

An Online Mindfulness and Gratitude Intervention for people with an Amputation

By Tessa Stewart, Jessica Leov, Dr Stephen Gallagher and Dr Nicola Swain

The Department of Psychological Medicine, University of Otago

Feedback or comment to: Nicola.swain@otago.ac.nz

Abstract.

There is little research looking at the well-being of people with amputations. Two current evidence based interventions used for chronic pain were hypothesized to also be helpful for people with an amputation. These were mindfulness which is the practise of directing one's attention to the present moment in a non-judgemental way and gratitude. We developed an online programme which presented both of these skills. Nine amputees (recruited through New Zealand Artificial Limb Service) took part in a four week online self-directed course teaching mindfulness (through audio and visual methods) coupled with a gratitude task and gave feedback on their experiences. Participants reported enjoying the course and finding it helpful in dealing with stresses in their lives.

This research was conducted by an Otago University Summer Research Scholarship to T.S. funded by New Zealand Artificial Limb Service

In New Zealand, there are over 4000 people who have an amputation [1] and this number will rise due to the increasing rates of vascular and diabetic disease severity, resulting in amputation. The challenges that people face after an amputation are not purely physical, but also psychological and social [2, 3]. A large proportion of patients (60-80%) suffer from stump pain and phantom limb pain, especially those who experienced pain before the amputation [4]. About 20 -40% of people with an amputation have depression or anxiety issues as a result of the amputation and often have lower levels of life satisfaction in comparison to healthy controls [3, 5, 6]. Social networks can be affected, as well as the ability to work or participate in the same activities that they did before their amputation, which cumulates in a lowered level of well-being and quality of life [3, 7]. Many of these people require both psychological and pharmacological interventions in order to help them maintain a good quality of life and mental health, especially in the early years following their amputation [8].

A large proportion of research has analysed aspects of how a person's own disposition, sense of control, goal setting and adaptability affect their well-being and mental health following an amputation [2, 9-11]. Few have reported on an intervention, which try to actively change these to a more adaptive way of thinking [2]. One possible intervention is mindfulness training, which has been shown to increase well-being and mental health and decrease pain in patients suffering from chronic pain [12, 13], yet has never been tried on amputee patients [14]. Amputee patients experience very similar challenges as chronic pain patients, through phantom limb pain and stump pain, disability, social isolation, increased rates of anxiety and depression and reduced levels of life satisfaction in comparison to healthy people [2, 3, 15]. As such, mindfulness could be an easy to implement and beneficial treatment to help increase their level of well-being and reduce distress levels and may even help reduce pain if present.

Mindfulness has its origins in Buddhism and meditation practises [16] but has been adapted to work in a clinical setting targeting people with chronic pain [17]. The premise of mindfulness is to become aware of the present moment, in a non-judgemental and open way, and to pay attention to the thoughts and feelings that occur. The goal is to be able to live a full life *with* pain and disability, not fighting against it [18, 19].

Mindfulness has been used in a wide range of fields targeting people with chronic pain [17, 20, 21], anxiety and mood disorders [22] and cancer [13, 23, 24] as a way to increase wellbeing and acceptance. It has been shown to reduce stress, anxiety and depression in breast cancer patients [25] and can even help reduce the risk of developing depression in people suffering from a chronic condition [26]. It has also been shown to reduce anxiety and psychological distress in non-clinical populations [27]. Mindfulness has been adapted to suit people with mild traumatic brain injury [28] and to work online [21, 29, 30] while retaining the key skills and positive results.

Mindfulness is not the only way to increase levels of wellbeing. Writing about what you are grateful for has also been shown to have a positive effect on wellbeing, life satisfaction and optimism [31]. An increase in positive affect and decrease in negative affect was found in people suffering from neuromuscular disease if they completed a daily gratitude journal for 6 weeks in comparison to those who did not [31]. This increase in well-being was apparent to the family of the participants and benefited their sleeping habits [31]. This benefit was also seen when gratitude journaling was completed at home without supervision [32]. As such, gratitude journaling was incorporated into this online course to complement the mindfulness components.

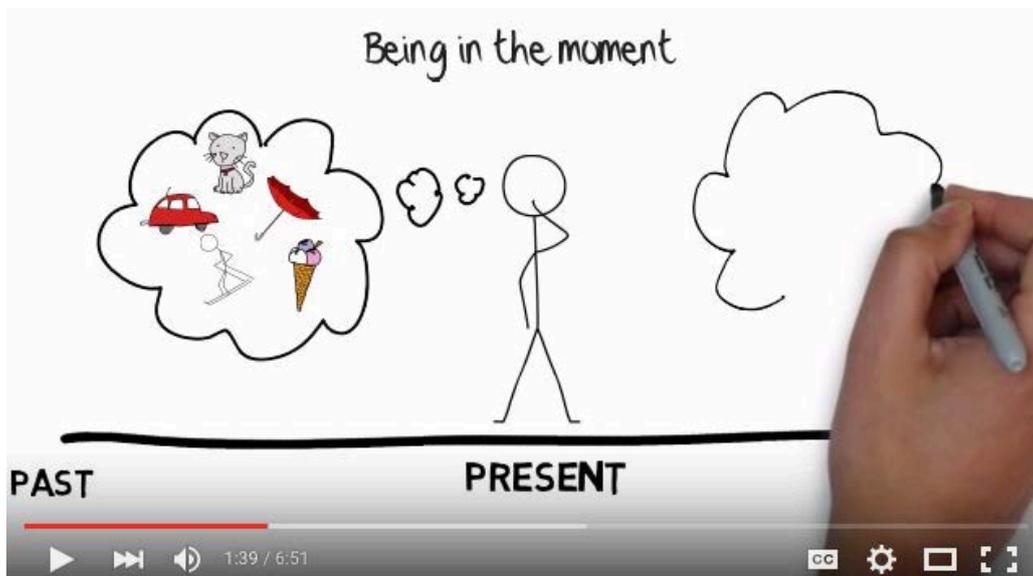
The main aim of this study was to create and implement an online four week mindfulness and gratitude course targeting people who have had an amputation to find out how the course worked for them and if they believed it could be a beneficial resource in their life.

Method: Nine people with limb amputations, recruited through the New Zealand Artificial Limb Service (NZALS) centres throughout New Zealand via posters and through a letter drop to amputee patients in the Dunedin area participated in the study. Interested people contacted the researcher and were emailed an information sheet, demographic survey and consent form. The study ran for four weeks and each week participants had access to a new mindfulness technique and gratitude journal.

An on-line course was developed by the researchers. This was based on previous research from this research group. An example from one of the purpose made videos is shown below. Table 1 has a summary of what was included in each week’s session. The gratitude journal task was based on the gratitude journal condition in study 1 of Emmons and McCullough (2003)[31].

Table 1: Summary of weekly tasks

Week 1	Gratitude journal + Introductory video to mindfulness + Mindful breathing audio + Summary video and Take 5 task.
Week 2	Gratitude journal + Non-reactivity video + Mindfulness for working with difficulties audio + Summary and mindfulness in your daily routine
Week 3	Gratitude journal + Beginners mind video + Body scan meditation audio+ Summary and mindful eating
Week 4	Gratitude journal + Video and audio on loving and kindness meditation + Summary of everything in the course + Mindful walking + feedback questionnaire.

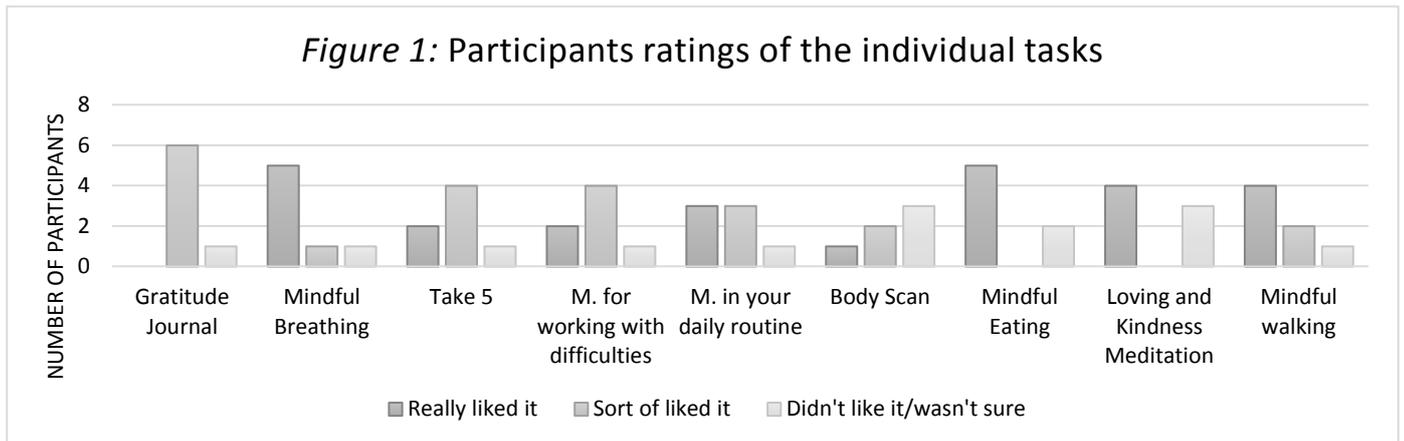


Results

Demographics: The majority of the participants were male (six) and all were New Zealand European. Their ages ranged from 29 to 72 years (median 55 years) with the median time since amputation being 20 years and 2 months (range 10.8 to 45.1 years). The majority of people had a lower limb amputation (eight) and lost their limb due to trauma (seven).

Eight of the nine participants provided feedback and it was predominantly positive. Most found the techniques enjoyable and beneficial, though there was variation between participants as to which techniques they enjoyed and used as well as how helpful they found the course overall. Some participants really enjoyed the course and found that it had helped them to deal with difficult situations in their lives and even show them a new way of dealing with their problems, rather than using escapism.

Most of the participants (5 out of 8) did not answer the first two feedback questions (Did you enjoy the course? and Was the course easy to use?), but those that did, said that they “enjoyed it a lot” and found it “very easy to use”. All participants answered question three and the ratings are presented below in Figure 1. The last three categories (Wasn’t sure, didn’t like it and didn’t like it



at all) were grouped together as only one person rated anything less than ‘wasn’t sure’. Most tasks were well accepted. The responses show a wide range in what people did and did not enjoy with the majority of people enjoying the mindful eating and mindful breathing tasks, and all save one person ‘sort of liking’ the gratitude journal task. When asked would they use this course or techniques again (question 4), 5 participants said “yes definitely”.

All of the participants said that they would recommend the course to someone else, though some of them would do so in order to let other people decide if it was something that they would like even if personally they did not find it very useful for themselves. Whereas others thought that other people could benefit from the course, as they did. One of the participants that really enjoyed the course (#38) said that it had allowed them to learn a new way to deal with stresses and difficulties in their life – rather than use escapism to deflect the realities of life. He found that as he practised the tasks he got better at focusing his mind as well as accepting that his mind wanders. Another participant (#40) found that it had helped them to deal with other people’s stresses and worries, especially that of a spouse. The mindful breathing exercises was also really helpful to participant #39 to deal with a family illness while away from home.

In contrast to this, participant #31 found that some of the tasks were not compatible with their temperament and had difficulty getting around the website.

Discussion: The results suggest that an online mindfulness and gratitude course did help teach people who had had amputation mindfulness techniques in a way that was informative and relatively easy to use. Some people found that they benefited a lot from the course, and used it more often and others not so much. The course exposed people to a new way of thinking and dealing with difficult times, pain and stress, and gave them a way to practise this and implement it into everyday life. Everyone found the course a positive experience but there were variations as to what tasks people enjoyed or found helpful, as well as how the course overall went for them. These findings suggest that an online mindfulness and gratitude course is feasible in an amputee population as it is in chronic pain patients [29] and the elderly with chronic pain [21]. The finding that the gratitude task was generally well accepted is in line with previous studies that use gratitude journals as a way to increase wellbeing [32].

An interesting outcome of this study was that the participants felt that the course helped them to cope with difficult situations such as a challenging marriage, or a sick partner, rather than something directly related to their amputation. A reason for this could be that all of the participants had been amputees for a long time (minimum of 10 years) and they were also self-selected, thus could have had a greater well-being and less disability than other people with a limb amputation.

One of the main issues with the online course was the lack of control over the audios, so sometimes the audio and video would play simultaneously. There was also inadequate recording of what tasks participants had completed. It was possible to determine that they had logged in or downloaded a link, but not if they had played a video or audio. As such, it is hard to verify if the participants took part in every task in the course, or just some of them. Due to these issues, and

that some participants found the layout and difficulties using the course off putting, it would be preferable to use a different website host for future studies. The participants offered constructive feedback about the design of the web site and suggested possible improvements such as the addition of a chat forum between participants and the ability to access the website on a smart phone.

Overall, this study supported the idea that mindfulness and gratitude can be taught online and can be a useful way to increase well-being in people who have had an amputation. It showed that while most people enjoyed the course, some people found it better for them than others. This highlights the need for individualised care, especially in chronic pain or amputee patients, as there is not a 'one size fits all' approach.

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