## ORGANISATIONAL MATTERS

# How can the principles of complexity science be applied to improve the coordination of care for complex pediatric patients?

**A G Matlow, J G Wright, B Zimmerman, K Thomson, M Valente**

Clinical and technological advances in medicine have resulted in more patients requiring multidisciplinary care and coordination of services. This is particularly challenging in pediatrics, given the dependency of children. Coordination of care is a key ingredient of quality care; when suboptimal, clinical outcomes and satisfaction can suffer. In this article we view coordination of care through the lens of complexity science in an effort to find new solutions to this healthcare challenge.

C linical and technological advances in medicine support numerous patients at the extremes of age and those with debilitating illnesses. Many are complex patients—that is, patients with multisystem disease who require multidisciplinary care and coordination of numerous services. The dependency of the pediatric population poses unique challenges for care, given the complete dependency of children on their care givers—most notably their parents.

Unfortunately, children with complex needs often experience poor coordination of care both in hospital and in the ambulatory care setting.[1][2] Family members might be considered best suited to assume a leadership role in this regard, but they may feel limited by their knowledge about their child's condition or by their skills and strength.[3] The primary care pediatrician might also play a pivotal role in coordination of care for these patients, but they too may be encumbered by lack of knowledge about the medical conditions and available resources, and lack of communication from specialists and services involved in the child's care.[4] There may be too many coordinators or, conversely, a designated or capable coordinator may be lacking. All the above may result in frustration for the patient and family, and inefficient and poor quality patient care.[4] As current strategies have not remedied the problem, a novel approach to coordination of care would be welcome. In this paper we hypothesize that complexity science can provide insight into how to improve coordination of care for patients with complex illness, and propose a research agenda to explore this hypothesis.

## WHAT IS COORDINATION OF CARE?

Coordination has been defined as "the process of orchestrating the sequence and timing of interdependent actions".[5] In health care, coordination involves "assessment, planning, implementation, evaluation, monitoring, support, education and advocacy, and it occurs in multiple systems".[6] The American Academy of Pediatrics has expanded on the components of care coordination as required for children with special healthcare needs to include itemizing planning treatment strategies, coordinating visits with subspecialists, organizing care to avoid duplication of diagnostic tests and services, sharing information among healthcare professionals and families, planning a hospital discharge, and reassessing and readjusting the plan of care over time.[4]

Poor coordination of care has many consequences. It has been perceived as a problem in care[2] and has been directly correlated with quality of care as perceived by the patient including lower levels of patient satisfaction.[7] Better coordination of care is associated with higher levels of perceived health status and receipt of preventive services.[8][9] Poor coordination is associated with increased medical errors, morbidity, and mortality.[1][10][11] Jaipaul *et al*[12] reported that satisfaction with care—specifically, satisfaction with coordination of care—was inversely correlated with mortality rates. In pediatrics, parents of children hospitalized at academic health centres (AHCs) reported 9% more problems with coordination of care than those at non-AHCs.[2] Because patients hospitalized in AHCs are likely to have more complex medical problems, the numerous providers in teaching institutions may amplify opportunities for communication gaps. In addition, lack of a timely and easily accessible repository of medical information may impede communication.

These problems of coordination can be amplified by social factors. For example, a study examining the relation between care coordination and mental health service use found lack of coordination more prevalent in those of black or Hispanic ethnicity reporting poverty and low parental education.[13][14] Factors which may impede communication include language barriers and differing cultural approaches to informed consent and communication of health information among family members. Thus, lack of coordination of care is a frequent problem with serious consequences, and improving coordination of care has the potential not only to improve satisfaction, self-perceived health status and equitability of health care, but also to reduce morbidity and mortality.

See end of article for authors' affiliations
.......................

Correspondence to:
Dr A G Matlow, Hospital for Sick Children, 555 University Avenue, Toronto, Ontario, Canada M5G 1X8; anne.matlow@sickkids.ca

## THE CHALLENGES OF COORDINATING CARE

Everyday system providers are troublesome for every patient, but for complex patients with extra needs such as transportation, errors become especially troublesome. This is because patients with complex healthcare needs require coordination of care between their providers and services—within hospitals, within their community, and between hospitals and community. Consider a child in a wheelchair who requires an outpatient CT scan. The family is taken by special transport to the diagnostic imaging facility and arrives late only to find that the CT scan is cancelled. The follow up clinic the family attends is not informed that the scan has not taken place. The family does not realize that the follow up visit is specifically to address the results of the new scan. The family goes to the clinic, again by special transport, and waits 2 hours to be seen, only to find that the clinician has nothing to offer without the new test results.

Lindeke *et al* have outlined the complexities of coordinating care for children with special health care needs.[5] A case is cited of an agency bringing together the many parties involved in the care of a single special needs child. Eighteen individuals (health service providers, teachers, social workers, etc) convened for the meeting, at the end of which a consensus surrounding care was achieved with the family. However, such meetings across boundaries (that is, hospital based and community based specialists) do not commonly take place,[5] and patients/families/parents often have to negotiate the difficult coordination pathway themselves. Physicians and nurses have been reported to spend hours of unremunerated time coordinating care activities (such as referrals and mental health issues).[15] In a fee for service model, remuneration is pegged to average case severity. The additional time required to coordinate care for the complex patients therefore serves as a subtle (or not so subtle) disincentive to spend time in such activities.

Organizations often seek to redress problems of coordination by increased standardization[16]—such as with the use of checklists, algorithms, or detailed information packets—with the underlying assumption that the adoption of these standards of care will result in a more reliable and systematic process. While these attempts to reduce complexity work some of the time, most practitioners and clinical staff intuitively understand that not all outcomes are predictable and that a single algorithm will not fit all patients.[17]

It is clear that the challenges of coordinating care, particularly for complex patients, have not been uniformly solved to date by current approaches. How can a science that embraces complexity offer an alternative approach?

| Table 1 | Complexity science compared with established science |
| --- | --- |
| **Complexity science** | **Established science** |
| Holism | Reductionism |
| Indeterminism | Determinism |
| Relationships among entities | Discrete entities |
| Non-linear relationships | Linear relationships |
|   Critical mass thresholds |   Marginal increases |
| Quantum physics | Newtonian physics |
|   Influence through iterative non-linear feedback |   Influence as direct result of force from one object to another |
|   Expect novel and probabilistic world |   Expect predictable world |
| Understanding; sensitivity analysis | Prediction |
| Focus on variation | Focus on averages |
| Behavior emerges from bottom up | Behavior specified from top down |
| Metaphor of morphogenesis | Metaphor of assembly |

From Begun *et al*.[18]

## LOOKING TO COMPLEXITY SCIENCE

Coordination of care necessitates traversing disciplinary boundaries and occurs both within and between multiple systems. A ''system'' is a set of connected or interdependent things or agents (such as a person, a molecule, a species, or an organization). Both systems theory and complexity science focus on the relationships between these elements rather than on each element alone within the system. The best way to understand complexity science is to contrast it with established science, since most have an understanding of this latter field of knowledge (table 1).

Healthcare delivery has been described as a living system or a ''complex adaptive system''[17 19 20]—that is, '' a collection of individual agents with freedom to act in ways that are not always predictable, and whose actions are interconnected so that one agent's actions changes the context for other agents''.[20] Although to anyone healthcare delivery would be considered a complex adaptive system, to someone with a complex illness it is even more so. Complexity science suggests that attempts to rigidly control a complex system can increase problems and unintended consequences as individuals in the system ''work around'' these controls.[19] For example, after the introduction of bar code medication administration in three VA hospitals, nurses were more likely to omit scanning the wristband in order to reduce workload during busy periods.[21] Complexity science also suggests that, in order to affect change in a complex adaptive system, we must understand the recurring patterns in the system including the patterns of relationships.[19 22] Complexity science applied to health care focuses on the pattern as well as the networks and social context of patients, and emphasizes the importance of context. Complexity perspectives consider the importance that identities (professional and personal) as well as the history and quality of relationships can have on the emergent quality of the coordination events for different cases. Table 2 outlines some of the key principles put forward by complexity science for managing complex adaptive systems.

The notion of applying the principles of complexity science to medical science is not new. Whereas we are proposing the application of complexity science to coordination of care, Wilson and Holt used a complexity perspective to describe alternative (that is, different from traditional) approaches to managing three clinical situations: glycemic control in diabetes mellitus, uncertainty in clinical diagnosis, and health promotion.[23] Using diabetic control as an example, these authors refer to the DAFNE (Dose Adjustment For Normal Eating) randomized controlled trial in which patients with type I diabetes were given intensive training in intensive insulin management in order to enable ''dietary freedom''. The intervention group had better glycemic control and quality of life than those adhering to a more traditional ''tight control'' group, with no increase in hypoglycemic or untoward cardiovascular events.[24] The authors concluded that appreciating the dynamic interactions between the individual and the health concern can empower the practitioner to explore unique emergent properties leading to creative solutions, rather than superimpose textbook dogma on the situation. Thus, sometimes the work around may suggest changing the system whereas other times it may suggest an innovative and imaginative solution. Ongoing observation and re-examination will determine whether the emergent system or solution is ultimately beneficial, and whether further promoting and/or nurturing the same or other relationships would be warranted.

If the provision of healthcare services is conceptualized as a complex adaptive system, then logic dictates that coordination in health care must be seen as a dynamic characteristic. Coordination can then be expected to manifest in diverse

**Table 2** Principles for managing complex adaptive systems

| Principle | Operationalization | Application to our example |
|---|---|---|
| Good enough vision | Provide minimum specifications rather than planning every detail | Focus on patient and family schedules (for example, CT bookings should be as close as possible to clinic visits) |
| Tune to the edge | Foster the right degree of information flow, connectivity, diversity, and difference instead of controlling information and forcing agreement | Foster relationships between booking clerk and families |
| Chunking | Allow complex systems to emerge out of the links among systems that work well and are capable of operating independently | Reinforce the links that are effective, such as interface booking systems between CT scan and clinic |
| Clockware/swarmware | Balance data and intuition, planning and acting, safety and risk | Explore whether the parents can do their own booking online. If so, follow to see what patterns emerge to build upon |
| Paradox | Uncover and use paradox rather than avoiding it as if it was unnatural | Ask questions that expose the paradoxes. For example, how can you coordinate CT scans and clinic visits when emergency CT scans take precedent over elective ones? |

Adapted from Zimmerman et al.[19]

ways and would not be an equilibrium state; it would be an emergent quality of various aspects of the system and would be different at different points in time. A complexity approach would suggest that attempts to reduce or rigidly control complexity and uncertainty may fail as the agents in the systems—that is, service providers, patients, and policy makers—are aware and able to learn and take action to affect outcomes.[19 22] A complexity perspective suggests that we must understand systems better by examining the structures, processes, and patterns that underlie the current approaches taken by the agents in the system.[25] Traditional attempts to change systems have focused mainly on altering the structures (for example, physical or administrative) and the redesign of processes (for example, input, output and throughout) of the system. Capra[25] has suggested that understanding the patterns or informal networks within the system is equally important, and that successful improvement requires integration and change in all three: structure, process and outcome. Only through understanding some of the structures, processes, outcomes, and patterns of a clinical situation or system can we begin to work within it to improve coordination of care in a complex environment. This final step requires quantitative and qualitative investigations of the systems with a focus on "failures" to understand complex systems.

## APPLICATION OF A COMPLEXITY PERSPECTIVE TO COORDINATION OF CARE

Let us return to our special needs patient whose CT scan was cancelled and who subsequently spent two unnecessary hours in clinic waiting for follow up advice. The traditional approach to preventing a repeat of a similar situation would be to attempt to standardize the protocol for the timing of the CT scan, the reporting of the results, and the subsequent follow up physician visit. Patients would often be given complicated instructions attempting to consider all contingencies and their expected response. Such an approach may fail to consider the unique requirements of a special needs patient (for example, physically or mentally challenged, lives

out of town) or the impact of a cancelled procedure. In contrast, a complexity approach which assumes interdependence among many systems—in this case patient, transport service, primary physician, CT facility and technologist, reporting of CT result, etc—would provide minimal rules or specifications that create greater understanding of the relationships in the system and allow for individualization. The key to understanding how to improve coordination here is to understand the functioning of the relationships. One of the first things to examine is the relationship between the CT scan unit and the clinic. How are they working together? Do they see themselves as connected? Can we improve the coordination by enhancing the relationship between the two units? For example, if the CT scan unit and clinic saw their work as complementary, then they might choose to link their booking systems. This could be a low tech solution, such as a "rule" that clinic bookings should be made as close as possible to the CT scan and, when booking the CT scan appointment, the appointment book for the clinic is also consulted. Or it could be a more integrated technical solution to address the same linkage. The issue here is to understand the nature of the relationship and how it is currently operating before creating new protocols. The process could also be individualized: the special needs patient may prefer to have the appointments on the same day because of stress and travel or perhaps on separate days because of low energy level. In such cases the relationship between the booking agent (likely in the CT scan unit) and the patient's family would also need to be understood. If the booking agents saw his or her role as one of facilitating the process of CT scan and follow up clinic appointments to best suit the patient, the booking agent could "override" the same day rule for appointments and ask the patient or family whether they preferred appointments on the same day or on subsequent days. In order for these solutions to emerge, the frontline staff—in this case, the booking agents—need to be understood in situ. Why are they acting as they are? Are there systemic barriers to coordination that could be addressed if the relationships were better articulated and understood?

Application of complexity science may be enabled by other innovative approaches. Incorporation of electronic health records that can facilitate information exchange across the spectrum of healthcare delivery offers further opportunity for coordination of care.[26] A strategy described for seriously visually impaired children requiring multidisciplinary care has been that of a "key worker"—that is, a hospital based individual designated to accompany the family at every hospital visit and to be the first point of contact for any questions the family might have.[27] Such an individual could facilitate coordination across numerous disciplines.

## Key messages

- Complexity science offers a unique lens through which to view coordination of patient care.
- Each of the basic principles of complexity science offers an avenue for further research.
- Prospective studies are needed to understand the complexity of care; an ethnographic approach would be one way of defining current relationships, establishing what works well and what are the existing limitations.
- The innovative strategies that emerged could then be further evaluated for local applicability and ultimate generalizability.

. . . . . . . . . . . . . . . . . . . .
## Authors' affiliations

**A G Matlow,** Department of Pediatrics, The Hospital for Sick Children, Toronto, Canada

**A G Matlow,** Department of Pediatrics, University of Toronto, Toronto, Canada

**J G Wright,** Department of Surgery, The Hospital for Sick Children, Toronto, Canada

**J G Wright,** Department of Surgery, University of Toronto, Toronto, Canada

**B Zimmerman, M Valente,** Schulich School of Business, York University, Toronto, Canada

**K Thomson,** Atkinson Faculty of Liberal and Professional Studies, York University Toronto, Canada

## REFERENCES

1 **Cleary PD**, Edgman-Levitan, Walker JD, et al. Using patient reports to improve medical care: a preliminary report from 10 hospitals. *Qual Manage Health Care* 1993;**2**:31–8.

2 **Co JPT**, Ferris TG, Marino BL, et al. Are hospital characteristics associated with parental views of pediatric inpatient care quality? *Pediatrics* 2003;**111**:308–14.

3 **Bishop KK**, WollJ, Arango P. *Family/professional collaboration for children with special health care needs*. Burlington VT: University of Vermont, Department of Social Work, 1993.

4 **American Academy of Pediatrics, Committee on Children with Disabilities**. Care coordination: health and related systems of care for children with special health care needs. *Pediatrics* 1999;**104**:978–81.

5 **Lindeke LL**, Leonard BJ, Presler B, et al. Family-centered care coordination for children with special needs across multiple settings. *J Pediatr Health Care* 2002;**16**:290–7.

6 **Flocke SA**, Stange KC, et al. The association of attributes of primary care with the delivery of clinical preventative services. *Med Care* 1998;**36**:AS21–30.

7 **Gittell JH**, Fairfield KM, Bierbaum B, et al. Impact of relational coordination on quality of care, postoperative pain and functioning, and length of stay: a nine-hospital study of surgical patients. *Med Care* 2000;**38**:807–19.

8 **Safran DG**, Taira DA, et al. Linking primary care performance to outcomes of care. *J Fam Pract* 1998;**47**:213–20.

9 **Bickell NA**, Young GJ. Coordination of care for early-stage breast cancer patients. *J Gen Intern Med* 2001;**16**:737–42.

10 **Knaus WA**, Draper EA, Wagner DP, et al. An evaluation of outcome from intensive care in major medical centers. *Ann Intern Med* 1986;**104**:410–8.

11 **Young GJ**, Charns MP, Desai K, et al. Patterns of coordination and clinical outcomes: a study of surgical services. *Health Serv Res* 1998;**33**:1211–36.

12 **Jaipaul CK**, Rosenthal GE. Do hospitals with lower mortality have higher patient satisfaction? A regional analysis of patients with medical diagnoses. *Am J Med Qual* 2003;**18**:59–65.

13 **Stille CJ**, Antonelli RC. Coordination of care for children with special health care needs. *Curr Opin Pediatr* 2004;**16**:700–5.

14 **Witt WP**, Kasper JD, Riley AW. Mental health services use among school-aged children with disabilities: the role of sociodemographics, functional limitations, family burdens, and care coordination. *Health Serv Res* 2003;**38**:1441–66.

15 **Antonelli RC**, Antonelli DM. Providing a medical home: the cost of care coordination services in a community-based, general pediatric practice. *Pediatrics* 2004;**113**(Suppl):1522–8.

16 **Young G**, Charns M, Desai K, et al. Patterns of coordination and clinical outcomes: a study of surgical services. *Academy of Management Proceedings* 1997:128–32.

17 **McDaniel RR**, Jordan ME, Fleeman BF. Surprise, surprises Surprise! A complexity science view of the unexpected. *Health Care Manage Rev* 2003;**28**:266–78.

18 **Begun JW**, Zimmerman B, Dooley K. Health care organizations as complex adaptive systems. In: Mick SM, Wyttenback M, eds. *Advances in health care organization theory*. San Francisco: Jossey-Bass, 2003.

19 **Zimmerman B**, Lindberg C, Plsek P. *Edgeware: insights from complexity science for health care leaders*. Irving, TX: Veterans Health Affairs, 1998.

20 **Plsek P**, Greenhalgh T. The challenge of complexity in health care. *BMJ* 2001;**323**:625–8.

21 **Patterson ES**, Cook RI, Render ML. Improving patient safety by identifying side effects from introducing bar coding in medication administration. *J Am Med Inform Assoc* 2002;**9**:540–53.

22 **Plsek P**, Wilson T. Complexity, leadership, and management in healthcare organizations. *BMJ* 2001;**323**:746–9.

23 **Wilson T**, Holt T. Complexity and clinical care. *BMJ* 2001;**323**:685–8.

24 **DAFNE Study Group**. Training in flexible, intensive insulin management to enable dietary freedom in people with type 1 diabetes: dose adjustnebt for normal eating (DAFNE) randomized controlled trial. *BMJ* 2002;**325**:746.

25 **Capra F**. *The hidden connections: integrating the biological, cognitive, and social dimensions of life into a science of sustainability*. New York: Doubleday, 2002.

26 **Burton LC**, Anderson GF, Kues IW. Using electronic health records to help coordinate care. *Milbank Q* 2004;**82**:457–81.

27 **Rahi JS**, Manaras I, Tuomainen H, et al. Meeting the needs of parents around the time of diagnosis of disability among their children: evaluation of a novel program for information, support, and liaison by key workers. *Pediatrics* 2004;**114**:e477–82.