Acknowledgments

This report funded by the Kansas Health Foundation. The Kansas Health Foundation is a philanthropy dedicated to improving the health of all Kansans. For more information about the Kansas Health Foundation, visit www.kansashealth.org.

The Public Policy and Management Center (PPMC) would like to thank the steering committee for leadership and input into this report. Their hours of effort in assisting this research report demonstrate their commitment to advancing excellence in public service to the Sedgwick County community and the state. Steering committee members include:

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The PPMC would like to acknowledge and express sincere appreciation to the following for their contributions to this report:

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Disclaimer

This study was conducted by the PPMC at Wichita State University (WSU). The PPMC is an independent research body unaffiliated with Ascension AVC, COMCARE or SACK. This report was prepared by the research team. It represents the findings, views, opinions and conclusions of the research team alone. The report does not express the official or unofficial policy of WSU.
Executive Summary

High utilizers of behavioral health services are generally defined as individuals suffering from mental illness or substance use disorders, whose complex physical, behavioral and social needs are not being served through the current fragmented health care system (The Center for Health Care Service, 2016). While there is no universal definition of what constitutes a high utilizer, it is generally recognized that high utilizers get trapped in a cycle of emergency department, inpatient admission, crisis services, detox and sobering and back on the street without successfully managing their illnesses. Many of these patients are uninsured or underinsured, utilizing significant community resources, while still not fully engaged in treatment for their illnesses. The Department of Health and Human Services (2013) reports that nationally these high utilizers represent five percent of all patients and comprise 50 percent of all costs paid by Medicaid.

This study reviewed data for high utilizers, from 2015 through 2018, from three Sedgwick County providers of mental health services including Ascension Via Christi (AVC), COMCARE of Sedgwick County (COMCARE) and The Substance Abuse Center of Kansas (SACK). Diagnosis codes, demographic and cost data were analyzed to determine a description of high utilizer patients. In addition, four composite patient profiles were developed.

High utilizer patients are seriously mentally ill. The primary diagnosis for most of AVC patients (35.7%) was mood disorders (e.g. depression, bi-polar, mania). The majority of high utilizers for COMCARE are diagnosed with schizophrenia, and all of SACK’s high utilizers are diagnosed with substance abuse, many with co-occurring mental illnesses. The majority of high utilizer patients are White males, falling between the ages of 35 to 54.

Of the 516 total high utilizer patients studied, 25 percent (127 patients) were also high utilizers of one of the other agencies in the study. Of this 25 percent, 85 percent (108) are high utilizers of two agencies, and 15 percent (19) are high utilizers of all three agencies. This percentage is estimated to be low because many patients may receive
services at all agencies but did not make the cut into the high utilizer sample drawn for this study.

Places of residence for high utilizers are clustered in the downtown region or near Ascension St. Joseph campus. SACK was the only agency that reported homelessness data for this study. Analysis of SACK’s data indicates that 66 percent (82 patients) of the 122 high utilizer patients are homeless.

**Over the years 2015 to 2018, the 519 high utilizer patients received almost $56 million of care from AVC, COMCARE and SACK.** AVC had the largest share at $46.8 million, COMCARE had $8.7 million and SACK had $319,000. The highest cost patient at AVC received $765,211 in services between 2015 and 2018, COMCARE’s highest cost patient received $379,337 and SACK’s highest cost patient received $11,866 of services. In 2018, the median cost per high utilizer patient was approximately $72,426 for AVC, $20,328 for COMCARE and $1,008 for SACK.

The majority of high utilizer patients are on Medicaid, Federal Block Grant or uncompensated care for payment of services. AVC has slightly over 47 percent, COMCARE has 56 percent and SACK has 100 percent of high utilizers funded by Medicaid, Federal Block grants or uncompensated care.

**Over the past four years, almost $17 million in high utilizer services (30%) was funded through public and uncompensated care assistance.** AVC provided $12.8 million, COMCARE $3.8 million and SACK $319,103 in services.

These costs represent a fraction of the full costs to the individual and society because they do not include the costs due to reduced quality of life, lost employment, lost productivity and social and emotional costs to the patient, families and society. Despite the disproportionately large costs for a relatively small number of high utilizer patients, health care research shows that medical and social outcomes remain low for this population (Siekman & Hilger, 2018).

This report provides several recommendations to better serve high utilizers of behavioral health services through: exploring and pilot testing improved models and
methods of service delivery, increased collaboration between agencies, creation of uniform indicators to define high utilizers, reform of payment processes, creation of better processes for health information exchange, collaboration of community leadership to secure adequate funding and support for the recommendations of the Mental Health and Substance Abuse Coalition.

Introduction

According to the National Survey of Drug Use and Health, an estimated 46.4 million adults (18.9%), aged 18 and older suffered from a mental illness in the past year and 11.2 million adults (4.5%) have a serious mental illness. Approximately 8.5 million adults (3.4%) have a co-occurring mental illness and substance use disorders. A subset of the most seriously ill population become “super utilizers” or “high utilizers” of mental health services (Rentas, Buckley, Wiest, Bruno, 2019; Kushner, Fondow, Schreiter, Thomas, Grosshans, 2019; Jiang, Weiss, Barrett, Sheng, 2012).

While there is no universal definition of what constitutes a high utilizer, it is generally recognized that high utilizers get trapped in a cycle of emergency department, inpatient admission, crisis services, detox and sobering and back on the street without successfully managing their illness. High utilizers are generally defined as individuals whose complex physical, behavioral and social needs are not being served through the current fragmented health care system (The Center for Health Care Services, 2016).

High utilizers consume a disproportionately large share of health care services. In the U.S., five percent of the population, who were the highest users of health care, were responsible for 50 percent of healthcare costs (Siekman & Hilger, 2018).

The Agency for Healthcare Research and Quality (AHRQ) used data from the Healthcare Cost and Utilization Project (HCUP) to assess hospital utilization and costs among Medicaid high utilizers and found that on average these users had higher hospital costs per stay and higher readmission rates compared to other Medicaid patients. In addition, mental health and substance use disorders were among the top ten principal diagnoses for high utilizers (Jiang & Sheng, 2014).
The Department of Health and Human Services (2013) also reports that nationally these high utilizers represent five percent of all patients and make up 50 percent of all costs paid by Medicaid. Many of these patients are uninsured or underinsured, utilizing significant community resources, while still not fully engaged in treatment for their illnesses.

Social determinants of health also play a role in high utilization of services. Factors such as poverty, lack of education, lack of health insurance, homelessness, food insecurity and interpersonal violence increase the risk of poor health and reduce the likelihood of timely care (Michigan Department of Community Health, 2014). In addition, high utilizers are increasingly at risk from the impacts of the opioid crisis (Davis, Lin, Liu, & Sties, 2017).

Sustaining support for high-utilizing patients is a challenge across the nation and is linked to a larger problem related to unaddressed healthcare needs, a lack of access and a lack of coordinated services, according to the Association of American Medical Colleges. In addition, the nationwide shortage of doctors is predicted to reach over 90,000 by 2025, with a large proportion of the burden falling on lower-income and rural communities. Across the nation our community health care systems are fragmented and exacerbate the problem of serving high utilizers by: (1) encouraging patients to seek healthcare in hospital emergency departments (ED’s), which are viewed as the hospital’s front door to access; (2) a lack of coordination to treat the complex physical and behavioral healthcare needs of high utilizers, and; (3) an inability to identify high utilizer patients in real time to implement interventions designed to meet their comprehensive needs (Michigan Department of Community Health, 2014).

Kansas, like other states, is also experiencing a mental health crisis. According to the Substance Abuse and Mental Health Services Administration, Kansas has about 76,000 adults (3.7%) with a serious mental illness, but only 48.5 percent received treatment. Among adults served in Kansas’ public mental health system in 2013, 60.5 percent were unemployed. In addition, Kansas reports a higher incidence of heavy alcohol use among adults at 8.1 percent compared to the national level of 6.8 percent.
In Sedgwick County, 17.9 percent of adults reported having been diagnosed with a depressive disorder and 11.4 percent report an anxiety disorder (Sedgwick County Health Department Data Book, 2012). The Sedgwick County Sheriff’s office reports that 25 percent of the inmate population is diagnosed with some form of mental illness and approximately 73 percent have a chemical dependency.

In December of 2015, the Federal Centers for Medicare and Medicaid Services de-certified Osawatomie State Hospital; consequently, they could not bill for Medicaid or Medicare reimbursements. In addition, the moratorium on the number of patients admitted and the prohibition to admit voluntary patients, coupled with changing admissions criteria, has created a long waiting list. These factors are reflected in the admissions to Osawatomie state hospital, which declined from 2,342 in FY2015 to 1,365 in FY2019.

These factors challenge communities across Kansas to manage the growing behavioral health crisis. In response to this need, the Kansas Health Foundation awarded AVC in Wichita, Kansas an Impact Grant to study the high utilizers of behavioral health services in Sedgwick County and determine costs for uninsured and underinsured high utilizers.

Three agencies participated in the study including AVC Behavioral Health, COMCARE and SACK. AVC hospital provides at least 90 percent of inpatient psychiatric care in the region and a large amount of the outpatient services. The goal is to provide inpatient and outpatient behavioral health services through a collaborative continuum of care that connects AVC and community resources to deliver patient-centered, clinically integrated care for psychiatric patients.

COMCARE provides mental health and substance abuse services to residents of Sedgwick County. It is the largest of the 26 community mental health centers in Kansas and serves over 19,000 individuals in the community. As the local mental health authority for Sedgwick County, COMCARE is the safety net for individuals in need of mental health services, regardless of the patient’s ability to pay.

SACK is a non-profit organization specializing in the prevention, treatment and case management of individuals affected by substance abuse. In addition, SACK provides sobering and detox services in a co-location partnership with COMCARE.
To conduct this study, AVC contracted with Wichita State University’s PPMC, an independent research body, not affiliated with any of the agencies participating in the study.

**Study Goals**

This study provides a description of the high utilizer behavioral health population in Wichita/Sedgwick County over the years 2015 through 2018. The study examines the demographic characteristics of the client population and how they differ by agency. Patterns of services are reviewed over time to determine which patients are using multiple community services. In addition, costs of services for this high utilizer population are compared between agencies and across time. The study also provides representative profiles of four high utilizer patients which tell the stories of this vulnerable population.

**Methodology**

To initiate the study, a steering committee, comprised of the executive leadership from each of the three agencies, was formed to guide the research. The committee met numerous times to determine how to define a high utilizer of mental health care services in Sedgwick County, select the study pool of patients, review the data, develop composite case profiles of patients and review and refine the final report.

The steering committee initially defined high utilizers as adult patients age 18 or older who had either: (1) two or more hospitalizations in a calendar year where a behavioral health diagnosis was in the top three diagnoses, or (2) ten or more emergency room encounters in the course of the four years where behavioral health was in the top three diagnoses. Each agency selected their study population of patients, for the years 2015 through 2018, who received services that fit the above definition of a high utilizer. Due to the large number of patients included in the initial study sample of high utilizers, the sample was further refined to include no more than the top 200 patients from each agency who had the largest costs for care over the four-year period. Following data cleaning and screening, 196 AVC patients, 199 COMCARE patients and 124 SACK patients were included in the study.
The PPMC analyzed the data to determine the high utilizer demographic characteristics, diagnoses and costs. The steering committee reviewed data and made suggestions for clarification and analysis.

Analysis also included development of composite profiles or scenarios to illustrate real-life stories for a few high utilizers. These profiles are realistic descriptions of characteristics and circumstances but cannot be attributed to any single individual.

The study used only data generated by these three agencies in the usual course of business or treatment. The PPMC staff did not collect primary data and did not have contact with clients. Only de-identified data is contained in this report.

**High Utilizers Profiles**

To understand the stories of high utilizers, the following profiles were developed from composites of patient cases. They do not reflect any individual patients but are realistic composites describing common scenarios or case studies of high utilizer patients.

Profiles are provided for the most expensive patient, a mental health diagnosis patient, a substance use diagnosis patient and a co-occurring diagnosis (mental and substance use disorder) patient.

*Will: The Most Expensive Patient*

Will is in his mid-forties and on Medicaid. Will is not violent, but as a 6’ 4”, 250-pound man, he intimidates people. He has poor social skills and a history of sexual abuse. He is very lonely and seeks to gain friends by spending his disability check on buying drugs and alcohol as an inducement for people to hang out with him. Will stands outside local convenience stores and asks people to pet his stuffed dog. He cannot hold down a job and is frequently in trouble with the law for minor issues such as sleeping in hotel hallways. Will is homeless, frequently abused by others on the street and cannot manage his money. Will’s only family is an elderly mother, but she has dementia and is living in a nursing home. Will has been admitted to the hospital as an inpatient 23 times and in the emergency department 20 times between the years 2015-2018 due to depression, suicidal thoughts and Human Immunodeficiency Virus (HIV) disease. Will
has been a patient at all three agencies: AVC, COMCARE and SACK. Will’s treatment costs totaled $765,000 over the past four years.

**Sandy: Mental Health as Primary Diagnosis**

Sandy is in her mid-twenties and has been brought to COMCARE’s Crisis Center on several occasions by law enforcement officers. She is frequently picked up because someone reports she is alone in the street talking and frantically gesturing. She experiences acute psychotic symptoms and her strong body odor and unkempt appearance indicate a lack of self-care. When law enforcement officers approach her, she becomes frightened and reports that others are trying to harm her.

Sandy has a long history of untreated trauma. As a teenager, she was sexually abused by an extended family member. She was afraid to tell anyone about the abuse, for fear she would be blamed if the abuser was removed from the home. She often drinks alcohol when she is feeling anxious and paranoid. At times, she uses street drugs with her friends. However, she makes excuses and minimizes her substance use when questioned by providers.

While Sandy has recently been seeing a psychiatrist at COMCARE, she doesn’t take her medications as prescribed and gets disorientated and confused. She does not think she is ill and is convinced the medications are poison. She has been assigned a case manager to determine if she is eligible for benefits because she will transition off her parents’ insurance in the next three months. The case manager is also researching housing options. Sandy’s frequent episodes are putting a strain on her parents, who worry about her when they are at work. Sandy fights with her mother and often stays with friends for extended periods until she is no longer welcome. Sandy has been in the emergency room 36 times and hospitalized five times in the past four years.

**Sam: Substance Use Disorder Primary Diagnosis**

Sam is in his early forties and is homeless. He presented at detox (SACK) a number of times with a blood alcohol level typically above .30 (exceeding the legal limit for driving). Frequently, his blood alcohol level is too high to be admitted to the SACK social detox treatment center, so he must be transported to a hospital emergency room for medical detox until his blood alcohol level is low enough for him to be cleared to return to
SACK’s social detox facility. However, Sam rarely stays in detox for more than a day. Staff report he tends to come to SACK for detox in adverse weather. Because Sam is not sober long enough, he then becomes ineligible to receive Medicaid.

Staff at SACK have made several attempts to get Sam into a residential treatment facility, but without a medical card or other coverage, the wait for a bed is six to eight weeks. Sam can’t maintain sobriety for that long so the pattern repeats. It’s also common for Sam to be despondent, hopeless and expressing suicidal ideation. There are also times when Sam’s thoughts of suicide include a credible plan, and this has caused Sam to be admitted to AVC’s inpatient unit. During these stays, once Sam’s blood alcohol level is lowered, he apologizes and says he wants to live and is discharged.

Sam started drinking at age 12 when he was offered alcohol by an uncle at a family gathering. Several of Sam’s family members are heavy drinkers, but over the years have managed to hold onto their business as house painters.

Sam has a very strained relationship with his family because he has repeatedly asked them for money and at times has stolen from them to buy alcohol. Consequently, Sam’s support network is primarily individuals he meets on the street or in a shelter. Sam is caught in a cycle of dysfunctional behavior that repeats with predictably poor outcomes.

**Bill: Co-Occurring Disorder of Mental Health and Substance Use Disorder**

Bill is in his early thirties. He has been in the mental health system since childhood. He struggled with school and had difficulty developing relationships with other children. He started using drugs and alcohol as a young teen, mostly to feel more relaxed around others and to fit in with his peers.

It has been very difficult for treatment providers to determine the cause of his anxiety and other psychiatric symptoms due to his significant substance use. He is rarely clean and sober and doesn’t engage in treatment long enough to experience gains in treatment. He has been at AVC’s inpatient unit 12 times in the past four years and has one short stay at Osawatomie State Hospital. He hasn’t been able to hold down a job
for extended periods of time and crashes on one of his buddy’s couches or stays on the street. He has been unwelcomed in two local shelters. These environments are too anxiety producing for him, and on several occasions, he has started fights.

About a year ago, Bill got into a serious altercation with another shelter resident and was knocked unconscious which resulted in a serious head trauma. He refused to follow up with providers after being treated at the emergency department following the head injury. His behavior has been very erratic since this injury. He was banned from the community soup kitchen and emergency shelters due to his explosive episodes. As a result of his behavior, he is provided with a meal at the back door of the community soup kitchen. Bill feels lost and anxious, but he cannot trust others enough to sustain a genuine relationship. Bill’s aggression has resulted in numerous encounters with law enforcement officers which resulted in several brief stays in jail. He is caught in a revolving door of acquiring Medicaid benefits, only to lose them and having to reapply upon release.

**High Utilizer Diagnosis**

High utilizers have serious and persistent mental illness and many have substance use addictions. They frequently have additional physical health conditions that are exacerbated by their inability to manage their personal health care and hygiene, their vulnerability to violence, physical injury, sexual abuse and their lack of adequate housing. Also, most high utilizers also have some type of co-occurring mental health and/or substance use disorder. Table 1.1 summarizes the primary diagnosis for AVC and COMCARE. SACK patients all have a principal diagnosis of substance use disorder, so Table 1.1 presents self-reported secondary diagnoses.
Table 1.1: Mental Health Diagnosis Summary

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>AVC</th>
<th>COMCARE</th>
<th>SACK*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychoactive substance use disorder</td>
<td>27.0%</td>
<td>0.00%</td>
<td>36.1%**</td>
</tr>
<tr>
<td>Schizophrenia</td>
<td>28.6%</td>
<td>47.3%</td>
<td>13.1%</td>
</tr>
<tr>
<td>Mood Disorders</td>
<td>35.7%</td>
<td>43.7%</td>
<td>41.8%</td>
</tr>
<tr>
<td>Anxiety Disorders</td>
<td>4.1%</td>
<td>6.5%</td>
<td>7.4%</td>
</tr>
<tr>
<td>Adult Personality Disorders</td>
<td>0.5%</td>
<td>2.5%</td>
<td>1.6%</td>
</tr>
<tr>
<td>Other</td>
<td>4.1%</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
</tbody>
</table>

* 100% of SACK clients have substance use disorder. Data is for secondary, self-reported mental health diagnoses.
** Multiple substances reported

**AVC High Utilizer Diagnosis**

The primary diagnosis for most of AVC patients (35.7%) was mood disorders (e.g. depression, bi-polar, mania). Schizophrenia is the second largest primary diagnosis (28.6%) and mental and behavioral disorders to psychoactive substance use is third (27%). Approximately 53% of the AVC high utilizers have either a mental illness or substance use disorder as a co-occurring condition. Thirty-four percent of AVC patients were diagnosed with an additional mental illness condition and 20 percent with substance use disorder. Of the patients with a co-occurring mental health condition, 73 percent reported suicidal ideation. Secondary conditions for the remaining patients included physical conditions such as injuries, diabetes, heart and respiratory problems.

**COMCARE High Utilizer Diagnosis**

Most high utilizers for COMCARE are diagnosed with schizophrenia (47.2%), while mood disorders comprise the next largest diagnosis category (43.7%). Examining secondary conditions, 31.6 percent of patients had substance use disorders and 23 percent anxiety disorders.
**SACK High Utilizer Diagnosis**

All high utilizer patients at SACK are diagnosed with substance use disorders. While SACK treatment providers cannot diagnose mental illness, self-reported conditions by patients indicate 41.8 percent have mood disorders, 36 percent report using multiple substances and 13 percent have schizophrenia.

**High Utilizer Demographic Descriptions**

Demographic variables analyzed include gender, age, race and ethnicity.

**Gender**

According to the World Health Organization, gender has been determined to be an important determinate of mental health and mental illness. Gender can influence the socioeconomic determinate of mental health, treatment in society and susceptibility to mental health risks. Gender differences have been reported in age of onset of symptoms, frequency of psychotic symptoms, progression of disorders, social adjustment and long-term outcomes. For example, depression and anxiety are more common in women, while men are more likely than women to have a substance use and antisocial disorders problem (Mann, 2011).

Most of Sedgwick County high utilizers are male for all agencies, with SACK having the largest male population at 84.5 percent compared to COMCARE at 56.8 percent and AVC at 52.0 percent. Women comprise only 15.3 percent of SACK patients, 43.2 percent of COMCARE and 48.0 percent of AVC patients. These percentages differ from the Sedgwick County population, which is almost evenly split with 49.5 percent male and 50.5 percent female (U.S. Census Bureau).

In this study, the percentage of high utilizer men is four to 13 percent larger than the percentage of women. According to the National Alliance on Mental Health (NAMI), evidence suggests that men are less likely to use mental health services compared to women. Consequently, men may be more likely to delay treatment, thus developing more severe mental and physical health problems that contribute to becoming a high utilizer of services.
According to the National Institute on Alcohol Abuse and Alcoholism (Green, n.d.), women are more likely than men to face multiple barriers in accessing substance abuse treatment and are less likely to seek treatment for substance abuse. However, women who do seek substance abuse treatment are more likely to go to mental health or primary care settings rather than specialized substance abuse treatment programs (Green, n.d.). These factors could help explain the low percentage of women (15.3%) treated at SACK.

Table 2.1: Gender of High Utilizers

<table>
<thead>
<tr>
<th></th>
<th>AVC</th>
<th>COMCARE</th>
<th>SACK</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>52.0%</td>
<td>56.8%</td>
<td>84.7%</td>
</tr>
<tr>
<td>Female</td>
<td>48.0%</td>
<td>43.2%</td>
<td>15.3%</td>
</tr>
</tbody>
</table>

Age

Age distribution is presented in Table 3.1. Only about five percent of high utilizer patients are ages 18-24. This may be because patients in this age range still fall under their parents’ insurance and are receiving treatment from private care doctors and facilities. The percent of high utilizers jumps to almost 24 percent for the ages 25-34. This increase may reflect the loss of parental insurance and the need to rely on community resources. However, it may also reflect a delay in diagnosis and treatment of mental health problems. According NAMI, half of all chronic mental illness begins by age 14 and three-quarters by age 24. Despite the availability of effective treatments, the average young person does not get treatment until eight to ten years after the onset of symptoms.

Over 50 percent of patients at COMCARE and SACK fall between the ages of 35 to 54. AVC patients fall into older categories, with over 50 percent of the patients clustered in the 45 to 64 age group. This may be due, in part, to development of more serious physical conditions associated with aging. For example, older people with chronic medical conditions such as diabetes and heart disease and co-occurring depression are at increased risk for disability, premature mortality, and high health care costs. In
addition, people with serious mental illness are at high risk for obesity, hypertension, diabetes, cardiac conditions, respiratory problems, and communicable diseases that contribute to a lower life expectancy than the general population (Mental Health America, n.d.).

The lowest percentage of high utilizers were in the 55 and older age categories. In a review of 203 studies from 29 countries, Walker, McGee and Druss (2015) found that people with mental illness had a median reduction in life expectancy of 10.1 years. The majority of early mortality in people with mental illness was attributed to co-morbid conditions, for example heart disease. However, 17.5 percent of deaths were related to unnatural causes like suicide and injuries. The lower percentages of patients over age 55 may be due to a variety of factors, but reduced life expectancy for serious mental illness is likely to be a significant contributing factor.

Table 3.1: Age of High Utilizers

<table>
<thead>
<tr>
<th>Age</th>
<th>AVC</th>
<th>COMCARE</th>
<th>SACK</th>
<th>Sedgwick County</th>
</tr>
</thead>
<tbody>
<tr>
<td>18 - 24</td>
<td>5.6%</td>
<td>5.5%</td>
<td>0.0%</td>
<td>7.0%</td>
</tr>
<tr>
<td>25 - 34</td>
<td>23.5%</td>
<td>23.6%</td>
<td>18.0%</td>
<td>14.3%</td>
</tr>
<tr>
<td>35 - 44</td>
<td>15.8%</td>
<td>24.6%</td>
<td>35.2%</td>
<td>12.0%</td>
</tr>
<tr>
<td>45 - 54</td>
<td>25.5%</td>
<td>24.6%</td>
<td>27.9%</td>
<td>12.3%</td>
</tr>
<tr>
<td>55 - 64</td>
<td>21.9%</td>
<td>18.6%</td>
<td>17.2%</td>
<td>12.5%</td>
</tr>
<tr>
<td>65 - 74</td>
<td>6.1%</td>
<td>2.5%</td>
<td>1.6%</td>
<td>7.5%</td>
</tr>
<tr>
<td>75+</td>
<td>1.5%</td>
<td>0.5%</td>
<td>0.0%</td>
<td>5.6%</td>
</tr>
</tbody>
</table>

Race and Ethnicity

The U.S. Department of Health and Human Services reports that minorities have less access and are less likely to receive mental health services than members of the majority population. A constellation of barriers deters minorities from reaching treatment. Many of these barriers operate for all Americans: cost, fragmentation of services, lack of availability of services and societal stigma toward mental illness.
(DHHS, 1999). However, additional barriers deter racial and ethnic minorities: mistrust and fear of treatment, racism and discrimination and differences in language and communication.

In a report from the Surgeon General, Department of Health and Human Services, culture also can account for variations in how consumers communicate their symptoms and which ones they report. Culture may also impact whether patients seek help in the first place, what types of help they seek, what coping styles and social supports they have and how much stigma they attach to mental illness.

The National Institute of Mental Health Substance Abuse and Mental Health Services Administration (SAMHSA) reports that the adults most likely to use mental health services are in the group reporting two or more races (17.1%), followed by White adults (16.6%), American Indian or Alaska Native adults (15.6%), African American (8.6%), Hispanic (7.3%) and Asian (4.9%) adults.

In examining race of high utilizers, as shown in Table 4.1, the largest percentage for each agency was White. AVC and SACK patients are about 80 percent White, which is consistent with the population of Sedgwick County (80.0%). COMCARE’s patients are 64 percent White, which is well below the county statistic. The second largest race category is African American with COMCARE reporting the largest percentage (22.1%) followed by AVC at 11.7 percent and SACK at 8.8 percent. COMCARE and AVC are well above the nine percent African American population for Sedgwick County.

COMCARE and SACK report 6.0 percent Native American, compared to 1.4 percent for Sedgwick County. Multiple races comprise 5.1 percent of AVC patients compared to 3.8 percent for Sedgwick County.

Hispanics comprise between 5.1 percent and 7.5 percent of high utilizer patients, which is well below the 14.1 percent Hispanic population for Sedgwick County (See Table 4.2).
Table 4.1: Race of High Utilizers

<table>
<thead>
<tr>
<th>Race</th>
<th>AVC</th>
<th>COMCARE</th>
<th>SACK</th>
<th>Sedgwick County</th>
</tr>
</thead>
<tbody>
<tr>
<td>African American</td>
<td>11.7%</td>
<td>22.1%</td>
<td>8.8%</td>
<td>9.3%</td>
</tr>
<tr>
<td>Asian</td>
<td>1.0%</td>
<td>1.0%</td>
<td>0.0%</td>
<td>4.6%</td>
</tr>
<tr>
<td>Native American</td>
<td>0.5%</td>
<td>6.5%</td>
<td>6.1%</td>
<td>1.4%</td>
</tr>
<tr>
<td>White</td>
<td>81.6%</td>
<td>63.8%</td>
<td>83.3%</td>
<td>80.0%</td>
</tr>
<tr>
<td>Multiple</td>
<td>5.1%</td>
<td>0.0%</td>
<td>0.9%</td>
<td>3.8%</td>
</tr>
<tr>
<td>Unknown</td>
<td>0.0%</td>
<td>6.5%</td>
<td>0.9%</td>
<td>0.0%</td>
</tr>
</tbody>
</table>

Table 4.2: Ethnicity of High Utilizers

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>AVC</th>
<th>COMCARE</th>
<th>SACK</th>
<th>Sedgwick County</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hispanic</td>
<td>5.1%</td>
<td>7.5%</td>
<td>6.6%</td>
<td>14.1%</td>
</tr>
</tbody>
</table>

Patterns of Services

Patterns of services was analyzed to determine the overlap of high utilizers at the three agencies: AVC, COMCARE and SACK. Of the 516 total high utilizers studied, 25 percent (127 patients) are also high utilizers of at least one of the other agencies. Of this 25 percent, 85 percent (108) are high utilizers of two agencies and 15 percent (19) are high utilizers of all three agencies.

It is highly likely, based on discussion of the steering committee, that many more of the 516 high utilizers have been patients of two or more of the agencies studied. However, because only the top 200 or fewer utilizers were selected from each agency, patients may overlap, but not fall into the high utilizer pool for more than one agency. For example, a patient may be in the AVC and COMCARE high utilizer study pool of patients, but not in SACK’s pool. However, they may have been a patient at SACK
during the four-year period, but not ranked high enough to be included in SACK’s high utilizer group.

The majority of high utilizers reside in the 67203 ZIP code area in downtown Wichita, where COMCARE and SACK services are located. Because many high utilizers are homeless, their residence is reported as the agency’s address and ZIP code.

Most high utilizers at AVC reside in the 67211 and 67216 areas, which are adjacent to the 67214 and 67218 area where the two largest acute care hospitals are located. The 67203 area, where SACK and COMCARE’s Community Crisis Center are located, is among AVC’s second most dense service areas.

To understand service patterns and where patients for each agency are residing, ZIP Codes were analyzed and mapped. Maps for each agency are located in the Appendices.

**Homeless**

The Substance Abuse Center of Kansas (SACK) is the only agency that provided data about homelessness. Analysis of their data indicates that 66 percent (82 patients) of the 122 high utilizer patients are homeless. SACK is located in the 67203 ZIP code, which is the red zone of high utilizers on the map in Appendix C.

**High Utilizer Costs and Cost Recovery**

The reasons for high utilizers’ care patterns are complex and often are the result of a combination of behavioral health and physical health needs. This study examines the treatment charges from each agency, but it does not reflect the additional costs to patients, their families and society. For example, NAMI reports that serious mental illness costs America $193.2 billion in lost earnings per year.

Table 5.1 summarizes costs. Over the last four years, high utilizer patients have had almost $56 million in care from AVC, COMCARE and SACK. AVC had the largest share at $46.8 million, COMCARE had $8.7 million and SACK had $319,000.
Table 5.1:

Costs of High Utilizer Services*

<table>
<thead>
<tr>
<th>Year</th>
<th>AVC</th>
<th>COMCARE</th>
<th>SACK</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>2015</td>
<td>$10,688,124</td>
<td>$1,342,658</td>
<td>$38,774</td>
<td>$12,069,556</td>
</tr>
<tr>
<td>2016</td>
<td>$12,469,614</td>
<td>$2,403,376</td>
<td>$99,866</td>
<td>$14,972,856</td>
</tr>
<tr>
<td>2017</td>
<td>$12,341,847</td>
<td>$1,794,067</td>
<td>$118,710</td>
<td>$14,254,624</td>
</tr>
<tr>
<td>2018</td>
<td>$11,362,043</td>
<td>$3,201,895</td>
<td>$61,752**</td>
<td>$14,625,690</td>
</tr>
<tr>
<td>TOTAL</td>
<td>$46,861,628</td>
<td>$8,741,996</td>
<td>$319,102</td>
<td>$55,922,726</td>
</tr>
</tbody>
</table>

*AVC: includes all charges incurred. COMCARE: billed charges per payment agreements. Due to sliding scales, charges are less than cost for actual care given. SACK: charges are based on the Federal Block Grant approved rate.

** In 2018, some SACK high utilizers were not included in the study sample due to incarceration.

Cost Per Patient

There was wide variability of costs per patient. The highest cost patient at AVC received $765,211 in services between 2015 and 2018, COMCARE’s highest cost patient received $379,337 and SACK’s highest cost patient received $11,866 of services.

Because of variability in the data, average costs would skew the data towards extremes, so the median cost was used to estimate annual costs per patient. Results are presented in Table 5.2. In 2018, each high utilizer patient received services of approximately $72,426 for AVC, $20,328 for COMCARE and $1,008 for SACK. Over the four-year period, costs per patient have increased by about 26 percent. These growing costs reflect care delivered to the 519 high utilizer patients in this community.

Table 5.2: Median Costs per High Utilizer Patient

<table>
<thead>
<tr>
<th>Year</th>
<th>AVC</th>
<th>COMCARE</th>
<th>SACK</th>
</tr>
</thead>
<tbody>
<tr>
<td>2015</td>
<td>$57,895</td>
<td>$15,801</td>
<td>$756</td>
</tr>
<tr>
<td>2016</td>
<td>$68,315</td>
<td>$16,936</td>
<td>$1,136</td>
</tr>
<tr>
<td>2017</td>
<td>$61,776</td>
<td>$12,725</td>
<td>$1,133</td>
</tr>
<tr>
<td>2018</td>
<td>$72,426</td>
<td>$20,328</td>
<td>$1,008</td>
</tr>
</tbody>
</table>
Payment for High Utilizer Services

The largest proportion of high utilizers are on Medicaid, Federal Block Grant funds or uncompensated care for payment of services. The distribution of payors is shown in Table 6.1. AVC has 47 percent, COMCARE has 56 percent and SACK has 100 percent of high utilizers funded by Medicaid, Federal Block grants or uncompensated care. Commercial, Medicaid, Medicare and Military do not cover the cost of SACK’s high utilizer services.

High utilizers covered by insurance (commercial insurance, Medicare, military, self-pay) comprised 50 percent of AVC patients, 56 percent for COMCARE and zero percent for SACK. This is a significantly lower percentage than the Chicago health system study which found that 72.4 percent of their hospital emergency department high users had either Medicare or private insurance, while 25.6 percent had Medicaid or no insurance (Szekendi et al., 2015).

Table 6.1: Payors for High Utilizer Patients

<table>
<thead>
<tr>
<th>Insurance/Payor</th>
<th>AVC</th>
<th>COMCARE</th>
<th>SACK</th>
</tr>
</thead>
<tbody>
<tr>
<td>Commercial</td>
<td>17.9%</td>
<td>10.6%</td>
<td>0.0%</td>
</tr>
<tr>
<td>Medicaid</td>
<td>23.5%</td>
<td>35.2%</td>
<td>0.0%</td>
</tr>
<tr>
<td>Medicare</td>
<td>28.1%</td>
<td>33.2%</td>
<td>0.0%</td>
</tr>
<tr>
<td>Uncompensated care*</td>
<td>27.0%</td>
<td>19.6%</td>
<td>0.0%</td>
</tr>
<tr>
<td>Military</td>
<td>1.0%</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td>Self-Pay</td>
<td>2.0%</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td>Federal Block Grant</td>
<td>0.0%</td>
<td>1.5%</td>
<td>100.0%</td>
</tr>
<tr>
<td>Other</td>
<td>0.5%</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
</tbody>
</table>

*Uncompensated care is a very conservative estimate.

To understand the cost of services covered by public assistance dollars and uncompensated care, data was sorted by funding source. Over the past four years, almost $17 million in services was provided to the high utilizers in Sedgwick County.
through Medicaid, Federal Block grant funds or uncompensated care. AVC provided $12.8 million, COMCARE $3.8 million and SACK $319,103.

Table 6.2: Public Assistance and Uncompensated Care for High Utilizer Patients

<table>
<thead>
<tr>
<th>Year*</th>
<th>AVC</th>
<th>COMCARE</th>
<th>SAC</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>2015</td>
<td>$3,447,339</td>
<td>$642,775</td>
<td>$38,774</td>
<td>$4,128,888</td>
</tr>
<tr>
<td>2016</td>
<td>$2,725,983</td>
<td>$1,189,317</td>
<td>$99,866</td>
<td>$4,015,166</td>
</tr>
<tr>
<td>2017</td>
<td>$3,553,473</td>
<td>$863,748</td>
<td>$118,710</td>
<td>$4,535,931</td>
</tr>
<tr>
<td>2018</td>
<td>$3,072,560</td>
<td>$1,113,685</td>
<td>$61,752</td>
<td>$4,247,997</td>
</tr>
<tr>
<td>Total</td>
<td>$12,799,355</td>
<td>$3,809,525</td>
<td>$319,103</td>
<td>$16,927,983</td>
</tr>
</tbody>
</table>

* includes Medicaid, Federal Block Grants and uncompensated care.

In summary, these costs represent a fraction of the full costs because agency costs are underestimated. Costs for COMCARE and SACK are billed services and do not capture all uncompensated care costs. In addition, they do not include the costs to individuals, families or society from reduced quality of life, lost employment, social and emotional costs to families and society’s lost productivity.

Despite the disproportionately large costs for high utilizers’ health care, research shows that medical and social outcomes remain low (Siekman & Hilger, 2018). The study steering committee expressed deep concerns that the current model of care for high utilizers in this community is unsustainable and additional research, collaboration, advocacy and actions are needed. The following recommendations, identified by the steering committee based on research provided in this study, provide promising practices that have the potential to improve the quality of services and patient care outcomes while reducing healthcare costs for high utilizers.

**Recommendations**

- Identify new models and methods of providing services to improve patient outcomes for high utilizers and pilot test recommended models to determine the impact of programs.
• Support collaboration of community leaders in the public and private sectors to educate the public and advocate to secure adequate funding for behavioral health.

• Establish a uniform set of indicators, which are based on frequency of use and volume level, to identify and monitor high utilizers’ care and interactions with care providers. Currently, there is not a uniform definition of a high utilizer patient or standards that qualify a patient as a high utilizer of services.

• Foster better coordination among healthcare providers, systems and support services. Specific areas for attention include:
  o Increase the ability of organizations to share data and patient information.
  o Support reform of the Health Insurance Portability and Accountability Act (HIPPA) and other privacy laws to favor a more open model of information sharing for high utilizers. Currently, information for patients with alcohol and substance use disorders are held to higher standards than HIPPA by the Federal regulation of 42 CFR.
  o Encourage the sharing of comprehensive patient care plans and care management strategies among agencies, to ensure wrap-around services for high utilizers.

• Reform the payment processes to reflect a value-based system tied to outcomes achieved verses a volume-based system. The current fee-for-service model is not designed for patients who are high utilizers.

• Identify and support methods to foster diversity in the professionals entering and working in behavioral health professions.

• Support the recommendations of the Mental Health and Substance Abuse Coalition and The Mental Health Task Force.
Conclusion

Kansas, like other states, is experiencing a mental health crisis. This crisis is linked to the larger national problems of unaddressed healthcare needs, a lack of access, the nationwide shortage of physicians and a lack of coordinated services. However, community solutions are evolving from the efforts of leaders, service providers, businesses and citizens joining together to find new models and strategies to produce more effective outcomes for high utilizers of behavioral health services. The agencies in this study and the Kansas Health Foundation are commended for their support of this research study to further assist this population.

This research demonstrates that the community’s current delivery model of services is extremely expensive and not sustainable. Over the years 2015 to 2018, the 519 high utilizer patients received almost $56 million in care from AVC, COMCARE and SACK. Almost $17 million in high utilizer services (30%) was funded through public and uncompensated care. Despite this significant investment, these patients are still not fully engaged for treatment of their illnesses, and patient outcomes are not sufficient.

This report is a first step to understanding the needs of the community’s behavioral health high utilizer population. The study’s recommendations provide the next steps to better serve high utilizers and promote an improved quality of life for these individuals and our community-at-large.
References


*JAMA Psychiatry, 72 (4), 334-341.*
Appendix A: Ascension Via Christi High Utilizer Map

Appendix B: COMCARE High Utilizer Map

Appendix C: The Substance Abuse Center of Kansas High Utilizer Map
It is understood that the Sedgwick County GIS, Division of Information and Operations, has no indication or reason to believe that there are inaccuracies in information incorporated in the base map. The GIS personnel make no warranty or representation, either expressed or implied, with respect to the information or the data displayed.
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Appendix B

**COMCARE**
**Behavioral Health High Utilizers (2015-2018)**

Sedgwick County, Kansas
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