Patient adherence to swallowing exercises in head and neck cancer

Mary Wells[1*] & Emma King[1]

[1]Nursing, Midwifery and Allied Health Professions Research Unit (NMAHP-RU), University of Stirling, FK9 4HN

*Corresponding author mary.wells@stir.ac.uk Tel: 01786 466118

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Abstract

Purpose of review: A younger population and improved treatments for head and neck cancer (HNC) mean that more people are now living longer with the consequences of treatment, including long-term swallowing problems (dysphagia). Exercises aim to improve swallowing function, however highly variable adherence rates are currently reported, with no standard measure of adherence.

Recent Findings: Measuring adherence to swallowing exercises depends on the definition of 'adherence', the tools used to measure adherence, and the acceptable threshold that is used to constitute adherence or non-adherence. Particular barriers to swallowing exercise adherence include the burden of treatment, the commitment required to undertake a home-based exercise programme, and the difficulty in motivating patients to exercise before swallowing problems have become apparent.

Findings from the wider literature on general exercise interventions highlight the importance of external and patient-related factors on adherence, including patient beliefs, social support, self-regulation, and goal setting.

Summary: Key barriers and motivators to adherence are presented, which will have implications for the design of future swallowing exercise interventions. The relevance of behaviour change theory in facilitating adherence is highlighted, with ongoing studies used to exemplify how behaviour change components and analysis of patient beliefs can be incorporated into intervention development.

Keywords

Adherence; Dysphagia; Head and Neck Cancer; Swallowing exercises; Behaviour Change

Key points

1. Swallowing exercises during and after head and neck cancer treatment may improve patient outcomes but are extremely challenging for patients, therefore understanding and encouraging adherence is extremely important.
2. Barriers to adherence to swallowing exercise include side-effect burden, perceived relevance and importance of exercises, support and motivation.
3. Diaries offer a practical and informative means of assessing adherence but questions remain over their optimal format and use.
4. Applying behaviour change theory to swallowing exercise interventions is likely to improve adherence, leading to more effective interventions.

Introduction

This review summarizes recent evidence related to adherence to swallowing exercises during and after head and neck cancer treatment. It considers the concept of adherence and how it is measured, presents recent studies exploring predictors, barriers and facilitators to adherence to swallowing exercises and discusses relevant theories of adherence. It concludes with some findings of systematic reviews of adherence to exercise and medication, which highlight issues that may be transferable to the field of dysphagia research.

The incidence of head and neck cancer (HNC) is increasing in many countries, predominantly those which are economically developed, where Human Papilloma Virus (HPV) infection is thought to be particularly relevant [1]. Curative treatment for HNC usually involves a combination of surgery, chemotherapy and radiotherapy, leading to considerable impact on quality of life. Patients with HPV-related cancers are diagnosed at a younger age, and have a better prognosis, hence the chronic burden of side effects is likely to affect an increasing number of long-term cancer survivors. Swallowing difficulties (or dysphagia) occur in up to two thirds of patients undergoing chemoradiotherapy and can persist long term [2]. As well as causing pain and discomfort, dysphagia can lead to significant weight loss, feeding tube dependency, social withdrawal and difficulties returning to work [3, 4]. The risk of aspiration pneumonia is significantly increased, contributing to hospitalisation and death [5].

Given the considerable impact of dysphagia on morbidity, mortality and quality of life, strategies to prevent, reduce and alleviate swallowing difficulties are urgently needed. A major focus of current research attention is the evaluation of new treatment techniques, including less invasive surgery [6], Intensity-modulated radiotherapy (IMRT), which further spares the pharyngeal musculature [7, 8], and the positioning and timing of feeding tubes (TUBE https://research.ncl.ac.uk/tube/).

The potential for intervention by Speech and Language Therapists (SLTs) to reduce short- and long-term swallowing dysfunction has been highlighted in the UK National Institute for Care and Health

Excellence (NICE) guidance which suggests that swallowing exercises should be 'considered' for patients undergoing radiotherapy to the head and neck [9]. It is thought that exercising the swallowing muscles increases blood flow, reduces atrophy and fibrosis, and maintains the range and speed of swallowing movements. A recent Cochrane review [10] builds on two earlier reviews [11, 12], concluding that there is no evidence that undertaking therapeutic exercises before, during and/or immediately after treatment leads to swallowing improvement. Although the primary outcome of this latest review was safety and efficiency of oral swallowing (measured by aspiration, adverse events and oropharyngeal swallowing efficiency measures (OPSE) taken from video-fluoroscopy), the effects of swallowing exercises on quality of life were also found to be inconclusive. The six randomised controlled trials (RCTs) included in this review were generally small, considered to be low quality, and used a variety of outcome measures. The Cochrane review authors conclude that there is an urgent need for well planned, rigorous and multi-centre RCTs in this area.

Adherence to swallowing exercises: concepts and measurement

One of the key issues highlighted by all studies of swallowing exercises in this patient group is adherence – defined by the World Health Organisation as "the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider"[13]. Adherence is important because there is evidence to suggest that patients who maintain their exercise schedule achieve improved swallowing outcomes [14-16]. However, highly variable adherence rates are reported in the literature, with some studies showing that only 13-14% of participants practised swallowing exercises exactly as recommended [15, 17]. One of the difficulties with interpreting the evidence on this issue is that there is a lack of consensus on what constitutes adherence. Viewed as a continuous outcome, adherence is the total amount of exercise achieved over a given period, usually expressed as a percentage of the recommended 'dose' or a number of minutes or sessions attended. Viewed as a dichotomous outcome, adherence relates to the achievement (or not) of a pre-defined threshold or goal e.g. three sessions of twenty minutes, three times a week [18]. The problem with both of these conceptualisations is that the optimum timing and number of swallowing exercises required to achieve improved outcomes is largely unknown [19], and therefore the 'cut-off' between what constitutes adherence and non-adherence is artificial [20].

Other conceptual difficulties complicate the study of adherence. The authors of the Cochrane review [10] refer to 'compliance' rather than 'adherence', stating that participants in all trials reported difficulty complying with swallowing exercise protocols and pointing out that low compliance rates are a significant source of bias. McKay and Verhagen suggest that although rehabilitation researchers

have often used the terms 'compliance' and 'adherence' interchangeably, there are important conceptual differences between the two terms [21]. They argue that compliance refers to the act of conforming to professional recommendations, thus addresses whether or not an intervention is performed as directed, but does not consider the context in which that intervention takes place. They define adherence as 'a process influenced by the environment, recognising that behaviour is shaped by social contexts as well as personal knowledge, motivation, skills and resources'. These issues are also recognised in the WHO's evidence for action report on adherence to long-term therapies, which acknowledges that a patient's ability to follow a treatment plan in an optimal manner is frequently compromised by barriers, such as socio-economic, patient-related, disease-related and health care team factors [13].

It is well recognised that treatment for HNC is already extremely challenging, and that a demanding exercise regime may pose an unacceptable burden on top of a range of treatment-related symptoms such as pain, sore mouth and fatigue. Understanding and addressing the barriers and facilitators to adherence to swallowing exercises is crucial if we are to generate meaningful evidence in this area, but information on *how* patients adhere on a daily basis and what factors *influence* that adherence is lacking [19]. Some studies have assessed adherence to exercises at SLT consultations (e.g. during week 3 and week 6 of radiotherapy) by asking patients to demonstrate the exercises, and rating them as 'fully adherent' if they were able to demonstrate all exercises competently, 'partially adherent' if they were only able to demonstrate some exercises competently and 'non-adherent' if they could not demonstrate any of the exercises or if they said they had not performed them at all [15]. This method evaluates competency on the day of assessment but does not give a reliable indication of daily adherence. Other studies have used daily diaries to assess adherence [19, 22] providing real-time assessment of how patients perform exercises and what factors prevent them from adhering to them, throughout a course of treatment, rather than just at specific assessment time-points. Real-time assessment has been found to be more accurate at monitoring adherence and symptoms (for example pain levels) than measures which rely on patient recall [23]. In addition to measuring adherence, diaries can also facilitate adherence by providing a reminder [24], although it has been suggested that the act of regular diarising needs to be non-reactive so that it does not impact on adherence levels [25] (for example regular reporting of pain levels could lead to patients being more aware of their pain).

Electronic diaries also offer an additional method of patient reporting, and in a study of chronic pain were found to be more popular than paper diaries, with increased levels of diary compliance [26]. Electronic diaries also have the advantage of accurate time-stamping for diary entries, which can

overcome the problem of 'hoarding' (filling out a number of diary cards at a time, using recall to fill in cards from the previous few days) often associated with paper diaries [27].

No studies have been conducted in the swallowing exercise field to determine the most effective method of measuring adherence. Two systematic reviews of measures used in rehabilitation and self-management suggest that there is significant room for further research in this area. Frost et al [28] reviewed methods used in trials measuring adherence to home-based rehabilitation therapies, the vast majority being physiotherapy and exercise interventions. Adherence diaries had moderately high validity and acceptability, and were the most commonly used, particularly for approximating adherence to intervention frequency and duration. Specific scales and activity measures were also found to have reasonable validity and acceptability for limited populations. Another review [24] of 58 studies (including two cancer studies) found 61 different measures of adherence, of which 29 were questionnaires, 29 were logs/diaries, two were visual analogue scales (VAS) and one a tally counter. Only two studies included any psychometric testing, illustrating that there is a real need for more robust validation of self-report measures.

Predictors, barriers and facilitators to adherence to swallowing exercises

The most recently published study evaluating a home-based swallowing exercise programme also used diaries to assess adherence [19]. Patients were encouraged to perform fifteen minutes of exercise every day during treatment and for six weeks afterwards, at least once and preferably three times a day. This programme included four different types of exercise to promote 1) mobility for the head, neck and shoulders; 2) swallowing; 3) vocal health and function; 4) speech and communication. The swallowing exercises were specified as 'Effortful swallow', 'Tongue retraction', swallowing two or three times per bite or swallow, taking regular sips of water, sitting up straight and minimising distractions during meals. Online, booklet and video resources were available to support patients with their exercise programme, introduced in a 15-minute face-to-face instruction session with an experienced SLT on the first day of chemoradiation and supplemented by a 10-minute telephone or email coaching session each week. Patients were asked to keep a paper or online diary for 6 weeks, recording which of the four types of exercises they performed and how often. Exercise performance was assessed as 'low' if patients performed all four types of exercise for 6 weeks at least once a day on average; 'moderate' if they performed all types between once and twice a day on average; and 'high' if they performed all types during 6 weeks at least twice a day. Non-adherence was defined as failure to perform any of the exercises during any of the weeks of assessment.

Patients in the feasibility study [29] and RCT [19] achieved a fairly high adherence rate - defined as starting and keeping up exercises - of 64% and 70% respectively in the first six weeks. However, only 27% fulfilled the aforementioned criteria of high exercise performance, with 40% rated as low performers and 30% as moderate performers in the RCT. A lower proportion (38%) were still performing exercises between 6 and 12 weeks after treatment, and the majority of these were only exercising at most once a day. In both studies, adherence to the exercise regime peaked in the first two weeks and then tended to drop over the course of treatment and beyond. The exercises most likely to be performed were those aimed at strengthening and exercising the shoulder, followed by swallowing exercises, speech and voice.

Chi-squared tests were used to assess the relationship between adherence levels and other factors [19]. Patients treated with chemotherapy *and* radiotherapy had lower exercise performance levels, but other clinical and sociodemographic factors were not found to be significant. Exercise performance levels over time were significantly related to mouth opening difficulties experienced in the previous week, however, this difference disappeared after correcting for treatment modality (i.e. chemo-IMRT vs IMRT only). The feasibility study conducted before the RCT explored barriers to exercise using reports of weekly coaching sessions, finding that physical symptoms, side-effects of treatment and emotional problems affected patients' ability to focus on or perform exercises. Some participants found it too difficult to carry out exercises because they were working, travelling for treatment, or because they were embarrassed to perform exercises in a ward environment. Others lacked motivation because they weren't experiencing swallowing problems, weren't sure that the exercises would help, needed more encouragement face-to-face or were overwhelmed by information. A number of barriers to using the DVD were also mentioned, with passwords being forgotten, installation problems and difficulties seeing the videos.

Facilitators to carrying out exercises included feeling physically and emotionally well and having improved symptoms, the motivation of doing something positive for recovery, having simple exercises to follow and being able to adapt them at home, support and encouragement from the SLT coaching sessions and from family members, and the instructions provided by DVD or online exercise demonstrations [19].

An earlier prospective study explored reasons for non-adherence to swallowing exercises in 109 patients referred to speech and language therapy [15]. Sixty-five patients were interviewed six months after treatment, and more than half of these reported that they had not even attempted the exercises. The most common reasons included; not feeling they needed them because they didn't have a swallowing problem; thinking they were too difficult; forgetting to do them; or experiencing

pain, fatigue, nausea and sore mouth. The authors concluded that, in the context of many competing demands and treatment-related symptoms during radiotherapy, many patients do not appreciate the importance of swallowing exercises or feel that they are just too much effort. They also suggest that it is particularly difficult to persuade a patient to engage in a preventive regimen for a problem that they have not yet experienced, so its significance is not recognised. Other studies concur with these findings, illustrating that in the context of facing a potentially life-limiting illness, patients struggle with preventative exercises that are not seen as integral to their overall care [30].

Insights from the wider literature

Lessons from the literature on adherence to physical exercise and to medications can also inform researchers and clinicians working with swallowing exercise interventions. Although it cannot be assumed that patients' attitudes and motivations towards physical activity or medicines are the same as their attitudes and motivations towards undertaking swallowing exercises, the underlying theories of adherence [31, 32] are relevant across all interventions which require the patient to engage in a behaviour. A recent review of the evidence to support the application of behavioural theory to the study and prediction of adherence to medication in adults identified the importance of addressing self-efficacy, treatment beliefs, perceived barriers and social support in the design of interventions to promote adherence [31].

Two systematic reviews of adherence to home-based or physiotherapy-prescribed exercise have been published recently [20, 33]. Both illustrate the importance of self-motivation and support from others. Essery et al [20] reviewed 30 studies to identify factors predictive of adherence to a broad range of home-based physical rehabilitation therapies, including post-operative strengthening/flexibility and programmes to prevent or treat specific conditions such as pelvic floor problems, pain, sports injury. Predictive factors with the strongest evidence were: intention to engage in the therapy; self-motivation; self-efficacy; previous adherence to exercise-related behaviours; and social support (therapist and/or friends/family). The authors conclude that home-based exercise programmes are particularly susceptible to non-adherence because patients are unsupervised, modifications to lifestyle may be necessary, and patients may have doubts about efficacy. Limitations include small samples, high dropout rates, lack of validated measures, and the heterogeneity of home-based exercise interventions. Studies of this type may be particularly susceptible to the problem of dropout bias because those who remain in the study are also likely to be more motivated to adhere to the intervention itself.

A review focussing specifically on interventions to aid adherence to physio-prescribed self-management strategies included 12 studies [33], all of which used exercise as the self-management strategy. Twelve different interventions were described, but there was insufficient evidence to recommend any particular strategy. Although limited by the variable quality of individual studies, the review suggests that strategies which provide motivation, feedback and support may be effective in promoting exercise adherence. These include activity monitors, feedback, written instructions and goal setting.

Studies of adherence to exercise in people with cancer reveal similar barriers and facilitators. A systematic review of adherence predictors in exercise studies found that patients' intentions, perceptions of behavioural control and stage of change were all important in explaining motivations and behaviour, highlighting the need for interventions to be tailored to individuals' beliefs and abilities [32]. The significance of external (environmental and treatment-related) as well as internal (patient-related) factors is also relevant. These are illustrated in a large RCT of a Combined Aerobic and Resistance Exercise (CARE) programme for patients undergoing chemotherapy for breast cancer [34], which calculated percentage adherence from the number of supervised exercise sessions attended versus the number prescribed. A multivariate regression analysis found the following factors independently predicted poorer adherence: more intensive chemotherapy; more endocrine symptoms; a greater number of exercise limitations and poorer respiratory function at baseline. Patients randomised to the less intensive exercise regime and those in one particular geographical centre (with fewer competing interventions and trials) were more likely to adhere.

Even more relevant, a systematic review of sixteen studies of physical activity interventions in 1582 patients with HNC found that adherence to exercise programmes varied considerably in relation to the degree to which programmes were supervised [35]. A study of an unsupervised home-based programme was associated with an adherence rate of 53% compared with greater than 95% adherence in patients undertaking a mixed programme starting with supervised sessions and then transitioning to a home-based programme. The authors conclude that exercise interventions need to include teaching for self-regulation so that patients are able to set goals, track progress, plan and manage barriers, but they also point out that further research is needed to identify the optimal timing of exercise interventions for this patient group, given the decline in functioning that most experience during treatment.

The relevance of theory

Many of the studies of physical exercise and medication adherence have used behavioural theory to inform their interventions, but this has not been the case in the swallowing exercise literature thus far. The importance of behaviour change theory in this context has been recognised in a well-conducted systematic review of swallowing intervention studies published this year [36]. This review aimed to examine and characterise which Behaviour Change Techniques (BCTs) were reported in dysphagia rehabilitation studies [37]. By applying the Behaviour Change Wheel and Taxonomy [38] to fifteen studies, including eight RCTs, the authors identified 20 different BCTs, of which three appeared in more than 85% of interventions. These were: instruction on how to perform the behaviour, setting behavioural goals and action planning. BCTs occurring more frequently in effective interventions included practical social support, rehearsing swallowing exercises e.g. in the baseline training session (behavioural practice), self-monitoring and recording the behaviour and having a 'credible source', for example a skilled clinician delivering and encouraging the intervention.

An ongoing feasibility study – the Swallowing Intervention Package (SIP) study [22] – will also provide useful information on the most common BCTs used by SLTs and nurses supporting patients undertaking swallowing exercises during treatment, through an intervention receipt questionnaire completed after the instructional session before treatment starts and a weekly on-treatment review log. Interviews with patients will also explore what aspects of the SIP were most useful. In addition, the SIP study is piloting a new Rehabilitation Intervention Beliefs (RIB) questionnaire, based on Cooper et al's [39] work exploring patients' beliefs about cardiac rehabilitation. Drawing on the 'necessity-concerns framework' [40], which explains medication adherence in terms of an individual's beliefs of how *necessary* the treatment is and how *concerned* they are about taking it, the RIB questionnaire aims to assess beliefs that may affect adherence to the SIP, including perceived benefit, concerns, practical barriers and perceived suitability for the intervention.

Conclusions

This review highlights the need for future studies of swallowing exercise interventions to pay more consistent and careful attention to the conceptualisation and measurement of adherence. It suggests that the consideration and application of behaviour change theory promotes a deeper understanding of the factors which encourage adherence, and it illustrates some of the lessons that may be learned from the literature on adherence to exercise and medications. There is no doubt that swallowing exercises in the context of head and neck cancer treatment are extremely challenging for patients, and that experienced clinicians play a crucial role in teaching and supporting patients, including setting

appropriate goals and encouraging patients throughout treatment. The importance of self-monitoring through the use of diaries is clearly important, but further research is required to ascertain the most reliable and practical methods of assessing daily barriers and facilitators to undertaking swallowing exercises, and to recording when and how well patients are able to adhere. Collaborative efforts are needed across the head and neck community in order to maximise the potential for definitive evidence for swallowing exercises to reduce dysphagia and improve long-term quality of life. Adherence should form a central component of those efforts.

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Conflict of Interest

None to declare