

Comment

Medication for asthma in childhood: Conflicting interests between prescriber and final user?

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A paper by Sanz published elsewhere in this issue of the Journal – as well as a recent EURO Asthma Forum – focus on various perspectives of asthma medicines used for children with moderate to severe asthma. There are a number of aspects which need to be considered other than the pharmacological success of the medicines and their “rational use”. It would be fair to say that in these cases *prescribers have one set of goals, whilst children, as the final consumers of the medicines, may have another*. For pharmaceutical preparations to be effective in treating asthma, both of these dimensions need to be taken into account.

What we must now do is to *initiate a dialogue that will begin to break the silence between the prescriber and the child user* of asthma medicines by raising some issues which do not usually appear in discussions about appropriate pharmacological asthma therapy. Our commentary is derived from the experience of children who are under the regular care of prescribers and who agreed (along with their parents) to participate in two European qualitative research projects about asthma.¹ We anticipate that our remarks, based on semi-structured interviews and focus group discussions with children, will provide a context for further thought. We cannot speak on behalf of children who do not have regular access to prescribers or to medication – or address the even more profound silence of those children.

Children’s perspectives about asthma medication

There is no doubt that medicines play a central role in the lives of children with asthma. When seven to eleven year-olds are asked to draw a picture of their “last” asthma episode, inhalers and other apparatus associated with asthma medication almost always appear in the picture. They depict themselves being administered their medicines by an adult or using a nebulizer in the hospital. Sometimes their drawings

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consist only of the medicine delivery devices, described as “pumps”, “breathers”, “chambers” or “discs”. Often they refer to the medicines by their brand names. They discuss the contents of the devices (e.g., “powder”, “air”), provide details about how and when they use them, and explain differences between medicines for everyday use and those for “crisis” use. Children know where the medicines are kept in their homes and sometimes report that they may have to remind a parent to purchase a refill.

When compared to the level of knowledge which physicians and producers of asthma education materials hope to promote, it appears that children’s descriptions of the functions and use of their medicines are quite comprehensive and accurate. In focus group discussions, children sometimes exchange brand names of the asthma medicines they are using or have used in the past, and they even enter into debates with each other about what is correct use and what is actually “in” their inhalers. Children assimilate the necessary “basics” about the appropriate use of asthma medicines and report a considerable degree of knowledge about them. They even discuss side-effects of long-term use, not in pharmacological terms, but rather as personal concerns related to dependency. For example, the younger children ask if they will need their medication “forever”; the older ones wonder if they might become like drug addicts, dependent on the daily use of their medicines.

During consultations, physicians often address the parents and do not speak directly to the children. Nevertheless, children, as critical observers of adult behaviour, absorb many of the messages. Not speaking directly to a child may be a plus or a minus. Children often appear disinterested or embarrassed when an adult speaks directly to them. This may be less dependent on psycho-social developmental levels and more related to children’s perceptions of authority figures. Parents are aware that children are often very interested in “overhearing” what adults are saying to each other – especially when the adults are speaking in whispers.

The “protocol” of the prescriber

Physicians are trained to interpret symptomology, investigate clinical signs, and assign a diagnosis. Working within the framework of a specific disease, they hope to make their patients symptom-free – or at least to provide therapy for patients to control their symptoms or the means to predict when they will experience an exacerbation. In the case of asthma, the biomedical goal is to maintain free airway passages for the patient. Explaining the biological dimensions of asthma and prescribing asthma medication comprise the main methods of attempting to achieve this goal for the patient.

The medical educational consultation protocol focuses on clean airways: Parents and children are shown anatomical pictures of the lungs and cross-sections of the bronchi. Normal lungs and bronchi are contrasted with those which are constricted and obstructed with phlegm during an asthma attack. Possible causes for the tendency for bronchoconstriction, “wheezy lungs”, asthma episodes and crises are explained and further tests or monitoring may be suggested in order to track down the cause(s) and estimate the degree of severity of lung malfunction. Physicians select appropriate asthma medicines, discuss their effects on bronchoconstriction, and prescribe the brand names and dosage. Parents and children may be introduced to the peak flow meter as a method of assessing lung function on a daily basis and helping to regulate dosages of maintenance medicines. Allergens and situations to be avoided so as to prevent exacerbations are discussed, and parents are instructed about asthma-proofing the indoor home environment.

Even though physicians encourage parents not to become over-protective or restrict their children’s social life, the picture of constricted lungs remains fixed in the minds of parents. Children, on the other

hand, do not seem to concentrate on lung function. Indeed, when they describe symptoms they more often mention feelings in their throat (e.g., choking), chest (e.g., tightness in general), or stomach (e.g., vomiting during a crisis). Thus, the use of lung physiology diagrams may be counter-productive. For parents such an instructional approach emphasizes the need for keeping clear airways, and parents may be tempted to give the medicines to their children for any slight sign (e.g., a sneeze) which may lead to medication over-use. For children, the interior workings of their lungs may appear quite irrelevant – they are more interested in other matters related to their asthma.

Children's concerns about asthma medicines

Children want to become free from asthma symptoms and crises, and in this respect their concerns coincide perfectly with those of their physicians who prescribe medicines to reach this goal. However, children also want to live “like other children” and the desire not to be “different”, to be socially “normal”, may prompt them to avoid using their maintenance medicines when their peers are present.

While paediatricians and nurses teach children about the technicalities of using asthma medicines, they may often overlook the preparation of children for the social dimensions of medicine use. It is often the social and personal aspects of using asthma medicines which ultimately determine their appropriate or inappropriate use or non-use by children.

Children want to avoid symptoms but they also want to be able participate in physical activities. They do not want to be chosen last when team games are organized, or be forced to drop out in the middle of a race or dance class, or be relegated to sitting on a bench during physical education class. They are faced with the dilemma between using their medicines during school parties, excursions with classmates (nature trips, visits to zoos, attending a circus), while visiting friends who have household pets – or avoiding these activities altogether. Some may be so intent on passing as “normal” that they over-use their inhalers before physical activity, out of sight of teachers and peers, or alternatively they try to test their limits without their preventive medicines.

In addition to the social aspects of “to use or not to use” their maintenance medicines, children face dilemmas in their personal preferences. Perhaps the best example is related to household pets, furry toy animals and other playthings attracting housemites – some of which may be their special favourites. Young children may become alarmed when they learn that they must be separated from these possessions or have their teddy bears placed in the freezer for 24 hours, as is sometimes recommended to reduce housemite infestation. They are concerned less about future asthma symptoms than about their present need for their personal comforters. They view their medicines as allowing a compromise – one which needs to be negotiated with their caregivers and themselves.

Final remarks

These are some of the concerns of children which might be kept in mind within the context of asthma medicine use by children. It is important to appreciate the factors which contribute to their medicine use knowledge and assimilation of information, and which motivate them to use their medicines as correctly as they can.

Forbidding athletics, restricting social life, discarding a pet, and living in a glass bubble may help to ensure clear airways. These restrictions do not allow children to participate in a plan for an asthma

medication programme which is compatible with their desires for living with asthma. Complete dependence of children on medications is also not an answer. The silent space between prescriber's needs and children's needs is an area of continual negotiation – requiring that both “sides” speak and listen to each other.