Multiple Sclerosis and Related Disorders 10 (2016) 127–133

Contents lists available at ScienceDirect

Multiple Sclerosis and Related Disorders

journal homepage: www.elsevier.com/locate/msard

How to refer to people with disease in research outputs: The disconnection between academic practise and that preferred by people with multiple sclerosis

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ARTICLE INFO

Keywords:
Multiple sclerosis
Public engagement
Patient public Involvement
Social media
Surveys

ABSTRACT

Background: Increasingly, Government and Charity funders require public engagement in research. Invariably these research outputs describe the condition of someone with the disease of interest. We therefore sought to identify the preferred descriptor of someone with a disease, such as multiple sclerosis (MS) and to determine what descriptors are currently used by academics.

Methods: Several surveys were undertaken: one from the Research Network of the MS Society (MSSRN), a major MS Charity within the United Kingdom, who are involved in reviewing grant applications, priority setting and research governance (n=146), and surveys from both the United Kingdom MS register (MSR; n=1713) and the North American Research Committee on Multiple Sclerosis (NARCOMS) registry (n=518). People were asked to rate descriptors of someone affected with MS. These were compared to that used by academic experimenters in basic science and clinical science research papers.

Results: Although the frequency of responses varied between surveys the overall findings showed many consistencies. This included use of *person/people with MS* (*pwMS*) as the preferred descriptor for someone with MS for social media and scientific publications. This was the preferred choice in about 55–60% people from the MRS and in over 70% in the NARCOMS and the MSSRN, respectively. Although *MSer* was the second preferred–choice for use in social media, there was as a large range of preferences from the 'most-preferred' to the 'most-disliked.' This reflected an earlier survey by UK-based research blogs using the term *MSer* (n=173). In contrast, *pwMS* had few 'dislikes' and results were skewed towards the 'liked' and 'most-preferred' choices. *Client* and *sufferer* were generally disliked terms, although there was some regional variation in levels of choice. *Patient* was generally seen as a neutral term that was neither strongly liked nor disliked. However, *patient* gained more public support for use within scientific publications (~20–25%) compared to social media (~10–15%). This descriptor was however most commonly used (98–99%) within both pre-clinical (searched in 6-month output of preclinical autoimmune MS models; n=161) and in clinical publications (specialist MS journals; n=220), whereas *pwMS* was not reported in over 75% of papers published in some specialised MS journals, and did not appear in the pre-clinical animal studies examined.

Conclusion: There is a clear disconnection between preferences by individuals living with MS and current academic practise. As *pwMS* are increasingly reading primary research publications and are involved in patient and public involvement in research and grant review activities, the sensitivities of lay readers should be considered when writing research outputs. This issue may affect other diseases and a change in writing style could be adopted to show that we respect the wishes of the people that we study and wish to help.

Abbreviations: IQ, Intelligence Quotient; MS, Multiple Sclerosis; MSR, MS Register; MSSRN, MS Society Research Network; NARCOMS, North American Research Committee on Multiple Sclerosis; PPI, Patient and public involvement; PwMS, Person/people with MS

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http://dx.doi.org/10.1016/j.msard.2016.09.007
Received 11 July 2016; Received in revised form 8 September 2016; Accepted 25 September 2016

1. Introduction

Multiple sclerosis (MS) is an immune-mediated, demyelinating and neurodegenerative disease of the central nervous system that affects about 2.5 million people worldwide (Compston and Coles, 2008). The disease is insufficiently controlled by currently available treatments and therefore people utilize the internet to investigate research and treatments options (Brigo et al., 2014). There is an increasing will amongst Government and Charity funders of research that there is patient and public involvement (PPI) in research and a strong aspect of public engagement in science. This includes the production of 'open access' research outputs, such that people paying for the research have access to the findings. This supports the development of an increasingly knowledgeable number of people with MS, who are reading original academic articles as they try to understand their disease and treatment options. Furthermore, members of the public are involved in review panels for ethics and research grant applications, all of which require a lay summary as part of the funding process.

To find a neutral term that best describes someone with MS, is empowering for people living with the disease, is non-patronizing and does not entrench stereotypes, we performed some surveys centred on web-based questionnaires (n=396) in which *MSer* was identified (Baker et al., 2014a). In our initial studies, *people with MS* (*pwMS*) did not like being called *client*, which is a 'politically-correct' term used by health economists, but also preferred not to be called a *patient* or an MS *sufferer*. In contrast *pwMS* received a good deal of support. The original surveys were from people visiting a United Kingdom (UK)–based, MS research blog (*www.ms-res.org*) and ShiftMS (www.shift.ms), which is a social media community for young people affected by MS. These sites used the term '*MSer*', originating from the founders of ShiftMS, and therefore may have influenced the preferences of people taking the surveys. Therefore to examine this is further, different groups of people with MS were surveyed and the results were compared to that used by the academic community.

2. Methods

2.1. Multiple sclerosis society research network survey

In consulting with the Queen Mary University of London Research Ethics Committee no personal identifiers were collected as part of this and previous surveys (Baker et al., 2014a). By completing the surveys, participants provided implied consent for publication of results, as indicated by disclaimers. A web link to an anonymous survey was sent, via the Multiple Sclerosis Society in the United Kingdom, to members (n=315) of the MS Society Research Network (MSSRN). This is a PPI network of people personally affected by MS, who are involved in priority setting, reviewing grant applications, governance of the research programme, advisory groups and other ad hoc PPI activities. (*www.mssociety.org.uk/ms-research/get-involved-in-research/research-network*). People in the MSSRN survey were asked how someone with MS should be referred to with 5 set options (*Client*; *MSer; Sufferer; Patient; PwMS* that were selected previously (Baker et al., 2014a)), and asked to rank these on a 1–5 scale, from most preferred to least preferred.

2.2. UK MS Register

The UK MS Register (MSR) received peer review via MS Society mechanisms and has ethical approval from the South West–Central Bristol Research Ethics Committee (11/SW/0160) as a research database (Ford et al., 2012). Although identifiable information was collected via the MS register, this was only used to create data linkages such that the functioning UK MS Register contains only anonymous data accessed and analysed within a Safe Haven environment, with scrutiny of research outputs before release (Ford et al., 2012; Jones et al., 2014). The survey was performed, hosted and analysed by the UK MS register.

2.3. North American Research Committee on Multiple Sclerosis registry

North American Research Committee on Multiple Sclerosis (NARCOMS) registry (www.narcoms.org; Kister et al., 2013) following ethical review by the University of Alabama at Birmingham (UAB) Institutional Review Board, sent the link to the original survey circulated to the MSSRN, to the NARCOMS registry.

2.4. Academic use of descriptors of pwmS

As part of a previous study (Baker et al., 2014b), 161 primary research papers concerned with experimental autoimmune encephalomyelitis studies, which were published over a six-month period in 2012 had been downloaded (Baker et al., 2014b). These were analysed for which descriptors were used. In addition the total publication outputs of some MS specialist clinical journals for the same year were analysed. We searched papers in: *Multiple Sclerosis and Related Disorders* (n=42), *Multiple Sclerosis Journal* (n=220) and *Multiple Sclerosis International* (n=23). These were read to determine which descriptors were used.

Table 1
Descriptors most preferred by People with MS to describe someone with MS.

Descriptor	Most preferred descriptor of someone with multiple sclerosis						
	MS Blog	MSS Research Network		NARCOMS		UK MS Register	
		Social	Academic	Social	Academic	Social	Academic
Client	2%	3%	2%	4%	3%	6%	6%
MSer	47%	18%	5%	11%	3%	17%	12%
pwMS	42%	70%	67%	76%	67%	58%	54%
Patient	10%	3%	15%	7%	23%	9%	21%
Sufferer	6%	8%	14%	2%	4%	12%	16%

Anonymous surveys were undertaken via: a MS blog site (n=174. Baker et al., 2014a); the UK MS Society Research Network (n=146); NARCOMS (n=518) and the UK MS Register (n=1731). It was requested that respondents ranked their most preferred descriptor for being referred to in either the social media or within academic media. In the MS Blog, MSSRN and NARCOMS surveys some responses recorded equal preferences. In the MS register survey, only data from fully competed surveys with a single preference were included in the analysis (n=1582–1618).