals may face, and more understanding of the condition”* – Annie (primary school teacher).

*“Just seeing them grow and meet their potential. All children have needs of some kind. I do not think that children with CL/P are any different”* – Lisa (secondary school teacher).

## Discussion

This brief, exploratory study is the first to qualitatively investigate teachers' knowledge, experiences, and training needs in relation to CL/P. The findings provide initial insight into the challenges faced by teachers, and offer suggestions of how to improve teachers' understanding of CL/P, and their confidence in dealing with cleft-related issues.

### Synthesis of findings

Based on their own experience of teaching young people with CL/P, teachers who participated in this study were able to identify a range of potential social, emotional and treatment-related challenges. While teachers believed that these challenges had the potential to impact upon pupils' school work on a day-to-day basis, they did not perceive this to be a risk to pupils' long-term educational outcomes, and emphasised that individuals born with CL/P should be given the same opportunities as other pupils. Further, many teachers believed there to be several positive impacts of teaching a child with CL/P, which included watching pupils progress and overcome challenges. Interestingly, this is in contrast to previous research, which has suggested that teachers may have lower expectations of pupils with chronic health conditions in regard to pupils' academic ability (Richman, 1978; Olsen et al., 2004). This discrepancy in findings may reflect improvements in comprehensive CL/P treatment in recent decades, and/or may demonstrate an improvement in public perceptions of CL/P and other disabilities (Staniland, 2009; Pausch et al., 2016) as well as the introduction of initiatives aimed at supporting those with disabilities more generally (World Health Organization, 2011). Additionally, the study by Olsen and colleagues (2004) revealed that the reservations teachers had about pupils' academic potential were based less on the child's actual ability and more on the teachers' perceptions of their own lack of knowledge about the condition. This interesting insight supports the current study, in which all participating teachers indicated a lack of training and resources to deal with issues specifically related to CL/P. Thirteen teachers had no knowledge of CL/P prior to teaching a child with the condition. Only two out of the twenty participating teachers had studied aspects of CL/P during their teacher training, and in several cases, teachers' only information about CL/P had been obtained through the affected family. Despite having taught at least one child with CL/P at the time of participation in this study, only six teachers reported feeling confident in dealing with cleft-related issues. These findings are also reflective of qualitative studies, which suggest that teachers' understanding of CL/P and its effects could be improved, according to the perspectives of individuals born with CL/P and their parents (Stock et al., 2015; Tierney et al., 2015; *paper under review*).

### Implications for research and practice



All teachers who participated in this study reported that training in relation to CL/P and its treatment, as well as advice as to how to best support pupils with any social and emotional issues, would be helpful. This is comparable to research investigating teachers' experiences of supporting pupils with other chronic health conditions (Taras & Potts-Datema, 2005). As a primary resource, written information, containing an overview of CL/P, its treatment and its possible impacts could be made available in all schools. This information could direct schools toward appropriate texts (e.g. Frances, 2004), websites (e.g. charitable organisations, such as the Cleft Lip and Palate Association (UK), Changing Faces (UK) and the Cleft Palate Foundation (USA)), and contacts to obtain further information. As a more intensive option, and as specifically requested by half of the teachers who participated in this study, Continuing Professional Development training could be offered. This could take the form of a formal training day led by a health professional or a charitable organisation, with the added benefit of teachers being able to meet and hear from families affected by CL/P and those responsible for their care. Alternatively, an online training module could be made available, which could be accessed and completed by school staff as and when needed. The benefits of continued e-learning for a variety of professionals have already been demonstrated (Klein and Ware, 2003), and such online platforms could also connect teachers to one another, to allow them to ask questions and share best practice. In all cases, further investigation of the content of training materials and resources for teachers, as well as an evaluation of their acceptability and effectiveness is warranted in the case of CL/P. Additionally, specialist cleft teams and local health professionals could endeavour to establish and maintain communication with schools in their local area, to provide additional professional support and information when necessary (e.g. at times of transition, or prior to a surgical intervention) and to support teachers to engage pupils in activities which complement the specialist interventions (e.g. speech and language therapy). A recent study (*paper under review*) suggested that young people with CL/P could also be encouraged to give a talk to their classmates, or during a school assembly, about their experiences of having a CL/P. If the young person felt comfortable, this could be another way of raising awareness among school staff, as well as among pupils. Finally, and on a more general level, school-based interventions to address appearance concerns relevant to all pupils, and to promote diversity and difference, have begun to show promise and may be useful in this context (see Diedrichs & Halliwell, 2013). Drawing further upon literature from other health fields, such as chronic illness and physical disability, may also be beneficial for future research in the area of CL/P (e.g. see Mukherjee et al., 2000).

### Methodological considerations

Open-ended surveys remain underused in health research, yet can be extremely useful in eliciting qualitative data, while requiring relatively few resources (Hunt and McHale, 2007). Open-ended surveys also allow for relative anonymity, are capable of eliciting participants' underlying beliefs, and provide responses to standardised questions in participants' exact words, without the need for transcription (Braun et al., 2017). The present study is one of the first in the field of CL/P to utilise open-ended surveys. This alternative method was

found to be particularly effective in collecting data from a participant group which is typically considered more difficult to access, possibly due to teachers being able to respond in their own time.

A number of limitations of the present study must be acknowledged. First, no information could be obtained about the phenotype of the children taught by participating teachers, and thus a judgement of the severity of the cases seen by teachers could not be made. Previous research has demonstrated that children with additional conditions and associated difficulties are more likely to report poor outcomes (Feragen & Stock, 2014), and thus future studies should account for these impacts where possible. Although teachers were asked to provide this information where they could, only three were able to do so, further highlighting the lack of knowledge about CL/P within this participant group. However, the content analysis was able to provide some understanding of the frequency of associated difficulties, such as issues with speech and hearing. A second limitation was that a convenience sample was relied upon, with the majority of teachers recruited via the direct efforts of pupils born with CL/P and/or their parents. This may have resulted in a biased sample; specifically one in which teachers were more informed than most due to the active involvement of the families. If this was indeed the case, the need for training and resources among teachers is further emphasised, since despite being relatively well-informed, participating teachers still reported a lack of knowledge and confidence. A final limitation is that the open-ended survey method is less complex than traditional qualitative methods, and results in an inability to follow-up or obtain further detail on points of interest. Nonetheless, the data obtained through this study were relatively rich, and insightful. This study aimed to describe teachers' knowledge, experiences and training needs in relation to CL/P, with a view to providing a platform for further research.

## Conclusions

Teachers who participated in the present study identified a number of potential social, emotional and treatment-related challenges within the school setting, yet did not believe that CL/P would have a long-term impact on pupils' educational achievement. Participating teachers had no or very little knowledge of CL/P prior to meeting a young person with the condition, and believed that specific training and access to relevant resources would be highly beneficial. The findings of this brief, exploratory study provide insight into the challenges faced by teachers, and have implications for educational policy, clinical practice and future research.

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