

Outpatient parents' views on shared-decision-making at an Italian children's hospital

Paola Rosati^{1,*}, Viviana Di Salvo², Roberto D'Amico³, Sara Balduzzi³, Rosaria Giampaolo², Mercedes Rita Marina Mazziotta², Cesare Guerra², Giovanna Menichella², Stefania P. Cosentino², Cecilia Carlino⁴, and Vincenzo Di Ciommo¹

¹Unit of Clinical Epidemiology Bambino Gesù, Children's Hospital, IRCCS, Viale Ferdinando Baldelli 41, Rome 00146, Italy, ²Department of Paediatrics, Outpatients' Unit, Bambino Gesù, Children's Hospital, IRCCS, Piazza Sant'Onofrio 4, Rome 00165, Italy, ³Department of Diagnostic Clinical and Public Health Medicine, University of Modena and Reggio Emilia, Via del Pozzo 71, Modena 41124, Italy and ⁴Faculty of Medicine and Surgery, Sapienza University, Piazzale Aldo Moro 5, Rome 00185, Italy

*Corresponding author. E-mail: paola.rosati@opbg.net

Summary

Information is lacking on what parents in southern European countries know and how they view clinical shared-decision-making (SDM) for their children. This survey assesses general parental views on SDM and patient-physician SDM relationships in an Italian paediatric outpatients' clinic. In a 3-month cross-sectional survey, we enrolled 458 consecutive native and foreign Italian-speaking parents bringing their children to our public hospital for various reasons. Parents completed an anonymous questionnaire exploring their general views on SDM, including what doctor-patient relationship predominates today, and what approach reassures them most. Multivariate logistic regression analysed outcome data from parental questionnaire answers. Results are reported as percentages, odds ratios (OR) and 95% confidence intervals (CI). Multivariate logistic regression showed that 440 parents (96.1%) appreciated SDM, 245 (53.5%) preferred SDM for choosing children's treatment, 126 (27.5%) answered that SDM is the predominant relationship today, and most parents 275 (60.0%) felt reassured by SDM. More native than foreign Italian-speaking parents preferred SDM (97.0 vs 89.7%, OR = 3.8; 95% CI = 1.4–10.8). Highly-educated parents preferred SDM for choosing their child's therapy (57.9 vs 34.1%, OR = 2.7; 95% CI = 1.6–4.4) and this approach reassured them (64.3 vs 41.2%, OR = 2.5; 95% CI = 1.6–4.1). In conclusion, parents bringing children to an Italian outpatient clinic, especially highly-educated parents, wish to be offered SDM and find it reassuring. These findings should encourage paediatricians working in a challenging multicultural environment to change their physician-centred approach and engage parents in tailored SDM strategies.

Key words: parental views, perception, tailored intervention, engagement

INTRODUCTION

Even though health care policy-makers and clinicians have for 20 years deemed shared decision-making (SDM) crucial for patient-centred care (Barry *et al.*, 1988; Institute of Medicine, 2001; Schor and The American Academy of Pediatrics Task Force on the Family, 2003), the idea still lacks widespread definition, and universal acceptance in the medical community (Levinson *et al.*, 2005; Légaré *et al.*, 2010; Troug, 2012; Gulbrandsen *et al.*, 2014; Shay and Lafata, 2014; Hargraves *et al.*, 2016). Equally important, the complex modern Western health-care systems know little about patients' desire to participate in choosing diagnostic or treatment options (Elwyn *et al.*, 1999, 2013; Dixon-Woods *et al.*, 2006; Shay and Lafata, 2014). How patients perceive SDM reportedly differs according to cultural and other factors (physician perceptions, patient perceptions, observer ratings) (Boote *et al.*, 2012; Coulter *et al.*, 2008; Flynn *et al.*, 2012). Few primary studies (Campbell *et al.*, 2006; Yin *et al.*, 2012; Lipstein *et al.*, 2012, 2015), and three systematic reviews and meta-analyses (Coyne *et al.*, 2013; Flynn *et al.*, 2012; Wyatt *et al.*, 2015) failed to conclude whether SDM improves clinical outcomes in children.

In our outpatient hospital clinic, day-to-day practice, especially at weekends, can entail chaotic and unforeseen situations, time constraints, and new clinical questions to answer (Stein *et al.*, 2005). Among other problems leading to poor physician-patient communication, no study has yet investigated cross-cultural differences related to an SDM clinical approach, especially in the increasingly multicultural outpatients' paediatric settings witnessed over the past 30 years. Speaking with digitally-informed parents and explaining the therapeutic options for their children is an especially challenging task for paediatricians (Shields *et al.*, 2010; Rosati, 2013). Our experience in encouraging parents to express their own views on their children's treatment (Rosati *et al.*, 2015) implies that paediatricians tend to take the easiest approach, ignore parents' wishes and require compliance rather than concordance (Merenstein *et al.*, 2005). Knowing more about whether parents' appreciate SDM, and whether they find it reassuring, would effectively help fully occupied hospital paediatricians to take parents' preferences into account in their day-to-day clinical practice.

To clarify whether parents appreciate being offered an SDM approach and whether cross-cultural differences influence parents' views on clinical SDM, we conducted a 3-month cross-sectional survey in our large multicultural outpatient clinic in an Italian public

children's hospital enrolling consecutive parents of children at various ages coming for widely ranging reasons. We developed a questionnaire to seek information on cultural variables (language, parental education, reasons for coming) and parents' willingness to share clinical decisions with the doctor, including their preferences for therapeutic decisions envisaging SDM, the kind of decision-making they think predominates today, and decision-making approach that reassures them most.

METHODS

Study design: We conducted this single-centre cross-sectional survey to investigate cultural differences in parents' general views and expectations about their children's treatment in our large Italian outpatient clinic, a public facility in Rome staffed by seven paediatricians who visit more than 19,000 children a year coming from European and other countries.

Participants. From the 2023 consecutive children's parents coming to our outpatient clinic during the trimester from June to September 2009, the time of year when acute respiratory infections tend to diminish, we excluded 1486 (1151 coming during weekends so as to avoid overanxious parents, 270 not understanding or speaking Italian, 48 who attended more than once, and 17 whose children had known chronic illnesses), leaving 537 eligible for enrolment. Of these 537 eligible parents, data for 79 were excluded (57 who came during weekends included erroneously in the database, 15 who failed to complete the questionnaire, 5 who answered twice for siblings, and 2 for whom no child's birth date was retrieved), 458 were therefore enrolled, and their answers analysed.

Outcome measures. Seven paediatricians on duty shifts at the outpatients' clinic, after examining the child and before sending the family home, asked one parent for each child to give written informed consent, and administered a written Italian questionnaire on SDM. They also gave parents written information (including the link to our hospital model of communication: http://www.ospedalebambinogesu.it/comunicazione-con-il-bambino-malato-e-la-sua-famiglia/-/asset_publisher/qzHAwnvXmrn9/content/macro.html#.WGVAqLbhCT8) saying that SDM goes beyond informed consent. SDM means that doctors involve parents in decisions, explain and discuss the benefits and risks of the various evidence-based diagnostic and therapeutic options proposed in language that patients can understand, listen patiently to their priorities, and doctors and patients decide together on the best course of action (Charles *et al.*, 1999; Sackett

Table 1. Demographic characteristics of the 458 children's parents, coming from a consecutive series of 2023 attending the outpatient clinic, surveyed to explore views on shared decision-making during a trimester in 2009

Parents surveyed	<i>n</i> (%)
Italian-speaking parents	
Native	400 (87.3)
Foreign*	58 (12.7)
Mothers	342 (74.7)
Native	290 (63.3)
Foreign	52 (11.4)
Fathers	115 (25.1)
Native	110 (24.0)
Foreign	5 (1.1)
Other (grandmother)	1 (0.2)
Native	0
Foreign	1 (0.2)
Educational level	
≤ 8 years	85 (18.6)
> 8 years	373 (81.4)
Coming to hospital	
Spontaneously	382 (83.4)
Second referral	76 (16.6)
Children's age	
≤ 5 years	323 (70.5)
> 5 years**	135 (29.5)

Note. *Countries of parental origin *n* (%): European Countries other than Italy 35 (7.6) (Romania 14, Moldavia 7, Poland 3, Spain 3, France 2, Great Britain 1, Belgium 1, Germany 1, Norway 1, Sweden 1, Switzerland 1); South America 14 (3.1) (Argentina 3, Bolivia 1, Brazil 2, Colombia 2, Ecuador 3, Peru 3); United States of America 3 (0.7); Africa 2 (0.4) (Morocco 1, Ivory Coast 1); other Countries 4 (0.9) (Australia 1, Philippines 2, Vietnam 1).

**Nine children ≥ 13 years.

et al., 2000). They also told parents that the study aimed to understand their general views on SDM, and what they expected this approach to involve. The questionnaire sought anonymous information on demographic variables that our experience (Rosati *et al.*, 2015), and scientific reports (Arora and McHorney, 2000; Cox *et al.*, 2009) implied would differ according to parents' cultural views on SDM and expectations, including native or foreign Italian-speaking parents, education level (more or less than 8 years), whether parents came to the outpatient clinic spontaneously (reportedly with or without consulting another provider first) or were referred by another specialist, and children's age (Table 1).

To seek information on the following general concepts—parents willingness to be involved in and appreciating SDM, what kind of doctor-patient relationship they think predominates today, and what type of decision-making reassures them most—the questionnaire ended with four self-reported multiple-choice questions

derived from the frequently cited framework model published and implemented by Charles *et al.* (Charles *et al.*, 1999; Murray *et al.*, 2006) modified and translated into Italian according to the unpublished results we obtained in an exploratory parent group. Parents coming with two or more siblings completed only one questionnaire. When the hospital visit ended, paediatricians on duty recorded information about children's diagnoses, medical decisions and parental comments. To report the results we translated the questionnaire into English (Table 2).

Statistical Analysis. From our unpublished clinical experience at the hospital during the summer, we determined that 450 children enrolled over 3-months would have 80% power to detect the clinically important difference at $\alpha = 0.05$ in parental answers to the questionnaire. Data were collected and summarized with descriptive statistics. Binary data were synthesised as percentages, whereas continuous data were reported as means and standard deviations (SD). Multivariate logistic regression was used to analyse questionnaire answers and parents' and children's variables, using as dependent variables the dichotomised answers to the four questions, and as independent variables parents' language, parental education, hospital referral and children's age (Table 2). Results estimating the association between questionnaire answers and parents' and children's variables are reported as percentages, odds ratios (OR) and 95% confidence intervals (CI). Data were analysed with STATA[®] software Version 11.

The study received Bambino Gesù hospital institutional review board approval.

RESULTS

Of the 537 eligible consecutive outpatient children's parents, 458 answered the questionnaire completely (85.2% response rate). Of these 458 children's parents, most came spontaneously (83.4%), mainly because they wanted a second opinion from a hospital paediatrician (40.4%), considered their child's condition uncured or worsened (10.7%), felt unsatisfied with a previous paediatric consultation (9.6%), supposedly suspected urgent problems (7.4%), or found their own paediatrician unavailable (5.0%) or the local medical office closed (9.2%) (Table 1). The 458 children brought by their parents to the outpatient clinic had a mean \pm SD age of 3.8 ± 3.61 years (range 7 days–17.5 years). Almost half of the children (47.5%) had never been brought to the outpatients' clinic before. Of the 76 children referred from elsewhere, 52 (11.4%) were referred

Table 2. Multivariate logistic regression analysis adjusting shared decision-making (SDM) questionnaire answers according to 458 parents' and their children's characteristics

		Questionnaire questions and answers											
		1-Do you wish to take part in the therapeutic choices made for your child (SDM)?		2-As a parent, what kind of relationship would you prefer for choosing your child's therapy?		3-What kind of doctor-patient relationship for choosing therapy predominates today?		4-What kind of clinical relationship reassures you most?					
Parents' and children's variables	No*/Uncertain	Yes	OR (95% CI)**	The doctor decides	Share clinical decisions with the doctor	OR (95% CI)**	The doctor decides	Share clinical decisions with the doctor	OR (95% CI)**	The doctor decides	Share clinical decisions with the doctor	OR (95% CI)**	
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	
Total	18 (3.9)	440 (96.1)		213 (46.5)	245 (53.5)		332 (72.5)	126 (27.5)		183 (40.0)	275 (60.0)		
Italian-speaking parents													
Foreign*** (<i>n</i> = 58)	6 (10.3)	52 (89.7)		2.5 (43.1)	33 (56.9)		38 (65.5)	20 (34.5)		28 (48.3)	30 (51.7)		
Native (<i>n</i> = 400)	12 (3.0)	388 (97.0)	3.8 [§] (1.4, 10.8)	188 (47.0)	212 (53.0)	0.8 (0.5, 1.5)	294 (73.5)	106 (26.5)	0.7 (0.4, 1.2)	155 (38.7)	245 (61.3)	1.4 (0.8, 2.5)	
Parental education													
≤ 8 years*** (<i>n</i> = 85)	1 (1.2)	84 (98.8)		5.6 (65.9)	29 (34.1)		65 (76.5)	20 (23.5)		50 (58.8)	35 (41.2)		
> 8 years (<i>n</i> = 373)	17 (4.6)	356 (95.4)	0.2 (0.0, 1.9)	157 (42.1)	216 (57.9)	2.7 [§] (1.6, 4.4)	267 (71.6)	106 (28.4)	1.2 (0.7, 2.2)	133 (35.7)	240 (64.3)	2.5 [§] (1.6, 4.1)	
Hospital referral													
Second referral*** (<i>n</i> = 76)	4 (5.3)	72 (94.7)		3.1 (40.8)	45 (59.2)		49 (64.5)	27 (35.5)		29 (38.2)	47 (61.8)		
Spontaneously (<i>n</i> = 382)	14 (3.7)	368 (96.3)	1.3 (0.4, 4.2)	182 (47.6)	200 (52.4)	0.8 (0.5, 1.3)	283 (74.1)	99 (25.9)	0.6 (0.4, 1.1)	154 (40.3)	228 (59.7)	0.9 (0.6, 1.6)	
Children's age													
5 years*** (<i>n</i> = 135)	6 (4.4)	129 (95.6)		6.7 (49.6)	68 (50.4)		92 (68.1)	43 (31.9)		48 (35.6)	87 (64.4)		
≤ 5 years (<i>n</i> = 323)	12 (3.7)	311 (96.3)	1.2 (0.4, 3.4)	146 (45.2)	177 (54.8)	1.3 (0.8, 1.9)	240 (74.3)	83 (25.7)	0.7 (0.5, 1.1)	135 (41.8)	188 (58.2)	0.8 (0.5, 1.2)	

Note. * Three parents answered 'no'.
 ** Odds ratio (95% confidence interval) adjusted for reference categories.
 *** Reference categories.
 § Significant at *p* < 0.05.

by another specialist and 24 (5.2%) came from the emergency department. Most children (390, 85.2%) had common complaints including respiratory symptoms and diseases (138, 30.1%), gastrointestinal problems (98, 21.4%), skin symptoms and diseases (41, 9.0%), infective diseases (37, 8.1%), or needed only a paediatric check-up (68, 14.8%). Of the 458 children visited, 185 (40.4%) were sent home with a prescription, 154 (33.6%) without a prescription, 62 (13.5%) were scheduled for a follow-up visit, 28 (6.1%) were referred to another specialist, 26 (5.7%) had diagnostic imaging or laboratory tests prescribed, 3 (0.7%) received dietary advice, and none were admitted.

The multivariate logistic regression analysis adjusting the 458 children's parents' answers (dependent variables) for the four previously identified children's and parents' characteristics (independent variables) showed that 96.1% wished to be involved in SDM, and 53.5% preferred SDM as an approach for choosing their children's treatment. More native than foreign Italian-speaking parents preferred SDM. Highly-educated parents preferred an SDM approach for choosing their children's treatment. Most parents answered that they felt reassured by SDM approach to treatment (60.0%), and highly educated parents were reassured most by an SDM doctor-parent relationship (Table 2).

DISCUSSION

The major finding from answers to the questionnaire in our cross-sectional survey conducted in a large multicultural public children's hospital in Rome is that nearly all parents (96.1%), including native and foreign Italian speaking parents bringing their children to our outpatient clinic for widely ranging reasons, appreciate being offered an SDM approach. Our findings imply that cross-cultural differences influence parents' views on clinical SDM (willingness to participate in medical decisions on their children's health) less than our lengthy hospital experience led us to expect.

Our Italian multicultural survey therefore helps to clarify Southern European parents' views and expectations on SDM underlining that regardless of parental native language, doctors should always encourage clinical conversations to allow parents to express their opinions unashamedly (Hills, 2006; Hargraves *et al.*, 2016; Kunneman and Montori, 2016), so as to 'integrate patient values with the best research evidence and clinical expertise' (Sackett *et al.*, 2000).

Although for practical reasons in our fully occupied outpatient clinic we excluded nearly 60% of foreign non Italian-speaking children's parents, the high response

rate to the questionnaire (85.2%), one of our study's main strengths, increases the credibility of our finding that a surprisingly large number of foreign Italian-speaking parents (89.7%) wish to take part in the therapeutic choices made for their child (Table 2). The results of our survey therefore underline the language constraints interfering when hospital doctors engage parents, and highlight their reluctance to express clinical concepts in plain language or rephrase less understandable information (Epstein *et al.*, 2015).

When we examined other cross-cultural differences that might influence parents' views on clinical SDM, our questionnaire showed that parents with more than 8 years education in both groups seem especially willing to participate in clinical therapeutic decisions (Cox *et al.*, 2009), as others have already noted in adults (Müller-Engelmann *et al.*, 2011). This finding, implying that an SDM approach is advantageous in highly-educated parents regardless of native parental language, might be useful for health promotion.

When we asked about parents' preferences for therapeutic decisions envisaging SDM, even though they wanted to participate in clinical therapeutic decision, unexpectedly nearly half the parents bringing their child to our outpatients' clinic enrolled preferred to let the paediatrician decide—presumably because they trust in the doctor's expertise. A possible explanation, regardless of whether parents find encounters with their paediatrician satisfying (O'Keefe, 2001; Gené-Badia *et al.*, 2014), comes from the overall verbal observations parents with higher cultural levels expressed when the questionnaire survey ended. Hence, even though parents appreciate being offered an SDM approach, many are so used to leaving medical treatment choices to the doctor that they find being asked whether they wish to share in choices between options surprising. This explanation accords with parents' answers about the kind of decision-making they think predominates today. Despite trusting in the doctors' expertise, many parents felt that most doctors nowadays base their decisions only on what they themselves believe is best without considering parents' opinions, and only some parents (126, 27.5%) answered that SDM is the predominant relationship today. No difference emerged for this finding between native and foreign Italian-speaking parents. This new observation should help paediatricians to change the way they make clinical medical decisions and envisage an SDM approach, namely 'a patient-clinician interaction that offers conversation, not just information, and care, not just choice' (Hargraves *et al.*, 2016).

To gain further insights into parents' views on doctor-parent relationships the last question we investigated was

which decision-making approach reassures parents most. Their attitudes towards SDM seem to depend largely on why they come to the outpatients' clinic. Parents who come for supposedly urgent problems or because their children's condition worsened, seem to shift from a clear desire to engage in medical decisions to a passive behaviour (Table 2). Hence, the emotional challenge parents unexpectedly face when coping with their children's diseases results in an indirect request for surrogating in the doctor or in the nurses their parental role in deciding for their children (Corlett and Twycross, 2006; Carnevale *et al.*, 2007; Flynn *et al.*, 2012). A new and unexpected finding is that parents coming spontaneously and parents referred to us from the emergency department express similar wishes to be involved in SDM (Flynn *et al.*, 2012). Conversely, parents referred after receiving a previous medical decision expect to find a consultant physician who is ready to share information and decisions, and to discuss the clinical risks and benefits (Ingram *et al.*, 2013). The lack of differences between foreign and Italian-speaking parents in this questionnaire answer therefore suggests tailoring SDM not to cultural backgrounds but to parents' personal wishes, thus reducing parental anxiety and their tendency to overestimate clinical problems (Romaniuk *et al.*, 2014).

When we analysed questionnaire answers according to the child's age, we failed to identify significant age-related differences in parents' views on SDM therapeutic decisions and reassurance. Older children's parents nevertheless seemed especially ready to share decisions with the paediatrician, presumably because they realize that older children tend to omit important information because they fear possible painful procedures (Nyström and Ohrling, 2004; Cemeroglu *et al.*, 2015). Our finding that few parents with adolescent children (9/135 older than 13 years) answered that SDM reassures them most could reflect the small number of adolescents in the group older than 5 years gathered in our survey, or the fact that parents often find it difficult to converse with adolescent children. These parents also stated in their comments at the end of the questionnaire that they wished paediatricians to discuss problems directly with older children. Older children's parents' opinions on SDM therapeutic decisions and reassurance (Knopf *et al.*, 2008; Stewart *et al.*, 2012) is therefore a question meriting further research to understand parents' and adolescents' views in outpatient and inpatient settings.

LIMITATIONS

Our study has several limitations. We conducted the survey over a short time span and enrolled participants

from a single multicultural public facility. Nor did we investigate multicultural differences related to other possibly important social variables including parents' age. We also avoided investigating whether religion influenced parents' view on the doctor-patient relationship and SDM because parents might perceive the question as discriminating. Neither did we explore the effect of diversity on SDM views by including foreign non Italian-speaking parents because in our fully occupied outpatients' clinic we had no time to administer a questionnaire on SDM written in languages other than Italian. Another limitation is that to avoid administering tailored questionnaires for children who receive various specific SDM approaches in our hospital, we excluded children attending with chronic illnesses, although they and their parents have the greatest experience in sharing decisions. Even though we did not undertake a psychometric validation of the questionnaire, we chose a highly-cited general questionnaire that was easy to understand and adapted it for surveying parents in our Italian outpatient setting. A final weakness is the social desirability response bias arising from questions that expect respondents to express their desire to participate (Loo and Thorpe, 2000).

CONCLUSION

Parents bringing children to a multicultural Italian outpatient clinic, especially highly-educated parents, wish to be offered SDM and find it reassuring. Even though parents' cultural differences shape their general views on SDM less than expected, overworked hospital paediatricians should take parents' views into account, change their doctor-centred approach, and consider an SDM approach in their day-to-day clinical practice. Our survey results should also prompt hospital managers and policy-makers to appreciate the value of SDM. The next step is to find out how to best tailor SDM tools to the various clinical paediatric conditions, and train doctors to encourage parents to take the initiative in clinical health needs concerning their children.

ACKNOWLEDGEMENT

We wish to thank Marta Ciofi degli Atti for her helpful suggestions on data analysis.

FUNDING

This work was supported by the Italian Ministry of Health [grant no 200702Q002212].

REFERENCES

- Arora, N. K. and McHorney, C. A. (2000) Patient preferences for medical decision making: who really wants to participate? *Medical Care*, **38**, 335–341.
- Barry, M. J., Mulley, A. G., Fowler, F. J. and Wennberg, J. W. (1988) Watchful waiting vs immediate transurethral resection for symptomatic prostatism. The importance of patients' preferences. *Journal of the American Medical Association*, **259**, 3010–3017.
- Boote, J., Wong, R. and Booth, A. (2012) 'Talking the talk or walking the walk?' A bibliometric review of the literature on public involvement in health research published between 1995 and 2009. *Health Expectation*, **18**, 44–57.
- Campbell, K. J., Crawford, D. A. and Hesketh, K. D. (2006) Australian parents' views on their 5–6-year-old children's food choices. *Health Promotion International*, **22**, 11–18.
- Carnevale, F. A., Canoui, P., Cremer, R., Farrell, C., Doussau, A., Seguin, M. J. *et al.* (2007) Parental involvement in treatment decisions regarding their critically ill child: a comparative study of France and Quebec. *Pediatric Critical Care Medicine*, **8**, 337–342.
- Cemeroglu, A. P., Can, A., Davis, A. T., Cemeroglu, O., Kleis, L., Daniel, M. S. *et al.* (2015) Fear of needles in children with type 1 diabetes mellitus on multiple daily injections and continuous subcutaneous insulin infusion. *Endocrine Practice*, **21**, 46–53.
- Charles, C., Gafni, A. and Whelan T. (1999) Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. *Social Science and Medicine*, **49**, 651–661.
- Corlett, J. and Twycross, A. (2006) Negotiation of parental roles within family-centred care: a review of the research. *Journal of Clinical Nursing*, **15**, 1308–1316.
- Coulter, A., Parsons, S. and Askham, J. (2008) Where are the patients in decision-making about their own care? World Health Organization, on behalf of the European Observatory on Health Systems and Policies. <http://www.who.int/management/general/decisionmaking/WhereArePatientsinDecisionMaking.pdf> (18 September 2015, last accessed 29 December 2016).
- Cox, E. D., Smith, M. A., Brown, R. L. and Fitzpatrick, M. A. (2009) Learning to participate: effect of child age and parental education on participation in pediatric visits. *Health Communication*, **24**, 249–258.
- Coyne, I., O'Mathúna, D. P., Gibson, F., Shields, L. and Sheaf, G. (2013) Interventions for promoting participation in shared decision-making for children with cancer. *Cochrane Database Systematic Review*, **6**, CD008970.
- Dixon-Woods, M., Cavers, D., Agarwal, S., Annandale, E., Arthur, A., Harvey, J. *et al.* (2006) Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC Medical Research Methodology*, **6**, 35. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1559637/pdf/1471-2288-6-35.pdf> (18 September 2015, last accessed 29 December 2016).
- Elwyn, G., Edwards, A. and Kinnersley, P. (1999) Shared decision-making in primary care: the neglected second half of the consultation. *British Journal of General Practice*, **4**, 477–482.
- Elwyn, G., Tsulukidze, M., Edwards, A., Légaré, F. and Newcombe, R. (2013) Using a 'talk' model of shared decision making to propose an observation-based measure: observer OPTION 5 item. *Patient Education and Counseling*, **93**, 265–271.
- Epstein, D., Unger, J. B., Ornelas, B., Chang, J. C., Markovitz, B. P., Dodek, P. M. *et al.* (2015) Satisfaction with care and decision making among parents/caregivers in the pediatric intensive care unit: a comparison between English-speaking whites and Latinos. *Journal of Critical Care*, **30**, 236–241.
- Flynn, D., Knoedler, M. A., Hess, E. P., Murad, M. H., Erwin, P. J., Montori, V. M. *et al.* (2012) Engaging patients in health care decisions in the emergency department through shared decision-making: a systematic review. *Academic Emergency Medicine*, **19**, 959–967.
- Gené-Badia, J., Ascaso, C., Escaramis-Babiano, G., Sampietro-Colom, L., Catalán-Ramos, A., Sans-Corrales, M. *et al.* (2014) Personalised care, access, quality and team coordination are the main dimensions of family medicine output. *Family Practice*, **24**, 41–47.
- Gulbrandsen, P., Dalby, A. M. L., Ofstad, E. H. and Gerwing, J. (2014) Confusion in and about shared decision making in hospital outpatient encounters. *Patient Education and Counseling*, **96**, 287–294.
- Hargraves, I., LeBlanc, A., Shah, N. D. and Montori, V. M. (2016) Shared decision making: the need for patient-clinician conversation, not just information. *Health Affairs*, **35**, 627–629.
- Hills, L. S. (2006) Putting patients at ease with conversation. *The Journal of Medical Practice Management*, **22**, 168–170.
- Ingram, J., Cabral, C., Hay, A. D., Lucas, P. J. and Horwood, J. and TARGET team. (2013) Parents' information needs, self-efficacy and influences on consulting for childhood respiratory tract infections: a qualitative study. *BMC Family Practice*, **28**, 14:106.
- Institute of Medicine. (2001) Improving the 21st century health-care system. *Crossing the Quality Chasm: A New Healthcare System for the 21st Century*. National Academy Press, Washington, DC.
- Knopf, J. M., Hornung, R. W., Slap, G. B., DeVellis, R. F. and Britto, M. T. (2008) Views of treatment decision making from adolescents with chronic illnesses and their parents: a pilot study. *Health Expectations*, **11**, 343–354.
- Kunnenman, M. and Montori, V. M. (2016) When patient-centred care is worth doing well: informed consent or shared decision-making. *BMJ Quality & Safety*, **26** September 2016, 1–3. doi:10.1136/bmjqs-2016-005969 (last accessed 29 December 2016).
- Légaré, F., Ratté, S., Stacey, D., Kryworuchko, J., Gravel, K., Graham, I. D. *et al.* (2010) Interventions for improving the adoption of shared decision making by healthcare

- professionals. *Cochrane Database Systematic Review*, 5, CD006732.
- Levinson, W., Kao, A., Kuby, A. and Thisted, R. A. (2005) Not all patients want to participate in decision making. A national study of public preferences. *Journal of General Internal Medicine*, 20, 531–535.
- Lipstein, E. A., Brinkman, W. B. and Britto, M. T. (2012) What is known about parents' treatment decisions? A narrative review of pediatric decision making. *Medical Decision Making*, 32, 246–258.
- Lipstein, E. A., Brinkman, W. B., Fiks, A. G., Hendrix, K. S., Kryworuchko, J., Miller, V. A. *et al.* (2015) An emerging field of research: challenges in pediatric decision making. *Medical Decision Making*, 35, 403–408.
- Loo, R. and Thorpe, K. (2000) Confirmatory factor analyses of the full and short versions of the Marlowe-Crowne Social Desirability Scale. *The Journal of Social Psychology*, 140, 628–635.
- Merenstein, D., Diener-West, M., Krist, A., Pinneger, M. and Cooper, L. A. (2005) An assessment of the shared-decision model in parents of children with acute otitis media. *Pediatrics* 116, 1267–1270.
- Müller-Engelmann, M., Keller, H., Donner-Banzhoff, N. and Kronen T. (2011) Shared decision making in medicine: the influence of situational treatment factors. *Patient Education and Counseling*, 82, 240–246.
- Murray, E., Charles, C. and Gafni, A. (2006) Shared decision-making in primary care: tailoring the Charles *et al.* model to fit the context of general practice. *Patient Education and Counseling*, 62, 205–211.
- Nyström, K. and Ohrling, K. J. (2004) Parenthood experiences during the child's first year: literature review. *Journal of Advanced Nursing*, 46, 319–330.
- O'Keefe, M. (2001) Should parents assess the interpersonal skills of doctors who treat their children? A literature review. *Journal of Paediatrics and Child Health*, 37, 531–538.
- Romaniuk, D., O'Mara, L. and Akhtar-Danesh, N. (2014) Are parents doing what they want to do? Congruency between parents' actual and desired participation in the care of their hospitalized child. *Issues in Comprehensive Pediatric Nursing*, 37, 103–121.
- Rosati, P. (2013) Shared decision making in a revolutionary child's healthcare journey. *BMJ* 346, f3917.
- Rosati, P., Di Salvo, V., Crudo, S., D'Amico, R., Carlino, C., Marchili, M.R. *et al.* (2015) Are parents of children hospitalized with severe community-acquired pneumonia more satisfied with care when physicians allow them to share decisions on the antibiotic route? *Health Expectations*, 18, 2278–2287.
- Sackett, D. L., Straus, S. E., Richardson, W. S., Rosenberg, W. and Haynes, R. B. (2000). *Evidence-Based Medicine: How to Practice and Teach EBM*. Churchill Livingstone, Edinburgh, UK.
- Schor, E. L. and The American Academy of Pediatrics Task Force on the Family. (2003) Family pediatrics: report of the Task Force on the Family. *Pediatrics* 111, 1541–1571.
- Shay, L. A. and Lafata, J. E. (2014) Understanding patient perceptions of shared decision making. *Patient Education and Counseling*, 96, 295–301.
- Shields, L., Zhou, H., Pratt, J., Taylor, M., Hunter, J. and Pascoe, E. (2010) Family-centred care for hospitalized children aged 0–12 years. *Cochrane Database Systematic Review*, 10, CD004811.
- Stein, T. S., Frankel, R. M. and Krupat, E. (2005) Enhancing clinical communication skills in a large healthcare organization: a longitudinal case study. *Patient Education and Counseling*, 58, 4–12.
- Stewart, M., Letourneau, N., Masuda, J. R., Anderson, S., Cicutto, L., McGhan, S. *et al.* (2012) Support needs and preferences of young adolescents with asthma and allergies: “just no one really seems to understand”. *Journal of Pediatric Nursing*, 27, 479–490.
- Troug, R. D. (2012) Patients and doctors—the evolution of a relationship. *New England Journal of Medicine*, 366, 581–585.
- Wyatt, K. D., List, B., Brinkman, W. B., Prutsky Lopez, G., Asi, N., Erwin, P. *et al.* (2015) Shared decision making in pediatrics: a systematic review and meta-analysis. *Academic Pediatrics*, 15, 573–583.
- Yin, H. S., Dreyer, B. P., Vivar, K. L., MacFarland, S., van Schaick, L. and Mendelsohn, A. L. (2012) Perceived barriers to care and attitudes towards shared decision-making among low socioeconomic status parents: role of health literacy. *Academic Pediatrics*, 12, 117–124.