

Medications for children with sickle cell disease. What do parents really know and what are their concerns?

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Introduction

Sickle cell disease (SCD)

- life long condition

- on diagnosis all children prescribed penicillin prophylaxis and folic acid supplementation

- depending on the severity of the condition may be prescribed Hydroxycarbamide (Hydroxyurea)

- compliance issues



Aims of audit

- ✓ To determine the prevalence of compliance to daily medications among children with SCD.
- ✓ To determine parental knowledge and understanding about their children's medications.
- ✓ To assess if parents were worried about their children's medications.



Methods

Study sample

- ✓ The study was conducted at OLCCH over an 8 month period from Jan.-Aug. 2010
- ✓ Participants- Parents of children diagnosed with SCD.
Parents were recruited at the haemoglobinopathy clinics or haematology day unit.

Instruments

- ✓ A self-report questionnaire consisting of 19 questions was used.
- ✓ The format of questions included Yes/No questions, multiple-choice questions, rating questions and the use of Likert scales.
- ✓ The questionnaire consisted of 5 sections: demographics, pharmacy details, administration issues, parental knowledge and parental worries/concerns.
- ✓ The compliance of the medications penicillin, folic acid and Hydroxyurea were assessed.

Data analysis

- ✓ Microsoft Excel was used to analyse the questionnaires.



Results

222 questionnaires were completed by parents.

1. **Demographics**

- ✓ 26% of parents had more than one child diagnosed with SCD.
- ✓ English was the predominant language used by 63% of parents. The 4 other languages spoken by parents were: Yoruba, French, Igbo and Portuguese.

Results

2. Pharmacy

- ✓ Although, 71% of parents have attended the same pharmacy for longer than one year only 64% could identify the complete details of that pharmacy.
- ✓ The majority of parents (91%) had no difficulties obtaining their children's medications.



Results

3. Administration (1 of 2)

- ✓ 79% of parents administer the prescribed medications to their children, while 6% their children take their own medications (age range 12 to 20 years). 15% of children take their medications with their parent's help.
- ✓ 79% give folic acid once a day.

- ✓ Only 72% of parents give their children penicillin twice a day. (8% give it only once a day)



- ✓ 100% give Hydroxycarbamide (Hydroxyurea) once day





Results

Administration (2 of 2)

- ✓ The main reason stated by parents for their child/children not receiving their medications was that the medication had run out (23%).
- ✓ 48% of parents stated that if they had forgotten to give the medication, they would give it as soon as they remembered.



Results

4. Parental knowledge and information

- ✓ 97% of parents believed that it was important to give their child/children medications daily.
- ✓ 98% knew why their child/children were on penicillin and folic acid, while 100% knew why their child/children were taking Hydroxyurea.
- ✓ All parents had received both verbal and written information from the hospital doctors/nurses (100%). Further information was obtained from the internet (10%) and from the pharmacist (6%).
- ✓ 50% of parents believed their child/children understood why they had to take daily medications, 40% felt their child/children were too young and 10% were unsure.

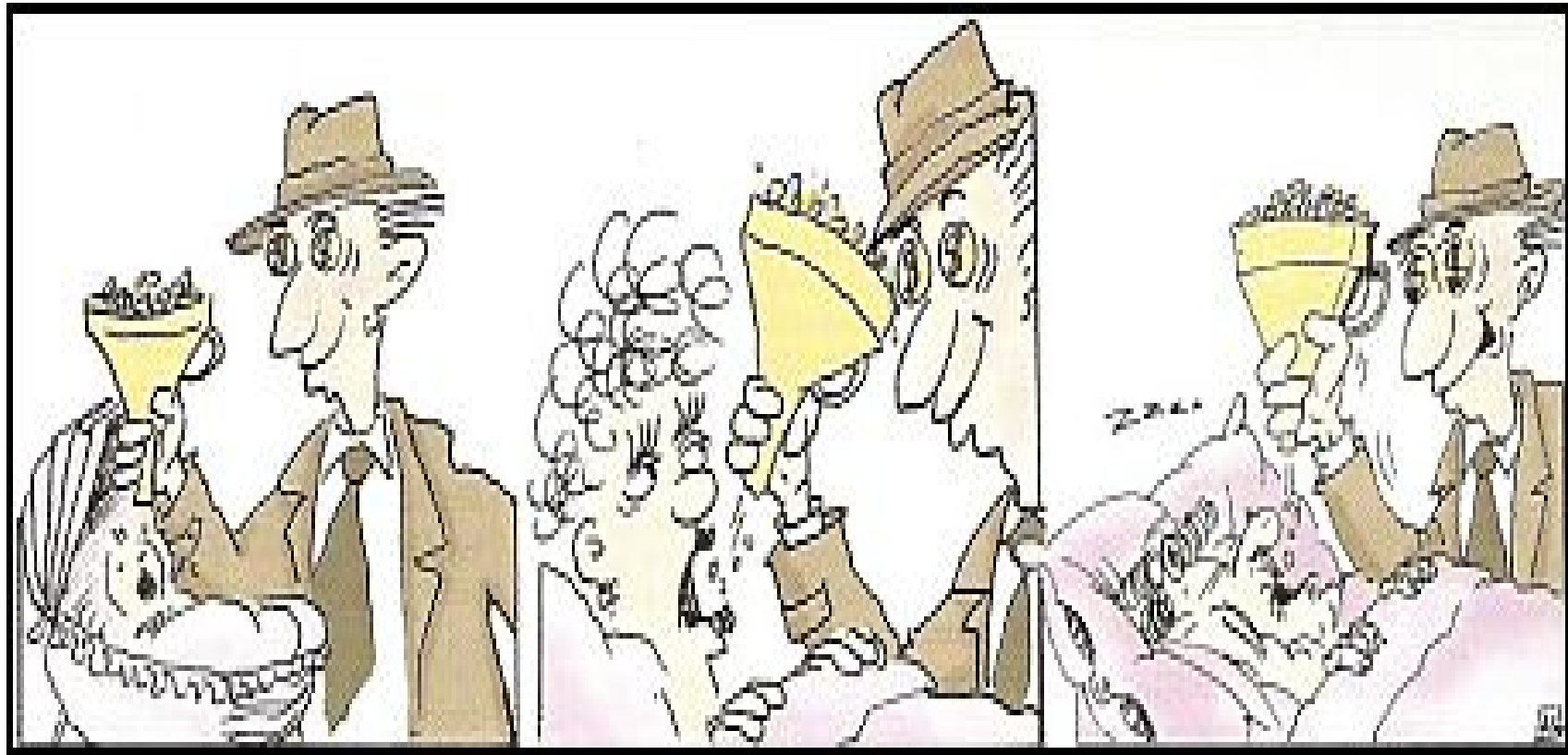


Results

5. Parental concerns/worries

- ✓ 38% of parents had worries about the medications they gave their child/children daily.
- ✓ The long term side effects accounted for 64% of these concerns. Other reasons included:
 - “because for how long will she continue to be taking it everyday. Why not four times a week instead of everyday”
 - “it is making them to be skinny”
 - “her teeth are coloured and she is dependable on the medications”
 - “because it is not easy on person living with medication. I prefer a life without medication is the better life”

Daily medication for life!





Our results compared to other studies

- ✓ A study conducted by Cummins, Heuschkel and Davies (1991) found compliance rates for penicillin prophylaxis above 49%.
- ✓ Berkovitch et al.(1998) found compliance was 67.4%.
- ✓ Patel et al. (2010) found compliance rates for penicillin was 54.9%, and folic acid 61.3%.
- ✓ Witherspoon and Drotar (2006) found that parents reported “perfect” compliance (56.7%)



Conclusion

- ✓ In our study we found that compliance was slightly higher than in other similar studies. This could be the result of the emphasis that is put on medications at each hospital contact.
- ✓ However, further investigation is warranted to determine the opportunities for improving compliance in this population.



Discussion

- ✓ Increasing overall compliance involves multiple factors such as better education, monitoring, access to pharmacy, medication calendars, support from family and relationship to healthcare professionals.
- ✓ Given that poor compliance can contribute to substantial worsening of their condition, increase healthcare costs and death, greater efforts are necessary to identify specific patients at increased risk for non-compliance.



Possible study limitations

- ✓ Measure of compliance was not a direct measure because we did not observe children's intake of medications. Therefore, medication compliance could be lower than what was reported/stated by parents.
- ✓ Parents may not have fully understood the questions.

Acknowledgements

- ✓ A special thanks to all the parents who took the time to complete the questionnaire.





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