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A Patient-Centered Approach for Evaluating Public Health Roles within Systems of Care for Children with Special Healthcare Needs

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A Patient-Centered Approach for Evaluating Public Health Roles within Systems of Care for Children with Special Healthcare Needs

Abstract

Despite the apparent success that local and state health departments have had integrating a public health approach to provide programs and services for families with children who have complex health needs, there continues to be mixed results in terms of satisfaction and degree of support from this system. Current evaluations collect performance data from system stakeholders, rarely including the patient perspective. Examining the system holistically using Social Network Analysis, to include both the stakeholder *and* patient perspectives of how well the system is functioning affords greater understanding of how a public health approach to systems of care leads to more successful outcomes. This research identifies the discrepancies between stakeholder and patient perspectives, and suggests assessing families' Patient-Centered Networks (PCNs) to integrate a more purposeful role for public health as gateway coordinator between the system of care, primary care physicians implementing a medical home, and leveraging of PCNs informal support networks to improve coordinated care for families.

Keywords

Systems of Care, Patient-Centered Networks, Evaluation, Public Health

Cover Page Footnote

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Summary Box

Despite the apparent success that local and state health departments have had integrating a public health approach to provide programs and services for families with children who have complex health needs, there continues to be mixed results in terms of satisfaction and degree of support from this system. Current evaluations collect performance data from system stakeholders, rarely including the patient perspective. Examining the system holistically using Social Network Analysis, to include both the stakeholder *and* patient perspectives of how well the system is functioning affords greater understanding of how a public health approach to systems of care leads to more successful outcomes. This research identifies the discrepancies between stakeholder and patient perspectives, and suggests assessing families' Patient-Centered Networks (PCNs) to integrate a more purposeful role for public health as gateway coordinator between the system of care, primary care physicians implementing a medical home, and leveraging of PCNs informal support networks to improve coordinated care for families.

Introduction

In the United States, more than 12 million children are identified as having special health care needs¹. In most states, a public health approach is prevalent², with local and state health departments playing a central role to provide coordinated, family-centered resources for this population as members of Systems of Care (SOCs). Despite these efforts, families are often overwhelmed as they navigate a complex system comprised of multiple organizations and providers in order to access basic services from qualified professionals. Although SOCs intend to provide “a spectrum of effective, community-based services and supports for children and youth ...organized into a coordinated network”³, specific attention to the role that families' personal, largely informal social support networks play in SOCs has been neglected in research. While the role served by public health might be evident to the system stakeholders, these efforts are often far removed from the Patient-Centered networks (PCNs) created by families to address the needs of their children, and even further removed from child health outcomes.

Well-managed, coordinated SOCs have the potential to successfully increase service coordination and responsiveness to client needs⁴. This potential for success may be amplified if efforts to improve systems' functioning better integrate the role of public health in coordination with PCNs and the manner in which these networks operate. Using case studies of PCNs and social network analysis (SNA), this study characterizes and quantifies how SOCs are perceived by both the stakeholders at the systems level and by families at the patient level. It seeks to answer the questions: 1) *How do stakeholders and families characterize the SOC?* 2) *How is the role of public health perceived by stakeholders and family members?* and 3) *What policy recommendations can be developed based on this information?*

Methods

To collect data from stakeholders, the PARTNER (www.partnertool.net) survey was completed by 100 stakeholders in the system. PARTNER is a SNA tool designed to measure and monitor collaboration among people/organizations. The tool is free (funded by the Robert Wood Johnson Foundation) and designed to demonstrate how members of a system are connected, how resources are leveraged and exchanged, the levels of trust among members, and to link outcomes

to the process of collaboration. The survey asked stakeholders to identify members of the SOC in Colorado that serves families, interactions among these members, assessments of trust (operationalized as reliability, mission congruence, and open communication) and value (operationalized as power/influence, resource contributions, and time commitments) of the members, and perceptions of success.

To collect data from families, cases studies of 10 families with children (ages 0-18) with special healthcare needs were conducted as an exploratory method to assess family support networks because no evidence of this approach exists in the literature. As part of the case study, families answered the question, " Please list those people, programs, or organizations that you consider important to providing services and support for your child's special healthcare and/or developmental needs" followed by questions about importance, levels of support, amount of communication, and trust. Each family was also asked to rate their perceptions of how successful the SOC is for their families.

Results

Perceptions of the level of success vary widely across both groups. While neither group reports consensus on the level of SOC success, disagreement in perceptions of success is greater among family members with an almost even distribution of responses (from not successful, somewhat successful, successful, very successful, to completely successful), while stakeholders shows *more* agreement that the system is predominantly "somewhat" successful or above. The variations in how each group reported success motivated this in-depth examination of how stakeholders and families characterized the SOC. We were interested in why there was so much disagreement on how well the system was functioning.

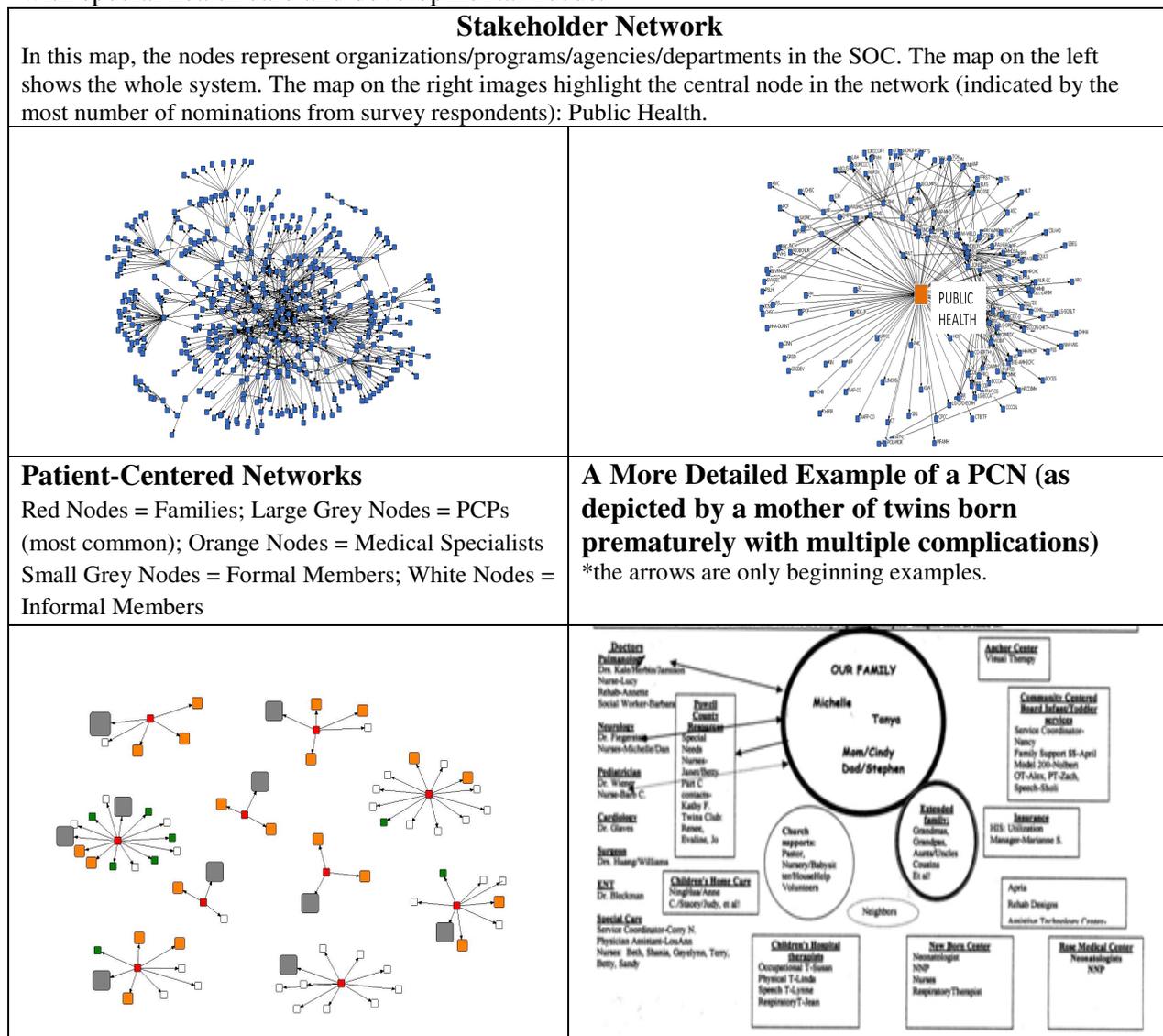
The SOC stakeholders report an active, fully connected system, high levels of trust and value, and overall success of the system. A total of 452 organizations were identified as stakeholders in the system level network, representing 25 sectors and 723 dyadic relationships (relationships between any two organizations). Respondents identified partners in the system as those "with whom you work with to meet your goals for the special needs infants and children". The state health department was identified as the most central member of the SOC (identified most frequently as a partner). None of the respondents to the SOC survey mentioned families as partners and few identified informal supports (e.g. other families).

In contrast, families report a system made up largely of informal actors, characterized by high trust but an overall lack of coordination. Ten families completed social network surveys, identifying a total of 38 unique types of support partners and 71 dyadic relationships (between the patient/family member and the SOC). Families identified a range of formal and informal members. None mentioned the State Health Department as part of their PCNs. While families characterized at least 70% of all their ties as "very important" and 60% as "highly trusted", these ties ranked low on "working with others in the network" and "talking with others in the network", indicating that there is little coordination in the PCN among the partners they listed. "Provided support" was inconsistent across the responses, indicating that families do not consistently report that their PCNs provide adequate support. When describing their "ideal" systems, families described an interconnected group of informal and formal supports with

facilitated communication and coordination through a single, designated entity functioning as a hub in their PCNs.

Network images illustrate the different perspectives. Collecting network data allows us to visualize, using network maps, the connections among stakeholders and clients. The network maps representing the responses from stakeholders in the SOC (Figure 1, top left) shows a completely connected system. When the map was manipulated to isolate the key player (the member with the most number of connections), it is evident that the State Health Department plays this role. The map representing families' PCNs (bottom left) shows how PCNs vary across the number and types of members. The common member of all but one PCN is the Primary care Provider (PCP). The final imagine (bottom right) is a more detailed example of how a family describes their SOC. This imagine shows the in-depth complexity of the system.

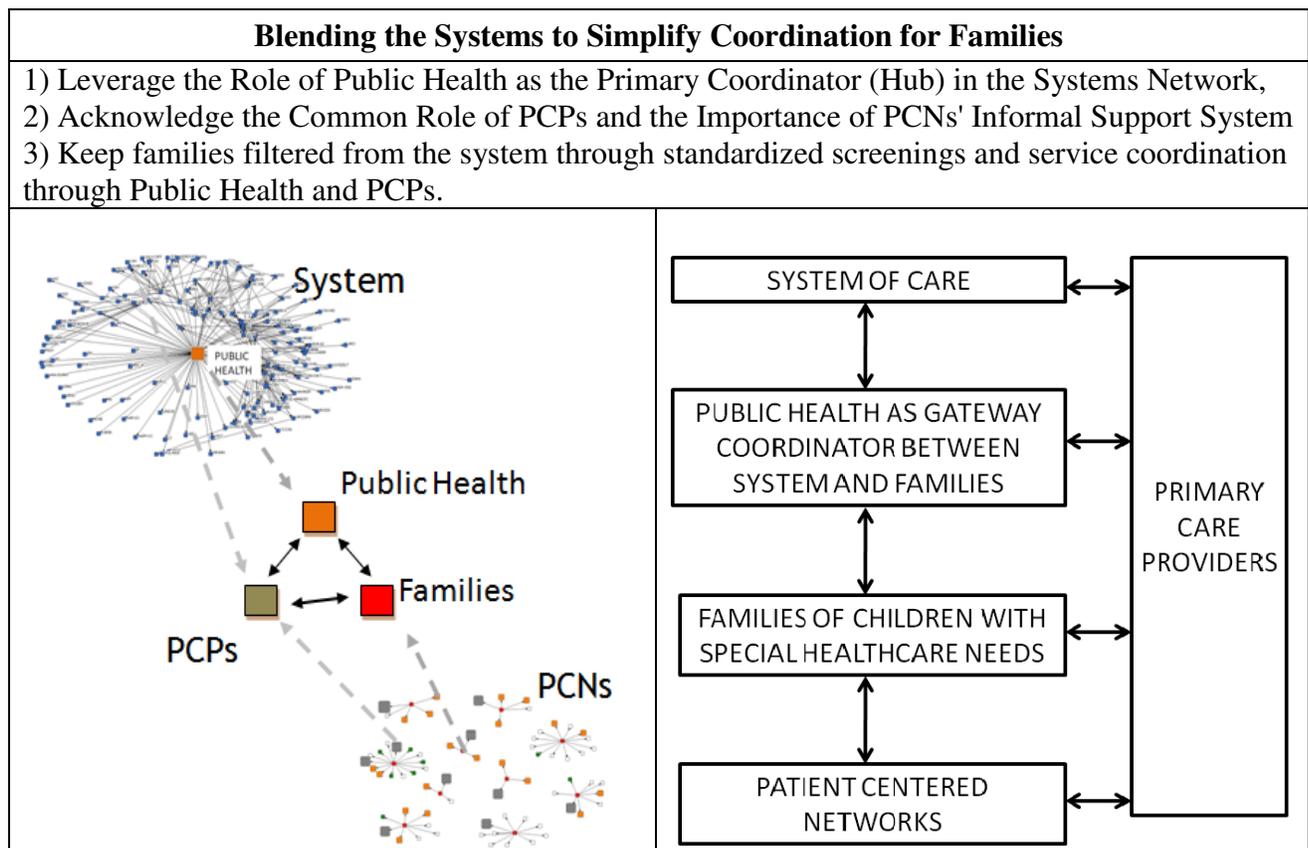
Figure 1. Network images illustrate the complexity, variation, and breadth of SOC for children with special health care and developmental needs.



Implications

In this exploratory look at the SOC, the perceptions of success suggest that there is disagreement among both families and stakeholders in terms of how well the system functions for families. The network diagrams illustrate a natural "hub" in the stakeholder map, held by the State Health Department. The family maps suggest that PCPs are the common player among PCNs, indicating that a patient-centered medical home approach is ideal. Current efforts lack a strategic use of the three primary "hubs" in the system identified by stakeholders, particularly the State Health Department. Figure 2 demonstrates the blending of these two perspectives, leveraging the role of the State Health Department as the coordinator (with implementation of public health services at the local level), emphasizing the importance of the PCP *and* the informal support network, and simplifying the complex nature of the system for families through a gatekeeper/care coordinator function.

Figure 2. Translating Social Network Data Comparing System and Patient-Centered Network Levels



As mentioned throughout the literature and in practice, and as reported by the families in our case studies, coordination of services (both working and talking together) is perhaps the greatest challenge that families face with respect to their PCNs. If system stakeholders continue to develop programs focused on coordination among formal organizations, without recognizing that families navigate the system through largely informal relationships, children and families will

have significant unmet needs and formal systems of care will struggle to provide family-centered, comprehensive, coordinated, and culturally responsive services.

However, if health departments collect and use information provided by stakeholders *and* families about their PCNs, new models for coordinating services for families may be possible. We recommend implementing an intervention that develops and administers a PCN assessment instrument to families, providing information to public health to better coordinate and leverage the role that PCPs and informal members serve for families. Continued research to assess the SOC from the patient perspective is necessary and ongoing.

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