



# Difficulties in estimating the human burden of canine rabies



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## ARTICLE INFO

### Article history:

Received 22 May 2015

Received in revised form

13 December 2015

Accepted 18 December 2015

Available online 22 December 2015

### Keywords:

Canine rabies

Surveillance

Disease burden

## ABSTRACT

Current passive surveillance data for canine rabies, particularly for the regions where the burden is highest, are inadequate for appropriate decision making on control efforts. Poor enforcement of existing legislation and poor implementation of international guidance reduce the effectiveness of surveillance systems, but another set of problems relates to the fact that canine rabies is an untreatable condition which affects very poor sectors of society. This results in an unknown, but potentially large proportion of rabies victims dying outside the health system, deaths that are unlikely to be recorded by surveillance systems based on health center records. This article critically evaluates the potential sources of information on the number of human deaths attributable to canine rabies, and how we might improve the estimates required to move towards the goal of global canine rabies elimination.

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## 1. Introduction

When assessing the need for and priority of human health interventions, a basic requirement is to measure the impact of a given disease. The starting point is to find out how many people the disease affects and especially how many die from it. From this point we can begin to estimate how many years of productive life are lost to a disease, the consequent economic burden to a country, costs of preventative measures and how cost-effective an intervention might be. Unfortunately, when considering neglected tropical diseases, the assessment can fall at the very first hurdle. For canine rabies, we simply do not know how many people die in any given year for almost all countries where the disease is endemic.

Although, human rabies is officially a notifiable disease in the majority of rabies endemic countries, this is not sufficient to ensure effective surveillance data for many reasons (Taylor et al., 2015). Enforcement of legislation on the reporting of case data and information systems for collating case reports are frequently not available. Laboratory confirmation of suspected human rabies cases is very rarely carried out due to limited capacity and training, poor access to approved diagnostic tests and reagents and the difficulties

of collecting the required post-mortem samples in rabies endemic countries (Banyard et al., 2013). Instead almost all human cases are diagnosed on clinical grounds, even though rabies may present in many ways (Suraweera et al., 2012) and misdiagnosis is common (Mallewa et al., 2007). Moreover, reporting of data from local to central levels is often incomplete due to limited use of reporting structures. Rabies case data reported to different authorities can conflict, for the same country and year of reporting, as found for Southern African countries reporting to the Southern and Eastern African Rabies Group, WHO and OIE databases (Nel, 2013). But perhaps the greatest challenges to accurate case reporting are that (i) canine rabies mostly affects the poorest sectors of society in the world's poorest countries and (ii) that rabies is a fatal disease. This combination means that most victims fail to access treatment, or return home to die having been advised that no effective treatment exists (Sudarshan et al., 2007; Taylor et al., 2015). These deaths, outside of health systems are not captured in surveillance systems based around health system records or in countries lacking civil registration systems to collect vital statistics on births and deaths (and their causes).

Given the absence of reliable surveillance data, where do we start in trying to assess the human cost of canine rabies in endemic countries? This paper seeks to critically assess the available surveillance and estimates of human deaths due to canine rabies and suggests ways in which these limited data can be improved upon

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to generate better information on which to base disease control decisions.

## 2. Using available passive surveillance data

The global collection of data on deaths from any neglected disease is a huge challenge, and early attempts to collate data for human deaths from canine rabies were no exception (Bogel and Motschwiller, 1986). Due to the lack of regular reporting of rabies cases to the World Health Organization (WHO) from many member states, the RABNET database was closed down in 2011 (WHO, 2013a), and has not yet been replaced. The World Organization for Animal Health's (OIE's) World Animal Health Information Database (WAHID) system is used to collect data on human cases of zoonotic diseases, as reported by veterinary health authorities (OIE, 2015), but the data is very incomplete (Table 1), and the frequent lack of intersectoral collaboration may mean that data reported by veterinary services do not accurately reflect health sector records.

Regional rabies databases are more successful. The Sistema de Información Epidemiológica (SIEPI) database across the Americas (Pan American Health Organization, 2015) is a well developed database, established in the 1970s, administered by PAHO (Belotto et al., 2005), and a critical part of canine rabies control across the continent. Reporting of data is relatively complete (in terms of the proportion of endemic countries reporting into the system) across Latin America and the Caribbean (Table 1) and has allowed detailed assessment of progress towards elimination (Vigilato et al., 2013). There are however, still some gaps from countries struggling with limited health infrastructure and capacity. A case in point is Haiti, thought to account for over 90% of the current human cases of rabies transmitted by dogs in Latin America (Hampson et al., 2015), but no human rabies cases were reported from there in 2013/4, and subsequent active surveillance there has further demonstrated how current systems under report rabies (Wallace et al., 2015). However, even for the countries reporting regularly, the level of detection of human deaths will depend on the surveillance capacity within the country.

The Rabies Bulletin Europe (RBE) database (Rabies Bulletin Europe, 2014) though voluntary, collects, collates and maps data on laboratory confirmed animal and human rabies cases from countries across Europe to assess progress of oral rabies vaccination efforts to eliminate wildlife rabies. Human rabies deaths in Europe are rare enough to attract significant media attention and extensive laboratory investigation to determine their precise origin, and therefore the RBE provides highly accurate records of human rabies deaths in Europe.

In contrast, across most of Africa and Asia, human deaths are much more common, rarely laboratory confirmed, and most often never captured by surveillance activities. Attempts to develop effective regional databases are beginning though, and country reports from regional rabies meetings have been compiled into datasets for Africa, the Middle East and Eastern Europe and Asia (Dodet and African Rabies Expert Bureau, 2009; Aikimbayev et al., 2014; Gongal and Wright, 2011; Searg, 2014; PARACON, 2015). Whilst these reports can provide insight into the issue, their current dependency on attendance at meetings makes these reports infrequent (annually at best) and data are usually not interpreted or compared to previous data (Dodet and African Rabies Expert Bureau, 2009; Aikimbayev et al., 2014).

There is variation amongst databases in frequency of reporting. Reports are submitted weekly to the SIEPI database, and quarterly to the Rabies Bulletin Europe. Whilst the main focus of these reports is monitoring of the rabies situation, timely information (at least within a month) is important to enable countries to enact control measures in the event of disease outbreaks.

Amongst canine rabies endemic countries a small number of governments regularly publish official data on human rabies deaths, for example India, Thailand, Sri Lanka and Nepal (Government of India, 2014b; Ministry of Public Health Thailand, 2013; Ministry of Health Sri Lanka, 2015; Department of Health Services Nepal, 2015). More often, reviews of multi-year surveillance data are published eg. in China (Yin et al., 2013; Song et al., 2014), Ethiopia (Deressa et al., 2010), India (Government of India, 2014a), South Africa (Weyer et al., 2011), and Turkey (Johnson et al., 2010). Data collation at the national level is important for the prioritization of outbreak responses and control program direction and analyses of national trends can reveal useful information about human cases over time, or areas where rabies risks are highest eg., (Song et al., 2014; Weyer et al., 2011), but such analyses are infrequent.

Besides the frequency of reporting, the quality of the reported data is a major concern. A recent survey identified a number of reasons for inadequate reporting, including (a) the challenges of reporting from remote areas, (b) inadequate follow-up of unconfirmed cases and confirmatory diagnosis, (c) inadequate financial investment in surveillance systems, (d) a lack of enforcement of existing legislation and guidance, (e) human rabies deaths occurring at home and outside the health system, (f) poor recognition of rabies by some health workers, (g) poor recognition of rabies' importance by politicians, (h) other competing health priorities, (i) lack of coordination between veterinary and medical authorities, (j) inadequate training of medical staff in rabies surveillance and case definitions and (k) a lack of understanding by bite victims on when and how to seek treatment (Taylor et al., 2015). At regional rabies meetings where surveillance data is shared, under reporting and the fact that deaths at home are often neither reported nor certified are widely recognized as significant problems (Dodet et al., 2015).

For these reasons, passive surveillance data for most canine rabies endemic countries is inadequate for accurately estimating the burden of disease, or the costs and benefits of control measures. Across canine rabies endemic countries we see a cycle of neglect—where there is no emphasis on control, there is no reliable data on how many people are affected, so there is no investment in control, and no progress is made (WHO, 2013b; Dodet et al., 2015). Passive surveillance for rabies generally only improves once control programmes are put in place, when awareness of the diseases is increased and good surveillance becomes necessary to assess effectiveness. A culture for reporting and sharing of data can develop and the value of these records can be widely seen, as in the Americas and Europe (Pan American Health Organization, 2015; Rabies Bulletin Europe, 2014). Hence, there are strong reasons to believe that surveillance databases will become increasingly valuable if canine rabies control efforts are initiated in currently endemic regions.

## 3. Utilizing local surveillance research

In the absence of reliable national statistics, research involving hospital-based and community-based surveys and epidemiological modeling has been carried out in a few countries (Kitala et al., 2000; Cleaveland et al., 2002; Hampson et al., 2008; Ly et al., 2009; Tenzin et al., 2011; Frey et al., 2013; Jemberu et al., 2013; Sudarshan et al., 2007; Suraweera et al., 2012; Sambo et al., 2013). Several studies have utilized an approach involving surveys of animal bite victims. Animal bites are an acute medical problem, likely to result in an interaction with health services, but there are still victims unable or unwilling to seek treatment overlooked by studies based at health facilities. Therefore, community-based studies involving interviews with bites victims and relatives of those who have died

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