Letters to the Editor AMJ 2014 7, 1

CredibleMeds: Independent information on medicines

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Dear Editor,

While prescribing medicines the possibility of drug-drug interactions (DDI) and drug-food interactions should always be considered. Cardiac arrhythmias are an important cause for drug-related morbidity and mortality, with prolongation of the QT interval being an important predisposing factor. DDIs can alter the concentration of medicines that prolong the QT interval and cause dangerous disturbances of heart rhythm. Provision of impartial objective information to clinicians and others about DDIs and the potential of medicines to prolong the QT interval and cause torsades de pointes (TdP) have the potential to reduce adverse drug reactions (ADRs) and improve medicines safety. The CredibleMeds website (www.crediblemeds.org) is a site developed specifically to provide objective evidence on DDIs and drug safety with special reference to drugs prolonging the QT interval to the general public, health care providers and research scientists.

CredibleMeds is maintained by AZCERT, an organisation founded in 1999 in the United States (Arizona) as a university based centre for education and research on therapeutics. In 2012, AZCERT became an independent non-profit organisation with the specific objective of maintaining the CredibleMeds website. The organisation monitors articles in the published scientific literature, information provided in the official drug label, and data from the FDA's adverse event reporting system.

There is a section for the general public providing a composite list of all drugs prolonging the QT interval and of drugs to be avoided in persons with long QT syndromes. In addition there is a selection of educational papers on basic heart function, females and medicines, and monographs on pharmacogenomics. There is also a virtual medicine cabinet that provides a pictorial approach to DDIs caused by common over the counter (OTC) medicines usually found in home medicine shelves, and links to external sites dealing with safe use of medicines. The pages for health care providers have a module on preventable ADRs that provides a comprehensive and practical overview of DDIs and strategies to avoid them. The overview of the long QT syndrome and TdP is a useful resource, and there is a section on clinically important common DDIs that focuses mainly on cardiovascular drugs and arrhythmias. The educational tool for warfarin prescribers and their patients is also likely to be useful.

The section for research scientists contains information on the CredibleMeds process for assigning risk, links to publications by AZCERT and educational papers. The quick links on the home page provide links to DDIs, educational papers, QT drug lists, and FAQs about QT drug lists. The website has Twitter, Facebook and LinkedIn pages like many websites these days, and is regularly updated providing update information to users. The news section on the home page may also be of interest.

The CredibleMeds website may be of interest to everyone who is involved in promoting the safer use of medicines and reducing DDIs, and especially to those people who have need of an information source for DDIs related to the cardiac QT interval.

Sincerely,

Dr P. Ravi Shankar Xavier University School of Medicine, Aruba

Carers and Patients Affected by Huntington's Disease

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Dear Editor,

Huntington's disease (HD) is a neurodegenerative disease resulting from a CAG triplet repeat expansion in the huntingtin gene.¹ Those affected experience progressive cognitive deterioration, motor dysfunction and affective disturbances resulting in complete loss of independence and palliation.² Though rare, it is estimated an additional



20 people suffer the consequences of one diagnosis.³ There is no cure; but perhaps the greatest tragedy is that HD is an inherited autosomal dominant trait.² Consequently, children of HD sufferers are not only burdened with the complex care and severe deterioration of their parent, but must also face the high probability of developing the disease themselves.²

Symptom severity and genetic implications of HD provide a distinct challenge for carers and appropriate health services.² In November 2012, an ethics approved survey was performed to elicit perceived areas of need and improvement of patients and their carers. The survey was presented to 50 people who attended a seminar on research developments in HD. Thirty-seven responses were received: patients (n=11, 29.7 per cent), spouses who are carers (n=10, 27 per cent), health care professionals (n=8; 21.6 per cent), children (n=6, 16.2 per cent) and carers (n=2; 5.4 per cent). All patients were cared for at their homes.

Patient's responses highlighted 'research' (17.3 per cent) as the principle area of need in HD care, followed by 'treatment' (15.4 per cent), 'management' (15.4 per cent) and 'carer's care' (15.4 per cent) (Table 1). In contrast, carers perceived the 'treatment' of HD as the most important area of need (19.5 per cent), placing 'research' (18.3 per cent), 'diagnosis' (13.5 per cent) and 'management' (13.5 per cent) thereafter. Interestingly, the carer group ranked 'carer's care' as the least pressing area of need (8.7 per cent). The differences between the patients and carer responses are not, however, significantly different (p=0.71).

Table 1: Reported Areas of Need in Huntington's DiseaseCare: Patients and Carers

Areas of Need in HD	Patients (%)	Carers (%)
Research	17.3	18.3
Treatment	15.4	19.5
Management	15.4	13.5
Carer's Care	15.4	8.7
Diagnosis	13.5	13.5
Respite	13.5	10.5
Daily Assistance	9.6	12.5
Other	0	3.8

* Chi-squared test p=0.77, not significant

Areas perceived to require improvements by both patients and carer groups included 'accurate assessment and diagnosis', 'carer support' and 'physiotherapy and exercise programs'. Carers emphasised 'insurance advice' and 'information and resources on HD care' as important. While HD remains an uncommon disease, the consequence of one diagnosis is devastating to our wider community. Identifying and integrating the perspectives of consumers should remain an important goal; ensuring the development and implementation of adequate HD support and management within an Australian context.

Sincerely,

Peter K Panegyres & Elizabeth Armari Neurodegenerative Disorders Research Pty Ltd

References

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