

## EDITORIAL

## Lack of self perception of illness in children with asthma: the real reason for referral?

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\*Alfred PE Sachs<sup>a</sup>

<sup>a</sup> Associate Professor, University Medical Centre Utrecht, Julius Centre for Health Sciences and Primary Care, The Netherlands

\*Correspondence:  
University Medical Centre Utrecht,  
Julius Centre for Health Sciences  
and Primary Care  
P.O. 85500  
3508 GA  
Utrecht  
The Netherlands  
Tel: +31 (0)88 756 81 81  
E-mail: a.p.e.sachs@umcutrecht.nl

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All training programs for general practitioners (GPs) share the same moment of awakening, not at the end, but during each session: a moment of unanimous attention followed by unanimous consensus, with GPs aligned on one side and the specialist on the other. All this is initiated by the question: "Patients managed by GPs or specialists: is there a difference?"

In terms of chronically ill patients – as opposed to patients with acute illness – the answer nearly always turns out to be a highly emotional issue. The reason is that GPs, as well as specialists, become poker players, each in an atmosphere of "emotionally-based medicine". Both sides take up a negotiating position, and have a fall-back position based on what they usually expect in daily practice. However, after a while there comes a moment when mutual bluff is revealed and both sides can become antagonistic, full of suspicious feelings. You do not need to be a psychiatrist to conclude that something very human is happening here; a balance between overestimation of oneself on the one hand, and on the other a sense of reality as one glimpses towards the horizon.

In the short term, the person who speaks most loudly and (ostensibly) clearly usually turns out to be the candidate leading his herd of believers. But will he or she also be leading in the longer term? We therefore have to keep our feet on the ground and realise that we are living in the Sackett era of "evidence-based medicine".<sup>1</sup> Focussing on the question of whether or not there is a difference between patients managed by GPs or specialists, the only answer is by means of a well designed prognostic study.<sup>2</sup> Prognostic studies are characterised by:

1. A mimic of real-life situations, considering multiple predictors while the factor time or follow-up is elementary.
2. A main objective, providing quantitative knowledge about occurrence of a certain health outcome during a pre-defined time period, in a well-defined group of persons or patients – all this with a certain condition as a function of (as mentioned) multiple predictors.
3. They are observational, in which a certain condition in a well-defined group of persons or patients will be followed for a certain period in order to monitor the occurrence of an expected outcome. Preferably, data are collected prospectively rather than retrospectively because this allows for optimal measurement of predictors and outcome, and inadequate (incomplete) follow-up.
4. The purpose to predict a future occurrence of a certain health outcome in a subject. It is important to understand that this goal is predictive or descriptive (non-causal). This most fundamentally distinguishes prognostic research from causal research. Causal research is aetiologic and intervention-based research. In aetiologic research, the mission is to assess whether an outcome can be causally attributed to a particular risk factor, which typically requires an adjustment for confounders. This is essential to prove causality.
5. Aiming at a prediction, as accurately as possible, of the probability or risk of future occurrence of a certain outcome as a function of multiple predictors. This aim is not to explain the outcome. Because no central factor or determinant exists whose causal effect must be isolated from the effects of other variables, in prediction research confounding is not an issue.

Why this focus on prognostic studies? Because, as far as I know, for the first time in clinical research, an evidence-based prognostic study titled, "Children with asthma on inhaled corticosteroids managed in general practice or by hospital paediatricians: is there a difference?" by Kuethe *et al.* has been completed and published in this issue of the *Primary Care Respiratory Journal*.<sup>3</sup> I am convinced that this study will be presented in many training programs for GPs, and paediatricians as well, and that it will find its way into several guidelines. Of course, more studies in this field will be initiated because they are so desperately needed.

However, whatever the amount or power of these studies, one should be aware that all prognostic studies do have their limitations: they do not explain the outcome – rather they present associations and not causalities. Thus, Kuethe *et al.* jump to the conclusion that regular review visits for children with moderate to severe asthma, as is the case in the paediatrician group, may lead to an improvement in their asthma control. As this is an association, and by no means a causality, the alleged variable number of visits should be the subject of a randomised controlled intervention study. The authors did choose asthma control as an outcome. This should serve as a model in further studies, because it is an outcome that really matters to patients. Indeed, one should not study so-called proxy or intermediate outcomes unless a clear causal relationship between such an intermediate outcome and outcomes more relevant for patients has been recognised. Outcomes should be interpreted in an objective way, independently of the role of the researcher, and we should therefore treat the authors' conclusion – a significantly better ACQ (Asthma Control Questionnaire)<sup>4</sup> in the paediatrician group – with caution. One should realise that after dichotomising at 0.75, this being a validated cut-off point for well controlled asthma, no significant difference in ACQ between the two groups exist. As confounding may not play any role in prognostic studies, other biases certainly do – for instance, when the outcome assessor is aware of the determinants.

Nevertheless, despite the fact that this is a retrospective (instead of a more preferable prospective) cohort study, despite the fact that aspects relating to patient inclusion should be part of the discussion, and despite the likely researcher bias interpreting the ACQ scores, Kuethe *et al.*'s study is very interesting.<sup>3</sup> Interesting, because we have to realise from our knowledge of daily practice that some of our chronically ill patients are in favour of being referred to a specialist, in this case the paediatrician. The question is: which patients derive benefit? Before answering this question, we should ask any patient what he or she expects from his or her doctor. The answer will be: dedication and knowledge. Dedication is beyond dispute, and therefore is *sine qua non*. But it is the knowledge we should focus on. Therefore, in answer to the question as to which patient derives benefit from a referral to the paediatrician (or other specialist), we have to look at the daily triptych of GPs in clinical practice, which says:

1. If, for good reason, GPs are confident about their knowledge,

and signs and symptom are in concordance with the diagnosis or prognosis, less need for a referral exists.

2. If signs or symptoms are not in concordance with the diagnosis or prognosis, a referral to the specialist might be considered.
3. If the perception of patients about the illness is not in concordance with its diagnosis or prognosis, this might also be a reason for referral.

Perception of illness is a topic on every patient's mind during every consultation. However, it is not always on every doctor's mind... And it is illness perception that is of such prognostic value for every patient during their life or illness period. This is especially true in the minds of parents, who may have a tendency to be (perhaps putting it mildly?) sometimes overanxious. If, as in the study by Kuethe *et al.*, parents want their child to be seen by a paediatrician – maybe because they underestimate, rightly or wrongly, the knowledge and experience of their GP – this could interfere fundamentally with the primary outcome; i.e. a selection bias could occur, since parents of children with asthma who request referral to a paediatrician will be more satisfied with the paediatrician's management of their child's illness, and as a consequence, will project their feelings of reassurance onto their children.

Unfortunately, perception of illness questionnaires are not very common in prognostic studies. It has to be considered that not only predictors concerning the illness itself – such as the ACQ in this study – but also the perception of the patient (or parents in the case of young children) about his or her illness, should be part of future studies.<sup>5,6</sup>

Till then, the results of this study<sup>3</sup> will be discussed during future training programs. This study should give food for thought and engender a less emotional and more rational discussion; if we, as GPs, want our patients to get better, we should first of all improve our knowledge as well as our patients' perception of their illness.

#### Conflict of interest declaration

None

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