



Realising the research power of complaints data

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...I did not want HDC just to be the ambulance at the bottom of the cliff. I wanted to help build the fence to the top of the cliff, to help make the health and disability system safer. We owe this to the people who are harmed when things go wrong.¹

Medical care is a vital ingredient in population health. However, health services research has repeatedly shown that it is also a hazardous enterprise.²⁻⁶ Fuelled by this realisation, monitoring and improvement of quality and safety has become a health policy priority in many national health systems. But efforts to achieve system-wide improvement face difficult challenges, and the harsh reality is that health care is unlikely to be much safer today than it was a decade ago.^{7,8}

Complaints by aggrieved patients have the potential to be an important window on healthcare quality. Each year the eight health care commissioners in New Zealand and Australia (hereafter, “Commissioners”) receive over 10,000 complaints, many of which highlight preventable adverse events. The complaints have considerable sentinel value: for every adverse event complained of, dozens more lie below the waterline.⁹ To date, however, that value remains largely unrealised.

Research into healthcare complaints

Commissioners have embraced a culture of quality improvement, including the time-honoured mantra that “every defect is a treasure”. They frequently acknowledge that there are valuable lessons to be learnt from their caseloads, and appear committed to using complaint resolution processes as a mechanism to facilitate improvements in the health services. Nonetheless, the fact remains that complaints data is rarely subjected to empirical research.

Commissioners’ annual reports¹⁰⁻¹⁶ typically contain statistics describing general features of the jurisdiction’s overall caseload, and present case studies to illustrate particular themes. But there are few examples of more comprehensive analyses of complaints. Several years ago, we partnered with the New Zealand Health and Disability Commissioner to conduct a pair of studies of complaints: one investigated patients’ motives for lodging them and the other analysed disparities in complaint-lodging behaviour.^{9,17}

Several studies in the United States have used complaints data to analyse quality problems arising in long-term care¹⁸ and acute care.¹⁹ In addition, there have been two notable studies of complaints in Australia: a survey of complainants to the New South Wales Health Care Complaints Commission²⁰ and a retrospective analysis of patient complaints in 67 Victorian hospitals.²¹

Temolkovski and Callaghan’s study joins this small but growing literature. One common thread running through this body of work is that, after observing both the wealth of information available in complaints and the paucity of previous research, investigators are consistently moved to conclude that the data are vastly under-

appreciated and underused as a quality improvement tool. Temolkovski and Callaghan make a similar point. We agree. Why does this situation exist?

Barriers

Several logistical and methodological hurdles have traditionally barred progress in using complaints and other types of medicolegal data to study healthcare quality and safety. First, rigorous analysis of complaints demands the application of public health methods, with the right blend of quantitative and qualitative research skills. This means moving beyond analyses of single cases to appropriately aggregated samples that permit statistically reliable identification of patterns and trends.

The technical expertise needed to conduct this work is not ordinarily found in Commissioners' offices. More importantly, pressing operational commitments and a lack of resources inhibit opportunities to get this type of research off the ground.

The result is a curious situation: Commissioners are swimming in information that could be used to inform improvements in care, and potentially even reduce their caseload in the medium- to long-term, but they lack the means by which to organise and deploy their data toward those ends. Like busy clinicians, Commissioners and their staff are frequently so "immersed in the narrative" of individual patient stories that it becomes difficult to lift their gaze to examine population-level questions.

Second, confidentiality concerns limit researchers' access to complaints data. As Temolkovski and Callaghan note, fewer than 10% of complaints received by the Health and Disability Commissioner result in an investigation with publicly reported (albeit anonymised) findings, and the basis for selecting those complaints is unclear.

Most of the information compiled and generated during complaints processes is held tight, and appropriately so, because complaints files contain private medical information and sensitive legal documents. A leak of confidential information into the public domain could undermine confidence in the entire system.

Third, as health services researchers are quick to point out, complaints data are unrepresentative of broader quality problems in health care. This is undoubtedly true. Complaints are "biased" in the sense that they are refracted through the lens of patients' behaviour.

Some patients who experience adverse events will initiate medicolegal action, but most will not. Moreover, some patients complain in the absence of any identifiable decrement in quality,²² creating a degree of "noise" in complaints data. The direction of some of these biases is predictable. For example certain specialties, such as surgery where adverse outcomes tend to be more severe and readily identifiable, generate disproportionately large numbers of complaints.

Similarly, sources of dissatisfaction with care that are highly visible to patients—communication breakdowns, for example, or breaches of informed consent—are staples in medicolegal caseloads. In addition, there is reasonable evidence to suggest that older patients and those with lower socioeconomic backgrounds are less likely to complain when adverse events occur.^{9, 23}

While it is important to recognise that complaints data is prone to being skewed in these directions, it does not follow that this feature undoes the value of such data.

Rather, it means that the nature and extent of quality problems identified through complaints should be interpreted carefully, and only ever construed as a partial indicator of the overall standard of health care.¹⁶

Complaints should not, for example, be used as a proxy for the incidence or prevalence of particular adverse events in healthcare systems. But *within* selected types of adverse events, complaints and other medicolegal events may still offer excellent insights into causal factors.

A final methodological hurdle is that, despite intensive efforts by the World Health Organisation and others to develop taxonomies for adverse events generally, uniform coding methodologies for complaints are lacking. Temelkovski and Callaghan's suggestion that the "systematic reporting formats" would greatly improve research in this area is on the mark. We believe the benefits could go even further and help stimulate research interest in complaints.

Benefits

For researchers able to navigate the barriers to analyses of complaints data, the rewards may be large. In particular, several features of complaints data boost their value in understanding and improving quality.

A "consumer-initiated" adverse event reporting system—Complaints are one of the few reliable sources of information on problems in healthcare delivery that worry patients most. Patients often struggle to have their voices heard in debates over quality and safety.²⁴

A sustained, public health focus on the content of complaints meets that concern head on. Some of the same biases in complaints data that worry epidemiologists may actually be strengths if they run in the direction of flagging the kinds of systemic failings that matter most to consumers.

Aggregation—For events that are infrequent but disastrous, such as wrong site surgery, complaints play a powerful triaging role. Commissioners' caseloads are able to draw together collections of relatively rare events from across entire healthcare systems, producing concentrated clusters of problems that institution-based adverse event reporting systems or random chart review audits never could.

For some types of events, there may be enough descriptive information about how different types of error occur to guide the design of successful interventions;²⁵ others may require case-control analyses (using the complaints as cases, and uninjured patients who underwent the same procedure as controls) to illuminate appropriate interventions.²⁶

Concordance with patients' desire for lessons to be learnt—Patients with incurable diseases often hope that lessons can be learnt from their suffering to help ease the pain of other patients and families. Hear, for example, the father of a family afflicted by Huntington's disease speaking of his decision to donate his son's brain to the New Zealand Brain Bank: "It's not going to help young Chris. It's too late for my boys but it will help someone else".²⁷

The motivations of many patients and families who seek redress through complaints systems bear striking similarities to this sentiment. They desire that lessons are learnt so that other patients will not have to suffer a similar harm.¹⁷

For example, Dale Ann Micalizzi, the mother of an 11-year-old who died during ankle surgery, explains her decision to take medicolegal action following her son Justin's death: "We weren't interested in money. We didn't want to retaliate. We just wanted answers. I don't want this to happen to somebody else".²⁸

In such cases, assurances that one's negative experience will be analysed alongside other similar experiences with the objective of improving quality of care broadly could provide families with a form of satisfaction that even optimal handling of their particular case will not.

Conclusion

Systems for receiving and adjudicating healthcare complaints today are built around legal procedure and analysis. There is assiduous attention to due process and consumer rights. It is a culture well-matched to the statutory purpose of complaints resolution and the standard training of Commissioners. However, the enormous potential for well-designed analyses of complaints to improve quality and safety opens up new possibilities for complaints systems.

Commissioners are well-placed to pursue a parallel set of activities focused on drawing lessons for preventing harms from population-level analyses of complaints data. In New Zealand, that role would be consistent with the Commissioner's statutory purpose of "protect[ing] the rights of health consumers and disability services consumers",²⁹ where a key "right" is the right to have services provided with reasonable care and skill and in a manner that minimises potential harm.³⁰

How to get from here to there? To become more active agents in improving public health, Commissioners require more than ideas. They need the right technical expertise; the right resources, including information technology systems capable of effectively organising complaints data; and the right research questions, prioritised according to considerations like the burden of associated harm and the potential for remediation.

Above all, they need the political will to reimagine the role of Commissioners as guard rail builders in national health systems, not merely paramedics at the base of the cliff.

Competing interests: None known.

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Acknowledgements: We acknowledge Ron Paterson (former Health and Disability Commissioner) for his commitment to learning from complaints to support a safer healthcare system.

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