A decade of healthcare improvement in cystic fibrosis: lessons for other chronic diseases

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Received 25 January 2014
Accepted 27 January 2014

To cite: Stevens DP, Marshall BC. *BMJ Qual Saf* 2014;**23**:i1–i2.

From 2002 to 2012, the median predicted survival age for people with cystic fibrosis (CF) increased nearly 10 years—from 31.3 years to 41.1 years.[1 2] Strategic efforts to improve care for CF marked this remarkable era. These efforts were supported by expert leadership among CF healthcare improvement professionals and resources from the CF Foundation. While process outcomes improved substantially—for example, more timely clinic visits, increased influenza immunisation rates, and more effective screening for associated problems such as depression and diabetes,[1 2] clinical outcomes improved even more dramatically—notably, pulmonary function, nutritional status and predicted survival.

This supplement, *Ten Years of Improvement Innovation in Cystic Fibrosis Care*, captures the larger perspective of this comprehensive improvement initiative and reports representative CF care centre-level examples. It also identifies strategies to widen the circle of improvement professionals who successfully publish their innovative work in scholarly journals.[3]

WHAT CAN BE FOUND IN THIS SUPPLEMENT?

Institution-based improvement reports in this supplement describe better airway clearance linked to patient education,[4] successful strategies to meet guidelines for regular CF clinic visits,[5] local care improvement to meet and sustain goals for nutritional status,[6] reduced airway infection rates through improved infection prevention and control measures,[7] implementation of care redesign to improve the management of acute exacerbations of CF,[8] and an initiative to facilitate the continuum of care for patients moving from paediatric to internal medicine specialists, important as CF increasingly becomes a disease of both children and adults.[9]

Additional commissioned papers describe overarching improvement approaches that include strategic benchmarking,[10] development of a transparent patient registry to track outcomes at the individual patient and CF care centre (system) levels,[11] effective integration of patients and families into improvement processes,[12 13] and a series of improvement collaboratives to spread knowledge for improvement among CF care centres.[1 14]

WHAT WORKED TO IMPROVE CF CARE?

Disaggregating the relative contributions of these various improvement strategies is difficult.[15] Schechter *et al* make a strong case for the influence of a patient registry,[11] while Boyle *et al* craft a compelling argument for the role played by benchmarking—the analysis and spread of improvement strategies from highly achieving institutions to the wider CF centre network.[10] In addition, there is face value for the strong role that patients and families perform in improving CF care.[12 13] Finally, participation by care centre personnel in improvement collaboratives has been associated with demonstrably improved process outcomes.[14]

Recent reviews have provided empiric evidence for the impact of selected elements of context in effective improvement initiatives[16 17]—for example, leadership, culture and information systems. In their critical review, Kaplan *et al*[17] found a particularly positive role for institutional and microsystem quality improvement team leadership, with the strongest case being made for active participation by senior leaders in improvement initiatives, and the effective communication by leaders of their vision and expectations.

We argue for the strong contribution provided by effective integrated leadership from the CF Foundation as well as national

leaders represented by many of the authors in this supplement. Other contributing contextual elements[16 17] in the CF improvement story include effective data management, substantial physician involvement, a pervasive culture of improvement among CF care centres, and microsystem-level motivation for change.

CONCLUSIONS

While we do not underestimate the impact of recent scientific and therapeutic advances in CF,[1] we argue that healthcare improvement strategies such as those reported here—tested and adopted in CF care centres over a decade—have had a profound role in the improvement of life and predicted survival for people with CF. Moreover, we suggest that the aggregate effects of these combined efforts—a widely available and transparent patient registry, benchmarking of best improvement practices, active involvement of patients and their families in improvement initiatives, and dissemination of improvement methodologies among CF healthcare professionals—may be transferrable to improving care for others with serious chronic illnesses.

Contributors Both authors contributed to the design of this initiative. Both contributed to the original and subsequent drafts of this report.

Competing interests DPS received honoraria and travel support from the Cystic Fibrosis Foundation for preparation of this supplement. He is a member of the SQUIRE Development Group for which he receives honoraria and travel support from The Health Foundation and the Robert Wood Johnson Foundation. BCM receives support for salary and professional expenses from the Cystic Fibrosis Foundation.

Provenance and peer review Commissioned; internally peer reviewed.

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BMJ Quality & Safety

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BMJ Qual Saf 2014 23: i1-i2
doi: 10.1136/bmjqs-2014-002871

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