Santé mentale au Québec

A Registry Based Approach to Suicide Research: Opportunities and Limitations in the Norwegian Population Representative Registries

Opportunités et limites des registres populationnels norvégiens pour la recherche sur le suicide

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Article abstract

Together with the other Nordic countries, Norway stands in a unique position internationally with its large population representative registries. By means of unique personal identification numbers assigned to all Norwegian citizens, as well as to immigrants who stay for more than 6 months, it is possible to construct individual record linkages covering an increasing number of years across different national registries. The Norwegian registries include, among others, information from the primary and specialist health care services, the prescription of drugs, and causes of death. In addition, they include sociodemographic information like year of birth, gender, immigration status, educational attainment, marital status, and the use of various social benefits. Norway is one of very few countries that have a nationwide registry on primary health care use. This registry gives the opportunity to explore the role of the primary health care services prior to suicide and in the follow-up of the suicide bereaved, which has been pointed out as one of the most promising areas for future suicide prevention. Linkages of Norwegian registries opens up new approaches in analyses and the possibility to explore a range of novel research themes, such as treatment trajectories and patterns of health care use prior to suicide and among the suicide bereaved.

In this paper, we give a description of the Norwegian population representative registries applicable for suicide research. We discuss the analytic opportunities as well as the challenges and obstacles of a registry based research approach to suicide.

The main strength of registry-based research on suicide is the ability to maintain data on the total population, the possibility to study small sub-populations or low-prevalent events, virtually continuous timelines in longitudinal data, few or no non-response or other missing data, no sample attrition, and the possibility of gaining access to large amounts of various health and sociodemographic information. In addition registry-based research allows investigation of hard-to-reach populations, such as groups of individuals with severe mental disorders or immigrants that traditionally have been difficult to recruit for participation in research projects.

The opportunities presented in the article could motivate to do similar research in Canada and even inspire for cooperation between Norwegian and Canadian researchers on registry based research on suicide. In our opinion, registry-based research on suicide will play an increasingly important role in suicide research in the years to come.

A Registry Based Approach to Suicide Research: Opportunities and Limitations in the Norwegian Population Representative Registries

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ABSTRACT Together with the other Nordic countries, Norway stands in a unique position internationally with its large population representative registries. By means of unique personal identification numbers assigned to all Norwegian citizens, as well as to immigrants who stay for more than 6 months, it is possible to construct individual record linkages covering an increasing number of years across different national registries. The Norwegian registries include, among others, information from the primary and specialist health care services, the prescription of drugs, and causes of death. In addition, they include sociodemographic information like year of birth, gender, immigration status, educational attainment, marital status, and the use of various social benefits. Norway is one of very few countries that have a nationwide registry on primary health care use. This registry gives the opportunity to explore the role of the primary health care services prior to suicide and in the follow-up of the suicide bereaved, which has been pointed out as one of the most promising areas for future suicide prevention. Linkages of Norwegian registries opens up new approaches in analyses and the possibility to explore a range of novel research themes, such as treatment trajectories and patterns of health care use prior to suicide and among the suicide bereaved.

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KEYWORDS national registries, suicide, suicide bereaved, primary health care, health care use, treatment trajectories

Opportunités et limites des registres populationnels norvégiens pour la recherche sur le suicide

RÉSUMÉ La Norvège, à l'instar des autres pays scandinaves, occupe une position internationale unique avec ses grands registres populationnels. Grâce à un numéro d'identification personnel attribué à chaque citoyen norvégien, de même qu'à tout immigrant depuis plus de six mois, il est possible de créer des dossiers individuels par le jumelage des différents registres nationaux, et couvrant un nombre toujours croissant d'années. Les registres norvégiens livrent, entre autres, de l'information sur les services des médecins de famille et des médecins spécialistes, la prescription de médicaments et les causes de décès. De plus, ils incluent des données sociodémographiques comme l'année de naissance, le genre, le statut d'immigration, le niveau de scolarité, le statut matrimonial et les avantages sociaux.

Cet article décrit d'abord ces registres populationnels en rapport avec la recherche sur le suicide. Il présente ensuite les différentes opportunités d'analyses de même que les défis et obstacles de la recherche sur le suicide basés sur de tels registres populationnels. Dans le cadre d'un programme de recherche en cours à l'Institut norvégien de santé publique, nous avons jumelé les données de cinq registres nationaux différents pour étudier l'utilisation des services de santé de première ligne en rapport avec le suicide. Les services médicaux de première ligne étant les services de santé les plus accessibles, les médecins de famille pourraient jouer un rôle important dans la prévention du suicide. Même si de nombreuses études internationales ont examiné les contacts avec les médecins de famille avant le suicide, plusieurs questions de recherche demeurent. Nos travaux poursuivent deux lignes de recherche. Premièrement, nous examinons l'étendue et les causes des contacts avec les services de première ligne avant le décès par suicide dans la population norvégienne. Deuxièmement, nous nous concentrons sur les endeuillés suite à un suicide, et leurs contacts avec les médecins de famille, avant et après le décès de leur proche. Nous examinons, par exemple, comment ces contacts avec les services varient selon les caractéristiques sociodémographiques des endeuillés et de leur proche décédé par suicide.

La grande force de la recherche sur le suicide basée sur des registres populationnels est la quantité et la richesse des données qui autorisent l'exploration de thèmes qu'il n'était pas possible de réaliser avec des modèles plus traditionnels. Les opportunités ici décrites pourraient intéresser la recherche sur le suicide au Canada, et même inspirer une coopération entre les chercheurs norvégiens et canadiens pour une telle recherche basée sur les registres populationnels. À notre avis, la recherche sur le suicide avec les registres populationnels est appelée à jouer un rôle croissant dans les prochaines années.

MOTS CLÉS registres nationaux, suicide, deuil suicide, première ligne, accessibilité soins, santé, trajectoire traitement

Background

Suicide is a significant public health problem and continues to be among the primary causes of premature death worldwide, particularly among men[1]. In Norway approximately 550 individuals die by suicide and some 6,000 attempt suicide each year[2]. For each suicide or suicide attempt, there are typically six to ten relatives affected, amounting to a population of about 60,000 individuals each year[2]. The sheer size of this population suggests that the consequences to society are far-reaching in terms of lives lost, and the costs of treatment and follow-up in health care and welfare services alike.

Historically, the majority of studies on suicide have been based on small samples with a psychological autopsy design[3]. During the last two decades, a sharp rise in studies applying large registry data has been observed. "A registry is defined as a complete listing of information in which each individual should be identifiable for updating of information"[4]. A base-registry defined as a registry that defines and identifies basic statistical units in a population such as births, marriages and deaths etc, is a typical example of a registry, whereas samples and anonymized complete listing of individuals are not[5]. Health administrative registries and patient registries that are individual identifiable and possible to update are other examples of registries. Registry based research includes study designs ranging from analyses based on a single registry to large linkages of multiple registries. Registry based research does not exclude use of other relevant data (hybrid-design)[6] such as data from research studies in addition to data from the registry.

The advantages of registry-based research to understand suicide are numerous[5]. To mention a few, registries offer the ability to maintain data on the total population, the possibility to study small sub-populations or low-prevalent events, virtually continuous timelines in longitudinal data, few or no non-response or other missing data, no sample attrition, and the possibility of gaining access to large amounts of various health and sociodemographic information[5]. In addition registry-based research allows investigation of hard-to-reach populations, such as groups of individuals with severe mental disorders or immigrants that traditionally have been difficult to recruit for participation in research projects[7].

The evolvement of registry-based research on suicide has led to a host of insights that are now possible to explore by linking information from a range of differing data-sources. To mention some examples, Danish researchers explored the high suicide rates observed in urban areas and found that this trend was eliminated and even reversed when taking in account a range of background variables such as marital status, income, ethnic differences and psychiatric status[8]. More detailed knowledge of how different risk factors for suicide relate to individual characteristics have also been explored with registry data, showing among other things that being a parent to small children was a protective factor in women but not in men, whereas unemployment and being single were risk factors only among men[9]. Urban living increases the suicide risk among women but reduces the suicide risk among men[8]. An increase in the use of registry-based data sources was also observed by our research team in a recently published review study[10], showing that the number of registry-based studies on contact with primary health care prior to suicide had increased dramatically compared to a similar review from 2002[11].

In the context of registry-based research, Norway and the other Scandinavian countries stand in a unique position internationally[5,12]. All the Scandinavian countries have nationwide health and administrative registries with long histories, which provide unique opportunities to conduct medical and psychological research on large cohorts over long time periods with complete follow-up[12]. The nationwide national registries contain information on nearly all residents, making it possible to study conditions with low prevalence such as suicide with sufficient statistical power. The unique personal identifier assigned to all Norwegian residents makes it possible to construct individual record linkages between the different registries, encompassing among others the use of primary and specialist health care services, mortality, the use of different welfare services, in addition to various demographic and socioeconomic characteristics[13,14]. The registries also contain family identification numbers, which makes it possible to identify family relations and hence gives the opportunity to study the suicide bereaved. Norway is also one of very few countries that have a nationwide registry on primary health care use. This registry allows us to explore the role of the primary health care services prior to suicide and in the follow-up of the suicide bereaved, which has been pointed out as one of the most promising areas for future suicide prevention[10,11]. Linkages of Norwegian registries opens up new approaches in analyses[15] and the possibility to explore a range of novel research themes, such as treatment trajectories and patterns of health care use prior to suicide and among the suicide bereaved.

Aims

In this paper, we present the registry-based data sources available for suicide research in Norway. We discuss the analytic opportunities as well as the challenges related to registry-based research on suicide.

Data sources

In Norway, we have four large national health registries with relevance for suicide research. These mandatory national health registries were established to maintain national functions such as health analysis, health statistics, improving the quality of health care, research, administration and emergency preparedness. All the databases contain complete data on every recorded individual and are person identifiable which allows linking to other registries.

Below follows an introduction to each of these registries, alongside data sources for sociodemographic information.

The Norwegian Cause of Death Registry

The Norwegian Cause of Death Registry provides information about the cause and date of death of all Norway residents including those who die abroad. The official cause of death statistics are based on death certificates filled in by medical doctors and are prepared in accordance with the International Classification of Diseases (ICD-10)[16]. The death certificates filled out by the doctors are then run through a semi-automatic coding program "Automated classification of medical entities" (ACME) module in the software program Iris[17] which selects the underlying cause of death according to the rules set by the World Health Organisation (WHO). Roughly 50% of the underlying causes of death in the Norwegian Cause of Death Registry is determined by ACME whereas the other half is determined manually by professional medical coders (nosologists)[18]. To ensure that the Cause of Death Registry provides valid data, the diagnoses on the death certificate are examined and controlled to check that they are plausible for a person of the specified age or sex. The data in the Norwegian Cause of Death Registry is of high quality and covers about 98% of all deaths in Norway[18].

Norwegian Prescription Database (NorPD)

The NorPD was established in 2004 by the Norwegian Institute of Public Health. The aim of NorPD is to collect and process data on drug consumption by humans and animals in Norway in order to map and monitor usage trends over time. NorPD also aids health authorities in quality control of drug use and in planning with regards to drug policies. In addition the registry is used in internal control and quality improvement with regards to prescription practices. NorPD receive monthly reports on all prescriptions and requisition from all Norwegian pharmacies[19]. Drugs sold over-the-counter are not recorded in the registry. Drugs supplied to hospitals and nursing homes are also included, but not at an individual level. The NorPD includes information about dispensing date and type of drug, coded according to the Anatomical Therapeutic Chemical classification system (ATC)[20]. The ATC system classifies the drug substances into groups at 5 levels. Level 1 specifies the organ or system on which the drug has an effect whereas level 5 specifies the chemically active substance. Level 2-4 specifies pharmacological sub-groups.

The Primary Health Care Database (KUHR)

The KUHR-Database contains data on claims for reimbursement of fee-for-service among GPs and specialists in emergency units and in primary health care services since 2006. Each registration in the KUHR-Database contains the date of contact, tariff codes reflecting type of service provided, and one or more diagnosis according to the International Classification of Primary Care version 2 (ICPC-2)[21]. The ICPC-2 is a specially developed system for recording encounters in primary health care. The system allows classification and registration of the reason of the encounter, specification of a problem/diagnosis according to the ICD-10 and the intervention executed. The KUHR-Database also contains information about the responsible health care provider (type of health care, speciality, municipality), information about the patient such as sex, age, and home address as well as the date and time for the treatment.

Norwegian Patient Register (NPR)

The NPR covers both inpatient and outpatient treatment in the specialist health care services since 2008. The registry also provides information on time from referral to start of treatment in the specialist health care services. It includes among others consultation dates and diagnostic information according to the ICD-10 coding system[16]. In addition, the registry contains data on the patient's living situation and care outside the hospital.

Sociodemographic information

Various kinds of background information is available from Statistics Norway, providing nationwide and individual identifiable administrative registries covering all years with data in the health registries above. Demographic information is retrieved from the Central Population Registry. This includes date of birth, sex, marital status, immigrant status, geographical information and the identity of family members, making it possible to link family and household members. This opens up for studies of family relations and more detailed and sophisticated analyses such as sibling designs. *The National Welfare Database (FD-Trygd)* provides information about employment histories, income, sickness absence histories, as well as diagnoses for individuals granted disability pension. *The National Educational Database* includes information on educational attainment, educational activities and grades.

Analytical opportunities

The analytic opportunities in registry based research is highly related to the main advantages of registries such as access to a large population representative sample, with long follow up and potential to link a range of variables from other data-sources if necessary. Perhaps the most important advantage in registry based research is the potential to study associations between rare exposures and rare outcomes in a very large population with almost complete follow up[6]. Access to large parts or the whole population really distinguishes the registry based design from other research designs. Suicide is a low prevalent event and even in very large population representative studies such as the well-known Nord-Trøndelag Health Study[22] very few suicide victims are identified[23].

The Norwegian Cause of Death Registry contain data on 98% of all deaths in Norway and gives access to a very large population of suicides over a time period of at least 40 years. This allows for a range of analytic opportunities.

First, the length of time covered in the Cause of Death Registry would make it possible to study long term health outcomes of suicide bereavement. Relatives to suicide victims could be identified by family numbers and information on health and socioeconomic outcomes could be collected from KUHR, NPR, NorPD and FD-Trygd. This design would allow to explore both short and long term risks associated with suicide bereavement such as death, somatic and mental morbidity or work participation. A registry linkage has already been used with success in the study of bereaved parents[24]. In this study they compared parents who lost a child during its first year of life (bereaved) to parents of infants who lived beyond its first year (non bereaved). Analyses of the data from this registry linkage revealed that the bereaved mothers had four times as high risk of death 15 years after the loss of her child compared with the non bereaved mothers. Moreover, an increased mortality with risk ratios of 1.5 and 1.2 was even observed 25 and 30 years after the loss respectively.

Second, the Norwegian registries are well suited for exploring health care use in the suicide bereaved, in patients with high risk of suicide and health care use prior to suicide. As an example Norwegian researchers linked data from the Cause of Death Registry to KUHR in order to investigate patterns of health care use prior to suicide[25]. In line with previous research[10] they found that 80% of males and 89% of females suicide victims had consulted primary health care within a year of the suicide. Corresponding rates one month prior to the suicide were 35% and 46% respectively. What sets this study apart from the majority of previous publications in health care use prior to suicide was that the Norwegian study included the rest of the Norwegian population as controls. Comparison to the population controls revealed that suicide victims had higher contact rates with primary health care at both time points. In addition, the large data set allowed for analyses of suicide victims with and without prior mental health contact. These analyses showed that suicide victims without prior mental health contact only had a modestly higher contact rate compared to controls. Both controls and suicide victims with prior mental health consultations had contact rates well above those without. This pattern was found for both sexes.

Third, the Norwegian registries would be perfectly suited to study the impact of suicide prevention campaigns or GP training programs. Linking data from the Norwegian cause of death registry to KUHR and the Norwegian prescription registry would allow for analyses of the timing of the suicide preventive measures and its direct impact on the following suicide rates. Danish registry data has already been used extensively to study the association between use of antidepressants and suicide rates in the population[26-28]. As an example the decreasing suicide rates observed from 1995 to 1999 in Denmark was studied in a registry linkage study among 400,000 who had used antidepressants compared with over 1,000,000 controls[27]. The study concluded that multiple factors had contributed to the decreasing suicide rates observed in the population, but the most pronounced decrease was observed among those who used antidepressants.

Fourth, the Norwegian registries would be well suited to study suicide risk among hard to reach populations such as immigrants. Study designs that rely on recruitment of participants would risk ending up with small to moderate samples with high risk of sampling bias. Norway has a relatively large immigrant population, and during the years from 1990 to 2015 more than 140,000 refugees have been granted residence[29]. With near complete data of cause of death and health care use of immigrants and the general population alike, it is possible to compare suicide risk, health care use, predictors of work participation and the like with regards to immigration status.

Another hard to reach population is young men who commit suicide with no prior history of mental health problems and with low contact rates with health care services[30]. Several studies have shown that a sub-group of suicide victims are young men with no recorded history of mental disorders, with high educational attainment and a high grade of work participation[31-33]. Linking data from several of the Norwegian registries could provide the opportunity to describe what characterizes this population and to identify alternative approaches to reach this group.

Challenges in registry based research

Even though registry based research on suicide has many advantages, one must keep in mind that there are numerous challenges involved[5,12,34,35]. First, it is challenging to gain access to each registry. A host of complicated legislations that are unique for each of the data sources further complicates the process. Linkage is even more difficult and often the Regional ethical committees, the Data inspectorate and each registry owner must give their approval before linking of the different data sources can be done[12]. This often involves a compromise in sample size, number of variables linked, as well as level of detail for the variables to be included. Careful planning of the project and thinking ahead with regard to data needed is important. The process of gaining access to data is often time consuming and expensive.

Second, restrictions with regard to possible research themes must be expected due to the delicate nature of the sensitive register data involving large parts of the population. Carefully thinking through the ethical sides of the project[35], and working out well-grounded arguments that legitimize the project, is an absolute necessity in order to gain approval.

Thirdly, all research approvals are time-limited. The time frame possible for holding data is also limited and evaluated uniquely for each project. Planning for renewals of approvals and for updating of the data is something that must be taken into account when planning for registry-based research on suicide.

Fourth, the large amount of data involved in registry-based research requires specialized expertise. Registry-based linkages require co-operation of a range of researchers with different specializations in order to maximally make use of the data and the possibilities that lie therein[12].

Finally, the registers are not perfect and do not cover as much information as would have been optimal. As an example the registries do not cover contact with health clinics, school health clinics or nursing homes, nor contact with psychologists running private practices. The registries are also limited to “external” type of data. Originally, the registries were not established for research purposes and hence do not contain information on personal experiences and the inner mental world of each individual that is often the objective of qualitative studies.

Concluding comments

Despite a steep increase in registry-based research on suicide, this specialized field is still best described as in its infancy. The Nordic countries stand in a unique position with a long history of registries suited for such research purposes. In this paper, we have discussed strengths and limitations in registry-based research on suicide, and presented examples of analytic opportunities in the Norwegian registries and linking of these. The main advantage of registry-based research on suicide is the ability to access a large sample of suicide deaths with very long follow up, and the amount and richness of the data, which allow for exploration of themes difficult to address through other study designs. In addition, a registry based approach could be a cost effective alternative to a prospective cohort design. The opportunities presented in the article could motivate to do similar research in Canada and even inspire for cooperation between Norwegian and Canadian researchers on registry based research on suicide. In our opinion, registry-based research on suicide will play an increasingly important role in suicide research in the years to come.

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