RSV surveillance by WHO has the potential to bring together data on life-threatening bronchiolitis from developed and developing countries. In addition, future collaborative efforts could focus much-needed attention on the longterm morbidity of bronchiolitis, including recurrent wheeze or asthma, and neuropsychological dysfunction, as well as post-traumatic stress and disruption experienced by family or caregivers after PICU admission.

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# (I) Understanding and improving quality of care in preschool wheeze



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For more on Donabedian's novel framework see N Engl J Med 2016; 375: 205-07

For more on understanding and measuring quality of care see the Bull World Health Organ 2017: **95**: 368-74

For the UK population-based study of asthma see Thorax 2018; 73: 313-20

For more on the impact of preschool wheezing on health-related quality of life see Eur Respir J 2013; 41: 952-59

For more on patient-reported outcomes see Arch Dis Child Educ Pract Ed 2019; published online Aug 31. DOI:10.1136/ archdischild-2018-316476

> For the report see Spotlight Lancet Respir Med 2019: 7:842-43

For the WAIT trial see Articles Lancet Respir Med 2014; **2**: 796-803 In October 1965, Avedis Donabedian proposed a novel framework for assessing the quality of health care based on evaluation of the structures, processes, and outcomes. His work influenced the theory and practice of quality improvement and health-care services research for years. The Institute of Medicine in the USA further expanded on this framework to suggest that efforts to improve quality of care should be focused around effectiveness, efficiency, equity, patient-centredness, safety, and timeliness. Further work has highlighted the importance of including patient or family perspectives when evaluating care quality. For example, a 2006 observational cohort study with elderly patients enrolled in managed-care organisations showed that their rating of quality of care did not match the clinical quality. The notion that improvement of quality of care will be better achieved within patient-centred models of care is now widely accepted. This consensus is growing and has accelerated moves to develop more integrated care; models are designed to ensure that patients receive the care they need from all sectors of the health system and adjusted to the patient's personal needs throughout the life course.

Developing a patient-centred model of care for young children presenting with wheeze is an important area as wheeze is highly prevalent in preschool children and although some clinical outcomes have been well defined, outcomes of care from the caregivers' perspective have not been well delineated (figure). Nearly 50% of children in the UK, USA, and Canada report at least one episode of wheeze (requiring medical review) during the first 6 years of life. A UK population-based study showed that preschool children presented with more severe and frequent wheeze attacks than school-age children. Caregivers of preschool children with wheeze are affected in various ways. A Canadian study assessing the functional

status (mental health, ability to perform at work, family quality time) of caregivers of preschool children with wheeze showed that their functional status was affected by the frequency of wheeze attacks. Birth cohort studies (eq, PIAMA, Generation R study) have shown that wheezing disorders, and especially their management, affect parental perceptions of health and health-related quality of life. Quality of care in preschool wheeze can be defined by clinical outcomes, patient-reported outcomes, and by patient-reported experience of care.

Although the age of onset of preschool wheeze is variable and symptoms might initially be insidious, the tipping point is when a pattern of recurrent exacerbations becomes established. The timing and severity of viral respiratory infections play a substantial part in wheeze attacks, with respiratory syncytial virus and rhinoviruses being most commonly detected. Studies using molecular diagnostics suggest the airway microbiome might also be involved in wheeze pathogenesis, could alter the disease course, and might affect the incidence of exacerbations. Other host factors, such as allergic sensitisation, acquired antiviral immune responses, and environmental exposures, might also have an important role. Moreover, surveillance data highlight that ongoing socioeconomic and racial disparities importantly influence the incidence of wheeze attacks, potentially due to poor access to health care, less time for caregivers' education, or even cultural characteristics that make education around the condition more challenging. One report highlighted that evaluating and disseminating interventions to eliminate disparities is an absolute priority.

There are several risk factors for recurrent wheeze exacerbations in children of preschool age, the most important being a previous admission with a severe exacerbation, a raised peripheral blood eosinophil count,

#### Improve the quality of care in preschool wheeze

Clinical quality

- Clinical outcomes
- Interaction between patient and physician
- Use of health-care resources to deliver clinical outcomes

Caregiver-reported quality

- · Patient reported outcomes
- Patient reported experiences

Understand the pathogenesis of frequent exacerbations, differences in management, and implications

Inception and recurrence of preschool wheeze exacerhations

- Microbial exposure
- · Susceptibility to viruses
- Early allergic sensitisation
- Air pollution Indoor environment
- Socioeconomic disparities
- Acute preschool wheeze management
- Definition of episode severity
- Use of oral steroids in management of acute wheeze exacerbations

Discharge management plan and follow-up

#### Work within a paediatric integrated care model

Facilitate public and patient engagement · In relevant research (from design to

- implementation)
- In clinical practice

Facilitate accessibility for families of preschool children with wheeze to health care

- Through practice nurses, health visitors, children's centres, and GP practices
- Put in place interventions that eliminate disparities and achieve greater parental satisfaction

Get experts in preschool wheeze to work together

• Including providers of care, researchers, commissioners, and third sector organisations (eg, voluntary and community organisations, such as charities, community support groups)

For an example of practice variation see PLoS One 2019: **14:** e0222421

for preschool children with recurrent wheeze see NPJ Prim Care Respir Med 2019; 29:7

For patient-reported outcomes

### Figure: A logic model on how to improve quality of care in preschool wheeze and why

Describes how quality of care in preschool wheeze can be improved and why we need to work within a paediatric integrated care model.

and aeroallergen sensitisation. The WAIT trial showed that nearly 65% of preschool children with wheeze had an unscheduled medical attendance with wheeze over the 1-year follow-up period. An Australian study showed that more than one third of hospital presentations with wheeze last fewer than 7 h and could, therefore, be preventable (as a shorter hospital stay implies that presentation is not severe). Using the number of preventable emergency medical presentations with wheeze as a quality-ofcare indicator might be difficult because defining the objective criteria for preventable is not always possible. However, reducing the number of preventable medical presentations with wheeze-eq, by parental education around assessment of severity and initiation of appropriate management—would definitely help improve the quality of life for these families.

Pharmacological management of acute exacerbations of wheeze has also remained controversial. Although evidence suggests that giving oral steroids to preschool children with wheeze exacerbations changes neither the duration of hospitalisation nor the need for escalated management, current practice differs between hospitals. Practice variation affects caregivers' experiences and impacts on their perception of quality of care for their children. Furthermore, discharge plans are often variable with different approaches in stepwise reduction of  $\beta$ 2-agonist inhalers over time (a practice devoid of any evidence base). These discharge plans are named wheeze weaning plans and might contribute to parental confusion around management of the condition at home.

Qualitative research highlights important outcomes of care for families of preschool children with wheeze. These include better coordination of care, ensuring family quality time, minimising time off work, the acquisition of a sense of reassurance and expertise, mental wellbeing, and less time off nursery or creche.

Health-care professionals working within an integrated care model provide services to reflect the patient's perspective and act as the central principle of service delivery. Through integration of specialists with generalists and integration of health, education, and social care (vertical and horizontal integration) providers of primary, community, hospital, and tertiary health care, and social services work in tandem to achieve better outcomes for patients: coordination of care and parental education is managed more effectively; interventions to reduce the psychological burden on families are put in place; and the effect of recurrent medical attendances on everyday life is reduced. Measuring patient-reported outcomes means services are better evaluated and commissioned. Research shows other benefits from this approach, such as regular meetings between researchers and patients' families or representatives through which researchers can better understand their perspective; bringing together a diverse pool of researchers in the field; and transcending compartmentalisation, with knowledgediffusion across medical professionals, academic researchers, and policy makers.

Donabedian suggested asking the question "What is the problem?", with the aim of approaching this holistically. A comprehensive approach for preschool wheeze will be achieved within an integrated care model. Breaking down the silos in preschool wheeze research and clinical practice can provide better outcomes and better quality of care for these patients.

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