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Abstract

Background—Among working age adults in the United States, there is a large, heterogeneous population that requires ongoing and elevated levels of healthcare and related services. At present, there are conflicting approaches to the definition and measurement of this population in health services research.

Objective—An expert panel was convened by [omitted for peer review] with the objective of developing a population-level definition of Adults with Chronic Healthcare Needs (ACHCN). In addition, the panel developed a screening instrument and methods for its use in health surveys to identify and stratify the population consistently.

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Methods—The panel employed multiple methods over the course of the project, including scoping literature reviews, quantitative analyses from national data sources and cognitive testing.

Results—The panel defined the ACHCN population as "Adults (age 18–65) with [1] ongoing physical, cognitive, or mental health conditions or difficulties functioning who [2] need health or related support services of a type or amount beyond that needed by adults of the same sex and similar age." The screener collects information on chronic health conditions, functional difficulties, and elevated use of or unmet need for healthcare services.

Conclusions—Adapted from the Maternal and Child Health Bureau definition that identifies Children with Special Healthcare Needs, aligned with the ACS-6 disability measure, and consistent with the HHS Multiple Chronic Condition Framework, this definition and screener provide the research community with a common denominator for the identification of ACHCN.

Keywords

people with disabilities; chronic conditions; health service utilization; health surveys; measurement

INTRODUCTION

Researchers have grown increasingly concerned with the proliferation of differing definitions and conflicting estimates of the size, composition, service utilization, quality and costs for high health service users in the United States.[1–4] Various methods have been used to identify these population groups in the US healthcare system, whether on the basis of specific health conditions,[5–7] discreet lists of chronic conditions or comorbidity indices,[4,8–11] the extent of functional or activity limitations and/or disability,[12–14] the degree of service use complexity[15–16] or the economic burden of disease.[17] Various terms referring to these groups are currently being popularized in the literature, such as "super-utilizers,"[18] "high need/high cost patients,"[19] or "hot spotters."[20] The methods used to identify such groups have yielded divergent population estimates because they capture different, if overlapping populations. The result is a cascade of studies, each making scientific claims about the importance of the access, utilization, quality or cost-related problems of people with condition X, disability Y, with or without co-morbidity Z.

Beginning in 2012, the Rehabilitation Medicine Department at the National Institutes of Health Clinical Center convened an expert measurement panel to better define and measure the population of working age adults with ongoing and elevated needs for healthcare. We endeavored to find a common denominator that could flexibly serve many kinds of health service research studies and to develop meaningful methods to stratify what we knew would be a large and heterogeneous population, many of whom requiring patient-centered, coordinated healthcare. We took our lead from the large body of research conducted on Children with Special Healthcare Needs (CSHCN) where such a measurement approach was already well established.[21–25] That research is characterized by its focus on health consequences and their associated service needs. CSHCN are therefore defined as those "who have or are at increased risk for one or more chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a

type or amount beyond that required by children generally."[22] In the early 2000s, the Child and Adolescent Health Measurement Initiative (CAHMI) initiated work on an adult adaptation of the CSHCN brief screener (the Adults with Special Healthcare Needs Screener, ASHCN), but a formal population definition was not offered. Though the ASHCN screener was documented in an extensive peer-reviewed manual to CMS,[21] with a loss of funding, that work was not published in scientific journals, despite its likely import.

Informed by the previous work conducted by CAHMI, and recognizing how the CSHCN definition and screener formed the basis of dedicated national surveys,[24–25] coordinated service delivery models,[26] and a platform for policy and clinical practice goals,[27–30] our panel pursued a parallel path. In what follows, we propose the formal definition of working age adults with chronic healthcare needs and present the newly developed screener. We provide the rationale for this instrument, supporting quantitative evidence, and initial results from cognitive testing as well. We conclude with a discussion of the research and health policy contexts, specific applications, and subgroup analyses this screener was designed to, and could potentially, support.

METHODS

Panel composition and operation

The panel was purposefully composed on the basis of their combined expertise in areas of knowledge critically important to this project. Depth and breadth of publication, clinical experience, federal agency involvement and personal lived experience with chronic conditions or disability were among our selection criteria. The panel was convened for ten teleconferences and two face to face meetings over a year and a half. Panelists variously contributed to all associated work products, including scoping literature reviews, a series of secondary data analyses, presentations, publications, and a final report.

Scoping literature reviews

We employed scoping literature review methods in this project. Scoping reviews are most appropriate for broad research questions that seek to map the main domains and types of knowledge available in a given topical area.[31] All five reviews we conducted were limited to publications made after January 1, 2000 that were written in English and relevant to working-age (18–65) individuals. Searches included pubmed and psycINFO, as well as key journals, relevant websites and bibliographic review of seminal articles, each as recommended by the panel members. Topically, the five questions for research covered: definition and measurement of chronic conditions and disabilities in health service research; health and functional characteristics among these population groups; the impact of comorbidity or secondary conditions upon health care access, utilization, quality or cost; self vs proxy reporting in health surveys of people with disabilities; and measurement of mental health service needs.

Secondary data analyses

Many of the decisions the panel made required examination of the relationships between or among chronic conditions, functional difficulties, and specific areas of service utilization.

Two secondary data sources were used extensively in these analyses. The first was a pooled dataset (2006–2008) drawn from the Medical Expenditure Panel survey (including the household component, medical conditions and medical events files, N=53,586).[32] The second was assembled from the 2011 National Health Interview Survey, where the adult sample file, the person level file and the ACS-6 disability test questions file were merged to yield the analytic dataset for working age adults (N= 13,043).[33] Work conducted with both of these datasets accommodated for the complex sampling designs involved and was weighted both to correct for non-response and to bring the results to U.S. non-military, non-institutionalized population totals for persons aged 18–64. Analyses included descriptive statistics, bivariate analyses and multivariate modeling; Taylor series linearization was used for variance estimation.

Cognitive testing

At the conclusion of its deliberations, the panel proposed competing questions for each domain of the ACHCN screener, each differing in wording, scope or structure. Cognitive testing of these items was performed through an inter-agency agreement with the National Center for Health Statistics (CDC/NCHS), in their questionnaire design research laboratory. Cognitive interviews were performed with a total of 56 individuals who were sampled to include individuals with, and without, a wide range of chronic conditions and functional difficulties. Interviews were conducted over three rounds, with adjustments to the items designed to improve clarity, reduce burden, and strengthen the relationship between question intent and respondent understanding.[34]

RESULTS

The Definition of ACHCN: Concepts, Terms and Clarifications

The expert panel crafted a definition that is intentionally broad, non-diagnostic and based upon real-life health consequences. This definition is purposefully brief. It describes adults with chronic healthcare needs as follows:

> Adults (age 18–65) with [1] ongoing physical, cognitive, or mental health conditions or difficulties functioning who [2] need health or related support services of a type or amount beyond that needed by adults of the same sex and similar age.

This definition encompasses three main domains: health conditions, functional difficulties and service needs/use. In each domain, the panel further defined key terms and concepts upon which the definition rests.

Health conditions—To meet this component of the definition, individuals must experience at least one ongoing physical, cognitive or mental health condition lasting or expected to last 12 months or more (or a related functional difficulty, described further below). "Conditions" are further defined as physiological or psychological dysfunctions of body systems or their components. Some examples of physical conditions include those affecting movement or creating pain such as arthritis, back problems, or limb loss, or affecting bodily organs, such as diabetes, cancer, heart, or kidney diseases. Some examples

of cognitive conditions include dementia, traumatic brain injury, or autism. Some examples of mental health conditions include depression, anxiety disorders, or schizophrenia. The panel concluded that it was neither necessary, nor possible, to develop a full diagnostic taxonomy of conditions associated with chronic healthcare needs. This was because there is great individual variation in the severity and health consequences of each condition and because individuals frequently experience more than one condition at a time.[2] Furthermore, health conditions may or may not be currently symptomatic. This is critical since many individuals maintain an ongoing need for medical or related services in order to remain well or to preserve functional capacity even while their conditions are responding well to treatment.

Last, the panel observed that there are many diagnoses that potentially represent a *future* health risk for the individual, but do not presently cause functional difficulties or require elevated levels of healthcare or supportive services. The characterization of such an "at risk" group goes beyond the scope of the ACHCN screener, which instead identifies individuals with chronic conditions and/or functional difficulties that are already consequential.

Functional difficulties—Difficulties functioning are further defined as the experience of limitations, need for equipment, or need for assistance when performing purposeful, everyday activities. This could include limitations with walking, climbing stairs, hearing or seeing, concentrating, remembering or making decisions. It could also connote difficulty doing such necessary activities as dressing or bathing, doing errands, going to a doctor's office, or shopping. The definition is thus focused upon the functional consequences of health conditions, particularly those with direct bearing on the need, use or receipt of healthcare or related supportive services or equipment. Hence, if an individual experiences direct bodily, cognitive, or psychological limitations when performing simple daily functional tasks that are of direct consequence to self-care or basic independence, that person is said to have "difficulties functioning."

It is important to note that not all functional difficulties result in ongoing or elevated needs for services or supports. For example, an adult born missing an arm below the elbow may well have a health profile and record of healthcare use that is barely distinguishable from another person who is, by all measures, healthy and without functional difficulties. Indeed, in other measurement contexts, the former might well be accurately categorized as a person with a disability. However, in the present context, this would be an adult *without* chronic healthcare needs.

Service need and use—The need for health and related supportive services is a foundational element of the definition. The panel further defined services in broad and encompassing terms to include supports such as regularly prescribed medications and therapies from all types of health professionals in a wide variety of settings, including: mental health services, specialized medical equipment, protocols involving diet or physical activity, long-term care, personal assistance services (whether formal or informal), as well as other types of community based services.

The panel devoted much discussion to a number of well-known issues in health services research. For example, the need for and use of health services differs by demographic characteristics, particularly age and sex.[35] Furthermore, individuals do not always know they have conditions requiring attention or recognize that they could benefit from treatment.[36, 37] And when the need for treatment is recognized, access barriers sometimes prevent individuals from obtaining needed services.[38, 39] Some of these issues could be directly addressed in the definition, such as those regarding age and sex. Others could be at least partially addressed through careful design of the questions themselves. While field testing will be required to assure the screener does not succumb to these threats to validity, these discussions reinforced the panel's conclusion that chronic healthcare needs must be triangulated over all three domains: health conditions, functional difficulties and service/ need use.

The ACHCN Screener: Rationale, Supporting Evidence and Cognitive Testing

The ACHCN screener (see table 1) should take less than 5 minutes to administer/complete and is intended for use in-person, by telephone or in online surveys. A positive screen requires: A) one or more chronic conditions (questions 1 and 1a) OR at least one difficulty functioning (questions 2 – 7), AND B) any evidence of elevated service use or unmet need (questions 8 – 12a).

Domain 1: Health/mental health conditions

Rationale—There is considerable evidence that establishes the relationship between chronic health conditions and elevated need, use or costs of healthcare over time.[1,2,8,17] However, a variety of approaches to the measurement of chronic conditions were found in the published literature. In many instances, "populations" sharing a single chronic condition in common (e.g. diabetes, or asthma) were selected for study.[6–7] Alternatively, hand-picked, short lists of conditions that reflect particular research priorities (such as morbidity or high cost) were used to define the study population.[10,40] Other analysts have employed criteria driven, wide-ranging lists of persisting health conditions in order to include hundreds of possible chronic diagnoses in their work.[8,41]

The broad wording and year-long time frame ultimately adopted by the panel in screener item 1 resulted from our scoping literature reviews, alignment of our findings with existing standards, quantitative analyses of secondary data and cognitive testing. It should be noted that the HHS Framework on Multiple Chronic conditions, the Institute of Medicine Call for Public Health Action on Chronic Illness, the Adults with Special Healthcare Needs Screener, and the Children with Special Healthcare Needs Screener each make general reference to, or directly operationalize, medical, mental health (or behavioral), or other health conditions which last a year or more as being "chronic". In order to further align the ACHCN screener with the MCC Framework, the panel added question 1A to directly capture individuals with multiple chronic conditions. In this way, the ACHCN screener is consistent with existing measurement initiatives and also allows for the identification of individuals with multiple chronic conditions.

Quantitative findings—The broad and inclusive nature of question 1 will capture a very large population group, even among the working age population. Using pooled secondary data from the 2006–2008 Medical Expenditure Panel Survey, we conducted detailed analyses of the relations between high healthcare utilization, functional limitations and chronic conditions.[42] In order to identify working age individuals with (and without) one or more chronic conditions, we used the HCUP chronic condition list (AHRQ) which specifies health and mental health conditions expected to last a year or more by ICD-9 code. We identified persons with limitations on the basis of the functional measures provided in MEPs. Finally, we flagged individuals with high (and separately, elevated) healthcare utilization based upon an algorithm that identifies individuals with utilization rates at or above the 90th percentile (or the 75th percentile for persons with "elevated" rates) in any of the following service areas: a) total ambulatory visits to doctors, mental health or other healthcare providers, b) total days hospitalized during the year, c) emergency department visits, d) total prescription fills/refills during the year and e) number of home health days. Figure 1 captures our most important findings on the possible size and overlap between these groups.

Similar to other published results,[8] we found that the population with 1+ chronic conditions is indeed quite large, at a bit over half of the working age population overall. But where virtually all high healthcare users had a chronic condition, the reverse was not true. Much the same can be said about disability; the large majority of persons with limitations reported at least one of the HCUP chronic conditions, but the majority of individuals with chronic conditions did not report a functional limitation over the year of the survey. Finally, people with disabilities accounted for approximately half of all high healthcare users among the working age population. These, and further such analyses demonstrated that the inclusion of direct measures of the presence/number of chronic conditions would be necessary, but not sufficient to screen for individuals with chronic healthcare needs.

Cognitive testing—Several different wordings and question structures were tested in an iterative fashion during cognitive testing. Traditionally, in both the existing CSHCN and ASHCN screeners, questions confirming the presence and 12 month duration of an underlying health condition(s) are asked within every service-related domain.[21] Since this adds significant length to those instruments, the panel opted to test that traditional structure against a new one. With the new structure, respondents are only asked about their chronic conditions once when taking the screener. In follow-up probing, this new structure made no discernable difference in the types of conditions reported (or not reported).

With both approaches, respondents easily named a wide range of health and mental health conditions that generally fit the intent of the question. When unsure of whether their condition(s) had or would persist for 12 months, respondents tended to answer on the basis of a prospective hope that the condition would resolve, thus answering "no". It should be noted that individuals with hearing or vision loss sometimes did not consider these functional issues to be equivalent to health "conditions," particularly when they had lived with them for many years. Such individuals were positively identified by the questions on functional difficulties instead.

Domain 2: Functional difficulties

Rationale—The panel elected to include measures of functional difficulties among the screener items for three primary reasons. First, such difficulties are consequential in their own right and may be paired with secondary consequences that individuals seek to ameliorate, contain or compensate for with the use of medical care, supportive services or equipment.[15,43] Second, several studies have demonstrated how functional difficulties can be used to segment or stratify individuals with chronic conditions into more actionable subgroups and the screener was designed to allow for this.[2,8] Third, there are now quite a few studies that document the problems that arise for people with functional difficulties (such as those affecting sight or hearing, physical mobility, cognition or mental health) when facilities, medical equipment, procedures, or policies are designed without consideration of their functional needs.[44–47] While the screener will not directly address these accessibility issues, the inclusion of functional difficulties will allow for the selection of ACHCN subgroups that may be particularly sensitive to access barriers.

The panel identified the existing American Community Survey 6 item disability measure (the ACS-6) as the best choice for the functional domain in the ACHCN screener. This was for four reasons, including: 1) The ACS-6 items are directly related to functional issues and simple activities that are central to most people's healthcare and in- or inter- dependence. 2) The ACS-6 questions are demonstrably related to utilization of healthcare services (see next section). 3) The ACS-6 constitutes a national standard in disability data collection that is already used in the American Community Survey, the National Health Interview Survey and others. 4) The ACS-6 presents minimal respondent burden and has already been cognitively tested and validated.

Quantitative findings—In support of its deliberations, the panel conducted a series of analyses of the 2011 National Health Interview Survey data, which included a test of the ACS-6 measure alongside the usual contents of that survey, including health conditions, service use, demographics and more. Among persons aged 18–64, weighted to US non-institutionalized, civilian population totals, we found that 13.3% reported any ACS-6 difficulty overall. We also flagged individuals who, among their total reported difficulties, included ADL or IADL limitations (dressing, bathing, doing errands alone, 4.2%), or who instead did not report ADL/IADL limitations (9.1%). Upon controlling for differences in age, gender, race/ethnicity, education, income and health insurance coverage status, we compared the probability of service use in five areas for persons with no ACS-6 difficulty, one or more difficulties without ADL/IADL involvement, and ACS-6 difficulties which include ADLs or IADLs. The results are shown in figure 2.

From these and additional analyses, the panel reached two conclusions. First, the ACS-6 is particularly useful for the identification of individuals who are likely to be vulnerable in our healthcare system, whether because of their high needs for multiple types of care, the number and types of health or mental health conditions they must manage, or the lower levels of resources they may have. Second, the ACS-6 identifies discreet functional subgroups that could well serve as points of stratification in healthcare research. In

particular, persons with ADL or IADL difficulties stand out as a cross-diagnosis subgroup that shares in common a very high level of healthcare need, use and cost.

Cognitive testing—Because the ACS-6 is a validated instrument, the panel did not put it through exhaustive testing. However, we did compare its performance to a question drawn from the ASHCN screener[21], where it is asked: "Do you have difficulty doing or need assistance to do day-to-day activities? (for example: work, go to school, do housework, socialize, cook, do paperwork)." The greater specificity of the ACS-6 questions, coupled with their focus on simpler functions and activities, proved more sensitive, with greater agreement between the intent of the questions and the answers received.

Domain 3: Service need and use

Rationale—The panel developed criteria to guide our decisionmaking as we considered which services to include in the screener and how to formulate the questions. First, as candidate items were considered, the panel sought efficiency, requiring the fewest possible services needed to capture the defined population as thoroughly as possible. Second, the panel paid equal attention not only to whom a question would likely screen in, but to whom it would screen out (analogous to sensitivity and specificity). Third, we sought to select service areas which were as discreet as possible in order to permit meaningful subgroup analyses or stratification by analysts using the screener; this becomes increasingly problematic when multiple service areas are merged in a single question. Fourth, the panel paid careful attention to what we needed to know, versus what respondents could actually tell us. For example, while respondents may well have a general sense that they use "a lot" or "a little" of a particular kind of care, recall bias may prohibit them from accurately reporting the exact amount of care received.

Operationally, we therefore composed meaningfully different, competing questions in each service area within this third domain. Where possible, we also tested our assumptions with secondary data analyses of the MEPS and NHIS data.

Quantitative findings—In support of its deliberations, the panel conducted a series of analyses of ambulatory healthcare utilization by working age individuals based upon data from the MEPS. We did so separately in each major service area under consideration in order to compare a) "non- users" (individual with no utilization over the course of the preceding year), b) "non-elevated" users (below the top 25th percentile) and c) "elevated" users (the top 25th percentile). These groups were derived from percentiles of annual utilization, whether in total visits to medical doctors (all specialties), visits where mental health services were provided, medical therapist visits, total fills/refills for prescription medications, or total expenditures for medical equipment. As shown in table 2, the covariate-controlled comparisons of these three groups in each service area included the number of chronic conditions reported, overall health and mental health status, need for help or supervision with ADLs or IADLS, as well as ED visits and hospitalizations during the year. The service areas presented in table 2 correspond with those chosen for the screener and are summated to record the number and characteristics of individuals with elevated utilization in any, versus none, of the five areas, as well as by number of areas with elevated utilization.

When selecting individuals with elevated use in *any* of these five areas, we obtained an estimated population of 54 million individuals, or approximately 29% of the working age population. After controlling covariates, on average, these individuals had over two chronic conditions at a time. Members of this group of elevated users had over double the percentages in fair to poor overall health and fair to poor mental health, and over five times the percentages of ADL/IADL limitations, when compared to individuals with no elevated use in any of these five areas. While approximately nine percent of individuals without elevated use visited the emergency department one or more times during the year, over twenty-one percent of the elevated user group did so. Similarly, while about two percent of individuals without elevated use were hospitalized, over sixteen percent of the elevated group was.

Another way these items were examined was by the count of service areas with elevated use. This yielded progressively smaller population subgroups, each with significantly higher health consequences. This approach parallels how the screener items might one day be used to stratify the ACHCN population on the basis of complexity of service use.

Cognitive testing—Multiple versions of the questions in each service area were competed in order to identify those which maximized respondent understandings of each question's intent, reduced respondent burden, and improved the simplicity and consistency of the underlying cognitive processes involved in formulating responses. A key issue that arose during cognitive testing of these question concerned how best to ask about *need and utilization* of healthcare services.

Among the first banks of questions we asked, we relied upon the precedent of combining these two domains as they are in the CSHCN screener, testing such questions as "Do you need or get special therapy?". However, in our cognitive testing in adults, we found respondents formulated their answers to questions of this kind by focusing upon their typical utilization, while ignoring need. It was therefore decided that questions concerning need and use had to be posed separately. In so doing, it was found that respondents could more consistently answer questions about services they routinely used, but struggled more to conceptualize and formulate answers about services they might need more generally. Figure 3 demonstrates the range of factors considered as respondents characterized their possible *need* for a given service or support.

In order to reduce the amount of speculation (and burden) required of respondents, the panel therefore decided to delimit the questions to the *experience of unmet need*. In this way, only respondents who are not using a given service will be asked whether or not that is because they were unable to obtain it. The end result is that individuals who are using a service, or who can name an existing unmet need for it, will be captured as ACHCN (assuming a concomitant positive finding of a chronic condition and/or functional difficulty). Further field testing, particularly in the context of medically underserved or uninsured population groups, will be required to analyze the validity and reliability of these questions more fully. [48]

Notes on the final service items—Some further clarifications of the items in the service need/use domain are necessary, as follows:

Question 8: Medical doctors: The question concerning medical doctors is purposefully left open with regard to specialty and location of service. In this way, the question is efficient because it will capture many different kinds of medical encounters, whether inpatient, outpatient, or in an emergency department. Though we focused upon doctors because of the near universal recognition of that term, physician assistants or nurse practitioners would also qualify as a positive answer to this question. This issue did not arise in cognitive testing.

Question 9: Mental health: The panel was originally concerned about including reference to substance abuse services for fear of the effects of stigma/social response bias. However, this was not found to be problematic in cognitive testing, where respondents spoke openly about these issues, as well as mental illness generally. Additionally, the inclusion of a brief screener for psychological distress, depression, and/or anxiety among the ACHCN items was carefully considered by the panel, but rejected because of the poor correlation between such indices and actual use of mental health services. It is also important to remember that the ACHCN screener is not intended to include the "at-risk" population. Other research tools can and should be used alongside this screener to further characterize mental health.

Question 10: Prescription medications: Over the counter, herbal, and other medicinal items were considered for inclusion in the screener but were ultimately rejected because the purposes of their use were too variable and because these items performed poorly in cognitive testing. It should also be noted that field testing will be needed to verify whether or not the stem question has sufficient specificity to ACHCN to be used as is, or whether the follow-up question (number of medication) is needed to set a cut-off based on number of medications used.

Question 11: Medical or other therapies: The question concerning medical or other therapies is broadly construed and intended to cover the full range of ongoing medical care individuals may require, excepting mental health. When probed, a few individuals did wonder whether this question might include counseling but most were able to answer accurately. Additionally, this question performed equally well with, or without the examples (dialysis, physical therapy, or therapy to manage or reduce pain).

Question 12: Medical equipment/assistive devices: Competing versions of this question were posed in cognitive testing with a wide variety of examples, such as medication pumps, breathing aids, mobility aids, communication devices and more. However, the final version, with no examples, performed best of all.

Finally, it should be noted that there are, of course, many hundreds of medical services, provider types, and medical goods that individuals with chronic healthcare needs likely rely upon. These are, by necessity, reduced to a short list. These five service areas are intended to serve as a series of catch basins which, working in concert, will capture most ACHCN even as they *also* use unlisted services.

DISCUSSION

The MCHB definition of CSHCN,[22] and its associated screener,[24] went on to become the basis of a coordinated body of scholarship, including several national surveys, national standards for assessing quality of care in health plans and practices, hundreds of peer-reviewed articles and direct mention in the federal Healthy People 2010 and 2020 goals. [29–30] Focused on service needs and health consequences, the CSHCN screener gave the health policy sector a new vehicle to track the access to, and quality, coordination, and costs of care required by children with diverse and consequential health conditions and disabilities. Despite the many new demonstration projects and reforms being implemented to improve these same aspects of care for various "high-need" adult populations under the ACA, in Medicare and Medicaid, as yet, the health services research field has no consensus definition to offer and no consistent manner by which to identify the population most in need of these reforms. The ACHCN definition and screener might begin to fill some of these gaps.

Applications

First and foremost, this definition and screener are designed for application in healthcare survey research. Once field tested, they could be useful for the identification of ACHCN in quality surveys conducted by health insurers or administrators of large patient panels, in state-level surveys as conducted by public health or mental health departments (including the BRFSS), or even in national surveys, whether general (such as the MEPS, NHIS or NHANES) or more topical (such as the National Survey on Drug Use and Health). Depending upon the sampling frame of the parent survey, the screener would then either allow for prevalence estimates of the full ACHCN population or for further characterization of chronic healthcare needs among the targets of the survey. Inclusion of the screener in existing national surveys would be powerful, potentially allowing for a full population profile of the demographics, health conditions, access to care, utilization rates, costs of care and the other domains which these surveys cover, and for comparisons between working age adults with and without chronic healthcare needs. Of course, as a screener, this instrument could also be used for sample selection in a dedicated survey of ACHCN as well.

Second, it should ultimately be possible to adapt or build upon these screener elements for clinical purposes or program administration. For example, the identification of patients in a primary care setting who could especially benefit from specific coordinated care activities, or who might best benefit from home visits, or who might require particular kinds of assistance or screenings during an office visit, are each areas where consideration of ACHCN (or a subgroup thereof) may prove fruitful. Though further research and development would be required, this instrument could well be usefully employed as a part of the electronic health record, giving clinicians, administrators and researchers an augmented view of the chronic condition status, functional difficulties, and ongoing needs of the patients they serve.

Third, the definition itself and the domains captured in the screener may prove useful to agency heads as they set goals, design new programs or evaluate existing practices. Returning to the example of CSHCN, the Healthy People 2020 goals specifically include the

objectives to increase the proportion of children with special healthcare needs who receive their care in family-centered, coordinated systems and to increase the proportion of youth with special healthcare needs who receive guidance while transitioning from pediatric to adult healthcare. The ACHCN definition and screener could serve an analogous function for the working age population, filling the present research gap when children with special healthcare needs have transitioned to adult care, and assisting in the development and evaluation of health policy goals for persons with chronic conditions or functional difficulties, such as care coordination or better integration of mental health in primary care.

Stratification

In each of the possible applications discussed above, there are circumstances where analyses of more specific subgroups of ACHCN could prove important, particularly given the heterogeneity of this population. One approach the panel considered carefully, and simulated with secondary data,[2] would parse ACHCN into three main subgroups: ACHCN without functional difficulties, ACHCN with functional difficulties that do not include ADL/IADL problems, and ACHCN whose functional difficulties do include ADLs or IADLs. When arrayed in this order, we would expect to see progressively smaller subgroups with increasingly poor overall health, rising numbers of chronic conditions, higher service utilization of general and specialty medical care, higher rates of hospitalization and ED use, as well as greater needs for mental health, home health, medical equipment and other community-based supports. At the macro level, surveillance of the shifts in size, demographic compositions, health conditions, access to care and service use profiles of these three primary subgroups, particularly in longitudinal fashion, would reveal much about the direction healthcare policy is taking the United States.

At a more micro-level, the screener elements were also designed to permit for the identification of more specific subgroups as well. Alternatively using ACHCN, individuals with multiple chronic conditions, or ACHCN with multiple chronic conditions as a base, researchers using this screener could go on to identify subgroups with specific functional difficulties (such as blindness or mobility impairment) and/or with specific service needs (such as prescription medications or medical equipment).

STUDY LIMITATIONS

The most important limitation to note is that the ACHCN screener has yet to be put through field testing and so we cannot yet report its sensitivity or specificity. With its foundation in the successful CSHCN screener and supported by literature reviews and quantitative analyses, we expect that it will perform as intended, but additional psychometric testing is needed. We also note the limitations associated with the datasets used in the panel's analyses. Survey respondents may under report service use or particular health conditions potentially viewed as stigmatizing. Additionally, these samples did not include people who reside in institutional settings. This may contribute to undercounting the population who could potentially be construed as ACHCN.

CONCLUSION

Much as the American healthcare system can be described as siloed by condition, specialty and payer, so too are the data that researchers rely upon to analyze it, particularly when the research foci are chronic conditions, disability and ongoing needs for care. For the working age population, health services research at the intersection of these issues is fragmentary, marked by ad-hoc approaches to measurement, diagnostically driven "populations" which overlap, and a convoluted body of knowledge that is difficult to follow. Whether as proposed here, or as yet to be proposed, a consensus definition of this total population, associated criteria for screening and research purposes, and a workable means of subgroup stratification are each clearly needed. If such an approach is widely adopted, particularly among the leading federal health and healthcare agencies, researchers studying people with chronic conditions, disabilities or high medical needs will be increasingly empowered to work from the same common denominator. Articulating their study populations in such fashion as to be fully replicable by other scientists and producing a body of literature with consistent terms and measures, such researchers will be empowered to provide evidence-based findings that are more clearly communicated, more consistent, and actionable, whether for clinicians, administrators, policymakers or the general public.

Acknowledgments

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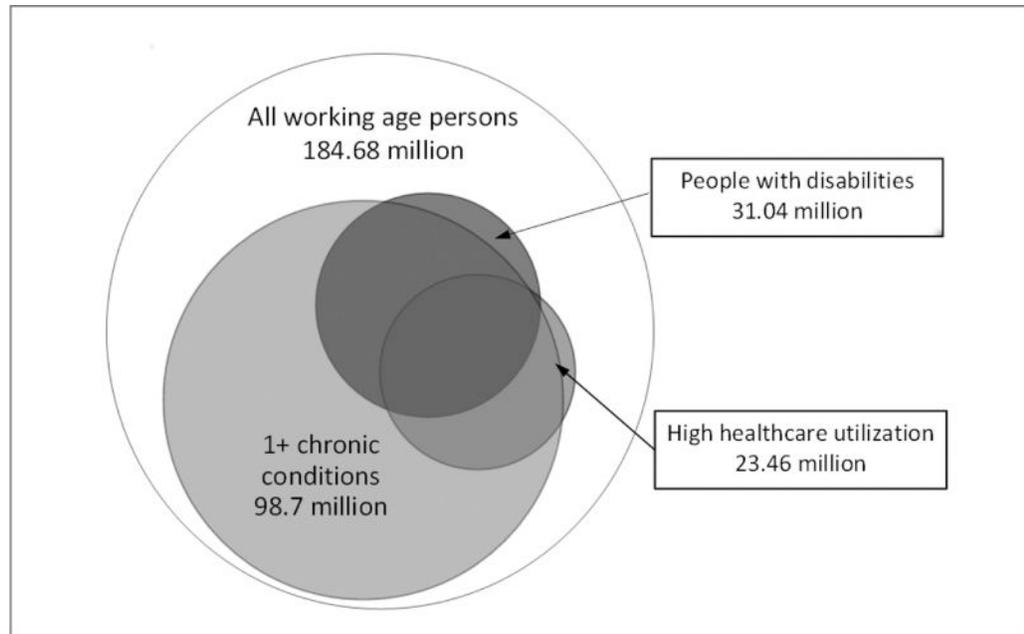
Figure 1.
The size and overlap of working age individuals with 1+ chronic conditions, disabilities and high healthcare utilization: Area proportional Venn diagram, pooled annual estimates, MEPS 2006–2008. (Republished with permission).
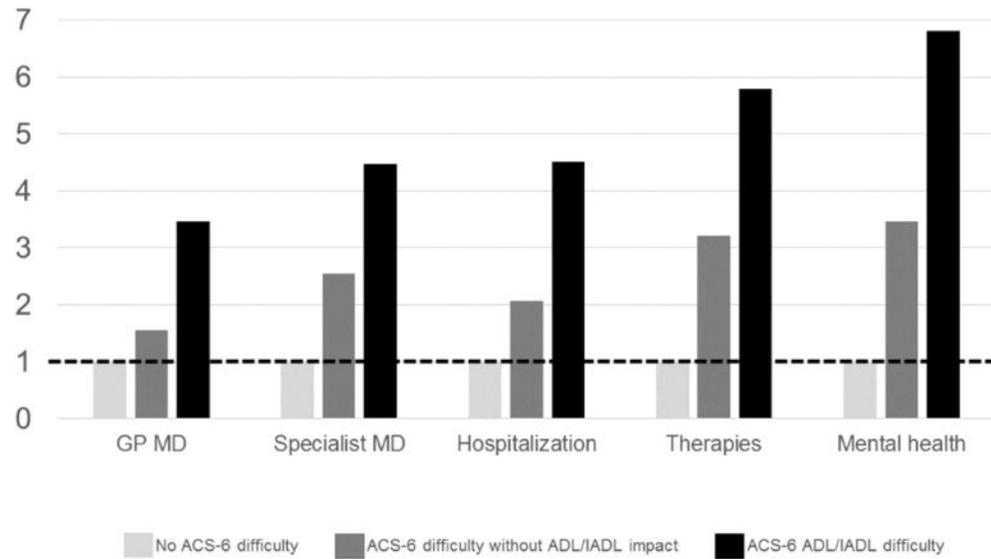
Figure 2.
ASC-6 summary variable over five types of healthcare: Covariate controlled odds ratios,
2011 National Health Interview Survey
Results based upon separate logistic regressions predicting likelihood of any visits in each
service area while controlling for age, gender, race/ethnicity, education, income and health
insurance status. In all models, no ACS-6 difficulty was set as the reference level (denoted
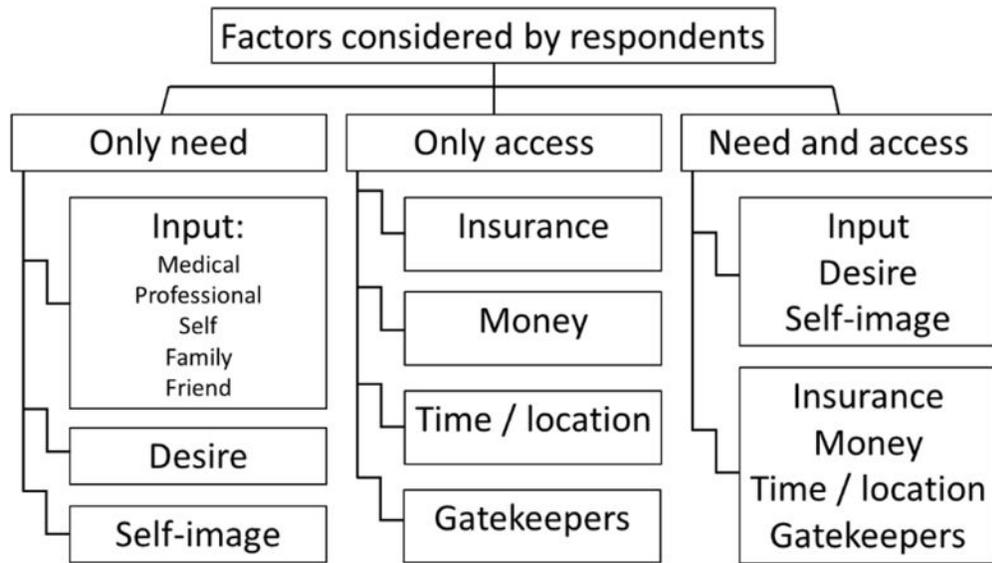by the dashed line). All comparisons significant at the p<.05 level.

Figure 3.
Cognitive factors associated with the construct of need for healthcare

Table 1

The Adults with Chronic Healthcare Needs Brief Screening Instrument

Domain	ACHCN Screener Items
Health conditions	1) Do you have any medical, mental health, or other health condition that has lasted or is expected to last for at least 12 months? (Y/N) 1a) If yes: Do you have two or more of these ongoing conditions? (Y/N)
Functional difficulties	2) Are you deaf or do you have serious difficulty hearing? (Y/N) 3) Are you blind or do you have serious difficulty seeing even when wearing glasses? (Y/N) 4) Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? (Y/N) 5) Do you have serious difficulty walking or climbing stairs? (Y/N) 6) Do you have difficulty dressing or bathing? (Y/N) 7) Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping? (Y/N)

Service need and use	8) Do you see medical doctors about your health often? Please do not include an annual check-up in your response. (Y/N)
	  8a) If no: Are you often unable to see a medical doctor when you need to? (Y/N)
	9) Do you use mental health treatment or support such as counseling or substance abuse services? (Y/N)
	  9a) If no: Do you need mental health treatment or support that you do not receive? (Y/N)
	10) Do you use prescription medicine regularly (other than vitamins or birth control pills)? (Y/N)
	  10a) If yes: How many different prescription medicines do you use? (Numeric)
	  10b) If no: Do you regularly need prescription medicine that you do not receive? (Y/N)
	11) Do you often use medical or other therapies such as dialysis, physical therapy, or therapy to manage or reduce pain? (Y/N)
	  11a) If no: Do you often need medical or other therapies that you do not receive? (Y/N)
	12) Do you use medical equipment or assistive devices often? (Y/N)
	  12a) If no: Do you need medical equipment or assistive devices that you do not have? (Y/N)

Table 2

Health and healthcare characteristics of population subgroups based upon type and amount of ambulatory care used: Covariate controlled, pooled annual estimates weighted to U.S. working age (18–65) adult population totals, MEPS 2006–2008 (N=53,586).

Ambulatory healthcare utilization over the course of the average annual year (2006–2008)	Working age sub-population size (millions)	Mean chronic conditions	Fair to poor health during year (%)	Fair to poor mental health during year (%)	Need help or supervision with ADLs or IADLS during year (%)	1+ ED visits (%)	1+ hospital visit(s) (%)
No medical doctor (MD) visits	65.62	.45 (.01)[bc]	11.16% (.32)[bc]	7.44% (.26)[bc]	1.20% (.11)[bc]	6.73% (.21)[bc]	1.10% (.08)[bc]
1st–75th percentile MD visits	79.62	1.22 (.02)[ac]	18.51% (.41)[ac]	10.91% (.31)[ac]	2.70% (.14)[ac]	12.30% (.30)[ac]	4.41% (.16)[ac]
75th percentile or higher for MD visits	39.44	2.16 (.02)[ab]	35.36% (.60)[ab]	21.22% (.52)[ab]	8.10% (.34)[ab]	23.14% (.56)[ab]	19.84%(.52)[ab]
No mental health/substance abuse (MH/SUB) visits	176.73	1.17 (.01)[bc]	18.73% (.31)[bc]	10.40% (.23)[bc]	3.16% (.11)[bc]	12.11% (.20)[bc]	6.35% (.13)[bc]
1st–75th percentile MH/SUB visits	5.81	2.45 (.05)[ac]	34.95% (1.45)[a]	42.15% (1.58)[ac]	10.46% (.86)[ac]	19.78% (1.21)[a]	9.78% (.80)[a]
75th percentile or higher for MH/SUB visits	2.14	2.97 (.13)[ab]	39.47% (2.61)[a]	51.08% (2.67)[ab]	15.33% (1.77)[ab]	19.94% (2.00)[a]	10.67% (1.33)[a]
No prescription (Rx) fills/refills	67.96	.26 (.01)[bc]	9.38% (.30)[bc]	6.40% (.25)[bc]	.99% (.11)[bc]	3.38% (.15)[bc]	1.60% (.12)[bc]
1st–75th percentile for Rx fills/refills	86.74	1.20 (.01)[ac]	19.06% (.38)[ac]	11.87% (.29)[ac]	2.30% (.12)[ac]	16.53% (.31)[ac]	7.34% (.20)[ac]
75th percentile or higher for Rx fills/refills	29.98	2.84 (.03)[ab]	43.00% (.80)[ab]	25.71% (.71)[ab]	10.63% (.51)[ab]	24.22% (.65)[ab]	14.73% (.57)[ab]
No medical therapies	169.86	1.19 (.01)[bc]	18.44% (.32)[bc]	11.43% (.24)[bc]	3.10% (.11)[bc]	11.70% (.20)[bc]	6.02% (.14)[bc]
1st–75th percentile for medical therapies	10.81	1.68 (.04)[ac]	29.04% (1.07)[ac]	16.53% (.79)[a]	7.07% (.55)[ac]	20.19% (.96)[ac]	11.35% (.62)[a]
75th percentile or higher for medical therapies	4.01	1.89 (.07)[ab]	36.94% (1.73)[ab]	20.26% (1.49)[a]	13.09% (1.18)[ab]	26.10% (1.62)[ab]	13.70% (1.16)[a]
No medical equipment/device expenditures	177.21	1.19 (.01)[bc]	18.55% (.31)[bc]	11.45% (.25)[bc]	3.03% (.11)[bc]	11.56% (.20)[bc]	5.86% (.13)[bc]
1st to 75th percentile for equipment/devices	5.59	2.07 (.06)[a]	38.32% (1.50)[ac]	22.30% (1.27)[a]	13.03% (.92)[ac]	29.89% (1.51)[ac]	17.84% (1.20)[ac]
75th percentile or higher for equipment/devices	1.87	2.20 (.09)[a]	47.56% (2.68)[ab]	21.06% (2.02)[a]	17.15% (1.83)[ab]	43.41% (2.62)[ab]	30.64% (2.26)[ab]

Ambulatory healthcare utilization over the course of the average annual year (2006–2008)	Working age sub-population size (millions)	Mean chronic conditions	Fair to poor health during year (%)	Fair to poor mental health during year (%)	Need help or supervision with ADLs or IADLS during year (%)	1+ ED visits (%)	1+ hospital visit(s) (%)
Screen:							
None of five measures above the 75th percentile	130.22	.70 (.01)[b]	13.11% (.30)[b]	8.22% (.48)[b]	1.37% (.08)[b]	8.92% (.19)[b]	2.41% (.10)[b]
Any of five measures above the 75th percentile	54.46	2.15 (.02)[a]	33.80% (.53)[a]	20.17% (.48)[a]	7.60% (.30)[a]	21.22% (.47)[a]	16.32% (.44)[a]
Count:							
By number of measures above the 75th percentile							
0	130.22	.70 (.01)[bcd]	12.97% (.30)[bcd]	8.11% (.22)[bcd]	1.32% (.08)[bcd]	8.86% (.19)[bcd]	2.39% (.10)[bcd]
1	34.91	1.74 (.02)[acd]	26.42% (.55)[acd]	14.96% (.50)[acd]	4.40% (.27)[acd]	18.08% (.51)[acd]	14.34% (.47)[acd]
2	16.44	2.75 (.03)[abd]	46.22% (.96)[abd]	28.09% (.89)[abd]	11.28% (.59)[abd]	25.98% (.81)[abd]	19.03% (.79)[abd]
3 or more	3.10	3.41 (.09)[abc]	66.5% (2.28)[abc]	41.57% (2.04)[abc]	25.21% (1.84)[abc]	36.66% (2.01)[abc]	30.68% (2.04)[abc]

Means and percentages are predicted marginal estimates from separate multivariate models for each cell in the table. Loglink regression was used for count data and logistic regression was used for dichotomous measures. Taylor series linearization was used to estimate variance. All reported estimates control for differences in age, gender, race, Hispanic ethnicity, education, poverty status, metropolitan statistical area status, insurance coverage status, access to medical care and access to prescription medications. Significance tests between the covariate controlled, predicted marginal estimates were conducted with an alpha of p=.01. Significant findings are flagged as follows:

[a] differs from the first estimate in the same table cell

[b] differs from the second estimate in the same cell

[c] differs from the third estimate in the same cell

[d] differs from the fourth estimate in the same cell (for results in the final row).