

An Initiative in Spain for the Study of Women's Health: The Murcia Twin Registry

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The present article describes the initial steps taken in setting up a twin registry in Spain. The Murcia Twin Registry (MTR) will focus initially on perimenopausal women's health. It will be administered and managed by the University of Murcia and the Murcia Health Council and will start with a database of 452 pairs of female twins born between 1940 and 1965 in the region of Murcia, Spain. Once the MTR is established and has gained some experience, our goal is to expand the age range and include males and opposite-sex twins. The current main areas of research interest are menopause, preventive behaviors, lifestyle and health as well as quality of life.

This initiative intends to start and develop a population-based twin registry in the region of Murcia, the Murcia Twin Registry (MTR). The general goal of the MTR is to constitute a basic research tool for the analysis of the relative contribution of genetic and environmental factors in the development of complex behavioral traits. In spite of the worldwide implementation of twin research, to our knowledge there are no established twin registries in Spain at the present date. This lack of experience has led us to design a step-by-step process, commencing with a relatively small sample of adults of limited geographical dispersion, and a narrow research focus, which we plan to enlarge in consecutive stages.

Specific Aims of the Murcia Twin Registry

The general goal of the MTR is to found a population-based resource for research on women's health, centered on the analysis of genetic and environmental factors which are involved in the development of health behaviors and, in particular, breast cancer detection behaviors and healthcare services utilization. Additionally, the MTR is expected to establish the bases for a long-term longitudinal study, centered on traits related to lifestyle and its interaction with the social environment and genetic characteristics in pre- and postmenopausal women.

Taking into account the above, the MTR focuses on the following main objectives:

- to start and to carry out the initial development of a twin registry in Spain
- to contribute to the analyses and understanding of factors involved in the development of health-related behaviors
- to establish the initial bases for a long-term longitudinal study centered on the development of complex behavioral traits and disorders
- to serve as a pilot project and validation of the methodology, in order to set up a more ambitious registry incorporating a wider sample
- to be used as a reference for researchers from other groups who may be interested in collaborations with the MTR.

Construction of the MTR and Data Collection

In order to fulfil these objectives, we intend to start gathering data from a sample of all female twin pairs living in the region of Murcia who were born between 1940 and 1965. Information about the sample comes from the computerized databases available at the regional health system. The Murcia Health Service is a free and universal health system and it keeps up-to-date databases of all the residents in the area (1,362,500 citizens). A preliminary analysis of these databases gave an estimated 452 female twin pairs.

Eligible women will be contacted and included in the MTR if the two main inclusion criteria are met: pairs with both members alive at the time of initiating the MTR, and no presence of disorders or disabilities which may limit their active and conscious participation. Inclusion in the MTR will be voluntary, not remunerated and it will comply with the Spanish legal requirements on personal data protection.

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The MTR will be supported by related databases with three levels of information: identification data, register data and research data. The MTR will be administered and managed by the University of Murcia and the Murcia Health Council, and will be located at the Health Psychobiology Unit of the University of Murcia.

Data gathering will start in the last quarter of 2006 with an initial interview focused on establishing first contact, making the MTR known to the twins, and collecting basic information on demographics, zygosity and health-related information. Twelve months later, a follow-up on their participation in health promotion activities will be conducted, using data registered in the computerized control system of the Regional Breast Cancer Prevention Program. First complete results are expected to be published by the end of 2007.

Zygosity Determination

Since biologically based zygosity classification is not feasible at present, zygosity determination will be carried out by means of a questionnaire that will be adapted and validated for the sample, assuming a 5% to 10% classification error (Kyvik & Derom, 2006; Peeters et al., 1998).

Assessments

At this point, our major research foci are centered on the changes associated with the menopausal period and their relationships to health-related lifestyles and behaviors. To this end we will start gathering data on four different aspects of twins: sociodemographic characteristics, subjective perceptions, health-related behaviors, and medical history.

Sociodemographic data include age, level of education, social class, main occupation and area of residence. Subjective perceptions include risk

perception, and self-perceptions of quality of life and health. Health-related behaviors encompass smoking, alcohol use, prescription drug use and abuse, health services utilization, mammography screening attendance and breast self-exam practice. Medical history data include record of surgery and main medical conditions, blood pressure, reproductive history, use of contraceptives and hormonal replacement therapy.

Ethical Questions

As mentioned, the MTR will fulfil all the legal requirements of the Spanish law regarding personal data protection (Act 15/1999), as a file of public ownership, with the maximum degree of protection. Only data from persons who have given voluntary and informed consent will be included in the MTR. Every participant will have full access to her data and the right to remove them from the MTR without restrictions.

This project has received a favorable report from the Bioethics Committee of the University of Murcia.

The Future

The MTR is still in the development stage. Although our current research interest focuses on perimenopausal women’s health, we expect to incorporate new research areas in the future, expanding the MTR to include male and opposite-sex twins as well as a wider age range.

Meanwhile, as a fledgling project, it is open to all possible forms of collaboration with other registries and researchers.

Table 1

Name of register	Murcia Twin Registry
Country	Spain
Kind of ascertainment	Population-based
Opposite-sex twins (yes or no)	No
Number of pairs (separated by birth range and sex)	452 female pairs 1940–1965
Major interests	Menopause, preventive behaviors, health-related lifestyles and quality of life.
Variables measured	Subjective perceptions of health and quality of life health-related behaviors and lifestyle, medical history
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Comments	The MTR is in the process of being set up and there are no data available to date.

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