Organization Profile
The University of Pittsburgh Medical Center (UPMC) is an integrated global health enterprise and one of the leading nonprofit health systems in the United States. By integrating 20 hospitals, 400 doctors’ offices and outpatient sites, long-term care facilities, and a major health insurance services division, and in collaboration with an academic university partner, UPMC has advanced the quality and efficiency of health care and developed internationally renowned programs in rehabilitation as well as transplantation, cancer, neurosurgery, psychiatry, orthopedics, sports medicine, and many others.

Program Goals and Measures of Success
Spina bifida is the most common permanently disabling birth defect, affecting more than 166,000 Americans. Cognitive impairments related to hydrocephalus (increased pressure in the brain) and impairments in mobility present challenges to routine self-care, resulting in serious secondary medical issues and institutionalization. Similar barriers to self-care affect those with SCI acquired from trauma or disease. SCI affects almost 260,000 Americans.

With an appropriate level of support, many people with disabilities like SB and SCI are fully capable of living healthy, productive lives while residing in the community, but chronic health conditions often lead to secondary disability and death. Research has shown that preventable conditions account for over a third of the U.S. hospitalizations of young adults with SB, which average 12.5 days and cost about $30K each. With three to four hospitalizations per patient annually, total costs for this population exceed $360 million. The most common reasons for hospitalization and death are preventable and include wounds, urinary tract infections (UTIs), and sepsis.1

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The pilot project produced remarkably improved outcomes, including fewer instances of pressure ulcers and UTIs and decreased incidence and duration of hospitalizations as compared to national data (see Table 1). These outcomes attracted the attention of UPMC for You, the Medicaid Division within UPMC Health Plan. Recognizing that an SMH has the potential to improve the patient experience and make a substantial impact on quality of life and delivery of care, UPMC Health Plan funded a more comprehensive SMH for members who have SB and SCI to be centered at UPMC.

The success of the program is being determined by evaluating the following hypotheses:

**Hypothesis 1**: Compared to before being enrolled in the SMH (baseline scores), those enrolled will have improved outcomes in the following areas:

1. **Home and community function** as measured by:
   a. the Craig Handicap Assessment Reporting Technique – Short Form (CHART-SF) which measures physical and cognitive independence, mobility, social integration, activity level, and employment outcomes
   b. Number of hours spent doing self-care or using caregiver assistance (CHART-SF)

2. **Psychological symptoms** as measured by:
   a. the Beck Depression Inventory-II

3. **Medical complications, cost, and unplanned care**
   a. Unplanned care: number of emergency room (ER), retail, or urgent care visits, and inpatient admissions from the ER
   b. Cost and number of services related to “preventable conditions”: chronic ulcer of the skin, skin and subcutaneous tissue infection, septicemia, complications of surgery or medical care, pneumonia, infective arthritis, infective osteomyelitis, and indwelling urinary catheter infection (ICD-9 codes of potentially preventable conditions)
   c. Frequency of self-reported incontinence episodes
   d. Body mass index
   e. Medication possession ratio (a measure of the extent to which patients are filling chronic prescriptions)
   f. Time lost from work or school
   g. Number of routine annual visits for primary care

4. **Quality of Life and Patient Satisfaction measures** as calculated from:
   a. the World Health Organization Quality of Life Brief, which evaluates life satisfaction across four factors (environment, physical health, psychological, and social)
   b. the Patient Assessment of Chronic Illness Care (PACIC), a measure of receipt of services that are patient-centered, proactive, and planned

5. **Patient Education** as measured by:
   a. Higher scores on a patient health knowledge assessment

**Hypothesis 2**: Compared to those not in the SMH, those in the SMH will have improved outcomes in the following areas:

a. Unplanned care: number of emergency room, retail, or urgent care visits, and inpatient admissions from the ER

**Hypothesis 3**: Average cost of care will be at least 10% lower for those in the SMH compared to those not in the SMH.
Results

The Table compares 1) healthcare services of privately insured individuals with SB in the United States (Ouyang et al\textsuperscript{2}), 2) the results of a survey of 142 adults prior to the development of the Wellness Program, 3) data from 31 individuals with SB in the general clinic population who do not receive wellness services, and 4) data from 31 individuals with SB in the SMH (matched by age, gender, and neurological history to the previous group). All individuals in the latter two groups live in an independent setting (not with parents or caregivers).

Within just the first two years of the pilot program, results showed a lower incidence of skin breakdown episodes, UTIs, and hospitalizations, and shorter length of stay among those in the pilot compared to the general clinic population or national averages for this group. The reduced cost of care afforded is dramatic. For example, direct costs of treating an individual with a pressure ulcer without hospitalization are approximately $20,000 to $30,000 per incident (National Pressure Ulcer Advisory Panel), while serious Stage IV ulcers are estimated to cost approximately $70,000 per incident (Braun et al\textsuperscript{3}). This reduction in incidence of wounds clearly allows the program to pay for itself.

UPMC’s plans for sustaining the gains in this program are to continue to demonstrate cost savings to UPMC Health Plan. A small portion of the cost savings will be reinvested into the program so that additional services or incentives can be provided. Future goals would be to expand the program to include other patient groups and to recruit investment by other third-party payers.

Population Identification

Inclusion criteria are:

- Has a primary diagnosis of spina bifida cystica, congenital spinal cord anomaly, or spinal cord injury (identified using ICD-9 codes 741.0x, 741.9x, 742.5x, 805.xx, 806.xx, 952.xx)
- Is age 18 years and up
- Resides in designated six-county region
- Has UPMC Health Plan insurance
- Is an active patient (seen within last 1 year in outpatient clinic or new patient recently discharged from inpatient rehabilitation)
- Volunteers to enroll

Exclusion criteria are:

- Has a primary diagnosis of spina bifida occulta (since medical problems are minimal).
- Has mental health issues qualifying patient for a separate behavioral health initiative
- Is currently living in a skilled nursing facility


Patients are primarily identified as potential participants during their face-to-face clinic visits; however, they are also identified through member registries at UPMC Health Plan and through clinics within the Department of Physical Medicine and Rehabilitation (PM&R), which runs UPMC’s Adult Spina Bifida and Spinal Cord Injury Clinics. The target population ranges in age from 18-80.

Official enrollment for the expanded SMH began in May, 2011. As of the time of this publication, the following demographics can be reported:

<table>
<thead>
<tr>
<th>Participants enrolled:</th>
<th>N = 13</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender:</td>
<td></td>
</tr>
<tr>
<td>F-61.5%</td>
<td></td>
</tr>
<tr>
<td>M-38.5%</td>
<td></td>
</tr>
<tr>
<td>Average age:</td>
<td>43.6</td>
</tr>
<tr>
<td>Participants with SB:</td>
<td>61.5%</td>
</tr>
<tr>
<td>Participants with SC:</td>
<td>38.5%</td>
</tr>
<tr>
<td>Admitted with preventable conditions addressed in Wellness Program:</td>
<td>69.2%</td>
</tr>
<tr>
<td>Receiving outpatient services upon admission:</td>
<td>92.3%</td>
</tr>
<tr>
<td>ED visit/hospitalized after program enrollment:</td>
<td>7.7%</td>
</tr>
<tr>
<td>ED visit without admission after program enrollment:</td>
<td>7.7%</td>
</tr>
<tr>
<td>Community placement upon admission:</td>
<td>69.2%</td>
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<tr>
<td>Referred following inpatient rehabilitation:</td>
<td>30.8%</td>
</tr>
</tbody>
</table>

The Intervention

The goal of the pilot program is to reduce and prevent avoidable complications, emergency room visits, hospitalizations, and unnecessary treatments, while maintaining patient autonomy, facilitating employability, and decreasing or limiting the need for caregiver assistance.

The SMH operates with the following personnel:

- Full-time Wellness Practitioner (nurse practitioner or registered nurse) (40 hrs/wk)
- 2 registered nurses (8 hrs/wk) experienced in SCI and SB care
- 3 physiatrists treating patients with SCI (8 hrs/wk)
- 1 physiatrist program director who treats SB (16 hrs/wk)
- Administrative support (40 hrs/wk)
- Registered dietician (8 hrs/wk)

The Wellness Practitioner provides direct patient care, education, and face-to-face reminders. Patients are counseled on their medical issues and what problems to anticipate. They are reminded to take medications, catheterize the bladder, self-inspect skin for wounds, and follow other physician recommendations. However, the Wellness practitioner also acts as a case manager and activates any additional needed services such as home care. In the latter role she is the “overseer” of all the clinical services the patients receive.

Three Wellness Coordinators (nursing assistants) from the pilot program also work in conjunction with the clinics to provide care to some individuals. The Adult Spina Bifida Clinic is run by a physiatrist within the Department of PM&R. He supervises a multidisciplinary team including a clinic nurse experienced in spinal cord care, a dietician, and an orthotist. He also works in conjunction with a team of other physician specialists including urologists, neurosurgeons, and
orthopedic surgeons to provide patient-centric specialty care. Three other physiatrists direct the SCI clinic at UPMC.

The structure of the SMH is based upon clinical practice guidelines and includes the delivery of a 10-module program by the wellness practitioner. The modules include patient education materials, clinical practice guidelines for clinical interventions, and associated outcome measures. For example, a module on skin integrity covers evidence-based clinical practice guidelines and algorithms for the prevention and treatment of wounds, patient knowledge assessment, and patient education materials. The preventable diagnostic outcomes linked to this module are skin and subcutaneous tissue infection, sepsis, infective arthritis, and infective osteomyelitis. The other modules are: medication and supplies management, bladder management, bowel management, nutrition and fluid intake, body mass index, exercise, psychological health, mobility/self care, and routine health maintenance and screening.

**Workflow**
The addition of the SMH program to the clinic did affect work flow; however, all clinic resources, including support staff, are shared, requiring very little retraining. Additional clinic time opened for the Wellness Practitioner during business hours did not require additional staff time.

**Funding**
UPMC in part receives funding from the Pennsylvania Department of Health, which supports the Adult Spina Bifida Clinic by reimbursing costs for annual visits for state residents. This type of funding may be available in other states through various grant mechanisms for special care populations and may also be a creative solution to developing and deploying an SMH and its services.

**Information Technology**
The organization utilizes the EpicCare electronic medical record for all aspects of the patient’s care in the clinic. Care providers, including physicians and nurses, communicate directly with each other; record patient history, medications, and allergies; write progress notes; generate orders and transmit electronic prescriptions directly to pharmacies; bill; generate referral letters; and access labs and radiographic studies.

Patients are encouraged to use a web-based patient portal or smartphone from which they can schedule appointments, ask questions, review their labs, read educational material on their health conditions, and update their personal health record. Data are also captured in HealthPlaNET, a patient-centric electronic care management system developed and utilized by UPMC Health Plan. The Wellness Practitioner has access to both the EMR and UPMC Health Plan’s care management system, creating a complete, integrated picture of the individual’s health status.

The University of Pittsburgh has funding from the National Institute on Disability and Rehabilitation Research (NIDRR) and the Verizon Foundation to develop a separate telemedicine arm of this project. The organization will evaluate whether providing some of these services remotely leads to outcomes similar to those of the face-to-face program. The organization has already developed an entire telerehabilitation infrastructure that links patients, family members, caregivers, and clinicians via a suite of smartphone applications linked to a web-based interface that will aid patients in managing many health conditions.
Leadership Involvement and Support

A Payer Provider initiative was established to support this project. Leadership at UPMC includes the physician director of the program and the chairman of the department of PM&R. Senior leadership at UPMC Health Plan includes the president of UPMC for You, vice president of health economics, senior director of program development, a project manager, nurse practitioner, registered nurse and intern. A Patient Advisory Committee is also being established.

Challenges of This Project

Funding is the major challenge in implementation. While UPMC has been very successful in obtaining funding, not all clinics have the resources and contacts to be able to fund such a program. Thus, a key objective in this project is to demonstrate cost savings. These data are crucial for demonstrating to third-party payers that these programs are worth supporting. Dissemination of findings on cost and healthcare utilization is crucial to the evolution of health care as a proactive model.

Lessons Learned

- Over-utilization of health care by patients receiving care in acute settings for subacute problems and wasted spending with duplication of tests and procedures can be avoided when the patient has a medical home and a clear point of contact he or she can trust to answer questions and activate needed services.
- Physical Medicine & Rehabilitation is a medical specialty that can serve as an SMH for patients with certain chronic conditions and disabilities.
- Care must be tailored to the patient’s goals and life situations. Patients who live in rural or underserved areas and patients with disabilities who face accessibility and transportation issues are most at risk. Care can be delivered to these patients through home visits or through telemedicine if necessary. These concepts are crucial to providing comprehensive, longitudinal care that is effective.
- Partnering with practitioners who are experienced in delivering home health care can be invaluable because they are experienced in delivering wellness services and may already have algorithms and educational materials developed for their patients. UPMC sought out a large team of advisors to include all aspects of wellness services.
- Once an SMH is in place and running, it is difficult to measure efficacy if the program’s structure or content changes. Outlining aims and outcome measures for which data can realistically be gathered and for which analysis will yield meaningful results is crucial to testing efficacy.
- Targeted recruitment, risk assessment, care tools, and educational material should be evidence based and linked to measurable outcomes and preventable diagnoses that have been systematically studied in the literature.
- This program offers the potential to impact large populations beyond those studied.

Authors

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