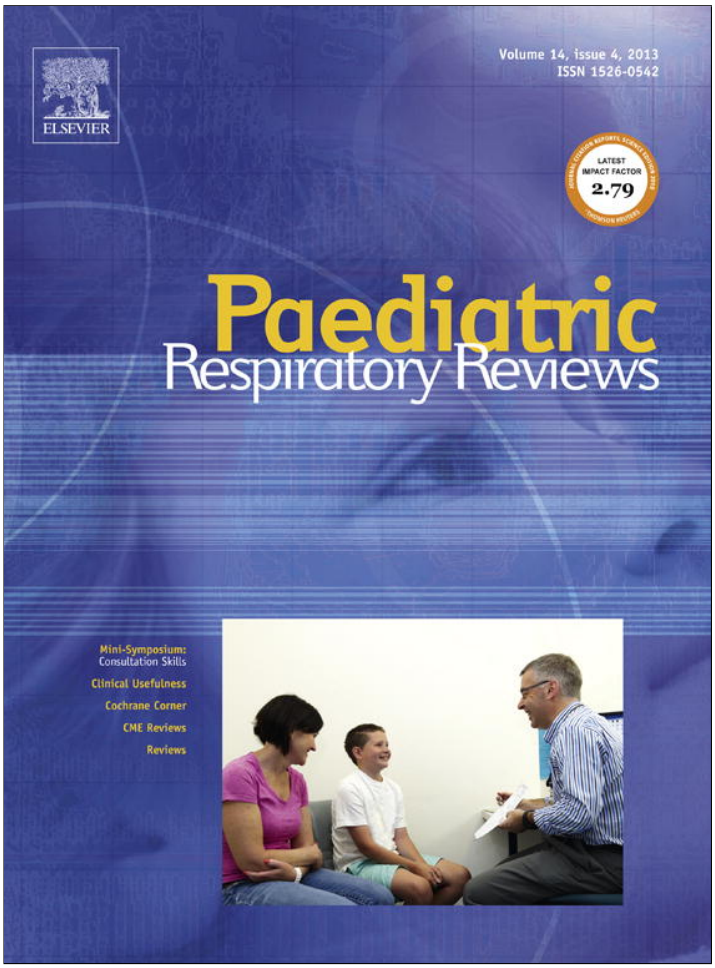

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Mini-Symposium: Consultation Skills

Using communication skills to improve adherence in children with chronic disease: The adherence equation

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EDUCATIONAL AIMS

- To review the evidence on interventions to improve adherence
- To discuss the four essential steps to improve adherence: achieving close follow-up, engaging in constructive dialogue, discussing barriers and beliefs, and educate with empathy
- To show that good adherence to maintenance medication in chronic disease can be achieved

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SUMMARY

Nonadherence to maintenance medication is common in paediatric chronic conditions. Despite the common belief that nonadherence is therapy-resistant, and the apparent lack of evidence for successful interventions to improve adherence, there is, in fact, a considerable body of evidence suggesting that adherence can be improved by applying specific communicative consultation skills. These can be summarized as the adherence equation: adherence = follow-up + dialogue + barriers and beliefs + empathy and education => concordance. Close follow-up of children with a chronic condition is needed to establish a therapeutic partnership with the family. Teaching self management skills is not a unidirectional process of providing information, but requires a constructive and collaborative dialogue between the medical team and the family. Identifying barriers to adherence can be achieved in a non-confrontational manner, by showing a genuine interest what the patient's views and preferences are. In particular, parental illness perceptions and medication beliefs should be identified, because they are strong drivers of nonadherence. Through empathic evidence-based education, such perceptions and beliefs can be modified. By applying these strategies, concordance between the child's family and the medical team can be achieved, resulting in optimal adherence to the jointly created treatment plan.

Adherence to medical treatment is defined as the extent to which a person's behaviour – taking medication, following a diet, executing lifestyle changes, corresponds with agreed recommendations from a health care provider (http://apps.who.int/medicinedocs/en/d/Js4883e/6.html). Nonadherence to medical treatment for paediatric chronic diseases is common, and is a strong predictor of poor outcome,[1] for example in childhood asthma.[2–4] It is a source of frustration to many clinicians: they know the condition the child is suffering from is treatable, they prescribe the appropriate therapy, but the patient does not receive this effective treatment. Paediatric nonadherence is primarily parental nonadherence until the patient reaches adolescence. When nonadherence is suspected or acknowledged, most physicians go into explaining mode, stressing the effectiveness of the treatment and the importance of adherence. Unfortunately, it has been known for decades that this approach of providing and repeating unsolicited advice is ineffective.[5,6] A recent systematic review of interventions to enhance medication adherence in paediatric patients with chronic illness concluded that "education interventions alone are insufficient to promote adherence in children and adolescents".[7] Paediatricians, when confronted with parents (or patients) who continue to be nonadherent despite the physician's efforts to educate the family, may give up trying to improve adherence altogether. We believe such pessimism is not justified. There is good evidence to support the hypothesis that physicians can improve adherence to treatment by their patients, and that good adherence can be achieved.

In accordance with an earlier study in teenagers from the United States,[8] we recently demonstrated that very high adherence

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rates (median 92%) can be achieved in young children with asthma over 3-months of follow-up.[9] Interestingly, this high adherence was achieved during regular follow-up, and was not the result of a specific study intervention aimed at improving adherence. Neither the asthma nurses, nor the attending physicians received specific training in adherence improvement skills. We believe that excellent adherence to maintenance medication in asthma is the result of the organization of care and follow-up for these children, focusing on tailored self-management by building and maintaining a strong and constructive partnership with patients and their parents.[10] In this article, we discuss the evidence underlying this approach. This is based on the understanding that adherence to medication (or to lifestyle advice) is not a single construct but a cluster of interacting behaviours influenced by social and cultural factors.[11] Therefore, adherence is unlikely to improve with a single simple intervention such as providing information or advice.[5,6] There is agreement in the literature that improving adherence requires a multidimensional approach.[7,12] Providing information, while necessary to allow patients to understand why and how to adhere, is only one of the essential components of this approach. The aim of this review is to provide insight in determinants of adherence, and to offer practical suggestions for busy clinicians how to optimize adherence by focusing on four essential components of paediatric chronic disease management, all of which centre around constructive collaboration between physicians and patients/parents.

THE ADHERENCE EQUATION

In the following sections, we will discuss the four building blocks of improving adherence, using asthma as the main example. As a memory aid, this can be remembered as an equation comprising the first six letters of the alphabet (Figure 1). This equation builds on the premise that good adherence can only be achieved if doctors and patients/parents are in concordance (i.e., agree) on the optimal disease management strategy, after discussing the pros and cons of different strategies.

FOLLOW-UP

Because children with a chronic disease receive almost all of their treatment in their own environment outside the hospital or clinic, adherence to treatment is determined almost entirely in that setting. Influencing such a complicated set of behaviours in the desired direction, i.e, improving adherence, requires regular follow-up as a first prerequisite.[7] The other building blocks of the adherence equation can only be achieved if repeated contacts are established between the patient/parents and the medical team. Building and maintaining a therapeutic partnership between the medical team and patient/parents, and helping patients and parents to develop adequate self-management skills, requires a number of visits, not only to provide information, but also to address concerns and questions that patients and parents have about the disease and the treatment plan.[12]

Regular follow-up is needed to support the development of self-management skills, producing a long-lasting increase in parental confidence in their ability to manage acute wheeze and breathlessness.[13] In a randomized controlled trial comparing follow-up in a hospital-based paediatric asthma clinic to that in primary care practices by general practitioners, all children in the hospital clinic had scheduled repeated follow-up, compared to only 20% of children in primary care. Conversely, unscheduled visits were more common in primary than in secondary care. Asthma was significantly better controlled in the group with regular scheduled follow-up in hospital.[14] Similarly, in an American study of ethnic minority patients from underprivileged families, who usually show poor adherence and poor asthma control, high adherence and excellent asthma control could be achieved by enrolling them into a program of regular follow-up and repeated tailored self-management skills training.[8] Thus, regular scheduled follow-up is the first step towards achieving good adherence to maintenance medication in paediatric chronic disease.

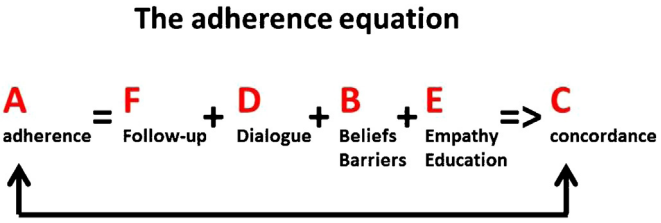

Figure 1. The adherence equation.

Obviously, follow-up per se does not ensure adherence. The next three steps of the adherence equation address the importance of a reciprocal relationship in follow-up consultations, the content of these visits, and the physician's professional communication skills in this process, all of which are also important in determining adherence.

DIALOGUE

For a range of chronic conditions, research has shown that patients (and their parents) prefer to collaborate with the medical team in constructive dialogue.[15,16] Parents of children with a chronic disease, while appreciating the role of the doctor as the medical expert, strongly feel that they know their own child best, and are therefore the best qualified people to decide what strategy suits their child best.[17,18] Many of these parental illness perceptions, however, are medically incorrect, and hamper optimal management of the child's disease.[18] There is observational evidence that these inappropriate parental beliefs can change during long-term management including self-management education and follow-up.[18] Unfortunately, many parents of children with chronic disease feel insufficiently supported by the medical team during this process, and are left with the feeling that they need to manage their child's condition completely by themselves.[15] Actively involving the child and the parents in a discussion of their preferences, concerns, context, and their treatment goals, and supporting them in adjusting their inappropriate illness and medication beliefs,[12,19] helps to create a mutually agreed treatment plan, which is likely to improve adherence.[12] This is a reciprocal process requiring constructive dialogue.

BARRIERS AND BELIEFS

Once a dialogue between medical team and patients/parents has been established, barriers for nonadherence can be explored in a non-judgmental manner.[6] Barriers for nonadherence can be divided into three groups (Table 1).[20]

Treatment related barriers comprise any factor that complicates treatment. Complex dosing schedules or inhalation procedures are likely to jeopardize adherence.[21] If not explained properly and stressed repeatedly, the lack of an immediately discernible effect of preventive medication will undermine the patient's motivation to take it.[22] Adverse effects, particularly when they are troublesome, highly visible, or considered dangerous, are also drivers of nonadherence.[23] In some countries or populations, excessive cost of medication, or lack of insurance reimbursement for such costs, increases nonadherence.[22]

Table 1
Barriers for nonadherence.

Treatment related barriers	Clinician related barriers	Patient-related barriers
Complex regimen	Difficulty scheduling appointments	Poor understanding of treatment
Lack of immediate medication effect	Uninterested clinician	Lack of trust in medical team
Adverse effects	Rotating physicians	Psychological or psychiatric problems in patient or family
Cost		Social problems (poverty, chaotic family structure)
		Lack of motivation to adhere (based on illness perceptions and medication beliefs)

Clinician related barriers include difficulties in scheduling appointments; unfriendliness, lack of support and interest by the physician; and encountering a different physician with every follow-up visits.[20] Such factors hamper constructive dialogue and the development of a patient-provider-partnership.

Patient-related barriers are a large and diverse group (Table 1), ranging from simply forgetting to take the medication,[24] poor understanding of the treatment rationale,[25] psychological or psychiatric disease limiting the patient's or the parents' ability to follow recommendations,[26] and social issues such as poverty and chaotic family structure,[22,27] to lack of motivation driven by illness perceptions and medication beliefs which are not in agreement with the medical view on the disease and its therapy.[18] We will now discuss the most important of these patient-related barriers, illness perceptions and medication beliefs, in more detail.

Most research suggests that these illness perceptions and medication beliefs are the key barriers impeding adherence.[28] Based on these cognitions, the patient (parent) takes a deliberate decision not to follow the medical team's advice.[28] For example, many patients do not consider asthma to be a chronic disease, but believe the disease only to be present when they experience symptoms ("no symptoms, no asthma").[29] Others may believe that asthma is a self-limiting disease, or that treating it with maintenance medication reduces the body's own power to heal itself.[18] In addition, almost all parents express strong resistance against giving medication on a daily basis to their child because it "does not feel right to pour chemicals into such a little body".[18] This may be augmented by fear of side effects, for example for corticosteroids.

Because of the key role of these illness perceptions and medication beliefs in determining nonadherence, ongoing and repeated attention to these issues is of paramount importance in the management of childhood chronic respiratory diseases. The next section will deal with *how* clinicians can explore this in a supportive and non-judgmental fashion. Identifying barriers is necessary to overcome them; most barriers emerge during the process of tailored teaching of self-management skills and home visits.[10,30] When identified, parental questions and concerns can be addressed through providing specific information when requested by parents.[31] In this process, listening and asking questions precedes, and guides, talking and providing information.

EMPATHY AND EDUCATION

Empathy. Discussing the patient's and parents' illness perceptions and medication beliefs requires empathy, the physician's ability to express a genuine interest in the patient's (parents') views, beliefs, convictions, and preferences. It has been shown that encounters with an empathic physician not only increase patient satisfaction,[32,33] but also improve health outcomes.[34] A warm, reassuring, and empathic physician, therefore, is more likely to generate adherence to the treatment plan by the patient and parents than doctors with a formal and business-like approach.[20] Unfortunately, research has shown that empathy tends to decline as physicians proceed through their postgraduate training and further career.[35] Applying empathy to its full efficacy in clinical consultations therefore requires a conscious effort, and a deliberate application and ongoing fine-tuning of communication

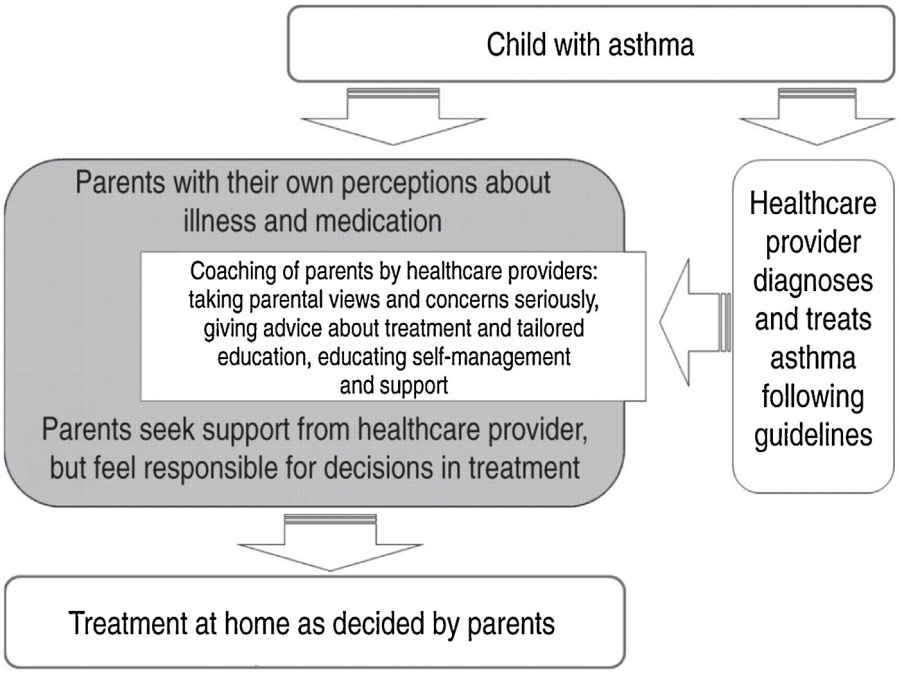

Figure 2. The coaching role of healthcare providers in educating children with asthma and their parents (reproduced from[10], with permission).

strategies. The acquisition and mastering of such communication skills through deliberate practice is discussed in the final paper of this series.

Education. The content of tailored self-management education has been discussed above. In this section, we will focus on the method of delivery of this education. Traditionally, educating children with chronic disease and their parents is approached unidirectionally, with the medical team as the sender, and the patient and parents as passive recipients of information. The ineffectiveness of this approach not only comes from systematic review evidence already discussed,[7] but it also widely recognized in the field of medical education, where an active role of the learner is a key factor in determining education results.[36] Education can only be effective if the learner is actively engaged, and is approached as a partner. Children with a chronic condition can only be managed effectively if the medical team succeeds in helping the patient and parents to acquire and maintain adequate self-management skills. The literature reviewed in this paper strongly suggests that such education requires a coaching, rather than a directive, role of the medical team (Figure 2).[10]

As a general rule, parents appreciate the medical team providing evidence based education, tailored to the patient's (and parents') context, views, and preferences.[31] Self-management education provided repeatedly in this fashion, coupled with goal setting and other behavioural approaches, is most likely to be effective.[7]

CONCORDANCE

If fulfilled successfully, the four building blocks of the adherence equation will result in concordance, physicians and patients/parents agreeing on the optimal management strategy and treatment plan for the individual patient,[37] as discussed in the previous paper of this series. If parents, patients and the medical team reach concordance, adherence is likely to be achieved and can be maintained. Therefore, striving for concordance with patients and parents on the therapeutic approach for the child with a chronic illness is a useful strategy in the management of these patients.

CONCLUSIONS

Good adherence to maintenance medication (and other components of the management plan) in childhood chronic illness can be achieved and maintained in most patients by paying attention to the components of the adherence equation (Figure 1): ensuring structured and repeated follow-up; engaging in a constructive dialogue aimed at understanding the patient's (and parents') views, preferences, and context; addressing barriers to nonadherence, in particular illness and medication beliefs in a non-judgmental manner; expressing empathy in providing tailored evidence-based self-management education; and thus achieving concordance. In addition to a number of organizational issues, this approach requires the deliberate acquisition, mastering, and application of a set of communication skills. Although changing one's consultation style is not easy,[38] these communication skills can be learned,[39] in particular through deliberate practice. This is the focus of the subsequent paper in this series.

References

1. Dimatteo MR, Giordani PJ, Lepper HS, Croghan TW. Patient adherence and medical treatment outcomes: a meta-analysis. *Med Care* 2002;**40**:794–811.
2. Milgrom H, Bender B, Ackerson L, Bowry P, Smith B, Rand C. Noncompliance and treatment failure in children with asthma. *J Allergy Clin Immunol* 1996;**98**:1051–7.
3. Jentzsch NS, Camargos P, Sarinho ES, Bousquet J. Adherence rate to beclomethasone dipropionate and the level of asthma control. *Respir Med* 2012;**106**:338–43.
4. Fuhrman C, Dubus JC, Marguet C, Delacourt C, Thumerelle C, de BJ, Delmas MC. Hospitalizations for asthma in children are linked to undertreatment and insufficient asthma education. *J Asthma* 2011;**48**:565–71.
5. Haynes RB, McKibbon KA, Kanani R. Systematic review of randomised trials of interventions to assist patients to follow prescriptions for medications. *Lancet* 1996;**348**:383–6.
6. Lask B. Motivating children and adolescents to improve adherence. *J Pediatr* 2003;**143**:430–3.
7. Dean AJ, Walters J, Hall A. A systematic review of interventions to enhance medication adherence in children and adolescents with chronic illness. *Arch Dis Child* 2010;**95**:717–23.
8. Scott L, Morphew T, Bollinger ME, Samuelson S, Galant S, Clement L, O'Cull K, Jones F, Jones CA. Achieving and maintaining asthma control in inner-city children. *J Allergy Clin Immunol* 2011;**128**:56–63.
9. Klok T, Kaptein AA, Duiverman EJ, Brand PL. High inhaled corticosteroids adherence in childhood asthma: the role of medication beliefs. *Eur Respir J* 2012.
10. Klok T, de Groot EP, Brouwer AFJ, Brand PLP. Follow-up of children with asthma. *Eur Respir Mon* 2012;**56**:210–23.
11. Steiner JF. Rethinking adherence. *Ann Intern Med* 2012;**157**:580–5.
12. DiMatteo MR, Haskard-Zolnierek KB, Martin LR. Improving patient adherence: a three-factor model to guide practice. *Health Psychol Rev* 2012;**6**:74–91.
13. Hederos CA, Janson S, Hedlin G. Six-year follow-up of an intervention to improve the management of preschool children with asthma. *Acta Paediatr* 2009;**98**:1939–44.
14. Kuethe MC, Vaessen-Verberne AA, Bindels PJ, Van Aalderen WM. Children with asthma on inhaled corticosteroids managed in general practice or by hospital paediatricians: is there a difference? *Prim Care Respir J* 2010;**19**:62–7. 8p.
15. Gore C, Johnson RJ, Caress AL, Woodcock A, Custovic A. The information needs and preferred roles in treatment decision-making of parents caring for infants with atopic dermatitis: a qualitative study. *Allergy* 2005;**60**:938–43.
16. Caress AL, Beaver K, Luker K, Campbell M, Woodcock A. Involvement in treatment decisions: what do adults with asthma want and what do they get? Results of a cross sectional survey. *Thorax* 2005;**60**:199–205.
17. Moreau A, Carol L, Dedianne MC, Dupraz C, Perdrix C, Laine X, Souweine G. What perceptions do patients have of decision making (DM)? Toward an integrative patient-centered care model. A qualitative study using focus-group interviews. *Patient Educ Couns* 2012;**87**:206–11.
18. Klok T, Brand PL, Bomhof-Roordink H, Duiverman EJ, Kaptein AA. Parental illness perceptions and medication perceptions in childhood asthma, a focus group study. *Acta Paediatr* 2011;**100**:248–52.
19. Borrelli B, Riekert KA, Weinstein A, Rathier L. Brief motivational interviewing as a clinical strategy to promote asthma medication adherence. *J Allergy Clin Immunol* 2007;**120**:1023–30.
20. Bender BG. Overcoming barriers to nonadherence in asthma treatment. *J Allergy Clin Immunol* 2002;**109**:S554–9.
21. Bender BG, Bender SE. Patient-identified barriers to asthma treatment adherence: responses to interviews, focus groups, and questionnaires. *Immunol Allergy Clin N Am* 2005;**25**:107–30.
22. Celano MP, Linzer JF, Demi A, Bakeman R, Smith CO, Croft S, Kobrynski LJ. Treatment adherence among low-income, African American children with persistent asthma. *J Asthma* 2010;**47**:317–22.
23. Laforest L, El Hasnaoui A, Pribil C, Ritleng C, Osman LM, Schwalm MS, Le Jeunne P, Van Ganse E. Asthma patients' self-reported behaviours toward inhaled corticosteroids. *Respir Med* 2009;**103**:1366–75.
24. Burgess SW, Sly PD, Morawska A, Devadason SG. Assessing adherence and factors associated with adherence in young children with asthma. *Respirology* 2008;**13**:559–63.
25. Weinstein AG. The potential of asthma adherence management to enhance asthma guidelines. *Ann Allergy Asthma Immunol* 2011;**106**:283–91.
26. Bender B, Milgrom H, Rand C, Ackerson L. Psychological factors associated with medication nonadherence in asthmatic children. *J Asthma* 1998;**35**:347–53.
27. Fiese BH, Wamboldt FS, Anbar RD. Family asthma management routines: connections to medical adherence and quality of life. *J Pediatr* 2005;**146**:171–6.
28. Kaptein AA, Klok T, Moss-Morris R, Brand PL. Illness perceptions: impact on self-management and control in asthma. *Curr Opin Allergy Clin Immunol* 2010;**10**:194–9.
29. Halm EA, Mora P, Leventhal H. No symptoms, no asthma: the acute episodic disease belief is associated with poor self-management among inner-city adults with persistent asthma. *Chest* 2006;**129**:573–80.
30. Bracken M, Fleming L, Hall P, Van Stiphout N, Bossley C, Biggart E, Wilson NM, Bush A. The importance of nurse-led home visits in the assessment of children with problematic asthma. *Arch Dis Child* 2009;**94**:780–4.
31. Brouwer AFJ, Brand PLP. Asthma education and monitoring: what has been shown to work. *Paediatr Respir Rev* 2008;**9**:193–200.
32. Henry SG, Fuhrel-Forbis A, Rogers MA, Eggly S. Association between nonverbal communication during clinical interactions and outcomes: A systematic review and meta-analysis. *Patient Educ Couns* 2012;**86**:297–315.
33. Cousin G, Schmid MM, Roter DL, Hall JA. Concordance between physician communication style and patient attitudes predicts patient satisfaction. *Patient Educ Couns* 2012;**87**:193–7.

34. Di Blasi Z, Harkness E, Ernst E, Georgiou A, Kleijnen J. Influence of context effects on health outcomes: a systematic review. *Lancet* 2001;**357**:757–62.
35. Neumann M, Edelhauser F, Tauschel D, Fischer MR, Wirtz M, Woopen C, Haramati A, Scheffer C. Empathy Decline and Its Reasons: A Systematic Review of Studies With Medical Students and Residents. *Acad Med* 2011;**86**:996–1009.
36. Mazmanian PE, Davis DA. Continuing medical education and the physician as a learner: guide to the evidence. *JAMA* 2002;**288**:1057–60.
37. Riekert KA, Butz AM, Eggleston PA, Huss K, Winkelstein M, Rand CS. Caregiver-physician medication concordance and undertreatment of asthma among inner-city children. *Pediatrics* 2003;**111**:e214–20.
38. Towie A, Godolphin W, Grams G, Lamarre A. Putting informed and shared decision making into practice. *Health Expect* 2006;**9**:321–32.
39. de Ridder DT, Theunissen NC, van Dulmen SM. Does training general practitioners to elicit patients' illness representations and action plans influence their communication as a whole? *Patient Educ Couns* 2007;**66**:327–36.