

KENTUCKY HOMEPLACE DEFEAT DIABETES SCREENING TEST: AN ANALYSIS OF RURAL KENTUCKY'S CHALLENGE TO OVERCOME THE GROWING DIABETES EPIDEMIC

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The University of Kentucky Center for Rural Health original research note, "Kentucky Homeplace Defeat Diabetes Screening Test: An Analysis of Rural Kentucky's Challenge to Overcome the Growing Diabetes Epidemic," provides the results of a yearlong diabetes risk survey that included more than 3,000 participants in rural Kentucky.

It is well known that diabetes poses serious health threats across our country. For various reasons, that is especially true in Kentucky, with rural Kentucky having the highest prevalence for the disease. From September 2002 through August 2003, lay health workers with the nationally recognized Kentucky Homeplace program distributed and processed 3,092 diabetes self-test surveys to their clients across five regions of the state to get a better picture of the diabetes epidemic. The screening test was developed as an educational and public awareness tool by the Defeat Diabetes Foundation Inc, a nonprofit organization based in Madeira Beach, FL. It was distributed to various health agencies across the country.

Each survey contained 16 questions, ranging from determining participants' urinary frequency and family medical history to their age and weight. Zero, five, or 10 points were allotted depending on respondents' degree of incidence for each question. A score of 0-15 points suggested a low risk for having diabetes, 20-25 points suggested that a respondent was at medium risk and should be tested for the disease, and a score of 30 points or higher suggested that he/she was at very high risk and "should seek (a) medical evaluation right away."

Several months of analysis of the data collected indicated that 74.6% of the Kentucky Homeplace clients who participated in the survey were at moderate to significant risk of having or developing di-

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abetes, a much higher rate than the approximately 50% of Kentucky adults in the general population that previous studies indicated were at risk. While findings from the survey of more than 3,000 Kentucky Homeplace clients cannot be generalized to Kentucky's population as a whole, they further confirm other evidence indicating that diabetes will continue to be one of the most serious health threats facing the state's rural populations.

The research note further offered some recommendations for curbing rural Kentucky's diabetes epidemic, including increasing the number of certified diabetes educators serving rural Kentucky, expanding lay health worker programs within the rural portions of the Commonwealth, and studying the method and effectiveness of diabetes education between physicians and patients.

OVERVIEW

Diabetes mellitus is a disorder in which the body does not properly produce or use insulin, a hormone that is needed to convert sugar, starches, and other food into energy inside our bodies' cells. Without enough insulin, blood glucose accumulates at dangerously high levels within the bloodstream. The recent emergence of diabetes as a serious public health condition has prompted the US Centers for Disease

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1. I go to the bathroom (urinate) often (every 2 to 3 hours):		
High 22.0%	Medium 31.8%	Low 46.1% (n=3088)
2. I am always thirsty and/or hungry:		
High 14.8%	Medium 26.0%	Low 59.2% (n=3091)
3. I am suddenly losing a lot of weight:		
High 3.6%	Medium 8.3%	Low 88.1% (n=3091)
4. I am always fatigued (weak, tired) and/or drowsy:		
High 19.7%	Medium 37.9%	Low 42.4% (n=3091)
5. I am irritable and have mood changes:		
High 14.5%	Medium 29.5%	Low 56.0% (n=3092)
6. I am nauseous and/or vomit often:		
High 3.9%	Medium 13.1%	Low 83.0% (n=3092)
7. I have blurred vision:		
High 10.9%	Medium 28.7%	Low 60.4% (n=3092)
8. I have a tingling or numbness in my legs, feet or fingers:		
High 13.6%	Medium 33.1%	Low 53.4% (n=3091)
9. I have frequent or recurring skin, gum and/or urinary tract in		
High 3.8%	Medium 9.8%	Low 86.4% (n=3092)
10. I have frequent itching of my skin and/or genitals:		
High 5.7%	Medium 16.0%	Low 78.2% (n=3091)
11. I have slow healing of cuts and bruises:		
High 7.3%	Medium 20.7%	Low 72.1% (n=3092)
12. My family history shows diabetes:		
Don't Know 3.3%	Yes 46.6%	No 50.0% (n=3091)
13. My Age is:		
Over 65 26.3%	45 to 65 46.3%	Under 45 27.5% (n=3092)
14. I am:		
Obese 7.1% (over 20% overweight)	Overweight 27.1%	Not Overweight 65.8% (n=3092)
15. For women, if you have a history of gestational diabetes (the occurs during pregnancy) or have delivered a baby over 9 pound		
Yes 12.1%	No 87.9% (n=1855)	
16. If you are Asian, Black, Hispanic/Latino, Pacific Islander or Native American, medical data shows that within these ethnic groups there are extremely high diabetic populations.		
5.4%	94.6% (n=3092)	
I am Asian, Black, Hispanic/Latino, Pacific Islander or Native American.	I am Caucasian	
17. Indications of Acanthosis Nigricans (AN), a skin condition characterized by darkened, velvety and/or thickened skin patches.		
Yes N/A	No N/A	
18. Necrobiosis Lipoidica Diabeticorum (NLD), slightly raised shiny red-brown patches on my lower legs, mostly in women.		
Yes N/A	No N/A	

Figure 1A. Survey Results

Control and Prevention (CDC) to categorize it as an epidemic. In fact, during 2002 the CDC estimated that 18.2 million Americans—or 6.3% of the population—had the potentially life-threatening illness, with approximately one-third of them undiagnosed.

Have you ever been told by a doctor that you have diabetes			
Gender:	Yes	Yes, pregnancy-related	No
Male	% 9.9 CI (8.4-11.4) n 302	0.0 N/A 0	90.1 (88.6-91.6) 2283
Female	% 7.3 CI (6.4-8.2) n 476	1.0 (0.7-1.4) 60	91.7 (90.7-92.6) 4494
<small>% = Percentage, CI = Confidence Interval, n = Cell Size Percentages are weighted to population characteristics. Use caution in interpreting cell sizes less than 50.</small>			
State:	Yes	Yes, pregnancy-related	No
Nationwide	7.1	0.7	92.
<small>http://apps.nccd.cdc.gov/brfss/sex.asp?cat=DB&yr=2003&qkev=1364&state=KY Accessed 09-02-04</small>			






Figure 1B. Survey Results

Diabetes is a major contributing factor to several other health complications, including blindness, kidney failure, amputations, nerve damage, heart disease and stroke. As such, it is extremely costly, accounting for an estimated \$132 billion annually in direct and indirect costs to the nation's healthcare system, insurance companies, residents, and employers.¹

Diabetes is particularly problematic in Kentucky, where it is the fifth leading cause of death. Studies have indicated that fully one half of the state's adult residents are at risk for the disease.² Each year in the Commonwealth, diabetes contributes to approximately 50,000 hospitalizations, 900 lower extremity amputations, 500 new cases of end-stage renal disease, and 225 cases of blindness. According to recent Kentucky Cabinet for Health and Family Services (CHS) reports, an average of 6.6 years of lost life—using age 75 as a cutoff—was reported for all Kentuckians for whom diabetes was listed as a primary cause of death.

Diabetes is 50% more common in Kentucky today than it was 10 years ago and is most prevalent in the state's Appalachian counties, where 7.3% of the population has been diagnosed with the disease. It has been estimated that more than 303,000 Kentuckians, or about 9.7% of the adult population, have diabetes, with one third of them undiagnosed.³ Kentucky also has the nation's highest rate—33.7%—of diabetic residents who report taking insulin.³

Kentucky Homeplace Statewide Service Area July 2005

-  Western 16 counties
-  South Central 10 counties
-  Southern 10 counties
-  Southeast 09 counties
-  Northeast 13 counties
- Total 58 counties**

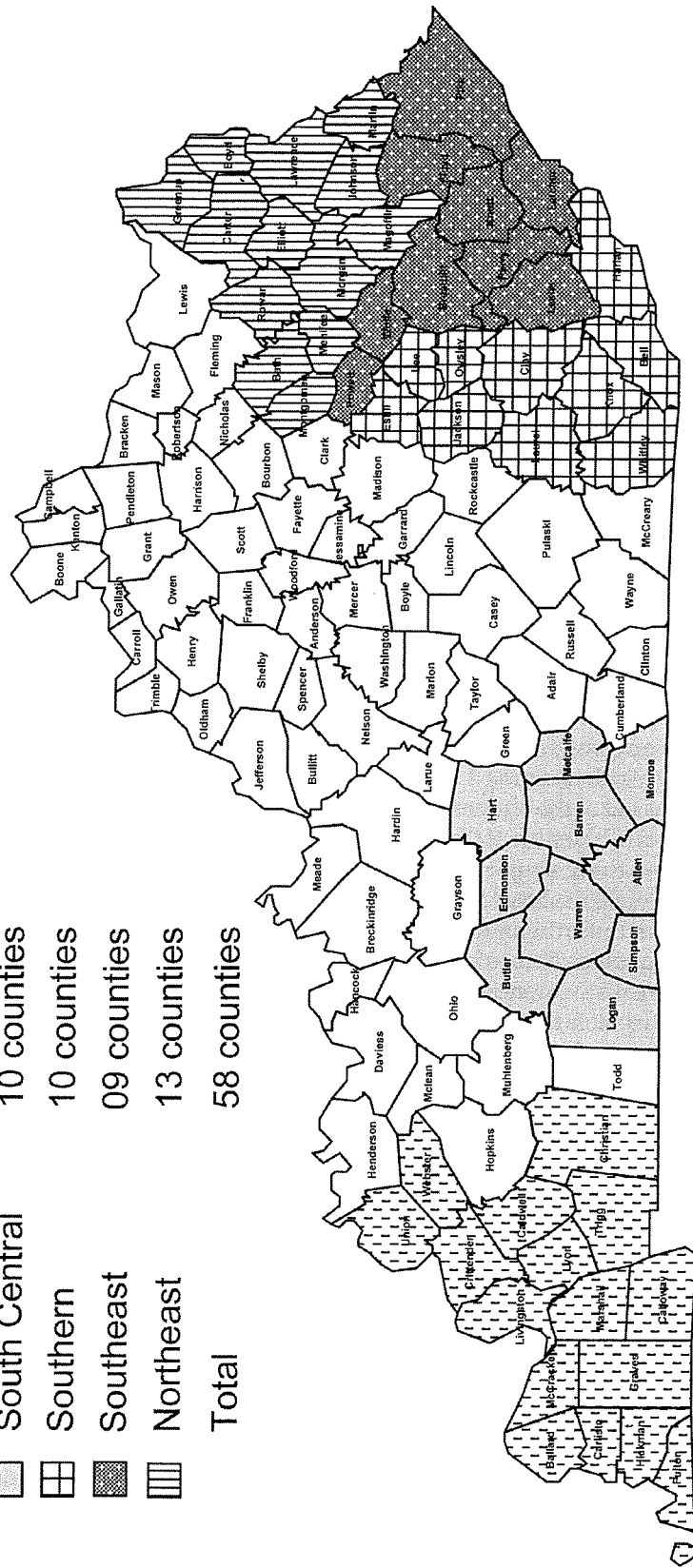


Figure 2. Kentucky Homeplace Statewide Service Area, November 2004. Prepared by: UK Center for Rural Health

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There are several reasons rural Kentuckians exceed the national average for diabetes prevalence and seriousness:

- Kentucky tops the nation in the percentage of residents who lead sedentary lifestyles, a major risk factor for diabetes, and in smoking, which worsens the disease's complications.
- Kentucky ranks among the top 10 states for obesity, another major risk factor.
- Older people are at higher risk for diabetes, especially when other risk factors are present. Kentucky already is one of the country's "grayer" states—12.5% of its population was age 65 or older, according to the 2000 Census—and is projected to be among the top five oldest states by 2020.²

It was against this backdrop that in September 2002 Kentucky Homeplace, an award-winning lay health worker program based at the University of Kentucky Center for Rural Health (UKCRH) in Hazard, began a yearlong project of collecting data using the Defeat Diabetes Screening Test. This survey instrument was disseminated by healthcare agencies across the nation in an effort to increase awareness and early detection of Type 2 diabetes, the insulin-resistant variation that accounts for about 90% to 95% of all cases of the disease.⁴ Kentucky Homeplace lay health workers, called family healthcare advisers (FHCA), administered more than 3,000 surveys in five rural regions of the state.

Analyses of the survey results by UKCRH researchers suggest that many rural Kentuckians may be at higher risk for having or developing diabetes than previously had been thought. While findings from the survey of more than 3,000 Homeplace clients cannot be generalized to Kentucky's population as a whole, they further confirm other evidence indicating that diabetes will continue to be one of the most serious health threats facing the state's rural populations. This circumstance makes it incumbent upon UKCRH to conduct additional research into rural Kentucky's growing diabetes epidemic and ways to reduce this health threat.

KENTUCKY HOMEPLACE DEFEAT DIABETES SCREENING TEST

Kentucky Homeplace is a state-funded program with a presence in 58 rural counties. It is nationally recognized for its use of lay workers in helping medically underserved residents obtain available health and social services. Each year, the program's employees routinely access millions of dollars worth of medical services, supplies, and pharmaceuticals for thousands of uninsured and underinsured clients who otherwise might forego primary and preventive health care altogether or resort to much more expensive emergency services that likely would go uncompensated.

One important emphasis of the program is education about disease prevention and self-management for chronic illnesses, such as diabetes. Kentucky Homeplace is committed to gathering information that increases understanding of the problem of diabetes in rural communities, as well as the implementation of screening and promotion of educational services that can help reverse this dangerous health trend. In dealing with thousands of rural clients who are indigent and underinsured, the program's FHCAs are in contact with some of the Kentuckians who are most vulnerable to developing Type 2 diabetes or those who already have the disease. FHCAs provide education for the prevention and control of diabetes, including the value of physical activity and weight maintenance or reduction. FHCAs also collect data from their clients for diabetes screening and management, including the measurement of blood glucose, annual dilated eye exams, daily self-examination and clinical foot examinations, quarterly or semi-annual hemoglobin A1C tests, and other preventive measures.

It was for these reasons that Kentucky Homeplace sought to participate in the national Defeat Diabetes Screening Test, a public awareness campaign produced and distributed by the Defeat Diabetes Foundation Inc, a nonprofit organization based in Madeira Beach, FL. The survey was designed as an educational

tool that would allow respondents to answer questions that might indicate the existence of a diabetic condition.

From September 2002 through August 2003, Kentucky Homeplace FHCAs distributed and processed 3,092 self-test surveys to clients across the program's five rural service regions. Each survey contained 16 questions ranging from determining participants' urinary frequency and family medical history to their age and weight. Respondents completed questions by indicating their degree of incidence of predisposing health conditions or behaviors associated with varying degrees of pre-diabetic health status, with points allotted on the following basis: high incidence = 10 points; medium incidence = 5 points; low incidence = 0 points.

As is the case with many screening surveys, the Defeat Diabetes Screening Test was designed to be inclusive—in this case, of anyone with a reasonable probability of being pre-diabetic or having undiagnosed Type 2 diabetes. For instance, a participant who answered the first three questions as "High" and all the others as "Low," had a survey score that placed him/her in the "very high risk" category. A score of 0-15 points suggested a low risk for having diabetes, 20-25 points suggested that a respondent was at medium risk and should be tested for the disease, and a score of 30 points or higher suggested that he/she was at very high risk and "should seek (a) medical evaluation right away."

Participant risk calculations based on researchers' numerous scientific evaluations of the Kentucky Homeplace Defeat Diabetes Screening Test were as follows:

- 25.4% (785 participants) = Low risk for having diabetes
- 29.7% (918 participants) = Medium risk
- 44.9% (1,389 participants) = High risk

These results show that 74.6% of the Kentucky Homeplace clients who participated in the survey were at moderate to significant risk of having or developing diabetes, a much higher rate than the approximately 50% of Kentucky adults in the general population that previous studies indicated were at risk.

Based on Kentucky Homeplace clients' median age being in the mid-50s, the fact that nearly all are at the federal poverty level or below, that they are under- or uninsured, and that they have solicited or have been referred to assistance from a public health program, it might be assumed that this population sub-group would test at a heightened level of risk for pre- or undiagnosed diabetes. But responses to some of the questionnaire items were not consistent with this assumption. For example, participants in the Kentucky Homeplace Defeat Diabetes Screening Test actually self-reported a much lower obesity rate (7.3%) than the statewide rate of 24.6%.

Despite the substantial effort of the Kentucky Homeplace program to conduct a large sampling of a potentially high-risk group, comparison of the results from the Homeplace study are not possible with other groups or sub-regions of the Commonwealth, such as area development districts. Homeplace did not design its sample for regional comparisons and no other known organization conducted large scientifically designed surveys within the state. Officials with the Defeat Diabetes Foundation report that few if any results from across the country were reported to them, therefore preventing meaningful interstate or national data comparisons.

Also, the program did not specifically track clients who tested at medium or high risk, so there are no data to indicate the percentage of those participants who actually were examined and told by a physician that they have diabetes.

CONCLUSIONS/RECOMMENDATIONS

As has been established, diabetes contributes to several serious health conditions and a higher probability of premature death. This is especially true in rural Kentucky, a fact that was further proven by the Kentucky Homeplace Defeat Diabetes Screening Test. This survey's results revealed a propensity for having or developing the disease among a certain segment of rural residents that was significantly

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above the risk level that previous studies had indicated for the general population.

There is, however, some cause for hope: with early detection and/or proper lifestyle interventions, diabetes has been found to be controllable and even preventable. Research studies in the United States and abroad have found that modifications such as a healthy diet and moderate-intensity physical activity can prevent or delay the onset of Type 2 diabetes, even among high-risk adults.⁴ Likewise, those who have been diagnosed with diabetes can take the same steps along with stricter control of their glucose, blood pressure, and lipid levels and preventive care practices for the eyes, kidneys, and feet, to lower their risk of complications from the disease.

It is clear that the level of knowledge diabetics and those most at risk for contracting the disease have about self-management and preventive measures is crucial. Through the Defeat Diabetes survey, Kentucky Homeplace FHCAs were able to provide education to thousands of rural Kentuckians and their families about the importance of getting tested and the value of proper care—both before and after a diabetes diagnosis.

Yet, while education about diabetes prevention and management is of critical importance, still more could be done to reduce Kentuckians' risk of contracting the disease and suffering the serious complications it can produce. These recommendations could help ease the disease's toll in rural Kentucky:

I. Increase the number of rural-based certified diabetes educators. Kentucky is a predominantly rural state, and its non-urban communities are chronically short of certified diabetes educators (CDE)—healthcare professionals who are specially trained to work with diabetics on self-care. According to current registration records, only 153 diabetes educators are now certified in Kentucky, and more than 37% of those serve urban Fayette and Jefferson counties—this despite the fact that diabetes rates in central Kentucky are substantially lower than those in the rural eastern and western portions

of the state. The state registration records show that only 30 of Kentucky's 98 rural-designated counties are home to at least one CDE.

Clearly, the number of certified diabetes educators based in rural areas must be increased. Health care agencies, civic groups, granting organizations and other public or private sources should be encouraged to help fund the approximately \$1,500 worth of costs involved in a healthcare professional getting trained as a CDE. Also, public and private insurance programs should be pressured to provide more reimbursement for diabetes prevention and self-management services provided by CDEs, primary care physicians, and nurses.

UK Center for Rural Health plans in this regard include:

- A) *Participating in a public awareness campaign about the importance of certified diabetes educators and their chronic shortage in rural Kentucky.*
- B) *Coordinating with the University of Kentucky and Eastern Kentucky University to make additional CDE training courses available in rural areas via teleconference and interactive television.*
- C) *UKCRH officials make regular presentations to civic groups in communities across rural Kentucky. Part of the future focus of these presentations will be to urge these organizations to make donations toward the training of additional CDEs within their region.*

II. Implement more lay health worker programs or expand those that already exist into counties that need them based on their number/percentage of high-risk patients. Programs such as Kentucky Homeplace and its spinoff patient navigation program, the Southeast Kentucky Community Access Program (SKYCAP), have helped thousands of low-income and lesser-educated patients through culturally appropriate care and monitoring of their adherence to self-management plans. Creation of additional lay health worker programs or significant expansion of Kentucky Homeplace could make these health assistance services available to virtually every rural Kentuckian.

The Center for Rural Health is working to stabilize current state funding of Kentucky Homeplace, with a goal of expanding into additional southcentral Kentucky counties as funding allows.

III. Study physician/patient diabetes communication. Rural Kentucky's primary care providers do an excellent job of treating the region's residents, but at the same time must be cognizant of their practice's bottom line. Hence, they need to treat as many patients as possible each day, which sometimes precludes them from devoting as much time as they would prefer to addressing self-management education about diseases such as diabetes. Also, numerous Kentucky Homeplace clients have reported a disconnection in what is said by physicians and nurses and what they, as patients, perceive during discussions about diabetes. Such exchanges, brief though they may be, generally are followed by the dissemination of several informational brochures, which the patient may or may not be able to read or understand. This practice is referred to by a former SKYCAP clinical team leader and community health center licensed practical nurse as "10 minutes and 10 pieces of paper."

UKCRH plans to seek funding for a study aimed at determining the best ways to effectively communicate self-management advice to rural diabetics.

Other diabetes-related topics on which the UK Center for Rural Health, Kentucky Homeplace, and the UK Family Medicine Clinic, which is housed at UKCRH, are strongly positioned to assist rural residents include control of obesity and hypertension, smoking reduction and cessation, level of daily physical activity, individual dietary practices, and family involvement and support.

Enhanced educational efforts, improved public policy, and continued research initiatives will be needed if Kentucky is to lessen the burden of illness and premature death for those suffering diabetes. Absent meaningful progress in these areas, diabetes is on course to cause widespread health complications

throughout rural Kentucky for years and even decades to come.

ENDNOTES

The scale used by Kentucky Homeplace was slightly different from that found at the Defeat Diabetes Web site. Homeplace launched its survey prior to the Defeat Diabetes Foundation completing the screening instrument for its Web site, which is at the following URL: <http://www.defeatdiabetes.org/screeningtest.htm>. Adjustments were made in the Homeplace scoring to account for the fact that two questions (numbers 17 and 18, see survey) were not included in its screening and that the point values for questions 15 and 16 (see survey) were either 5 for "Yes" or 0 for "No."

INTERNET RESOURCES

Here are Web addresses for several statewide and national organizations working to reduce new cases of diabetes and the complications of those who already suffer from the disease:

- American Association of Diabetes Educators—www.diabeteseducator.org
- American Diabetes Association—www.diabetes.org
- Centers for Disease Control and Prevention—www.cdc.gov/diabetes
- Defeat Diabetes Foundation Inc.—www.DefeatDiabetes.org
- Diabetes Prevention and Control Program, Kentucky Cabinet for Health Services—<http://chs.ky.gov/publichealth/diabetes.htm>
- Kentucky Diabetes Network Inc—www.kentuckydiabetes.net
- National Institute of Diabetes and Digestive and Kidney Diseases—<http://www.niddk.nih.gov>
- University of Kentucky Center for Rural Health—<http://www.mc.uky.edu/ruralhealth/>

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