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**INTERNATIONAL JOURNAL OF  
 ADVANCED RESEARCH (IJAR)**

Article DOI: 10.21474/IJAR01/5916  
 DOI URL: <http://dx.doi.org/10.21474/IJAR01/5916>



### RESEARCH ARTICLE

#### ESTIMATING BURDEN OF MULTIPLE SCLEROSIS IN MALTA: A REVIEW OF AVAILABLE DATA SOURCES.

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#### Manuscript Info

##### Manuscript History

Received: 19 September 2017  
 Final Accepted: 21 October 2017  
 Published: November 2017

#### Abstract

from the supernatant and precipitated pellet of 50% methanol concentration. Therefore, since anti-inflammatory activity was detected from the water phases in the supernatant and precipitated pellet of 50% methanol concentration among *P. brevitarsis* larva extracts, it was estimated that the active substances have a tendency of both strong and weak hydrophilicities.

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#### Introduction:-

This report provides an overview of the available data sources that can be used to characterize distribution and determinants of Multiple Sclerosis (MS) in Malta. Estimating burden of Multiple Sclerosis in Malta is a challenging undertaking owing to its low prevalence, unknown etiology and evolving diagnostic criteria. (Vassallo, Elian & Dean, 1979) (WHO 2008)

#### Background:-

Burden of disease studies rely on a combination of primary and secondary data sources for estimating prevalence, incidence, risk factors, treatment outcomes besides summary measures like Disability Adjusted Life Years (DALYs). (Mathers, et al. 2001) Secondary data may be affected by unknown biases and confounding influences. Data triangulation is often used to complement the respective strengths and weaknesses of different data sources. (WHO 2008) Lastly, some sort of adjustment and extrapolation is often required to bridge data gaps. (Mathers, et al. 2001)

#### Multiple Sclerosis in Malta:-

Literature review indicates a low prevalence of MS in Malta (Dean, et al, 2002) (Vassallo, Elian& Dean, 1979). The disease course is marked by episodic exacerbations and remissions. Several key aspects of its etiology remain unknown. (WHO 2008) However, both genetic and environmental causes appear to play a role. (Pugliatti, et al. 2006).

#### National Hospitals Information System (NHIS):-

The Directorate for Health Information and Research (DHIR) is the nodal agency for all aspects of health data management in Malta. NHIS collates data from various public and private health facilities. Annual hospital reports are available online for the last 10 years and contains details of diagnoses, treatment modalities, average length of stay and discharge related data. In several instances, the diagnoses column shows symptoms rather than disease. The in patient records are only entered at the time of discharge (as against admission). Hospital Activity Analysis database is part of the NHIS and contains administrative data and data from hospital activity forms.

**Limitations:-**

Case linked data (an essential pre requisite for estimating MS burden) is not accessible outside the health division. There is a lack of distinction between disease episodes and people affected in hospital records. Due to the possibility of a patient being counted more than once, counting episodes of care may lead to overestimation of prevalence. (Mathers, 2001) Certain diagnoses and procedure codes tend to be favored over others if they increase a hospital's reimbursements. Therefore overuse of codes indicating more serious diseases may distort time trends. Hospital data may not be entirely representative of Malta's population as patients requiring specialized interventions are often referred to other countries. Lastly, faith-based and private sector facilities hospitals are also involved in providing long-term care. Data recording mechanisms at the time of transition from acute care to long term care are sub optimal and likely to affect data integrity in case of chronic diseases.

**Malta National Mortality Registry (NMR):-**

Malta NMR provides mortality data based on Cause of Death (COD) reporting. Annual reports from year 1998 to year 2012 are available online. Data validity and reliability is likely to be suspect. Institutional practices and skills of certifying health personnel often affects quality of COD reporting. (Mathers, et al. 2001) Data coding also depends on the preferences of the registry manager. (Azzopardi 2014) A mechanism for validation of COD is in place. Coding is ICD-10 compliant which lends itself to international comparisons. Crude mortality rates disaggregated by age and gender are calculated by using mid-year population, sourced from the National Statistics Office of Malta, as the denominator. (DHIR, 2013) To summarize, several factors can potentially compromise the quality of cause of death reporting. These factors will need to be assessed. Nonetheless, mortality-related indicators are probably the most reliable of the currently available data in the DHIR.

**Standardization of death rates:-**

Difference in population composition and numbers at different age groups can skew death rates. This can be controlled for by direct standardization techniques. (Beaglehole, Bonita, Kjellstrom, 1993) This essentially will involve adjustment of mortality rates by applying age/gender specific rates in Malta to a standard population. (e.g., European standard) This is a reliable method for comparing mortality data. ((McMohan, 1996) (Mathers, et al. 2001)

**Disease Registers:-**

Registers are a compilation of disease-specific data sourced from health providers. (Hurwitz, 2011) MS registries are invaluable for characterizing disease patterns and determining therapeutic outcomes. (Mathers, et al. 2001) (McMohan, 1996).

**Limitations of Registers:-**

Under reporting often effects the quality of data sourced from disease registers. Changes in diagnostic technology, disease classification practices, demographic and environmental changes over time, all have a bearing on the usefulness of registries. (Mathers, et al. 2001) (McMohan, 1996).

**Population surveys:-**

if certain population groups are excluded from national surveys the results maybe distorted. E.g., if old age homes are not covered during a household survey, it may underestimate the disease burden since MS is likely to be more prevalent in these settings. Selection biases need to be excluded before interpreting survey data.

**Epidemiological studies:-**

Epidemiological studies yield reliable information on incidence, clinical progression, and mortality. (Beaglehole, Bonita, Kjellstrom, 1993) They can be useful for comparing incidence and prevalence in different populations, at different times and across different environmental settings. (Flachenecker, et al. 2008) (Hurwitz 2011) (Yaouanq, et al. 2014) However, methodological rigor is a key criteria for data validity. (Mathers, et al. 2001) Besides, such studies tend to be limited to small units and inferences may not be easily extrapolated to other contexts. In combination with prospective data collection, epidemiological studies can provide valuable insights on natural history of MS. (Mathers, et al. 2001).

**Migrant studies:-**

Migrant studies are important because of Malta's small population. Besides patients are often referred to other European countries. (Azzopardi 2014). Further, age at the time of migration can help ascertain the time periods

during which environmental factors are operative. (McMohan, 1996) (Mathers, et al. 2001) (Dean, et al. 1976). Further, migrants are not usually representative of the populations of their countries of origin.

#### **Database studies:-**

(Weinshenker 1999)

#### **MSBase:-**

Is a real time international non-interventional registry sourcing its data from neurologists across the globe. With a primary mandate of researching MS outcomes, this unique collaborative initiative can help create smaller sub-regional registries.

#### **European “health for all” database (HFA-DB):-**

HFA-DB provides health statistics for 52 Member States of the WHO European Region. It is helpful in making reliable comparisons of disease trends across countries. Data is regularly updated. Disaggregated mortality data by cause of death/age-grouping is available. Demographic, socioeconomic, mortality and morbidity indicators besides data on utilisation can be calculated. Data may be affected by differences in data practices between countries.

#### **To conclude:-**

Estimating burden of Multiple Sclerosis in Malta is challenging owing to a paucity of good quality data. This report has assessed the strengths and limitations of various available data sources. Several externalities discussed in the report will need to be controlled for in the final analysis.

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