

# Embracing carers: when will adult hospitals fully adopt the same practices as children's hospitals?

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Everyday, in children's hospitals across the world, medical teams meet with hospitalised children and their family members on rounds. Why did this become routine in paediatrics? Parents demanding involvement in their child's care and paediatricians' willingness to listen and collaborate with families certainly contributed. Moreover, national organisations asserted that this should be the standard of care in children's hospitals. For example, the American Academy of Pediatrics and the Institute for Patient- and Family-Centered Care formally defined patient-centred and family centred care in 2012, recognising that 'the family is the child's primary source of strength and support'.<sup>1</sup> This policy statement emphasised how the perspectives and information provided by families are 'essential components of high-quality clinical decision-making, and that patients and family are integral partners with the health care team'. Moreover, the policy statement affirmed that physician rounds should occur in patients' rooms with nursing staff and family members, to involve them and optimise information exchange and decision-making.<sup>1</sup> A publication 2 years earlier defined family centred rounds (FCRs) as multidisciplinary rounds involving parents' perspectives in decision-making, and identified FCRs as the most common approach to rounds, occurring in almost half (44%) of the 265 respondents from children's hospitals across North America.<sup>2</sup> FCRs are now endorsed as the 'standard of care' in US children's hospitals.<sup>3</sup> Reviewing the research on FCRs therefore prompts an important question: why is this not routine in adult hospitals?

Systematic reviews have documented the benefits of FCRs, primarily in terms of improved family experience.<sup>4,5</sup> Families strongly desire such FCRs, which result in

increased understanding of information, increased confidence in the medical team and reduced parental anxiety.<sup>4</sup> FCRs also promote increased empathy, partnership, respect and communication.<sup>5</sup> Notably, targeting patient and carer barriers, such as health literacy or limited English proficiency, enhanced such benefits. Research by Bogue and colleagues reinforced these findings, concluding that incorporating family members in interdisciplinary rounds in a paediatric intensive care unit enhanced satisfaction, trust and the patient outcome of reduced length of stay.<sup>6</sup> Finally, a rigorous study of implementing a co-produced family centred communication programme, involving more than 2000 family caregivers at seven North American hospitals, documented a 38% decrease in harmful errors, and improvement of multiple aspects of family experience and communication processes.<sup>7</sup> Notably, there did not appear to be any negative impacts on the duration of rounds or on teaching. Nonetheless, another systematic review analysing 53 studies cited persistent structural barriers to nurse and family attendance and noted the paucity of high-quality evidence regarding the effectiveness of FCRs improving patient outcomes.<sup>8</sup>

Patients and carers identify leaving the hospital as an important initial goal in recovery from a patient's acute illness and seek engagement in rounds with the healthcare team to learn how to accomplish this. With this in mind, the study by Bristol and colleagues published in this issue of *BMJ Quality and Safety* evaluated the impact of a key event—intrahospital transfer—on patients' hospital care and patients' and carers' subsequent readiness for discharge.<sup>9</sup> The paper reports one component of a larger study evaluating the impact of providing information



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on patients' social needs and supportive resources to medical and surgical teams during discharge planning. Extensive research documents the hazards of intrahospital transfers, including increased hospital-acquired infections among elderly patients, delirium, increased fall risk, prolonged length of stay, miscommunication between healthcare providers, and death (especially among critically ill patients).<sup>10–12</sup> Evaluating the impact of intrahospital patient transfers on discharge readiness, for carers as well as for patients, therefore represents novel research that might inform efforts to improve the care transition from hospital to home or postacute care settings.

This is particularly relevant given implementation of the Caregiver Advise, Record, Enable (CARE) Act, now enshrined into law in 42 states in the USA.<sup>13</sup> It requires hospitals to: (A) Record the name of the family caregiver (ie, carer) in the medical record of their loved one, (B) Inform them when this patient is to be discharged, and (C) Provide them education and instruction on the medical tasks they will need to perform for the patient at home. Despite the CARE Act becoming law, implementation is slow with a survey of hospital executives in one state reporting that carer education and instruction is occurring in less than a third (32%) of all inpatient stays.<sup>14</sup> Thus, studies evaluating patient and carer readiness for discharge represent important research to inform hospital providers aiming to improve hospital discharge care transitions.

As part of their mixed-methods study, Bristol and colleagues conducted semistructured interviews with 23 individuals to explore the influence of intrahospital transfers on carers' readiness for discharge home.<sup>9</sup> The sample was relatively homogenous with the 23 carers being almost entirely white, English speaking and insured, somewhat limiting generalisability of findings. This may explain why patients in the included quantitative study (n=268; 80% of whom were white, 8% of whom preferred not to report their race and 94% of whom were insured) reported high levels of discharge readiness. Additionally, this study was performed in a hospital with solely private rooms and a median length of stay of only 3 days. These factors likely reduced the frequency of intrahospital transfers compared with hospitals where patients share rooms and may be moved frequently based on issues such as needing isolation or telemetry. The researchers' finding of no relationship between intrahospital transfers and patients' readiness for hospital discharge may therefore reflect the specific characteristics of the hospital and patient population, rather than the reality in many other hospitals. Nonetheless, the finding that increased intrahospital transfers was negatively associated with carers' perceptions of patient discharge readiness is important and deserving of consideration by hospital providers. More research is required to explore this issue in lower income populations.

### Box 1 Achieving healthcare that delivers what matters most to patients in care transitions<sup>17</sup>

What matters most to patients and carers (family caregivers) when transitioning from hospital to home

1. To feel prepared and capable; they want:
  - a. Hospital providers to tell them what to expect when they leave the hospital.
  - b. To be shown what to do and be given tools to care for themselves.
  - c. To be prepared for potential issues and know what to do if they occur.
2. Clear accountability; they want:
  - a. Clear understanding of who is responsible for different aspects of their care when they leave the hospital.
  - b. To know who I can contact if there are any problems.
3. To feel cared for and cared about; they want:
  - a. To be confident that their healthcare providers are taking care of them and care about them as individuals.

Five behaviours healthcare providers can perform

1. Include patients and carers in discharge planning and provide actionable information that is tailored and understandable with confirmed comprehension (ie, 'teach back').
2. Provide timely information about the patient's diagnosis and treatment.
3. Show they care with language and gestures that communicate compassion and empathy.
4. Anticipate patients' needs to support self-care at home.
5. Provide uninterrupted care with minimal handoffs between providers.

Findings from Project ACHIEVE (Achieving Patient-Centered Care and Optimized Health In Care

Transitions by Evaluating the Value of Evidence),<sup>15</sup> funded by the US Patient-Centered Outcomes Research Institute, provides extensive relevant information about factors affecting discharge readiness and utilisation of FCRs. An observational study of 27 participating US adult hospitals noted widely varying structure, participants and content in implementation of interdisciplinary rounds; only 4 hospitals (15%) included patients and carers in some of their rounds.<sup>16</sup> ACHIEVE also included a large qualitative study (focus groups and key informant interviews) to determine what matters most to patients and their carers as they go through the hospital discharge care transition.<sup>17</sup> The diverse sample clearly communicated what they want when leaving the hospital and how healthcare providers can help achieve their goals (box 1). Notably, patients and carers noticed when members of the healthcare team provided contradictory information, and this concerned them. FCRs offer a proven way to have the care team speak to patients and their carers with one voice. A subsequent survey of nearly 8000 patients going through the hospital discharge process identified the importance of trust.<sup>18</sup>

When hospitals and healthcare providers combined care coordination activities that bridged the transition from hospital to home, clear communication, and fostering of trust in delivering discharge care to patients and carers, a strong association with better patient-reported outcomes and reduced healthcare utilisation surfaced.

As we attempt to optimise hospital care transitions, whether intrahospital or discharge, abundant research provides guidance for what needs to be implemented in adult hospitals. As with children's hospitals, bedside rounds that incorporate patients and their carers can improve outcomes, including reductions in re-admission.<sup>19</sup> Incorporation of patients and carers in rounds, similar to FCRs in children's hospitals, offer a potential approach to deliver what matters most to patients and their carers. The rapid advances and expansion in telemedicine may facilitate involvement of carers who must remain at home or work during typical rounding times. Preliminary research, adapting to the requirements of social distancing from the COVID-19 pandemic, showed that tele-rounds with videoconferencing were an acceptable alternative approach in a children's hospital, and again families emphasised the importance of being included on rounds (10 out of 10 on a Likert Scale).<sup>20</sup> Providers reported a high level of satisfaction with minimal disruption. Other research has documented the success of telemedicine for remote parent participation in FCRs in a paediatric intensive care unit, indicating enhanced parent-provider communication and high parent satisfaction with minimal disruption of rounds.<sup>21</sup> Finally, virtual nursing care in the discharge process yielded improved patient satisfaction communication scores.<sup>22</sup> We suggest that it's now time for standardised implementation of patient-centred and carer-centred rounds in adult hospitals.

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