

The National Comorbidity Survey Replication (NCS-R): background and aims

RONALD C. KESSLER,¹ KATHLEEN R. MERIKANGAS²

¹ Department of Health Care Policy, Harvard Medical School, Boston MA, USA

² Intramural Research Program, National Institute of Mental Health, Bethesda MD, USA

ABSTRACT *The National Comorbidity Survey Replication (NCS-R) is a new nationally representative community household survey of the prevalence and correlates of mental disorders in the US. The NCS-R was carried out a decade after the original NCS. The NCS-R repeats many of the questions from the NCS and also expands the NCS questioning to include assessments based on the more recent Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) diagnostics system (American Psychiatric Association, 1994). The NCS-R was designed to (1) investigate time trends and their correlates over the decade of the 1990s and (2) expand the assessment of the prevalence and correlates of mental disorders beyond the assessment in the baseline NCS in order to address a number of important substantive and methodological issues that were raised by the NCS. This paper presents a brief review of these aims.*

Key words: community survey, epidemiologic research design, National Comorbidity Survey Replication, psychiatric epidemiology

Introduction

During the past three decades, advances in the diagnostic nomenclature, fully structured diagnostic interviews, and the application of sophisticated household survey technology have led to substantial progress in knowledge about the descriptive epidemiology of mental disorders in the US. The landmark Epidemiologic Catchment Area (ECA) surveys of over 20,000 respondents selected from mental health catchment areas in five US communities (Robins and Regier, 1991) were made possible by the development of the first fully structured research diagnostic interview that could be administered by trained lay interviewers. This instrument, the Diagnostic Interview Schedule (DIS) (Robins, Helzer, Croughan and Ratcliff, 1981), assessed disorders using the definitions and criteria of the American Psychiatric Association's (APA) Diagnostic and Statistical Manual of Mental Disorders, Third Edition (DSM-III) (American

Psychiatric Association, 1980), the first truly operationalized diagnostic criteria for mental disorders in the US. However, the generalizability of the ECA results was limited because the study was conducted in five local sites rather than at the national level. A decade after the ECA, the National Comorbidity Survey (NCS) (Kessler, McGonagle, Zhao, Nelson, Hughes, Eshleman, Wittchen and Kendler, 1994) was carried out in a nationally representative sample of the US. The diagnostic instrument in the NCS was a revised and expanded version of the DIS known as the World Health Organization (WHO) Composite International Diagnostic Interview (CIDI) (Robins, Wing, Wittchen, Helzer, Babor, Burke, Farmer, Jablenski, Pickens, Regier, Sartorius and Towle, 1988). The CIDI was designed to assess disorders based on the newer DSM-III-R (American Psychiatric Association, 1987). The development of the CIDI reflected the increasing international communication on diagnosis and assessment

methods that began with the classic US/UK study of schizophrenia (Zubin and Gurland, 1977), leading to increased methodological concordance between studies carried out in the US and in other parts of the world (Helzer, Canino, Hwu, Bland, Newman, Yeh, 1988; Meltzer, Baljit, Petticrew and Hinds, 1995; Merikangas, Mehta, Molnar, Walters, Swendsen, Aguilar-Gaziola, Bijl, Borges, Caraveo-Anduaga, DeWit, Kolody, Vega, Wittchen and Kessler, 1998).

The ECA and NCS surveys both revealed that approximately 30% of the general population in the age range 15–54 met diagnostic criteria for at least one mental disorder in the 12 months prior to the interview (Regier, Kaelber, Rae, Farmer, Knauper, Kessler and Norquist, 1998). Likewise, both surveys found very early ages of first onsets of most mental disorders (Christie, Burke, Regier, Rae, Boyd and Locke, 1988; Kessler and Walters, 2002), high rates of comorbidity among mental disorders (Boyd, Burke, Gruenberg, Holzer, Rae, George, Karno, Stoltzman, McEvoy and Nestadt, 1984; Kessler, 1995), substantial role impairments caused by mental disorders (Kouzis and Eaton, 1994; Kessler and Frank, 1997), and low rates of treatment of mental disorders (Regier, Narrow, Rae, Manderscheid, Locke and Goodwin, 1993; Kessler, Zhao, Katz, Kouzis, Frank, Edlund and Leaf, 1999).

The National Comorbidity Survey Replication (NCS-R) is a new survey of a probability sample of the US carried out a decade after the original NCS (Kessler et al., 1994). The NCS-R repeats many of the questions from the NCS and also expands the questioning to include assessments based on the more recent DSM-IV diagnostics system (American Psychiatric Association, 1994). The methods and procedures used in the NCS-R are described in a separate paper in this special issue (Kessler, Berglund, Chiu, Demler, Heeringa, Hiripi, Jin, Pennell, Walter, Zaslavsky and Zheng, 2004).

The two major aims of the NCS-R were: (1) to investigate time trends and their correlates over the decade of the 1990s; and (2) to expand the assessment of the prevalence and correlates of mental disorders beyond the assessment in the baseline NCS in order to address a number of important substantive and methodological issues that were raised by the NCS. We briefly review these aims in the remainder of this paper.

Time trends

The investigation of time trends was motivated by the enormous changes in the mental health treatment arena during the 1990s. The rise of managed care followed by mental health carve-outs led to important changes in access to mental health treatment for many Americans. The introduction of new medications with improved side-effect profiles made it possible for primary care physicians to play a central role in the treatment of common anxiety and mood disorders. The introduction of direct-to-consumer advertising by the pharmaceutical industry, the initiation of several high profile public education programmes by the National Institute of Mental Health (NIMH) and various mental health patient advocacy groups, and the rapid expansion of the Internet with its vast array of mental health information Web sites, all provided consumers with unprecedented amounts of information about the treatment of mental illness. This information explosion, in turn, led to a dramatic increase in demand for treatment of mental disorders.

The next decade is likely to see even more change in mental health treatment. As the managed care system continues to evolve, demand for treatment increases, and the debate over parity of mental health treatment evolves in response to that increasing demand. An understanding of time trends during the 1990s has the potential to provide insights that can help us chart a course forward into the next decade. With this in mind, we designed the NCS-R in such a way as to collect trend data in comparison to the baseline NCS on prevalence of DSM disorders, patterns of service use for these disorders, quality of treatment, and several policy-relevant determinants of service use.

Disorder prevalence

Trend data on the prevalence of mental disorders have been a subject of considerable interest since the early 1980s, when evidence based on retrospective reports was first presented to suggest that the prevalence of major depression has been on the rise since the end of World War II (Weissman, 1987). This evidence was subsequently called into question based on both theoretical (Giuffra and Risch, 1994) and empirical (Simon and Von Korff, 1995) data suggesting that a combination of recall bias and age-related selective attrition could have accounted for

the suggestion of an upward trend in the retrospective recall data. Nonetheless, at least three other types of information are indirectly consistent with the possibility of a meaningful upward trend in the prevalence of some mental disorders.

First, the results of numerous community surveys have shown a striking increase in teenage drug use since the 1970s when the baby boom generation entered adolescence (Johnston, Bachman and O'Malley, 1998). As drug use disorders are significantly related to mental disorders (Kessler, Nelson, McGonagle, Edlund, Frank and Leaf, 1996) and, in some cases, are known to precipitate mental disorders (Aronson and Craig, 1986), this result suggests that there has been a rise in secondary mental disorders (Merikangas, Mehta, Molnar, Walters, Swendsen, Aguilar-Gaziola, Bijl, Borges, Caraveo-Anduaga, DeWit, Kolody, Vega, Wittchen and Kessler, 1998). Second, data from the National Center for Health Statistics (NCHS) show a clear increase in the suicide rate, another correlate of mental disorders, over the past half century (Cantor, Leenaars, Lester, Slater, Wolanowski and O'Toole, 1996). Third, there is also a clear rise in self-reported clinically significant levels of distress assessed in community surveys of psychological distress conducted from the late 1950s to the early 1980s (Veroff, Douvan and Kulka, 1981). Although there may be methodological explanations for some of these trends, such as increased willingness of responsible officials to code apparent suicides on death certificates or increasing willingness of survey respondents to admit psychological distress, the trends are sufficiently impressive to fuel speculation that upward trends in mental illness might exist.

The NCS-R was designed to provide, in conjunction with the baseline NCS, the first nationally representative survey trend data on the estimated prevalence of clinically significant mental disorders. The trend data on current disorders will, of course, focus on the decade between 1990–2 and 2000–2. We also collected retrospective data on lifetime prevalence in both surveys, so it will be possible to evaluate directly the criticism of earlier retrospective studies: that recall bias and selective attrition lead to overestimation of increases in the prevalence of mental disorders. By blending the recall data in the NCS and NCS-R, we will be able to obtain two separate retrospective estimates for the same interval of

time up through 1990–2 varying in duration of recall. For example, the lifetime age-of-onset distribution of major depression up through the year 1989 among respondents who were born in the years 1966–76 can be estimated in the baseline NCS with only a small recall interval by focusing on respondents who are in the age range 18–25 at the time of interview. This same distribution can then be independently estimated in the NCS-R by focusing on respondents in the age range 28–35 at the time of that interview. Any discrepancy in these two distributions that exceeds the bounds of chance can be attributed to some sort of differential recall bias related to time of interview. Failure to find any such discrepancy would be indirectly consistent with the possibility that recall accuracy is stable over that interval of time. We anticipate finding that discrepancies of this sort will increase with the age of respondents and possibly with socio-demographic factors that might be related to recall accuracy (such as education).

In addition, the NCS-R includes a core battery of questions about non-specific psychological distress that will be used in a separate investigation of longer term trends in mental illness using measures from two national surveys that were carried out in 1957 (Gurin, Veroff and Feld, 1960) and 1976 (Veroff et al., 1981). Rather than making simple comparisons with the reported overall patterns from the earlier surveys, we obtained the original raw data from these surveys to create a consolidated individual-level data file that combines data across the three surveys. This will allow us to perform detailed disaggregated analyses of patterns and correlates in time trends.

Service use

The NCS-R also provides an excellent opportunity to investigate prospective trends and patterns of service use. Several studies have shown a dramatic increase in the treatment of mental disorders in the healthcare sector during the past decade (Olfson, Marcus, Druss, Elinson, Tanielian and Pincus, 2002). However, there is scant information about trends in treatment in other sectors, such as mental health specialty treatment outside of a healthcare system (for example, psychotherapy provided by non-MD therapists who are not reimbursed by health insurance), the human services sector (for example, spiritual advisors or counsellors in human services organizations), and the self-help sector. These non-medical

types of treatment accounted for the majority of all mental health visits in the US (Rush, Gullion, Basco, Jarrett and Trivedi, 1996) at the time of the baseline NCS (Kessler, Zhao, Katz, Kouzis, Frank, Edlund and Leaf, 1999). It will be of considerable value to see if these visits have changed in the intervening decade.

Trends in treatment intensity and adequacy can also be charted based on the fact that the NCS included questions regarding the number of visits in the past 12 months within each treatment sector and the use of broad classes of medications. We expect that the growth in treatment over the past decade has been concentrated in the general medical sector, with a drop in average number of visits, an increase in the use of pharmacotherapy, and a decrease in psychotherapy. Among people receiving pharmacotherapy, we expect to find an increase in the use of newer antidepressants. We will also evaluate treatment adequacy defined by published treatment guidelines for a minimum number of visits and the consistency of medication types with diagnosis. Our earlier work revealed that treatment adequacy was substantially lower in the general medical sector than in the specialty mental health sector as of the middle 1990s (Wang, Berglund and Kessler, 2000; Wang, Demler and Kessler, 2002). It is not clear whether this was still true at the time when the NCS-R data were collected.

In addition to studying recent treatment we will examine lifetime speed of initial treatment contact after first onset of mental disorders. In the original NCS, we found that even though the majority of people with a persistent mental disorder eventually receive treatment, there are pervasive delays in initial treatment contact that span more than a decade from the time of first onset for some disorders (Kessler, Olfson and Berglund, 1998). We also found that these delays are greatest for people with early onset disorders (Olfson, Kessler, Berglund and Lin, 1998; Christiana, Gilman, Guardino, Mickelson, Morselli, Olfson and Kessler, 2000). One positive trend that emerged was a decrease in the average duration of these delays in more recent cohorts.

Treatment dropout is another important aspect of service trends that we will examine. The mental health services literature consistently finds that a high proportion of patients drop out before they complete a full course of treatment (Demyttenaere,

Enzlin, Dewe, Boulanger, De Bie, De Troyer and Mesters, 2001; Berghofer, Schmidl, Rudas, Steiner and Schmitz, 2002). However, with an increase in the number of patients in mental health treatment over the past decade who have more knowledge about their disorders than in the past, coupled with the availability of medications with more favourable side-effects profiles than in the past, we might see a change in patterns of treatment dropout.

Other trends

National Comorbidity Survey Replication trend analyses will also study attitudes and perceptions about mental illness and its treatment. We anticipate finding significant changes in these attitudes and perceptions based on the unprecedented volume of mass media attention given to mental illness and psychotropic medications over the past decade. Another important development over the past decade has been the rise of alternative therapy. It is conceivable that an increase in self-medication with St John's Wort and other alternative therapies has led to a decline in the use of conventional treatments among some segments of the population (Kessler, Soukup, Davis, Foster, Wilkey, Van Rompay and Eisenberg, 2001).

Expanded assessments of prevalence and correlates

During the decade between the NCS and NCS-R, the APA revised the DSM system to emphasize the requirement for clinically significant distress or impairment in making diagnoses (American Psychiatric Association, 1994). This new emphasis was made, in no small part, in reaction to the perception that the prevalence estimates in community epidemiological surveys based on fully structured research diagnostic interviews were unrealistically high (Regier, Kaelber, Rae, Farmer, Knauper, Kessler and Norquist, 1998). Clinical reappraisal studies of NCS cases showed that the NCS prevalence estimates were not significantly different from those obtained by independent clinical interviewers who blindly administered semi-structured clinical interviews and generated diagnoses based on DSM-III-R criteria (Kessler, Wittchen, Abelson, McGonagle, Schwarz, Kendler, Knauper and Zhao, 1998). However, the situation might be different when DSM-IV criteria are applied (Narrow, Rae, Robins and Regier, 2002). As a result, we substantially modified

the NCS diagnostic interview for use in the NCS-R in order to operationalize DSM-IV criteria, while retaining enough of the original NCS questions to allow trend analyses to be carried out. We also substantially expanded the clinical reappraisal component of the study in order to obtain independent clinical evaluations of the validity of NCS-R diagnostic decisions as well as to calibrate NCS-R diagnostic classification rules to match aggregate clinical classifications.

As the controversy regarding the accuracy of prevalence estimates in community studies centres on clinical significance, we also added five elements to the NCS-R interview to enhance the assessment of clinically significant distress and impairment. First, each diagnostic section of the interview includes a number of new questions to assess the lifetime persistence of the focal disorder as well as the intensity and duration of the distress and impairment associated with the disorder over the lifetime of the respondent. Second, respondents who reported the disorder as being present at any time in the past 12 months were queried about the persistence of the disorder over the past 12 months. Third, the Sheehan Disability Scales (Leon, Olfson, Portera, Farber and Sheehan, 1997) were used to assess the severity of role impairment associated with the focal disorder during the worst month in the past 12 months. Fourth, fully structured versions of standard clinical symptom severity scales were used to evaluate 12-month symptom severity. For example, the Quick Self-Administered version of the Inventory of Depressive Symptoms (Rush, Gullion, Basco, Jarrett and Trivedi, 1996) was used to assess the severity of major depression, while the structured version of the Panic Disorder Severity Scale (Shear, Brown, Barlow, Money, Sholomskas, Woods, Gorman and Papp, 1997) was used to assess the severity of panic disorder. Fifth, the World Health Organization's Disability Assessment Schedule (WHO-DAS) (Rehm, Ustun, Saxena, Nelson, Chatterji, Ivis and Adlaf, 1999) was included to provide an overall assessment of the impact of each respondent's multivariate profile of current disorders.

The refinement of diagnostic assessments

Data from the NCS and NCS-R could also be useful in providing information about the epidemiological implications of the current process of revising the

DSM diagnostic criteria. DSM-V is planned for release in 2010. Parallel work is going on at the WHO to update the diagnostic criteria of the International Classification of Diseases (ICD). The diagnostic sections of the NCS-R assessment were designed to capture detailed sub-threshold assessments of each disorder so as to allow the implications of lowering diagnostic thresholds to be explored. Information was also collected that can be used to investigate the implications of raising diagnostic thresholds as well as the implications of several subtype distinctions.

The expansion of the diagnoses assessed

The NCS diagnostic assessment focused largely on anxiety, mood, and substance-use disorders. While these assessments are repeated in NCS-R, a number of additional types of disorder are also being considered. The three most important of these are personality disorders, retrospectively assessed child and adolescent disorders, and impulse-control disorders. Personality disorders were assessed with a screening version of the International Personality Disorders Examination (IPDE) (Loring, Sartorius and Janca, 1996). We attempted to follow up with a separate full IPDE clinical interview with all respondents who were positive on the IPDE screen. The retrospectively assessed child and adolescent disorders include attention-deficit/hyperactivity disorder (ADHD), oppositional-defiant disorder (ODD), conduct disorder, and separation anxiety disorder. Most of these assessments are based on earlier diagnostic modules developed by Lee Robins in her most recent version of the DIS. We were keen to include these retrospective assessments both because they dovetail with the current assessments of the same disorders in the nationally representative survey of adolescent mental health that is being carried out in conjunction with the NCS-R and because we want to investigate the associations of these child and adolescent disorders with subsequent onset of comorbid anxiety, mood, impulse-control, and substance disorders.

The impulse-control disorders included in the NCS-R are intermittent explosive disorder, pathological gambling, bulimia, antisocial and borderline personality disorders, adult ADHD, and adult ODD. Although some of the disorders assessed in the baseline NCS, such as substance dependence, have core

elements of impulsivity; impulse-control disorders have been a neglected topic in previous psychiatric epidemiological studies. This is of special importance for studying sex differences, as clinical studies suggest that impulse-control disorders are more common among men and anxiety and mood disorders are more common among women. The assessment of impulse-control disorders is also important for investigating comorbidity, as a number of impulse-control disorders are thought to be part of a soft bipolar spectrum that accounts for some comorbidity of reverse vegetative non-bipolar depression with a number of anxiety disorders, substance disorders, and personality disorders (Perugi and Akiskal, 2002).

Another area of expanded diagnostic-related assessment involves violence. Violence is an issue of increasing concern that is being assessed in the NCS-R in several ways. For instance, we are evaluating the possibility that, as with the ICD and DSM criteria for depression among children and adolescents, irritability should be considered an alternative to dysphoria or anhedonia in evaluating the prevalence of depressive disorders among adults. Second, as noted in the last paragraph, we are including intermittent explosive disorder, which assesses anger attacks. Third, we are assessing hostility as a personality characteristic and the use of violence (in interpersonal relationships as well as in broader interactions) as a strategy for resolving disagreements. We are also collecting data on the number of Americans who carry weapons and who have recently been involved in physical fights.

An additional diagnostic assessment that was not included in the NCS is pathological gambling. The dramatic growth in the US of state sponsorship of gambling (for example, state lotteries) and legalization of gambling venues has led to a great deal of concern about government complicity in vice and the rise in problem gambling. We also know from a number of screening surveys that a substantial proportion of the population gambles regularly and that a meaningful number of these people have gambling problems (National Research Council, 1999; Toce-Gerstein, Gerstein and Volberg, 2003). However, no national survey has yet carried out a detailed evaluation of the prevalence of pathological gambling in conjunction with a larger set of potentially comorbid underlying mental disorders. This is being investigated in NCS-R. Detailed information

on gambling patterns and motivations for gambling is also being collected in order to study pathological gambling subtypes.

Comparative impairments of mental and physical disorders

In order to provide comparative information on the impairments of mental and physical disorders, a checklist of chronic physical disorders is included in the NCS-R interview schedule. The problem of under-reporting due to some people with chronic conditions not being aware of their disorders is dealt with for symptom-based conditions by using screening scales of these conditions in addition to the disorder checklist. Our plan is to carry out multiple regression analyses in which we study the separate and joint effects of these physical and mental disorders assessed in the survey on the dimensions of functioning assessed in the WHO-DAS. We expect to find, consistent with more superficial analyses in the baseline NCS (Kessler, Ormel, Demler and Stang, 2003), that mental disorders have effects on functional impairment that are as great or greater than those of most chronic physical disorders, that mental and physical disorders interact in their effects on functioning, and that a substantial number of the effects of chronic physical disorders on functioning are due to the more proximate effects of comorbid mental disorders.

Overview

Descriptive studies like the NCS and NCS-R are of more importance for psychiatric epidemiology than for other branches of epidemiology due to the fact that psychiatric epidemiology has traditionally been hampered by difficulties in conceptualizing and measuring disorders. The baseline NCS has been important in this way mainly because it helped provide accurate nationally representative descriptive data on the prevalence and correlates of mental disorders. However, as we expand the NCS-R in the ways described in this chapter, it is important to realize that the ultimate goals of epidemiology are to understand and control disease by empirically studying associations between variation in exposure to disease-causing agents external to the individual, variation in the resistance of individuals exposed to the disease-causing agents, and variation in resistance resources in the environments of exposed individuals. Although these investigations are

initially carried out by examining natural variations of the sort assessed in the NCS and NCS-R, we have to move beyond this initial step to develop hypotheses that can be tested in naturalistic quasi-experimental situations with matching or statistical controls used to approximate the conditions of an experiment. If the hypotheses stand up to these preliminary tests, they then need to be evaluated in interventions aimed at preventing the onset or altering the course of the disorders. These evaluations cannot be carried out with the NCS or NCS-R data.

This perspective on the role of the NCS and NCS-R suggests that they should be seen as a necessary step in the evolution of epidemiological research on mental disorders that provide a firm descriptive foundation for further analytic and experimental epidemiological research. The NCS and NCS-R can also be used to provide provisional tests of a number of hypotheses about psychosocial risk factors for the onset and course of mental disorders as well as about barriers to seeking treatment. As multi-purpose data-collection efforts, rather than focused investigations of single disorders, the NCS and NCS-R lend themselves to a great many descriptive and analytic purposes. As such, they should be considered resources for the field. Because of this fact, the NCS is archived for public use and the NCS-R will be archived in a similar way. Information about access to these public data files as well as the NCS technical reports can be obtained from the NCS Web page at <http://www.hcp.med.harvard.edu/ncs>.

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Correspondence: RC Kessler, Department of Health Care Policy, Harvard Medical School, 180 Longwood Avenue, Boston MA 02115, USA.
Telephone (+1) 617-432-3587.
Fax (+1) 617-432-3588.
Email kessler@hcp.med.harvard.edu.