

CHIVA Paediatric Nurses Audit: experiences of HIV positive children in UK schools

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The Children's HIV Association (CHIVA) is a UK registered charity that manages a network of those providing medical and social care to HIV positive children and families across the UK and Ireland.

The audit

In autumn 2014 an audit was sent out through the CHIVA membership to capture the experiences of HIV positive children in schools in the UK. The audit asked the number of patients treated at each centre; how many of these were in full-time education and then asked about planned and unplanned disclosures of a child's HIV status to a school and schools responses to this information.

THE FINDINGS

In March 2014, 1,037 patients were alive and in active follow-up at clinics across the UK and Ireland, 5% of these were in Ireland, so there are around 970 HIV positive children from 0-18 in active follow-up in the UK.

12 centres responded to the audit, collectively treating 596 patients of which 560 were in full-time education. Therefore these findings represent 61%¹ of the cohort of HIV positive children in the UK.

8% (n=45) of families had asked clinical staff to support them in talking to a school about their child's HIV status

Number of schools told and how they were told

11% (n=61) of HIV positive children's schools have been told the child's HIV status.

Of these 62%(n=38) were planned disclosures, with 38%(n=23) being unplanned.

Of the unplanned disclosures, 5%(n=3) were spontaneous disclosures made by the HIV positive child.

33%(n=20) of unplanned disclosures occurred when the child's HIV status was revealed by someone else without given consent. This equates to a third of disclosures to a school happening in an unplanned way without the consent of the family or child.

From this we can conclude that only 7%(n=41) of HIV positive children and their families wanted to tell a school about HIV. Although there is no comparison data to other chronic health conditions, this is because

¹ We do not know how many of the 970 children are of a school age, so this is a percentage of the overall figures of patients, as a similar proportion of the 970 will not be in full-time education.

unstigmatised chronic health conditions are routinely told to schools as this is in the best interests of the child.

Types of education institutions

The audit asked the 'type of educational institution' to see whether there were more disclosures for those children who have additional health or educational needs.

60 of the 61 schools that had been told were included in this data and of these 60, 82%(n=49) were mainstream schools, 13%(n=8) were schools that specialise in additional needs and 5%(n=3) were 'other' (2 being Universities).

Of these, 56 offered further details about what Key Stage the schools were:

Nursery 5%(n=3)

Primary 27%(n=15)

Secondary 55%(n=31)

Further education 13%(n=7)

This shows that over half the schools that had been told are secondary schools.

The experiences of telling schools

As HIV is highly stigmatised, the key motivation for not telling a school about a child's HIV diagnosis is due to fear of the schools' response. The final question in the audit related to the experiences of those who either chose to tell a school or where this information was revealed without their permission.

Of the 61 child who's HIV status is known by a school, 58 were represented in this part of the audit. The nurses were asked whether the patients experience was:

A bad experience 10%(n=6)

Initially bad, but became better with interventions 36%(n=21)

A good experience 54%(n=31)

From this we can see that 46% of the schools that were told one of their pupils was HIV positive responded in a way that made the experience bad for the child and family. Fortunately, once interventions had taken place to support the school, 36% of children and families then had a good experience. Even after interventions from medical professional, 10% of children and families still had a bad experience.

Conclusion

Although this was a simple audit, it does represent the experiences of 61% of HIV positive children and their families living in the UK.

The findings highlight that:

In general, schools are not told that they have an HIV positive pupil, with only 11% of HIV positive children attending a school that knows their diagnosis.

Only 7% of children and families have decided to tell schools, the other 4% were disclosures by a third person without the child or families consent.

82% of the schools told were mainstream schools.

46% of the responses by school initially lead to a bad experience for the child and family, with 36% of these then responding supportively after interventions from outside practitioners.

10% of schools, even after interventions from outside practitioners, still responded to this information in a way that made the experience bad for the child and family.

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