Feature Article

Modeling the Complex Activity of Sickle Cell and Thalassemia Specialist Nurses in England

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Objective:
Specialist advanced practice nursing in hemoglobinopathies has a rich historical and descriptive literature. Subsequent work has shown that the role is valued by patients and families and also by other professionals. However, there is little empirical research on the complexity of activity of these services in terms of interventions offered. In addition, the work of clinical nurse specialists in England has been devalued through a perception of oversimplification.

Purpose:
The purpose of this study was to understand the complexity of expert nursing practice in sickle cell and thalassemia.

Design:
The approach taken to modeling complexity was used from common methods in mathematical modeling and computational mathematics. Knowledge discovery through data was the underpinning framework used in this study using a priori mined data. This allowed categorization of activity and articulation of complexity.

Result:
In total, 8966 nursing events were captured over 1639 hours from a total of 22.8 whole time equivalents, and several data sources were mined. The work of specialist nurses in this area is complex in terms of the physical and psychosocial care they provide. The nurses also undertook case management activity such as utilizing a very large network of professionals, and others participated in admission avoidance work and education of patients' families and other staff.

Conclusion:
The work of nurses specializing in hemoglobinopathy care is complex and multidimensional and is likely to contribute to the quality of care in a cost-effective way. An understanding of this complexity can be used as an underpinning to establishing key performance indicators, optimum caseload calculations, and economic evaluation.

KEY WORDS
clinical nurse specialist, sickle cell, specialist nurse, thalassemia, value

Sickle cell disease is the most common of the hemoglobinopathies affecting at least 12 000 people in England with an estimated 380 000 carriers.[1] The highest prevalence of sickle cell disease is among the black African and black Caribbean populations. One in 7 births in England to those of black African origin and 1 in 8 of those from black Caribbean origin are carriers.[1] Sickle cell disease is also found in other populations such as those from the Mediterranean Southeast Asian and Middle East.[2] In thalassemia, there are estimated to be 800 patients with β-thalassemia major and an estimated 300 000 carriers of the gene in England.[1]

Over the last 3 decades, the care of patients and families with sickle cell and thalassemia (SC&T) has developed in the United Kingdom as a model of expertise in specialist nursing care,[3] from the world's first linked antenatal and newborn screening program,[1] to dedicated health professionals supporting service users of all ages and at every stage of the care pathway. Central to this provision have been SC&T specialist nurses, the first of these established in London in the 1970s to champion holistic care[4] and now numbering approximately 117 in England ("Sickle and Thalassaemia Association of Counsellors and Forum of Acute Sickle Cell and Thalassaemia Nurses," 2011, unpublished membership data, e-mail communication). Sickle-cell-and-thalassemia specialist nurses are

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found in both the community and acute setting in the United Kingdom and cover the entire patient life span including prenatal counseling. Specialist advanced practice nursing in hemoglobinopathy has a rich historical and descriptive literature. Key authors and influencers such as Elizabeth Anionwu,[4] who brought together community groups and healthcare professional groups in Brent to champion holistic care in the mid-1970s, set the scene for the need for the specialist practitioner. Subsequent work has shown that the role is valued by patients and families and also by other professionals.

In recent years, the value of specialist nurses and the contribution they make have been questioned by using institutions who seek cost improvement. Nursing does not lend itself to parametric modeling because of its multidimensional nature and lack of defined parameters, but the case for keeping and increasing specialist nursing posts has already been made for several other conditions including Parkinson disease, rheumatology, and dementia[5–7] by demonstrating that the work associated with efficiency is complex clinical work.

The aim of this work is to understand the complexity and contribution that SC&T nurses make to patient care. By understanding such complexity, it may be possible to understand the contribution that this group of nurses makes to QIPP (quality, innovation, productivity, and prevention) agenda, which is the strategy the English Department of Health is utilizing to introduce cost-effective, efficient care.[8] The professional group that represents SC&T nurses suggests that there are around 117 SC&T specialist nurses in England, including 76 counselors and 39 acute and 2 combined counselor-acute posts. With 41 SC&T nurses covering the acute sector in England, this equates to a caseload per nurse of 325. About 55% of specialist nurses are based in Greater London, and 45% outside London ("Sickle and Thalassaemia Association of Counsellors and Forum of Acute Sickle Cell and Thalassaemia Nurses," 2011, unpublished membership data, e-mail communication). Local studies have shown improved outcomes and lower rates of emergency admission where care is proactively managed by specialist nurses.[9,10] This study seeks to examine the complexity of the nursing interventions in hemoglobinopathy.

The work of nursing is complex,[11,12] and specialist nursing work can also be described as complex as the work is not purely deterministic.[13–15] To measure in the conventional sense proves a futile exercise as these are multidimensional acts.[13] It is possible to determine a sampling of complex work by iterative modeling of the work, and this study seeks to understand the complexity in those terms. This has been undertaken in other groups of specialist nurses, particularly those in long-term conditions.[16] The challenge of extracting knowledge from data draws upon research in statistics, pattern recognition, machine learning, data visualization, optimization, and high-performance computing to deliver advanced intelligence and is common in other disciplines but little utilized in nursing. There is no one agreed definition of complexity; however, most complexity researchers agree that there are certain features that define a phenomenon as complex. A system that consists of a collection of many different interacting objects (or agents) that can adapt and are open (ie, can be influenced by environment) can be considered complex.[17] This work takes place with an assumption that specialist nursing work is complex and seeks to describe this complexity within the framework of expert, culturally sensitive care

METHODS

The approach taken to modeling complexity was utilized from common methods in mathematical modeling and computational mathematics. Knowledge discovery through data is a common technique in other areas—by mining data, it is possible to discover new knowledge.[18–20]

A number of data sources were mined to examine the complex activity of the specialist nurse in hemoglobinopathy. These were the literature, historical literature for context, gray literature, unpublished data provided by the screening service in regard to competency frameworks and outcomes, the published competency framework,[3] consensus data from a workshop held at the Royal College of Nursing, and data collected via the adapted Cassandra matrix. Data mining and pattern recognition techniques have been described elsewhere,[18] but a short description of the process used for this study is given here.

Such modeling techniques are iterative. For the past 7 years, the activity of specialist advanced practice nurses in the United Kingdom has been modeled using an 8-dimensional model captured previously in a relational database and its antecedent data. In this model, n = 4010 whole-time-equivalent (WTE) clinical nurse specialists detailed activity data (mean 44 events per day) plus subsidiary data from another 8102 specialist nurses such as diaries, annual reports, and service reviews/audits were examined for association patterns. These activities were then matched to the literature (n = 6052; peer-reviewed and gray literature) using syntactic pattern techniques such as parsing. Parsing allows the analysis of strings or sets of words, numbers, and symbols; the result is a parse tree, which shows the relationships different items have to each other. These data have been mined, and pattern recognition techniques[21] and in particular syntactic pattern recognition or parsing[22] to examine common activity and to construct a data capture matrix (Cassandra matrix[22]) in 2 dimensions (intervention that has 2 levels of data collection and context/place of activity) was utilized. The Cassandra matrix was adapted with specific items as a result of the data collected in the workshop and an iterative review of the literature.

Four in-depth interviews were also undertaken with those working at an advanced level of practice. These data were then also mined. Data mining and pattern recognition

techniques have been described more fully elsewhere.[18] The workshop and remining of the literature enable this version of the matrix to be more specific to this group by consensus, and it was retested within a user group (n = 6). In addition, unstructured interviews were undertaken with specialist in the field to elicit more items of common activity and to confirm activity already identified. Syntactic pattern recognition was reapplied and parsed. This was done through content analysis and the construction of a logic and parsing tree. The result of this work was a bespoke data collection matrix that collected a sample of activity in 2 dimensions (intervention and context place).

This matrix was then transferred to MS Excel and used to record the work over a period of 70 hours of 22.6 WTE SC&T specialist nurses between February and April 2012 (total 1639 hours). These data were collected on Excel and subsequently analyzed by summing the number and context of the activity to look at proportion and distribution of nursing events across intervention and context/place. A subset analysis of each grouping of activity also took place to allow for more granularity in the intervention category.

Ethics

This study was presented to ethics by the commissioners and deemed not to require ethical approval.

RESULTS

In total, 8966 nursing events were captured over 1639 hours from a total of 22.8 WTEs. The group was split into subsets of community (15) and acute (11). In addition to WTE hours, the nurses also recorded unpaid overtime. The mean unpaid overtime was 3 hours per week (range, 0–10 hours per week); thus, the assumed WTE equals 40 hours of activity. Interview data (unstructured) were subjected to content analysis for common themes and perceptions of contribution.

The ratio of clinical to nonclinical/clerical work was 80:20 in acute settings and 74:26 in community settings.

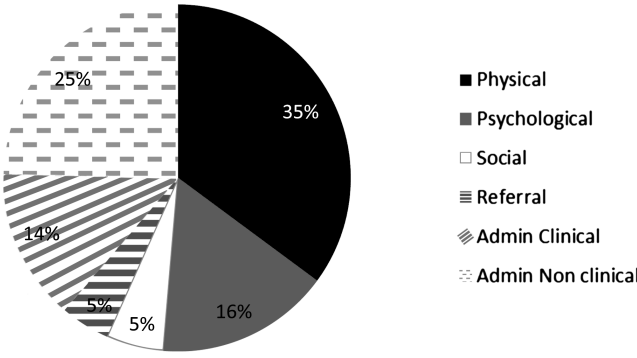

FIGURE 1. The distribution of activity for a sickle-cell-and-thalassemia nurse based in the community (n = 4763 events).

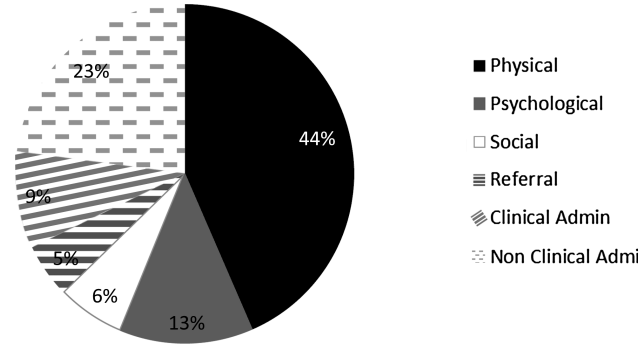

FIGURE 2. The distribution of activity for a sickle-cell-and-thalassemia nurse based in the acute setting (hospital) (n = 3883 events).

Nurses were engaged in a wide range of clinically complex, interrelated activities including symptom control, managing disease crises, addressing psychosocial issues, directing ward rounds, nursing assessment and complex care planning, promoting self-care, supporting and educating other professionals, leading new and innovative services such as exchange transfusion, administrative tasks, and making referrals (Figures 1–4). The psychosocial activity in both the acute and community groups is high—greater than 20% of the total activity reflecting the complex psychosocial issues associated with the impact of the disease.

Proactive case management was an embedded activity, and members of the combined acute and community group had an extremely large network (mean average n = 27 shown in the Table) of professionals in which the nurses brokered care and to which they referred to and took referrals from.

Telephone activity is lower than other clinical nurse specialist groups where around 30% of the activity is based on the phone.[6,16,24] In contrast, much of the care delivered by the SC&T nurses was in face-to-face settings such as clinics, outreach, or emergency departments reflecting the unpredictable nature of sickle cell disease.

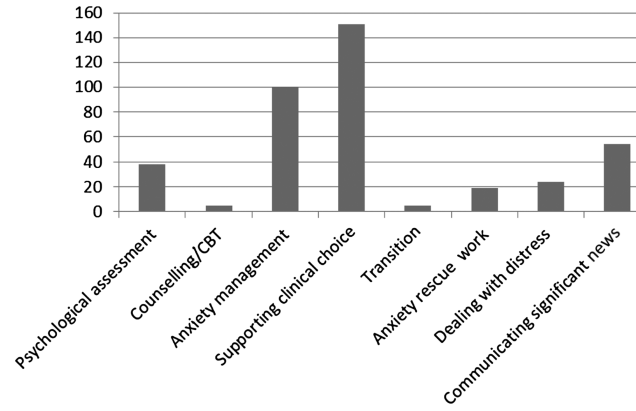

FIGURE 3. The psychological interventions provided by the sickle-cell-and-thalassemia nurses in the acute setting.

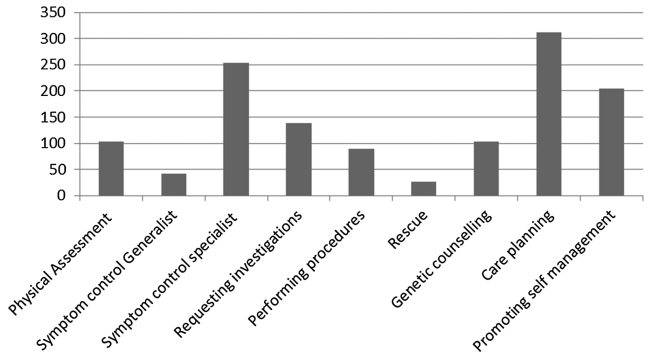

FIGURE 4. The physical domain interventions provided by the sickle-cell-and-thalassemia nurses in the acute setting.

A considerable amount of activity (26% and 20%) is spent on nonclinical administration—it is likely that more clinical time could be released if this burden were alleviated.

DISCUSSION

The data collected, and in particular its range, illustrate the layers of complexity of care delivered by the SC&T nurses. Rather than a linear series of tasks, a multidimensional network of interrelated activities becomes apparent. The SC&T nurses manage caseloads throughout the patient journey and at all stages of life antenatal, pediatric, teenage, adult, and older people. This is reflected in the complexity of the system of professionals and community groups they utilize to care for patients (Table). Moreover, sickle cell conditions are particularly unpredictable, with unexpected sickling crises often occurring at night when routine services are not available. The group invested time in empowering patients through teaching self-care and promoting self-management (Figures 3 and 4) Although the types of nursing intervention may be similar to those for other long-term conditions, patterns of activity are very different, for example, to those in rheumatology[6] or metastatic breast cancer.[24] Local studies have shown how coaching, teaching self-care strategies, and prompt response to symptoms can alleviate the high emergency care need, and the psychosocial interventions reflect the need for lifelong term self-care and which is often multigenerational; this study reflects that activity (Figures 3 and 4).

Unlike other specialisms such as cancer or other long-term conditions, the literature lacks peer-reviewed empirical research into the contribution of specialist nursing in SC&T. However, there is some comparative literature around nursing interventions. An article examining ambulatory management (with the predominate intervention being transfusion) demonstrates an emphasis on proactive management and health promotion/self-management, which is usually a nursing activity,[25] and thus may form the basis for further evaluation. It was not made explicit in this article, however, that transfusion is a nursing intervention.

The complexity of the work of the specialist nurse in sickle cell disease has been recognized in other health economies. The use of home healthcare specialist nurses in the Unites States has shown benefit in ambulatory management. By proactive management of pain and other crisis points, patients—particularly older patients—are more likely to stay in the ambulatory setting.[26] The prevalence of psychological interventions is clinically relevant. Patients with hemoglobinopathies, particularly sickle cell disease, are more

Table. The Common Case Management Network of the Sickle-Cell-and-Thalassemia Nurses[a]

Clinical	Psychosocial
Own medical team (hematology, pediatrics)	Housing workers
Other medical team (cardiology, otorhinolaryngology, etc)	Social worker
Genetic counselor	Psychologist
Physiotherapy (physical therapist)	Benefits/welfare advisor
Occupational therapy	Educational worker
Speech and language therapist	Religious/spiritual
Dentist	Counselor
Other CNS in team	Support groups
Other CNS/midwife/community psych nurse	Voluntary sector
Technologist/scientist (hematology, virology)	Advocate/asylum advisor
Research teams	Judicial advisors/workers
Dietitian	Local authority
Audiologist/ophthalmologist	Safeguarding
Health visitor	Citizens Advice Bureau
School nurse	Prison/probation service
Fertility services	Immigration
Pharmacist	
Radiologist/radiographer	
District nurse	
Community matron	
Specialist community nurse/midwife	
GP (ongoing)	
GP (new problem)	
Coroner	
Geneticist: outside organization	
Community children's nurse	

Abbreviations: CNS, clinical nurse specialist; GP, general practitioner.
[a]These are the organizations and other professionals utilized to manage and enable care.

likely to suffer from depression, depressive symptoms, distress, and stigma. A study found that African Americans with sickle cell disease were 3 times more likely to suffer from depressive symptoms than those without; they are at risk for untreated depression, making psychological assessment vital.[27] Psychological interventions were a core component of the activity in both the acute and community setting representing 17% of the activity overall (Figures 1 and 2) focusing on supporting clinical choice and anxiety management (Figure 3) Hemoglobinopathy nursing is linked with cultural and transitional issues due to the nature of the diseases, for example, dealing with pain not only in terms of pathophysiology but also in the cultural context. Sanders'[28] 2010 study in the Unites States found that younger patients were likely to use taught self-management strategies, whereas older patients utilized prayer and hope. Others[29] concluded that religious involvement probably plays a significant role in modulating the pain experience of African American patients with sickle cell disease.

There are many articles that challenge attitudes of staff in areas such as perception of pain[30] found that 63% of nurses caring for patients with sickle cell disease thought addiction was prevalent, and 36% were hesitant to administer high-dose opioids. Pain is often managed at home by those with the ability to do so, as opposed to using unscheduled care services.[31] In addition, pain and depression are inextricably linked in sickle cell disease.[32] Managing pain, anxiety, biographical disruption,[33] and distress through self-management and prompt proactive case management (which includes the important sociocultural dimensions when intervention is required) is likely to be a cost-effective solution. Successive policy makers have been slow to recognize the needs of this population[34] and meeting the need for expert nursing care at different points in the life course. The complex care provided by SC&T specialist nurses appears to meet that need. It is also interesting to note that the complexity of SC&T specialist nursing compares with the work of specialist nurses in other long-term conditions such as Parkinson disease, rheumatology, and dementia.[5–7] The referral network is more extensive in SC&T nursing, and the SC&T nurses provide more face-to-face interventions than do other group of specialists. It would be particularly interesting to explore if the proactive case management of SC&T nurses produces the same benefits in terms of cost benefit and unnecessary acute admission as other long-term conditions, for example, multiple sclerosis.[35] Currently, in the United Kingdom, the value of these roles is called into question because of their nonparametric nature. The work of the clinical nurse specialist is oversimplified and the complexity not understood. By articulating the complexity of the activity and the parameters of work, it is possible to promote an understanding of this work, which can be used to inform the need for services and could also underpin a set of key performance indicators or be used to perform a more detailed cost-benefit analysis of this role.

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