

Complexity and challenge in paediatrics: a roadmap for supporting clinical staff and families

Hilary Cass ¹, Sarah Barclay,² Clare Gerada,³ Daniel E Lumsden,^{1,4} Kaji Sritharan^{5,6}

INTRODUCTION

There is much that paediatricians love about their job. The attraction of working with children and families, colleagues who are supportive and non-hierarchical, and the diversity of the specialty are all integral to a stimulating and fulfilling career. Yet, despite these positive features, paediatricians are seeing an insidious decline in morale and well-being within the profession.

Most of the current cohort of consultant paediatricians started their careers at a time when competition ratios for entry to the specialty were high. The perception was of a specialty that was tough due to the long hours and high-intensity work, but amply compensated by the rewarding nature of the job. However, between 2015 and 2018, although the calibre of applicants remained high, recruitment to Specialist Trainee 1 in paediatrics fell from 97.5% to close to 80%, with this once-popular specialty having the lowest competition ratio of all the medical specialties.¹

Recruitment shortfalls are one manifestation of broader problems in the specialty, with paediatricians now representing around 5% of referrals to the NHS Practitioner Health Programme (PHP), a confidential mental health and addiction service for doctors.² This is an over-representation compared with other specialties. In addition, the service sees a higher percentage of trainees (70% compared with an average of 54% across all specialties). Neonatologists and intensive care specialists form a significant subset of the paediatric group. Almost

all paediatricians presenting to PHP have mental illness as opposed to addiction problems, with the vast majority displaying anxiety, depression and symptoms of burn-out. Most tragically, a small number have committed suicide.

In 2018 two meetings (*'Spotlight on Paediatrics'*) were convened to discuss the issues which may have contributed to this worrying trend, and to try and find solutions. This paper describes the format and outputs of the two meetings and provides key insights into how recent changes in the paediatric environment have produced adverse conditions for clinical staff. Drawing on this information, the authors make recommendations for how individuals and organisations can come together to improve the situation, not just for paediatricians but for the whole multidisciplinary team, and the patients and families they serve.

THE 'SPOTLIGHT ON PAEDIATRICS' MEETINGS 2018

The *'Spotlight on Paediatrics'* meetings comprised two invitation-only events held at the Royal Society of Medicine in April and October 2018, both operated under the Chatham House Rule.³ This allows for openness during debates by committing that comments made are anonymised and non-attributable in any record of the event, thus protecting participants but sharing important insights.

Event 1 (16 April 2018)

The first event was designed to focus specifically on paediatricians and their perceptions of the issues, with invitees being practising paediatricians from across the clinical community. Although there was an appreciation that all members of the multidisciplinary team experience stresses in the work environment, it was agreed that open discussion could best be achieved using structured and small-group discussion in a safe setting without other professional groups being present, except in a facilitatory capacity. The group of 25–30 participants was selected to include

intensivists, neonatologists, general paediatricians, palliative care consultants, academics and community paediatricians. Most participants had a management or leadership role in addition to their clinical role (eg, the group included senior officers from the Royal College of Paediatrics and Child Health (RCPCH), two medical directors of children's hospitals, specialty group leads, clinicians from NHS England, a Head of School of Paediatrics, network leads and two paediatric trainees). Non-paediatric facilitation was provided by individuals working in psychology, psychiatry and medical mediation.

Individuals were given a very brief opening statement about the issues of concern and asked in a facilitated but non-directive plenary session how this resonated with their own experience, both as practising clinicians and through their leadership roles. The attendees then split into smaller groups to produce recommendations for multilevel solutions to the problems.

Event 2 (16 October 2018)

Recognising that the problems were experienced more widely, and could not be solved by the paediatric or indeed the wider healthcare community alone, the second event was designed to engage a broader multiprofessional and multi-agency group; this included doctors, nurses, allied health professionals, parents, ethicists and leaders of third-sector bodies, as well as a barrister specialising in medical law and a mainstream media health journalist. The aim of event 2 was to triangulate the conclusions of event 1, but more importantly to share existing work in the area and discuss how the healthcare community could work with involved third-sector bodies, the public and the media to address the underlying issues. The recommendations made at event 1 were augmented at event 2 by examples of existing good practice and additional proposals for solutions.

Collation and dissemination of proceedings

The proceedings of both *'Spotlight'* events were collated and written up in a single report. While the events did not constitute a formal qualitative research study, some consistent themes emerged both within and between groups. Given the fact that the contributions of many of the participants reflected their national or leadership experience, as well as their personal perspectives, it was anticipated that the results would have broader generalisability.

¹Neurosciences Department, Evelina London Children's Hospital, London, UK

²Medical Mediation Foundation, London, UK

³Hurley Group, London, UK

⁴Dept of Women's and Children's Health, King's College London, London, UK

⁵Department of Vascular Surgery, Royal Liverpool University Hospital, Liverpool, UK

⁶Royal Society of Medicine, London, UK

Correspondence to Dr Hilary Cass, Evelina Children's Hospital, St Thomas' Hospital, London SE1 7EH, UK; drhilarycass@gmail.com

The draft write-up was circulated to all participants, and corrections or amendments were incorporated prior to wider dissemination to interested parties. Informal feedback from individuals who received the report reinforced the authors' impression that the issues resonate broadly across the paediatric community.

Main themes identified

The views that emerged on the changing nature of paediatric practice and its implications for clinicians can be divided into the following themes:

- ▶ There has been an increase in patient complexity, linked to the increased survival of children with chronic health conditions, disability and life-limiting illness.
- ▶ Societal expectations of what can and should be done to extend life have changed, and this has culminated in polarised and, in some cases, damaging and hostile social media debate.
- ▶ The impact of these changes has been an increase in the practical, ethical and moral dilemmas faced by clinicians and families, leading at times to conflict, and feelings of disempowerment and moral distress.
- ▶ These issues are played out against a background of workforce shortfalls, resource pressures and service gaps, which add to the exhaustion and duress for both clinical staff and families.

Figure 1 illustrates the interplay between the above factors and the self-reinforcing vicious cycle of conflict and stress that can develop for all parties, with box 1 containing representative quotes from the meetings. Although the experience of other clinical staff was incorporated into the second 'Spotlight' event and the full report, most of these quotes

are from paediatricians. Further work is needed to fully explore the perspectives of other professional groups.

Despite the time spent identifying these negative perceptions, the 'Spotlight' meetings were strongly solution-focused, and the range of recommendations put forward by participants can be found in the full report, available on request from the lead author. The balance of this paper elaborates in greater detail the authors' interpretation of why paediatricians have become particularly vulnerable at this time and goes on to discuss the proposed solutions.

LEARNING FROM PREVIOUS PAEDIATRIC SERVICE CHALLENGES

Paediatricians are not unfamiliar with the media spotlight falling on their services. Over the last two decades, children's services have been at the centre of a series of high-profile cases which have had an impact across the whole of the National Health Service (NHS), initially generating adverse publicity, but in the longer term genuine improvements in practice. For example, the Public Inquiry into children's heart surgery at the Bristol Royal Infirmary gave birth to modern clinical governance⁴ and opened the debate on the need to protect whistle-blowers.⁵ The Alder Hey organ retention affair⁶ led to a major rethink about the meaning and process of consent, and the anti-MMR vaccine campaign raised questions about trust and the presentation of information to the wider public.⁷ However, although children were at the centre of these cases, for the most part paediatricians and paediatric care were not the subject of criticism.

By contrast, the pressures and public scrutiny which followed some of the high-profile safeguarding cases had a

Box 1 Quotes from 'Spotlight on Paediatrics' meetings

Patient complexity.

- ▶ "The patients are often complex and there are expert parents, so you are not involved in the decision-making."
- ▶ "There is a feeling of worthlessness, as the family want to see the specialist, rather than a general paediatrician."
- ▶ "There is a feeling of increasing stress which is palpable because of the complexity of patients. Moreover, if you are feeling vulnerable, then you are more susceptible to stress."
- ▶ "Patients can't go home and therefore sit on the hospital wards with frustrated parents."

Societal expectations and social media.

- ▶ "There is the expectation from society of perfect health and that no child is allowed to die."
- ▶ "Social media has taken away the greyness in decision-making."
- ▶ "You can be recorded, and this can be used against you on social media."
- ▶ "High profile cases can have an effect on other parents. They may feel guilty that they have not tried hard enough to save their child."

Ethical dilemmas, disempowerment and conflict.

- ▶ "There is no system for determining who gets high cost care and so he who shouts loudest gets it. On an ethics committee, you are not able to discuss cost."
- ▶ "You are the ground force as a trainee, but not involved in the decision-making."
- ▶ "Don't forget nursing! There is a significant stress associated with not being able to leave a cubicle and not being able to take a break at will."
- ▶ "There is an impact of chronic stress and fatigue on your health and on your family when you are in the spotlight or the focus of malicious behaviour."
- ▶ "In acute general paediatrics, there is a low-level conflict constantly. The team are on their knees."
- ▶ "Whilst the big cases are upsetting, the ongoing cases are more of a death by a thousand cuts."
- ▶ "In memory (25 year practice), conflict hardly used to happen. Now conflict is happening more and more, and

Continued

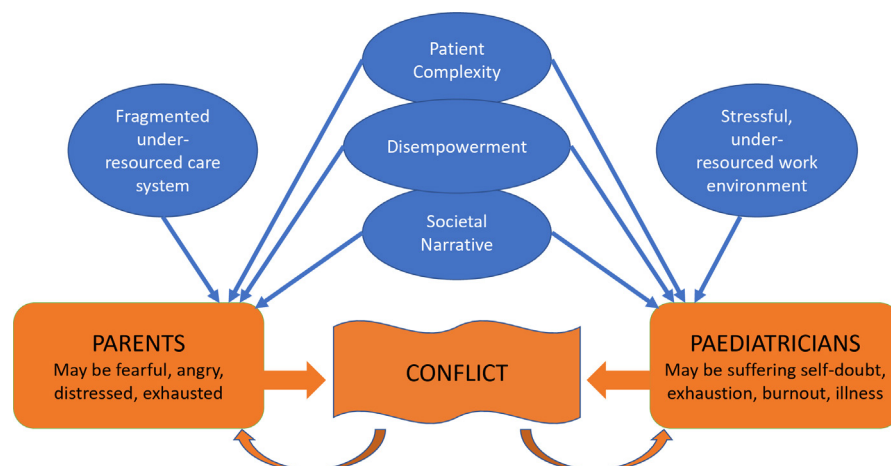


Figure 1 Vicious cycle of conflict and stress.

Box 1 Continued

you then question are you a worse doctor? There is self-doubt and guilt that maybe you could have done something better."

Service gaps, workforce pressures and lack of support in the workplace.

- ▶ *"Due to a lack of resources, you become concerned that you are not delivering the best quality care."*
- ▶ *"There is a mismatch between community services and the hospital's expectations. We cannot provide care in the community and the impact of cost is huge - trying to expand community care with no money is stressful."*
- ▶ *"Management have a responsibility for not only patients, but also staff."*
- ▶ *"There is a chronic low level of exhaustion."*
- ▶ *"Rota gaps place pressure on juniors, making them feel guilty if they don't cover them."*
- ▶ *"I am haunted by the death of the 6-year-old in resus and no one wants to talk to me about it."*
- ▶ *"If I made a mistake, there is a punishment cycle. There should be a recognition that people will make mistakes."*
- ▶ *"You can be threatened potentially physically and need police presence. We do not have the same rights as the family or patient - there is a lack of public voice for us."*

more profound impact on paediatricians. The death of Victoria Climbié in 2000, followed by that of Peter Connelly in 2007, highlighted the complex judgements made by those involved with at-risk children; errors in either direction, either missing an abused child or incorrectly identifying abuse, are likely to have long-lasting and tragic consequences for the child and family, but can also be traumatic for the professionals involved.⁸ Yet for many years child protection was a poorly researched area, and the science was inexact and error-prone.⁹ Alongside these cases, paediatricians were becoming increasingly anxious about the controversies surrounding fabricated or induced illness, and the series of disputed cot deaths which led to expert witnesses Roy Meadows and David Southall facing protracted General Medical Council cases and a very personal media backlash.¹⁰

A decade ago, there was a growing fear that the pressures of child protection work,

alongside an increasing blame culture, would adversely affect recruitment into paediatrics.¹¹ Paediatricians recognised that urgent action was needed, and through a concerted approach of strengthening the evidence base,¹² improving training in safeguarding and court work, and ensuring rigorous support to trainees, the impact of the adverse publicity was mitigated, and recruitment to the specialty remained buoyant. This is an important lesson for today's challenges.

CURRENT CHALLENGES IN PAEDIATRIC SERVICES

A changing demographic

Safeguarding apart, where the interests of the child are not always aligned with those of the parents, paediatricians have traditionally enjoyed a close working relationship with children and families, and this has been a mitigating factor for the long intense hours. A further attraction of the specialty has been the almost magically transformative act of being able to make sick children better at speed, with many quotes from a recent paediatric trainee twitter campaign (#paedsrocks) making reference to this; for example, "*#paedsrocks because less than 36 hours ago I was considering inotropic support for the patient I'm currently chasing around the ward.*"

However, advances in technology and medicine mean that the inpatient demographic is changing. More children are surviving with medically complex conditions and paediatric wards are no longer filled with patients who bounce back to health within 24 hours; instead, many beds are occupied by the rising numbers of

children with multiple healthcare needs, disability and/or life-limiting illnesses.¹³ The fragmented health, education and social care systems often fail to serve these children and families well, through a combination of inadequate resources, difficulty managing complexity and uncertainty, and a mismatch between expectations and what is deliverable. As a result, their parents are often distressed, frustrated and exhausted.

Paediatricians report high stress levels just performing a routine ward round in the face of this tension and may feel disempowered or experience a sense of failure at being unable to achieve consensus on treatment plans. This is in line with a study of conflict in a children's hospital, which demonstrated that conflict is prevalent across paediatric specialties, with the three most common causes being 'communication breakdown', 'disagreements about treatment' and 'unrealistic expectations'.¹⁴

An important underlying issue is the way in which paediatricians are trained and paediatric care is organised. In North America, the concept of 'Children with Medical Complexity' (CMC) has been embraced.¹⁵ CMC have been characterised as those with significant and/or multiple chronic health conditions, functional limitations and substantial healthcare use. Different models of care are emerging in America to address the particular challenges and needs of this group.^{16 17}

The UK has lagged behind in recognising and adapting to the health requirements of the rising numbers of children who would meet the American CMC definitions. General paediatricians are still being trained to work in an acute

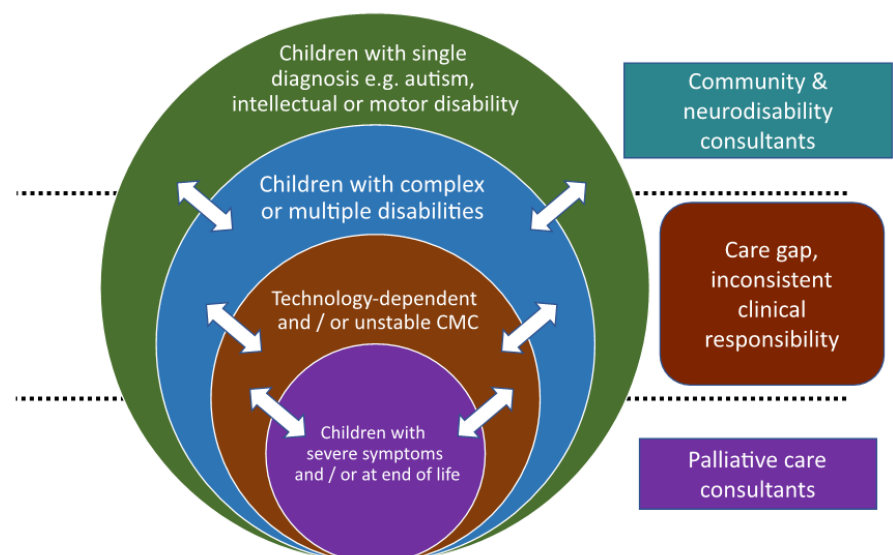


Figure 2 Inconsistent clinical responsibility. CMC, children with medical complexity.

Box 2 Recommendations from 'Spotlight on Paediatrics' meetings

Staff training.

Three aspects were discussed:

- ▶ Better individual and team training in self-care and recognition of mental health problems.
- ▶ A changed approach to training staff in the advanced communications skills needed to manage difficult conversations and shared decision-making, as well as in early recognition of signs of conflict.
- ▶ Improved training in management of children with complex disabilities, palliative care, ethics and law.

Supporting the workforce.

- ▶ A wide range of measures were discussed, including new approaches to clinical and personal supervision, debriefing following critical events, better peer and team support structures, and enhancement of social networks in the work environment.

Team/Organisational strategies.

- ▶ These included strategies for early recognition of potential conflict and breakdowns through 'ward-walking', review of complaints to Patient Advice and Liaison Services, shared learning from previous high-profile events, and 'learning from excellence'.

Supporting parents.

- ▶ Some resources already exist for supporting parents through the voluntary sector, and these need to be augmented. Parents, like staff, also need access to targeted training and resources to manage some of the situations in which they find themselves.

Use of national guidance and frameworks.

- ▶ Clarification needs to be sought from the General Medical Council on application of patient confidentiality in an era of social media, particularly in relation to cases that go to court.
- ▶ Several national documents have recently been produced or are in development relating to care of children with complex healthcare needs and children's palliative care, in addition to existing frameworks about withdrawing life-sustaining treatment.
- ▶ There were also discussions about ways in which a national approach

Continued

Box 2 Continued

and/or access to ethics guidance could be developed.

Creating a single narrative.

- ▶ There was extensive debate about how to engage in a constructive and open narrative with the public about the issues, addressing the societal, political and ethical taboos and polarised positions, with a range of constructive ideas. The most consistent view across both meetings was that parents and the voluntary sector need to be engaged as part of the solution.

care model, and community and neuro-disability paediatricians to work in predominantly non-acute and outpatient settings. Nursing teams may cross boundaries more effectively but are still predominantly based in either acute or community services. So who should be taking responsibility for this growing cohort of children oscillating between home and hospital, wellness and illness, good quality life and poorly controlled symptoms? Arguably, if the parents of these children had a trusted clinician to provide continuity of care and support across all settings, the difficult decisions that can deteriorate into conflict and stress might be better managed.

The community or neurodisability consultant might be expected to take this role, and in some services they do. But too often these consultants are facing escalating waiting list pressures to see and assess children with autism and attention deficit hyperactivity disorder, as well as dealing with safeguarding, looked-after children and a rising tide of mental health problems.¹⁸ They of course see children with cerebral palsy and complex healthcare needs in clinic when they are relatively stable, but do not often have the capacity to follow them through their hospital admissions. Specialist palliative care consultants may be brought in when the children are increasingly unwell, but they are facing their own workforce crisis¹⁹ and do not have the capacity to take long-term responsibility for symptom management in this growing population of life-limited children. This leaves a gap in continuity of care (figure 2), with general paediatricians and intensivists trying to provide consistency and coordination, despite a weekly consultant attending system and a lack of specific disability training.

A changing relationship with the wider public

With paediatricians already feeling fragile through changes in their day-to-day interaction with patients, vulnerability has been increased by a more recent series of high-profile cases.

First, while looking after children has always been 'high stakes', with the spectre of missing a sick child ever present, the case of Dr Hadiza Bawa-Garba, found guilty in 2015 of the manslaughter of 6-year-old Jack Adcock, has heightened anxiety among doctors,²⁰ with paediatricians feeling this particularly keenly. Controversy still swirls around the GMC's case to have her erased from the medical register, with real concern about the impact of such an action on Duty of Candour. There is considerable potential for putting patients at even greater risk if a blame culture predominates over transparency and the need to address system failures.

Second are cases such as those of Ashya King,²¹ Charlie Gard²² and Alfie Evans. The hallmark of these cases was that the parents and treating clinicians differed in their views about how the best interests of the child should be met. This is not a unique or unfamiliar situation, but the game-changer in these cases was the explosive role of not just the mainstream media, but also the social media,²³ particularly in the latter two cases. The perfect storm was generated through medical staff feeling demonised but unable to tell their side of the story, the growing public belief that 'if it can be done it should be done', and a 'post-truth' culture where trust in experts and evidence is at a low ebb.

Workforce pressures

Analyses of Care Quality Commission reports demonstrate that workforce shortfalls are a major contributor to poor ratings of children's services,²⁴ putting additional pressure on a demoralised workforce. Rota gaps have become an increasing problem, due to a combination of trainees working less than full time, other out-of-programme activities and an increase in attrition rates. A briefing from the RCPCH²⁵ reported middle-grade rota gaps of up to 24%, with a majority of clinical directors being seriously concerned about staffing through the winter. Trainee surveys²⁶ have highlighted poor morale due to a combination of rota pressures, being required to work extra shifts to cover gaps and feeling undervalued.

These problems provide a backdrop to the rising distress among paediatricians

but are not the sole driver, nor is paediatrics the only specialty dealing with rota gaps.²⁷ However, it is important to recognise that these rota gaps detract from essential training and experience. With trainees being consumed by the demands of acute care and 4-hour targets in the emergency department, they are less able to attend outpatients, gain experience of working in new integrated care programmes in primary care, and acquire training in the management of the long-term diseases and mental health conditions, which are an increasingly important part of the specialty. This only serves to exacerbate feelings of anxiety and disempowerment when they enter the consultant grade where this is a growing part of the case load.

SOLUTIONS AND RECOMMENDATIONS

If we are to address these problems effectively, work is needed at the local, regional and national level, and needs to be jointly owned by the healthcare community and the wider public.

Recommendations from the 'Spotlight on Paediatrics' meetings

Box 2 provides a high-level summary of the combined recommendations of both 'Spotlight' meetings. Topics covered include staff training, particularly in early recognition and management of conflict (an intervention for which there is an emerging evidence base²⁸); support for both parents and staff; team and organisational strategies; and the use of national guidance and frameworks; for example, both RCPCH²⁹ and the Nuffield Council on Bioethics³⁰ have produced guidance on managing disagreements and achieving consensus. Most challenging is the need for an open narrative between clinicians and the wider community about the difficult choices that must be made when what *can* be done to extend life is not always what *should* be done.

Establishment of a collaborative to progress the work

Although solving these problems seems like a large mountain to climb, there are immediate practical steps that can be taken. A collaborative is now being established with a remit to work on strategies to improve the following:

- ▶ The well-being of CMC and their families, including reviewing the service models that would best serve this group.
- ▶ The professional and clinical skills of the professionals looking after them,

to enable them to work most effectively with the children and their families.

- ▶ The organisational approach to supporting staff working in children's services.

This is not to imply that all the problems outlined in this paper are related to the care of CMC, but the development of a different strategy for this group would support transferable skills to address many of the wider challenges. Since the 'Spotlight' meetings, there has been growing enthusiasm for such an endeavour among relevant organisations (eg, at Royal College level, among specialty groups and the children's voluntary sector, and among children's hospitals, as well as approaches from many interested individuals). The proposed activities of such a collaborative would be as follows:

Sharing of good practice and quality improvement initiatives

There is already much good practice being developed around the country, and better sharing will accelerate the pace of change. Examples of innovation include several projects providing better integrated care of children with long-term conditions between primary, community and secondary care, a dedicated team for CMC at Birmingham Children's Hospital, and a 'ward walking' strategy by senior staff to proactively identify early conflict situations. A collaborative would enable not just sharing, but multicentre piloting of new initiatives. There would also be scope for developing and sharing examples of good practice in staff support (eg, consideration of adopting Balint group approaches or alternative models of personal supervision that have been successful in other professional groups).

Development and sharing of educational initiatives and resources

Box 2 touches on some of the training initiatives that are needed, but the issue of education for career-grade staff warrants specific mention. It is essential that those already in career-grade posts, as well as trainees, have access to programmes which equip them to adapt to changing clinical demands, and that educational materials are developed and used as efficiently as possible. Development of a shared suite of modules covering topics such as 'care of the technology dependent child at home', 'end of life care for neonates', 'assessment of the child with disability in the emergency department', 'ethics and law in child health', and 'pain

management in complex disability' would mean that paediatricians, nurses and allied health professionals could chart their own learning pathways relevant to their specific and evolving roles.

Literature review and research on models of care

Finally, it seems timely to critically review the needs of the CMC population, and to revisit paediatric training and service delivery models. Can elements of the North American models of care and approaches to training be adapted and developed in a UK setting? A literature review and research on best practice in this area drawing on international models where available should be an early objective of the collaborative, and this should feed in to the Paediatrics 2040 programme being run by the RCPCH.

CONCLUSION

The stresses on paediatricians are not unique, with other children's healthcare professionals, as well as clinicians in other specialties, facing a range of complex pressures and problems. However, paediatricians are perhaps a 'canary down the mine' given that sick or dying children generate such dramatic and polarised public reactions. In addition, the availability of specialty-specific data from the PHP 10-year review and from RCPCH surveys, as well as qualitative information from the 'Spotlight' meetings, provide insights that are not as readily available for other members of the multidisciplinary team.

It would be easy for paediatricians to feel that they are unable to influence the challenges that have arisen through major changes in case load, new societal expectations and the stress that accompanies conflict with parents and carers. However, the historical perspective of the child protection predicament should teach us that careful collection of data and evidence, an active programme of education, exploration of new service models, and national collaboration and guidance can turn a crisis into an exciting new area of innovation and research.

Acknowledgements The authors wish to acknowledge the generous support of the Royal Society of Medicine and True Colours Trust in sponsoring the 'Spotlight on Paediatrics' meetings.

Contributors HC wrote the full manuscript and also led the two 'Spotlight' meetings described herein. SB facilitated parts of both the Spotlight meetings, contributed to the components about conflict and was involved in editing of the text. CG contributed data and background information on mental illness and stress in doctors and was involved in the planning of the first

Spotlight meeting. She was also involved in editing of the text. DEL contributed to the section on children with medical complexity and thinking about this aspect of the paper. He was involved in editing of the text. KS facilitated both meetings in her capacity as Associate Dean at RSM and also wrote up the proceedings of the first Spotlight meeting. She was involved in editing of the text.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient consent for publication Not required.

Provenance and peer review Commissioned; externally peer reviewed.

Author note Any individuals or organisations interested in joining the planned collaborative should contact the lead author.

© Author(s) (or their employer(s)) 2020. No commercial re-use. See rights and permissions. Published by BMJ.



To cite Cass H, Barclay S, Gerada C, *et al.* *Arch Dis Child* 2020;**105**:109–114.

Received 4 January 2019

Revised 1 May 2019

Accepted 17 May 2019

Published Online First 11 June 2019

Arch Dis Child 2020;**105**:109–114.

doi:10.1136/archdischild-2018-315818

ORCID iD

Hilary Cass <http://orcid.org/0000-0001-8598-9134>

REFERENCES

- 1 Royal College of Paediatrics and Child Health. Supporting evidence for paediatric doctors to be included on the shortage occupation list 2019 [ONLINE]. https://www.rcpch.ac.uk/sites/default/files/2019-01/RCPC%20supporting%20evidence_final%2014-1-19.pdf (Accessed 27 Apr 2019).
- 2 Gerada C. *The Wounded Healer: Report on the First 10 Years of Practitioner Health Service* London: NHS GP Health Service / Practitioner Health Programme, 2018.
- 3 The Royal Institute of International Affairs. Chatham house rule. <https://www.chathamhouse.org/chatham-house-rule> (Accessed 27 Apr 2019).
- 4 Walshe K, Offen N. A very public failure: lessons for quality improvement in healthcare organisations from the Bristol Royal Infirmary. *Qual Health Care* 2001;10:250–6.
- 5 Cassidy J. Name and shame. *BMJ* 2009;339:b2693.
- 6 Bauchner H, Vinci R. What have we learnt from the alder hey affair? *BMJ* 2001;322:309–10.
- 7 Allan N, Harden J. Parental decision-making in uptake of the MMR vaccination: a systematic review of qualitative literature. *J Public Health* 2015;37:678–87.
- 8 Parish E, Emma P. Who should we blame for the death of Baby P? *BMJ* 2014;349:g6643.
- 9 Munro E. Avoidable and unavoidable mistakes in child protection work. *Br J Soc Work* 1996;26:793–808.
- 10 Dyer C. David Southall: anatomy of a wrecked career. *BMJ* 2012;344:e3377.
- 11 Haines L, Turton J. Complaints in child protection. *Arch Dis Child* 2008;93:4–6.
- 12 Royal College of Paediatrics and Child Health. Child protection evidence [ONLINE]. <https://www.rcpch.ac.uk/key-topics/child-protection/evidence-reviews> (Accessed 27 Apr 2019).
- 13 Fraser L, Miller M, Aldridge J, *et al.* *Life-limiting and life-threatening condition children and young people in the United Kingdom: Final Report for Together for Short Lives*. Leeds: Paediatric Epidemiology Unit, Leeds University, 2012.
- 14 Forbat L, Sayer C, McNamee P, *et al.* Conflict in a paediatric hospital: a prospective mixed-method study. *Arch Dis Child* 2016;101:23–7.
- 15 Cohen E, Kuo DZ, Agrawal R, *et al.* Children with medical complexity: an emerging population for clinical and research initiatives. *Pediatrics* 2011;127:529–38.
- 16 Cohen E, Berry JG, Sanders L, *et al.* Status Complexicus? The emergence of pediatric complex care. *Pediatrics* 2018;141:S202–S211.
- 17 Pordes E, Gordon J, Sanders LM, *et al.* Models of care delivery for children with medical complexity. *Pediatrics* 2018;141:S212–S223.
- 18 British Association for Community Child Health. *Covering all bases. Community child health: a paediatric workforce guide*. London: RCPCH, 2017.
- 19 *The All-Party Parliamentary Group (APPG) for Children Who Need Palliative Care 2018: End of life care: strengthening choice*. Bristol: Together for Short Lives, 2018.
- 20 Cohen D. Back to blame: the Bawa-Garba case and the patient safety agenda. *BMJ* 2017;359:j5534.
- 21 Bridgeman J. Misunderstanding, threats, and fear, of the law in conflicts over children’s healthcare: in the matter of Ashya king [2014] EWHC 2964. *Med Law Rev* 2015;23:477–89.
- 22 Hurley R. How a fight for Charlie Gard became a fight against the state. *BMJ* 2017;358:j3675.
- 23 Richards BJ. Social media: the unnamed plaintiff. *J Bioeth Inq* 2018;15:309–12.
- 24 NHS Improvement. Improvement and assessment framework for children and young people’s health services 2018 [ONLINE]. <https://improvement.nhs.uk/resources/improvement-and-assessment-framework-children-and-young-peoples-health-services/> (Accessed 27 Apr 2019).
- 25 RCPCH. Workforce briefing winter 2018. [ONLINE]. <https://www.rcpch.ac.uk/resources/workforce-briefing-winter-2018> (Accessed 27 Apr 2019).
- 26 General Medical Council. Key findings from the national training survey. 2018 [ONLINE]. https://www.gmc-uk.org/-/media/documents/training-environments-2018_pdf-76667101.pdf (Accessed 27 Apr 2019).
- 27 General Medical Council. The state of medical education and practice in the UK 2018. [ONLINE]. <https://www.gmc-uk.org/somep2018> (Accessed 27 Apr 2019).
- 28 Forbat L, Simons J, Sayer C, *et al.* Training paediatric healthcare staff in recognising, understanding and managing conflict with patients and families: findings from a survey on immediate and 6-month impact. *Arch Dis Child* 2017;102:250–4.
- 29 Linney M, Hain RDW, Wilkinson D, *et al.* Achieving consensus advice for paediatricians and other health professionals: on prevention, recognition and management of conflict in paediatric practice. *Arch Dis Child* 2019;104:413–6.
- 30 Nuffield Council on Bioethics Disagreements in the care of critically ill children 2019 [ONLINE]. <http://nuffieldbioethics.org/wp-content/uploads/Disagreements-in-the-care-of-critically-ill-children.pdf> (Accessed 27 Apr 2019).