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Drug treatment data as an epidemiological indicator: methodological considerations and improved analyses

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ABSTRACT

Data collected in drug treatment agencies have played a prominent role in informing policy makers. Such data often represent the only information collected regularly and consistently over a certain period of time. The first treatment reporting systems were introduced in countries in the late 1960s and early 1970s. In Europe, the 1990s was the most important period in terms of the standardization and widespread implementation of such reporting systems.

In the present article, the advantages and limitations of treatment reporting systems are discussed; the shortfalls of certain methodological approaches are also described. Despite its limitations, the treatment reporting system is a simple but powerful instrument for tracking the changing patterns of problematic drug use and, as such, is a valuable epidemiological tool.

As data need to be adequately exploited, a concrete four-step model is presented that analyses data with the aim of building incrementally upon the expanding knowledge base that exists with regard to drug use behaviour. Good knowledge of the local drug situation is essential to the sound interpretation of results.

The conclusion reached is that treatment data need to be supplemented by additional information from other indicators and from qualitative studies in order for that data to contribute to the still developing theory of trends in drug use behaviour.

Keywords: drug information systems; drug treatment; drug trends; epidemiology; statistical method.

Introduction

Reviewing epidemiological information systems on drug use behaviour reveals a great number of different indicators stemming from a variety of sources, including population surveys, the police and justice system, mental health institutions and specific research projects. In particular, data collected in drug treatment agencies have played a prominent role in informing policy makers about actual situations

and recent developments. In many regions of the world, such data often represent the only information collected regularly and consistently over a certain period of time.

Historical overview

Starting in the late 1960s and early 1970s, several countries introduced the first systems for collecting data from treatment institutions. In the United Kingdom of Great Britain and Northern Ireland, the Home Office launched the Addicts Index, requiring doctors to list patients whom they considered to be addicted to illegal drugs ([1], p. 186). In the United States of America, the first such system was set up in 1972, collecting data on the admission and discharge of clients from federally funded treatment programmes ([2], p. 3). Also in 1972, the Mental Health Reporting Programme was introduced at the national level in Indonesia, making it possible to question all patients from 35 mental care institutions in that country ([3], p. 267). In 1976, the territory of Hong Kong started its Central Registry of Drug Abuse ([3], p. 273), utilizing a wide range of sources that included treatment data and information from law enforcement and welfare agencies. A similar but more comprehensive system was established in Malaysia in 1977 [4]; again, law enforcement agencies (such as the police, prisons and customs) were the focus, but treatment institutions (including hospitals, private doctors, offices and rehabilitation centres) were also included. At that time, similar case registry systems existed in many communist countries, although the information contained in them was rarely used for epidemiological research.

In Europe, the 1980s saw the introduction of several specialized treatment reporting systems in different countries:

(a) In Germany, the treatment-unit-based information system known as the einrichtungsbezogenes Informationssystem (EBIS) was set up in 1980 [5];

(b) In the Netherlands, the Central Methadone Registry was introduced in 1980 and the National Information System on Alcohol and Drugs (LADIS) was set up in 1986 [6];

(c) In Spain, the Sistema Estatal de Información sobre las Toxicomanías (SEIT) was established in 1987 [7];

(d) In the United Kingdom, the Drug Misuse Database was developed in Manchester in 1986 and used at the national level in 1990 [1].

While such developments were taking place, pilot studies were being undertaken with the aim of establishing a European standard for treatment reporting [8, 9].

Standardization

In Europe, the 1990s represented the most important period in the standardization and widespread implementation of treatment reporting systems. The

Treatment Demand Protocol, for example, was developed within the framework of the activities of the group of epidemiology experts in drug problems of the Pompidou Group of the Council of Europe.* The aim of the protocol for treatment reporting systems, the first that is Europe-wide, was to provide professionals and researchers with a standardized methodology for collecting and reporting core data on the profile of drug users in contact with treatment services, so that the data would be comparable between different treatment services, cities and countries [11]. The main steps towards producing the final protocol included a pilot study carried out in 1991 in Dublin and London, a developmental project with the participation of 11 cities, and several meetings of the expert group where standard definitions, a core data set for a model questionnaire and data collection procedures were agreed upon. The protocol was finalized in 1994 [12].

The Treatment Demand Protocol received further attention in Europe with the establishment of the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA), which placed a Europe-wide treatment demand indicator among its first priorities. The Pompidou Group protocol and the experience gained through its application served as a starting point for the initiative of EMCDDA in the late 1990s to harmonize treatment reporting systems in Europe. In 2000, the joint EMCDDA and Pompidou Group protocol was published [13, 14]. That protocol introduces all core definitions and provides extensive methodological guidelines. It offers the most up-to-date and comprehensive guidance for the establishment of a treatment reporting system. The present article, therefore, focuses on issues other than the practical ones addressed in the protocol.

Implementation at the municipal and national levels

Producing a protocol in itself is not enough: a guarantee that it is implemented and used later for international comparisons is also necessary. For that reason, the Pompidou Group initiated a six-year project in Europe, beginning in 1991. In that project, the treatment demand protocol was implemented in an increasing number of countries in Eastern and Western Europe, primarily at the municipal level. In addition, data checking routines and internal consistency checks were developed. The computer programs checked for answers that were out-of-range or inconsistent and those that represented impossible combinations. Data aggregation at the municipal level was simplified and unified by provision of another small program. Guidelines for data reporting were made available in spreadsheet format to automate the calculation of percentages and minimize possible mistakes. Over the years, data from major cities across Europe were compiled in six annual reports.

*The Pompidou Group, formed in 1971 and operating within the framework of the Council of Europe, provides a forum in which it is possible to discuss and exchange information and ideas on a range of problems concerning drug use and drug trafficking. There are more than 40 members of the Pompidou Group, including all of the States in Western Europe and many of the States in Central and Eastern Europe. The main tasks and obejctives of the epidemiology expers are to improve the quality and comparability of data on drug use and to collect, monitor, compare and interpret trends in drug use in Europe [10].

In the first year (that is, comprising data from 1992), nine cities provided data; in 1997, more than 20 cities from all over Europe were covered and data were compiled and analysed in a final project report [15]. Besides annual data reports presenting basic descriptive statistics, more detailed analyses were conducted and results were exchanged at annual meetings. Three volumes of proceedings show many interesting examples of such analyses. The papers focused on methodological aspects of treatment reporting (such as the reliability of self-reporting), the practical implementation of a treatment reporting system, drug use patterns (including the evolution of new use patterns in Eastern Europe) and trends comparing findings at the municipal and national levels.

Since 2000, the new joint protocol of the Pompidou Group and EMCDDA has been implemented at the national level in all member States of the European Union, in many more countries in Central and Eastern Europe and in major cities of the Russian Federation. Results comparing national levels are published as part of EMCDDA annual reports on the state of the drug situation in Europe [16].

Outside Europe, treatment attendance data play a considerable role in several community epidemiology work groups, modelled on the Community Epidemiology Work Group based in the United States and established in 1976 [17], including the Epidemiologic Surveillance System of Addictions in Mexico; the Canadian Community Epidemiology Network on Drug Use; the South African Community Epidemiology Network on Drug Use; the Asian Multicity Epidemiology Program on Drug Abuse; and the Queensland Community Based Drug Reporting Working Groups in Australia. In a comprehensive and easy-to-read document, all indicators used in those systems, including treatment data, are presented and explained in detail [18].

Methodological considerations

Both the original Pompidou Group and the new joint protocol of the Pompidou Group and EMCDDA share major methodological principles. All starting treatment episodes over one year are collected (such collecting involves full coverage and does not allow sampling). In that sense, it is an event reporting system [3], although it goes a step further, as only one episode per person is actually reported. Controlling such a variable is normally done within a treatment centre using personal identifiers. In various centres, a generic code that includes date of birth, age, gender and initials is used. Ideally, a reliable register of individuals is the result. Treatment is broadly conceptualized to allow the inclusion of all drug users with institutional contacts.

Advantages

In principle, treatment data provide results on two levels: a direct measurement of the demand on treatment services and an indirect measurement of trends in drug use. Treatment data provide an insight into what sorts of clients go to which services for service planners and treatment providers. In addition, they provide a

basis for evaluating attempts to attract particular subgroups into treatment. With sufficient coverage, such data provide the actual incidence of treated drug use and—if data on treatment admissions are complemented with a yearly census of the population undergoing treatment—treated prevalence. Data on first treatment demand can also indicate changing patterns of more severe, problematic drug use in the communities or populations ([12], p. 5). In that respect, they provide a complement to the results from the general population and school surveys. The latter provide an overall picture of, for example, lifetime drug use, as no information is typically available about different patterns of drug use (such as routes of administration or combinations of different drugs). Furthermore, because the use of heroin or cocaine is rare in most countries, very little information about problematic drug use is available. In contrast, comparing profiles of drug users and drug use patterns in different treatment centres, regions or cities, taking into consideration reporting years and age cohorts, can provide a detailed picture of drug users in treatment centres.

It is important to distinguish first treatment admissions from subsequent, or repeated, ones. Tracking changes among those having received treatment for the first time can indicate new developments. To that end, the period of time between the first use of the primary drug and the first treatment needs to be followed carefully. Findings suggest that some subgroups with a shorter period of time between the two stages indicate evolving trends in the drug user population.

In summary, treatment data provide a great deal of relevant information on the actual situation and prevalent trends within the group of problematic drug users. The treatment indicator is the best developed indicator. It is easy to implement, because it fits readily into the routine administration at the beginning of a treatment. It can be adapted to different situations, such as treatment modalities, or cities and countries. The size of the instrument used by the Pompidou Group (it fits on a normal size page) partly explains its success. Larger instruments involve more work and prevent many treatment centres from participating. There is often a conflict between the researchers, who look for more data, and treatment personnel, who are reluctant to collect more. One possibility for addressing such a dilemma is to work with different modules: the core module could be filled in for all clients, while additional questions could be used for a (defined) sample only.

The cost of data collection is low, as much of the information needs to be collected and recorded as part of the treatment procedure. The low cost means that continuous collection of data for treatment related information is possible. For most other data sources, including surveys, such data collection would be impossible. However, of perhaps greater importance than cost is the continuity over almost 10 years and the dedication of several individuals within the Pompidou Group in implementing and continuously improving the indicator. In general terms, close contact and regular communication between data collectors or researchers and (potential) users of results are a prerequisite to a successful system. Systematic and ongoing collection, analysis and result reporting of treatment related data within a monitoring system offer a stable and long-term means of data collection. Those elements increase validity and make trend analyses possible.

Limitations

Firstly, given that there can be a delay or time lag, sometimes of several years, between the first time a drug is used and the first demand for treatment ([12], p. 6), any very recent developments are excluded. It is important to note that, in some regions, such a time lag is less than two years; even if it is longer, it applies to the overall population. Given a mean of, for example, six years, approximately one third of the first treatments can be administered within up to three years after their first use. Again, comparing different subgroups of the treated population is important. Nevertheless, changes in the time lag are crucial. A change between different reporting years may be traced back to the introduction of new treatment approaches or new drug trends. If new treatment centres attract those drug users who have not previously been in contact with a treatment centre, the effect may be an increase in the mean time lag. That may cause an overestimation of certain trends, including trends in the mean age of the treated population or changes in the pattern of drug use. In such a situation, adequate analytical techniques are important in helping to distinguish between observed and real effects.

The proportion of the population of drug users included is dependent on the treatment facilities available in different countries, on the accessibility of the centres and on existing waiting lists. Changes in treatment policies, which influence availability and accessibility of treatment, can also have an important impact on treatment data. That means that with the establishment of, for example, methadone programmes attracting mainly long-term heroin users, changes in the group studied are bound to occur. If the coverage is restricted either to State-owned specialized or residential treatment centres, for example, an important part of the information is probably missed. Usually institutions run by non-governmental organizations are reluctant to collect and communicate data. General practitioners involved in the treatment of drug users constitute another group that is not always willing to cooperate. Inadequate coverage can be addressed in two ways: by making data collection compulsory by law or by convincing all treatment managers (individually or as a group) to provide data. If coverage cannot be complete (which will usually be the case), several responses are necessary. First, a complete and updated list of all treatment centres is indispensable. Most treatment agencies collect basic data and provide figures in annual reports. Those results can be used to assess potential differences within the population covered (for example, age, gender and drugs used). It may be possible to influence those collection agencies to collect more data. If they are not willing to collect information continuously, they might agree to collect for a sample only (such as a random sample or for a period of one month each year). All such information enables the assessment of existing biases. There again, changes are more important than continuous underreporting.

A further problem is that drug users often attend different treatment centres in the course of one year. That leads to double counting, overestimation of the total treatment demand and possible biases in several variables. Many possibilities exist to avoid double counting; the easiest at first glance would be to create a case

register. Not all countries have the possibility of using a national identification system (registry), owing to practical constraints (such as high costs), legal problems (including confidentiality issues) or lack of trust (for example, some drug users may be afraid of the misuse of data). In the guidelines [12], a code consisting of an individual's initials, date of birth and gender is proposed which is distinctive but which conceals that individual's identity. Such a code or something similar is used successfully in many places. It is important to remember that it is not necessary for the code to be fully successful in eliminating all double counting. The objective is to reduce the probability of double counting to a level that gives a reasonably accurate count of the number of treatment admissions in a given year.

On a more general level, it is important to take into account that the data come from treatment reporting systems. Possible conclusions are, therefore, limited to generalizations about the treated population. As in any other study based on treatment statistics, the hidden or out-of-treatment population is excluded. For that reason, treatment data need to be supplemented with qualitative data (for example, snowball sampling, observation or other ethnographic research methods) as well as other indicators (such as drug-related deaths, data about infectious diseases and police arrests).

Other problems, apart from those involving the indicator itself, include, for example, the process of data collection, analyses and presentation of results. Like any other routine statistics, the administration of the project exploits most of the available resources. Normally, the time available is not sufficient for further and deeper statistical analyses. That situation weakens the possible benefit of the treatment reporting system and requires additional effort, at the municipal as well as at the international level. Much more information is available than most experts actually use.

Finally, the general limitations of the chosen methodological approach must be acknowledged. As the study is restricted to starting treatment episodes, an outcome measurement is not possible. In addition, the questionnaire utilized is not a clinical instrument; thus, no diagnoses are generally recorded. For those reasons, further instruments would be necessary (see, for example, the Maudsley Addiction Profile [19] or the Addiction Severity Index [20]). As no register of all people in treatment exists and no assessment of the waiting list is made, the information on the actual treatment demand is inadequate. Such information, however, can be added using other modules. Furthermore, treatment data collected during administrative procedures are no substitute for thoroughly designed research instruments. Such data, therefore, will not be able to explain, for example, why people use illicit drugs. To summarize, the treatment reporting system is a simple but powerful instrument for tracking patterns of problematic drug use and as such is a valuable epidemiological tool.

General lack of analyses

It is important to recognize that the analysis of treatment data requires more than descriptive tables and graphs. Much more can be and needs to be done.

Significant resources are invested in the development and running of treatment reporting systems. Ideally, equally significant resources should be invested in the actual use of the collected data. Treatment data still represent a major source of information with regard to epidemiology. Such data, however, need to be exploited adequately. Having reliable data is essential to any statistical analysis. Another prerequisite is a researcher's comprehensive knowledge of the data relevant to the research being undertaken. The use of statistical software programs does not replace competent statistical analyses.

Why statistical analyses?

The rationale for using statistical methods to analyse treatment data is sometimes questioned. It can be argued that, on a general level, real data are random. Suppose, for example, that there is a difference in mean age between groups with different patterns of drug use. Statistical analyses can indicate how significant such a difference is. Furthermore, the difference in the mean age may be attributed to other causes, such as a selection effect owing to insufficient coverage of specific treatment modalities. To reduce such threats, statisticians have developed techniques that control for the difference in other variables. The latter refers to analyses concerned with the comparison of more than two variables, called multivariate analyses, controlling for group differences and spurious relationships.

More specifically, in the field of treatment data, it is important to emphasize that treatment monitoring systems do more than mere bookkeeping. As with any other routine statistics, administration of the project exploits a large part of the available resources. That weakens the possible benefits of such a system. Much more information is available than most system managers actually use. It is important to frame specific questions, with the intention of pursuing specific answers. For that reason, it is not sufficient to be content with describing frequency distributions. It is essential to develop concrete hypotheses and test them. Similarly, annual result reporting is not sufficient: building incrementally upon an expanding knowledge base should be the broad aim in analysing treatment data.

Four steps to analysing data from treatment reporting systems

Reliability of data

An important prerequisite to any statistical analysis is the reliability of the data. The first stage is to agree on uniform key definitions, that is, to use definitions that are well known and used in all treatment centres. That requires continuous training efforts. An important element here is regular feedback on the quality of data and results. Data collectors aware of the potential uses of treatment monitoring are likely to support the idea and contribute to rigorous data reporting.

Reported data need careful checking, a process known as data cleaning. For example, if a multiple answer was given where only one answer was possible, either a missing value needs to be assigned or a decision needs to be made about applying a clear rule when recoding takes place. If a question concerns an

individual's living situation and the answer given is both "alone" and "in an institution", the decision can be made to recode all such answers as "in an institution". It is then necessary to verify that only valid answer codes have been used (for example, checking that an answer such as "six" is not given to a question concerning employment status, where there are only three possibilities). The verification stage also includes conducting consistency checks and inspecting out-of-range data in continuous variables. The most reliable method is computer-assisted data collection, that is, using specific software for data input, data checking and reporting.

A statistics program is strongly recommended. Such a program involves defining the data by attaching meaningful labels to variables (that is, questions) and codes. It is important to remember that even correct data can be wrong. The assumption underpinning treatment monitoring systems, for example, is that self-reporting by drug users is valid—an assumption, in fact, that is supported by evidence. Nevertheless, specific studies that question and test the validity of data are helpful and can provide essential details.

Descriptive analysis

Statistical analyses should begin with basic analyses, illustrated in the following steps:

(a) Computing frequency distributions on all variables; summarizing data using measures for central tendency (mean, median) and variation (standard deviation, range);

(b) Cross-tabulating the most important variables (for example, route of administration by primary drug, level of education by injecting behaviour);

(c) Visualizing the results and using graphs to gain more insight into the data.

The steps of the basic analysis outlined above should lead to a thorough understanding and knowledge of the data set in question and can be considered a prerequisite to advanced statistical analysis. The ease of using statistical software, however, should not lead to conducting tests indiscriminately, simply because they are available and easy to run. Good results and sound interpretation are unlikely to come from such efforts.

Testing hypotheses (bivariate and multivariate analysis)

At the stage of testing hypotheses, the data set should have been verified and the data themselves should be completely familiar. Testing hypotheses at the bivariate level can begin, as can undertaking more advanced statistical analyses. As treatment data are collected consecutively over years, most analyses will deal with changes over years, or trends. Some analyses involve describing frequency distributions, as well as testing hypotheses. A few good examples include: Smyth and others [21], who show the change in the route administration from injecting to smoking heroin reflected in their treatment reporting system in Dublin; de la

Fuente and others [22] followed the same question, comparing different regions in Spain; Falcato and others [23] showed the impact of the closure of an open drug scene for Zurich, Switzerland; Agar and Schacht Reisinger [24], in a wide-ranging account of some important developments in heroin use in the Baltimore area, in Maryland, United States, showed how important regional and local breakdowns of collected data are. Certain trends, for example, may show up only in the inner city or in the suburbs. To that, further breakdowns as age cohort or cohorts of calendar years of first drug use could easily be added.

Interpretation

Good knowledge of the local drug situation is essential to the sound interpretation of results. Treatment data need to be supplemented with additional information from other sources. As for any study based on treatment statistics, the conclusions should be restricted to the treated population, or restricted to those involved in the study. It is always necessary to cross-check results with information from other sources, such as expert opinions, surveys, police data and information from field observation. It is also necessary to conduct qualitative studies that can fill in the detail of the picture of current drug use. The complementary use of quantitative and qualitative methods is crucial to the development of effective responses to drug use. Close links with ethnographers and other field researchers can both help interpret results and provide ideas for further analysis. Again, the work of Agar and Schacht Reisinger [24] is important. They combined and cross-checked different indicators with qualitative information from mass media and oral accounts from students.

A new project supported by the Council of Europe develops those ideas [25]. The project looks (retrospectively) for important trends found in treatment data from cities and tries to describe and explain them in detail. The project takes an epidemiological perspective, using treatment data as an indicator for drug-related problems in cities (for example, incidence and prevalence of high-risk use and morbidity). The aim is to develop detailed descriptions of emerging trends and explanations of those trends. It is hoped that the project will contribute to the developing theory on trends in drug use [26, 27].

Conclusions: combining with other indicators and further information

In the field of drug use epidemiology, treatment-based indicator data remain a source of some of the most valuable information available. The collection of such data is relatively easy and cost-effective and can be combined readily with the administrative work of personnel involved in the treatment process. Accepting the methodological framework and analysing in detail the growing body of data can give a wealth of important and useful information.

Among the observations made, it was noted that treatment data need to be supplemented with information from other indicators to allow for sound

conclusions to be drawn. There are several frameworks that describe in detail the combined use of different indicators [9, 18]. Most of them, however, remain on a purely descriptive level, presenting data from all indicators either in parallel or consecutively. In contrast, Hartnoll [28] cross-validates information from different indicators to an extent, although the result remains descriptive and restricted to the macro level of data (that is, the data are not broken down). In some chapters in the third multi-city study of the Pompidou Group [29] (in particular, those sections written by Uwe Kemmesies), correlations between different indicators and different groups of countries are analysed. A model of epidemiological stages is also explored. Further efforts, nevertheless, continue to be necessary, in order to explore trends in drug treatment data and to use different kinds of breakdowns (including age, primary drug, route of administration and calendar year of first use).

As for any study based on treatment statistics, the hidden population is excluded. Access to such users can be gained using, for example, snowball sampling. Experience shows that in many cities, there is a pressing need to develop a more detailed understanding of patterns of drug use. Such an understanding is unlikely to come from quantitative methods alone. What is required is the implementation of qualitative studies. The complementary use of quantitative and qualitative methods is crucial to the development of effective responses to drug use [30]. Once again, the work by Agar and Schacht Reisinger [31] deserves mention: results are cross-checked with their independent analysis of all indicators and many other sources of information, comparing them with different parts of the country and assimilating the elements into a preliminary theoretical model of trends in drug use behaviour. The latter is especially exceptional in the field, where descriptive analyses and fractional testing of arbitrary hypotheses still prevail. Only by formalizing knowledge and testing it with real data will our understanding about changing drug use behaviour successively increase.

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