More than feeling 'a bit rocky'. Mal de Debarquement Syndrome (MdDS) Australia, quality of life survey 2016.

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Abstract

This report is the first study to investigate quality of life for those suffering with Mal de Debarquement Syndrome (MdDS). In June 2016, members of MdDS Australia were invited to participate in an anonymous online survey investigating their quality of life in regards to general health status; work and social activities; depression and fatigue; life enjoyment; and MdDS inference in daily activities.

Sixty-three members (73% response rate) completed the survey over the four-week period. Average age of the respondents was 41 years, with 96% of the respondents being female. Time of onset to official MdDS diagnosis was 2 years. The general health of respondents was fair to good but there was noticeable response regarding the future of their health status in the future. MdDS has a notable effect on activities of daily living, and also the work environment (including housework), where many respondents noted that they have modified their working hours/load to accommodate MdDS. There was almost unanimous agreement that there is significant ignorance or misunderstanding of MdDS by clinicians and allied health workers. Also, the lack of understanding of MdDS in the wider community may also play an effect on the working environment for respondents.

Overall, this preliminary survey has found that the multiple variables of ignorance/misunderstanding, modification of the working environment (including housework), and being unsure of the future, collectively contribute to constant anxiety and worry about MdDS which is likely to have an affect on cognitive abilities and the mental health of a majority of respondents. Future research should look at creating an individual quality of life score to understand how MdDS affects each person specifically.

Introduction

First described 1881, Mal de Debarquement Syndrome (MdDS) occurs when an individual habituates to unstable movement, failing to readapt upon return to stable conditions. Whilst MdDS is generally reported following a sea voyage, MdDS has also been reported following other forms of travel such as plane and motor vehicle journeys.¹

Classified as an “orphan disease” through a definition of limited prevalence, individuals have characterised MdDS using descriptive terms such as “rocking”, “bobbing” or “walking on a trampoline”, despite being on stable ground. In most cases this perception disappears quickly as individuals re-adjust to stable surfaces. However a percentage of cases present with persistent MdDS, where symptoms may persist for months and, in some cases, years.¹

For those with persistent MdDS, further to the symptoms of rocking and bobbing, individuals also report symptoms indicative of fatigue, cognitive slowing and intolerance to visual motion.² It has been described that those with persistent MdDS develop depression and anxiety due to the chronic effect of MdDS across daily life activities.^{1, 2}

Whilst there is literature describing the condition of MdDS, the symptoms associated with it and potential treatment options,³⁻⁸ there is very little understanding of the ‘human cost’ of MdDS. To date, the only data exploring the impact of MdDS on an individual’s quality of life (QOL) was completed in 2012, in a USA MdDS population, by Macke et al.² Macke and colleagues found in 101 MdDS participants, a ‘poor’ overall QOL score of 59.26 ± 1.89 (out of 100). The overall physical health composite score was ‘poor’ (49.40 ± 1.69) and the overall mental health composite score was also ‘poor’ (52.40 ± 1.83). Further, Macke et al reported that the sub-categories having the lowest QOL score were relating to physical problems (18.32 ± 3.20), energy levels (34.24 ± 1.47), and emotional difficulties (36.30 ± 4.00).²

Given that no follow up study has been undertaken, and further, no studies have been completed in the Australian MdDS population group, this report presents general quality of life experiences in the Australian MdDS population group. Work of this nature is imperative to establish an understanding of the issue, from a personal standpoint, of people with MdDS in Australia.

Methods

An online survey was commissioned and administered by MdDS Australia. The survey used was a modified version of the QOL, developed by Macke et al.² Specifically, modification of the QOL for this study involved rewording of questions for an Australian audience. Also, exact calculation of economic cost to obtain an MdDS diagnosis was not undertaken in this study; rather anecdotal medical costs for diagnoses and treatment were included in the open-ended question section.

Survey questions ranged across several key themes. Specifically: general health status; work and social activities; depression and fatigue; life enjoyment; and MdDS inference in daily activities. Open-ended questions explored the misunderstanding of MdDS; life adjustments to MdDS; and personal financial expenses to diagnose or treat MdDS. Survey and open-ended questions are presented in Appendix A.

Data was collected over four weeks (June) of 2016. Members of MdDS Australia (n=114) were advised by the MdDS Australia about the online survey. All members were emailed the survey link, and instructed that the survey was fully anonymous, and completely voluntary to complete.

Reliability of responses was completed through repeated questions throughout the survey. Reliability analysis was undertaken by comparing difference in percentage responses between 1st and 2nd presentation (test-retest correlation) and expressed as a ratio (max 1.00).

Due to nature of data collection from the online survey, only descriptive data is presented. Data is presented as grouped percentage response for each question, and individual QOL score could not be calculated. For open-ended questions, qualitative data were content analysed, where possible, for key themes and phrases, or reported verbatim in the words of the participants.⁹

Results

The online survey found 86 of the 114 members (at time of data collection) viewed the survey. Sixty-three members (73% response rate) completed the survey over the four-week period. Average age of the respondents was 41 years,

with 96% of the respondents being female. From time of onset to MdDS diagnosis was 2 years.

Test-retest reliability analyses of repeated questions showed moderate to high reliability (0.61 – 0.81). The highest reliability was found in questions relating to tiredness/fatigue. Conversely moderate reliability was observed in questions addressing work activities.

General health status

Figure 1 presents general health status. The majority of participants (60%) responded with 'fair' (26%) or 'good' (34%). 28% responded with 'very good' (24%) or 'excellent' (4%). Conversely, 12% responded with poor general health.

When asked to compare their general health to one-year prior, 14% responded that their health was *better* than one year ago, whilst 58% responded that their health had not changed. 28% responded that their health had worsened (16% responded with 'somewhat worse', and 12% responding with 'much worse').

<Figure 1>

General health expectations

Further to questions asking about participant's general health, figure 2 presents data with respect to the expectations of respondent's health in comparison to a 'healthy' person.

<Figure 2 here>

Across the three questions, the majority of respondents were mostly unsure about their general health status when comparing their health to other people. For example when asked if they get sicker easier than other people, 35% of respondents were *unsure*, followed by 23% for *mostly true* and *mostly false*. Similarly, when asked if they were as healthy as anybody else, 35% of respondents were *unsure*, followed by 26% and 28% for *mostly true* and *mostly*

false respectively. When asked if respondents expected to have their health worsen generally, 63% where *unsure*, followed by 21% for *mostly true*.

Respondents where then asked about their general health concerns for the previous *four weeks* only (figure 3). When asked if respondents were discouraged by their health problems, 98% said they were discouraged, with 14% reporting *all of the time*, 52% *some of the time*, and 32% *a little of the time*. When asked if they were frustrated, again 98% said they had frustrations, with 29% reporting *all of the time*, 48% *some of the time*, and 21% *a little of the time*. Similarly 98% of respondents revealed they had health worries with 29% reporting *all of the time*, 40% *some of the time*, and 26% *a little of the time*. And 93% felt weighed down by their health problems with 25% reporting *all of the time*, 45% *some of the time*, and 23% *a little of the time*.

<Figure 3>

<Figure 4a to c>

Figure 4 breaks down responses towards general daily activities. Daily activities are outlined in figure 4a. When asked about their ability to undertake shopping, for example, nearly three quarters (74%) reported that they were *somewhat limited* to undertake shopping. Similarly four-fifths of respondents revealed that they are *somewhat limited* in attempting to descend a flight of stairs. Respondents noted that bending, kneeling or stooping down was either *very limited* (41%) or *somewhat limited* (55%). Bathing/showing also showed that the majority of respondents reported that they were *somewhat limited* in this activity (67%).

Figure 4b illustrates the overall limitations their general health has on activities. For all questions asked, the majority of respondents felt that they have been limited or have cut down on activities to accommodate their health; 71% had cut down on the *time spent on work or other activities*, 85% had *not accomplished what they would have liked*, 86% had reported that they were *limited in the kind of work or other activities they would like to do*, and 92% had *difficulty in performing work and other activities*.

When asked about social activities (Fig 4c), 26% reported that their social activities had decreased *slightly*, 31% *moderately*, 26% *quite a bit*, and 10% *extremely*. 7% had revealed that their social life had not changed at all.

When asked about limitations on work or other daily activities in the *previous four weeks* (fig 5), the majority of respondents agreed that they have cut down on the *amount of time on work or other activities* (67%), and similarly, 67% reported that they were *not able to do work or other activities as carefully as usual*.

<Figure 5>

Figures 6a and 6b asked respondents about their general physical well being, specifically with regards to fatigue. Just over half of the respondents (51%) cited that physical fatigue moderately/severely affected their social activities. 68% agreed feeling generally *especially tired*, whilst 63% responded that tiredness or fatigue moderately/severely affected their work/housework. Interestingly, 37% of respondents cited they felt *full of vigour* most or all of the time and 24% responded they felt *full of vigour* some of the time.

When asked about general sleep quality (Fig 6b) the majority of participants responded that they felt rested after their sleep *a little of the time* (39%) with 27% responding with *some of the time*. Conversely, a quarter of respondents said they *never feel rested* after sleep.

<Figure 6a and b>

Health in the previous four weeks

Respondents were asked about general symptoms of anxiety and depression specifically in the last month (Fig 7). Most respondents (69%) felt *calm and peaceful*, whilst equal majority of responses for some of the time and a little of the time were found for *nervousness* (46% and 43% respectively), *melancholic* (43% equally), and *depressed* (38% and 40% respectively).

<Figure 7>

Further to Figure 6a which asked about general physical well-being, Figure 8 outlines responses to physical energy levels in the past four weeks. Most responded that they have had *a lot of energy* a little or none of the time (84%). Conversely participants responded that they *felt worn out* some or all of the time (68%). Similarly, 69% responded that they *felt tired* either some or all of the time. However, 85% responded that they *felt happy* either some or a little of the time in the previous four weeks.

<Figure 8 >

Participants were asked to rate their cognitive performance over the last four weeks (Fig 9). When asked about *difficulty thinking and concentrating*, 62% responded that they had difficulty either all of the time (14%) or a good bit of the time (48%). Similar findings were also observed for *difficulty with maintaining attention* with 17% and 36% for all or a good bit of the time respectively, and *difficulties with short-term memory* (15% and 40% respectively). When asked if *others had noticed trouble with memory or attention*, most responded with a little of the time (45%) followed by a good bit of the time (35%). Interestingly, 10% had noted that no-one had noticed any issues with memory or attention.

Specific questions regarding MdDS

Figure 10-12 addressed specific questions with regards to participants experiences with MdDS. Most reported (83%) that they suffered with mild (37%) or moderate (46%) severity (Fig 10).

<Figure 10>

When asked about MdDS interfering with life, over half of the respondents reported that MdDS interfered with the ability to enjoy life (56%), however 43% responded that it only slightly or moderately interfered with their enjoyment of life (Fig 11a). Respondents were equal in their perceptions of MdDS interfering with work with 37% responding that MdDS interfered with their work a little bit, while 34% reported that their work was interfered quite a bit (Fig 11b).

<Figure 11 a and b>

Participants responded having general anxieties about MdDS (Fig 12). Most respondents reported having either moderate (37%) or extreme (37%) anxiety about MdDS, and 49% reported feeling *discouraged by MdDS*. However, *time spent worrying* about MdDS was relatively equally distributed from a little of the time (37%), some of the time (24%) and a lot of the time (27%).

<Figure 12>

Overall quality of life (QOL) rating

Figure 13 outlines participants' general overall quality of life. The majority of respondents rated their QOL as fair (44%), whilst there was a mixed distribution of responses for *description of life as a whole* with the majority reporting unhappy (27%) or mixed (29%). Mostly dissatisfied showed 17% of responses.

<Figure 13>

Overall quality of life (QOL) rating

Participants were also asked a series of open-ended questions regarding their diagnosis, looking for a 'cure' or relief from MdDS, re-emergence of their condition (if they had been in remission), the impact on their work, and others' perceptions of their MdDS.

Most responses (n=20/31) did not have any pre-existing condition prior to the onset of their MdDS. For those who did respond that they did have a pre-existing condition, 9 of the 11 reported that MdDS exacerbates their other conditions. When asked about their diagnosis of MdDS, the majority of those who responded (n=31) agreed that they had felt frustrated by a lack of understanding regarding MdDS from clinicians or health care workers.

...neuro-otologists who claim to understand MdDS don't seem to have a clue, some of the time. One neurologist I met dismissed MdDS as being 'psychological' and a neuropsych dismissed it as being 'functional'. Some physios know a little but if they treat MdDS as a vestibular condition rather than a neurological condition, they could be doing us more harm than

good. The ENT who diagnosed me initially knew less than nothing about MdDS and sent me off in completely the wrong direction when he told me what he thought caused it.

My present GP hasn't heard of it and shows no interest in understanding it. He thinks it is in my head.

A number of others had reported that they were told to tolerate their condition.

...very frustrated, everyone I have seen Doctors, and specialists have not heard of MdDs except for the Neurologist who said he has heard of MdDS and you will just have to live with it until it goes away. There is not (sic) treatment or cure.

...professionals have studied and know what it is but have no idea how debilitating it is to be constantly moving and not present in your body connected to the earth in my case also deaf on one side with 100% vestibular loss on deaf side ...their response is there is nothing that can be done...LIVE WITH IT!

Further to responding about diagnosis and dealing with clinicians, 27 respondents provided feedback on the financial outlay in finding a 'cure' or 'relief' from symptoms. Financial costs ranged between no cost (either through bulk billing) or small amount through to over \$4,000 and in one response over \$10,000.

Not money was all bulk billed, lots and lots of time spent

I have spent over \$10,000 on my health I have lost track over the last 4.5 years. The breakdown as follows ENT diagnosis and follow up. MRI and Brain scans. Hearing and Balance tests twice. Full body X-rays. Acupuncture. Chiropractor. Remedial massage. Vestibular therapy. Bowen Emmet therapy. Cranial therapy. Most of the treatments were done for a period of over 4 months.

Further to Figures 5 and 11 (pages 9 and 13 respectively) which asked about the effect of MdDS on work, a number of respondents (n=25/30) reported either leaving/losing their job or having to adapt their working life to accommodate MdDS.

Had to leave long term employment - always main income earner - now a couple and a dog existing on one low income - approx. 1/3 of previous joint income. Small disability allowance which helps with medication and some medical expenses. Studied to become a Counsellor, qualified, but physically unable to actively pursue a business and do the work I love apart from supporting family and friends, who prefer not to pay.

I lost my job through being an 'uninsurable fall risk'. Since then I have been self employed but MdDS severely limits my capacity to earn an adequate income.

I was forced to resign from my job as a Travel Consultant. I was unable to function under florescent lights and sit at a computer screen all day. My application for Disability Allowance was denied by the Department of Human Services. After 2 appeals, I was granted the allowance and MdDS is now on the list as a disability within the Department as a disability. My income has obviously decreased by some 30%. I get by.

...I've had to cut back my hours a lot! Only work a couple of hours a week & sometimes not even that. It has been a huge financial strain.

Responses also indicated that the mis-understanding of MdDS also extends to co-workers. Further research may be required to explore the association between co-workers attitudes towards orphan conditions such as MdDS and the affect on employment status.

...co-workers don't even know I am sick. Don't expect anyone to know what it is like as it is impossible to describe all symptoms, but people don't realise how sick you are as they just see you as normal.

...they always think that it is like vertigo, but I have to explain no it's more like the feeling of my brain rocking around in my head. Sometimes yes, because I look like fine.

People have no concept of what we are going through and treat it in a jocular fashion. "Wow, aren't you lucky to be able to be on a constant cruise for the rest of your life!!"

...all of the time! When i am trying to describe my situation to anybody else it sounds crazy to me so why wouldn't it to anybody else? After all, I'm 'just feeling a bit rocky', doesn't sound like a big deal, its just that it goes on constantly and drives one CRACKERS.

However, some responses were positive about friends and co-workers understanding, their situation.

My workplace is very understanding. Some people just look at me and say you look normal. Its very difficult to explain to people how you feel.

I am lucky that both friends and co-workers have been sympathetic towards me and supportive.

I'm lucky because my family understand and support me. It's only ever been doctors and health benefits assessors who may have thought I'm exaggerating symptom levels but who knows what they think!!

The final open-ended question explored people (n=29) having re-emergence of MdDS following remission. Thirteen of 29 expressed they had a remission, with 15 admitting they have never had a remission (and therefore no re-emergence).

...I have had multiple episodes. Mostly retriggered by motion events but more recently I was triggered by watching a movie with subtitles.

In 2007 I went on my first ocean voyage (7 day South Pacific cruise) It was smooth sailing. The moment I stepped off the gang plank I was rocking. Probably bad enough to keep me off work for a few weeks. It slowly dissipated over time (6 moths). So I guess I was in remission for 4.5 years. In December 2012 I went on a 5 day river cruise in Germany. Been rocking ever since.

....2 months, then 4 years remission. After a big trip had onset of mdds for almost 5 years. Ten months remission, symptoms back for 13 years, last year had a three month remission and I'm now 'back on the boat'. YIPPEE!

No, I have never had remission since the onset of MdDS in Dec 2009.

I have not experienced any remission. My MdDS has been constant since I acquired it nearly two and a half years ago.

Summary and conclusions.

The aim of this preliminary research was to ascertain the overall impact MdDS has on people who responded to this survey. The general outcomes of this survey indicate:

1. The general health of respondents was fair to good but participants with MdDS are unsure of their health status in the future.
2. MdDS has a notable effect on activities of daily living but also the work environment. In particular many respondents have modified their working hours/load to accommodate MdDS, further the lack of understanding of MdDS in the wider community may also play an effect on the working environment.
3. There was almost unanimous agreement that there is significant ignorance or misunderstanding of MdDS by clinicians and allied health workers. It is likely this ignorance/misunderstanding (or misdiagnosis) by clinicians contributes to poorer quality of life; however further research is required to quantify the association.
4. The constant anxiety and worry about MdDS appears to have an affect on cognitive abilities and the mental health of a majority of respondents.

Further research is required to clearly quantify the notable effects reported by MdDS respondents in this survey. A limitation of this research is the inability to quantify terms such as “somewhat” or “moderately”. Future research should look towards gathering data at the individual level. Similar to previous research²

using the QOL index will assist in gaining more precise insights into the effects chronic MdDS has on sufferers. This will allow for associations between severity of MdDS and impact on QOL.

Also noticeable was the perception of the severity of MdDS by respondents, with the majority of responses being mild or moderate. This illustrates an important issue that requires further research, particularly if some objective measure could be introduced to quantify the severity of MdDS. Previous studies have demonstrated that traditional balance tests are insufficient to determine MdDS severity.^{7,8} It may be that the development of an instrument to measure MdDS takes the form of both questions and physical tests. This may also assist with understanding QOL issues.

In conclusion, this preliminary QOL has illustrated the current status of MdDS sufferers in Australia. The data collected here will assist not only in providing awareness to the wider public, but also act as a leverage for further research to quantify the QOL status, leading towards increased research and education regarding MdDS.

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Figure 1. General health status

Figure 2. General health expectations

Figure 3. General health concerns in previous 4-wks

Figure 4 (a) Daily activities limitations, (b) work/other activity limitations, and (c) Social limitations in previous 4-wks

Figure 5. Limiting work or other activities in previous 4-wks

Figure 6a. Physical problems/fatigue in previous 4-wks, and (b) sleep quality

(b)

Figure 7. Symptoms of anxiety and depression in previous 4-wks

Figure 8. Physical energy levels in previous 4-wks

Figure 9. Cognitive difficulties in previous 4-wks

Figure 10. (a) MdDS severity

Figure 10. MdDS severity

Figure 11. (a) MdDS interfering with enjoyment of life, and (b) interfering with work

(a)

(b)

Figure 12. General anxieties regarding MdDS

Figure 13. Personal rating and description of quality of life