

How culture may influence adherence to ventilatory support systems. A case report of a Sikh with amyotrophic lateral sclerosis

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Abstract

Previous literature has developed an evidence base for the use of ventilatory support systems for promoting quality of life, managing respiratory complications and reducing risk of mortality for patients with amyotrophic lateral sclerosis. The adherence literature in this population has predominantly focused on barriers and facilitators to ventilatory support systems, but not the potential influence of culture. This case report explores how Sikh culture may influence and impact upon adherence to ventilatory support systems for patients with amyotrophic lateral sclerosis. It concludes that the patient's Sikh and the clinician's western culture may have influenced adherence and that culturally congruent information may help bridge the gap between the two.

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Introduction

Amyotrophic lateral sclerosis (ALS) are degenerative neuromuscular diseases characterised by progressive neurodegeneration and death of upper and or lower motor neurons (Kiernan et al. 2011). It clinically presents as global progressive muscle atrophy and weakness, bulbar dysfunction, early presence of respiratory failure and premature death (Kiernan et al. 2011). There is currently no cure, so disease management focuses on symptoms and enhancing Quality of Life (QoL) (NICE 2016). Mortality in this population is commonly due to respiratory weakness and subsequent respiratory failure with or without pneumonia (Zarei et al. 2015).

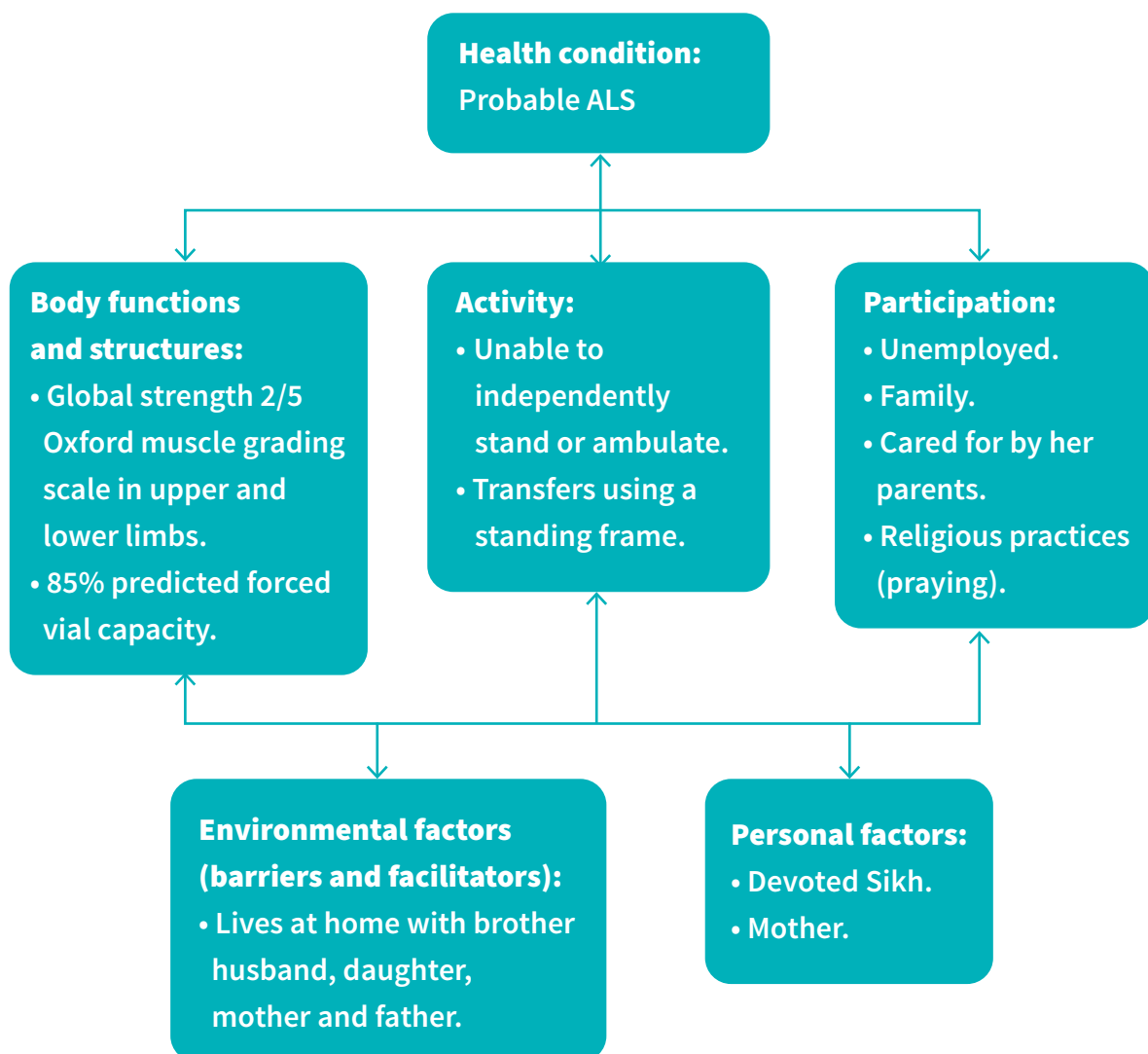
Patients with ALS spend the majority of their time at home due to the high level of disability seen in this population (Kim et al. 2018). In this environment domiciliary ventilatory support systems, such as non-invasive ventilation (NIV) and mechanical insufflation and exsufflation, are used to reduce the effects of hypopnea and facilitate sputum clearance (Sancho et al. 2004; Kiernan et al. 2011). A study ($n = 41$) has shown NIV to benefit QoL ($p = <0.0001$) and survival ($p = 0.0059$) for patients with ALS and good bulbar function (Bourke et al. 2006).

Patients with predicted premature death are managed by palliative care teams. In this population, management of the patient centres on building a 'good death' by considering how best to manage the dying process and death. Three themes were highlighted within a study group including patient control, autonomy, and independence (Debate of the Age Health & Care Study Group 1999). Patient-centred shared decision making promotes these themes and facilitates informed decisions by bringing together clinician expertise with the patient's preferences, circumstances, goals, values and beliefs (NHS England 2020). Despite research on how to best facilitate decision making and overcome the barriers to ventilatory support systems (Bélanger et al. 2011) there is still a disparity between patients' choices and clinicians' perception of evidence, knowledge and experience (Hogden et al. 2012). This may be because patients with ALS adopt a 'wait and see' coping strategy (Hogden et al. 2015), perceiving non-adherence as maintaining control, autonomy and independence. Additionally, patient preferences have been difficult to identify and explain (Bélanger et al. 2011), potentially due to the underrepresentation of the potential influence of culture in the literature. Most recently Murphy et al. (2000) explored the influence of culture on decision making and behaviours in 46 patients with ALS and concluded that spirituality had an effect on attitudes towards the dying process and adherence to invasive procedures. The aim of this article is to further explore how Sikh culture may influence adherence.

The Case presentation

A female aged 45 was admitted to hospital with shortness of breath and was later diagnosed with community acquired pneumonia (CAP). Two years prior to this admission she was diagnosed with ALS; she had no known other comorbidities. She was prescribed

domiciliary ventilatory support systems at diagnosis of ALS for nocturnal use and to facilitate sputum clearance. The patient had recurrent admissions to hospital with CAP and was treated both on general medical and respiratory wards using ventilatory support systems. During this time the patient was observed adhering to ventilatory support systems as prescribed, however, collateral history from her family described poor adherence to domiciliary ventilatory support systems. This was noted by the team, who used shared decision making to explore alternative treatment options and common barriers such as ventilator pressures, dry mouth, discomfort and understanding of application. No common barriers were identified and despite issues with adherence the patient chose to continue with domiciliary ventilatory support systems. Figure 1 outlines an overview of her presenting disability and functioning using the International Classification of Functioning, Disability and Health (WHO 2002).



📌 **Figure 1: Patient information presented using the International Classification of Functioning, Disability and Health (WHO 2002) framework.**

Discussion

The patients' culture

Palliative care is focused around promoting QoL (Stewart et al. 1999) and one's self-identity plays a role in patients' perception of QoL. Self-identity can be defined as the perception or recognition of one's characteristics as a particular individual, in relation to a social context (James 2015). Prior to diagnosis and progression of disability, she perceived herself as a devoted Sikh through believing and behaving in line with the teachings of Sikhism. As disability progressed, she could no longer participate in these self-defining activities, prayer rituals, and explained that she had lost this sense of self. In terms of NIV, patients describe a fear, or belief, of becoming dependent on NIV as a means for survival (Ando et al. 2015). This challenges Sikh's beliefs that death and illness should be that of God's will and not external influence (Singh 2009). The belief of dependency could have further challenged the teachings of Sikhism and thus her self-identity, potentially contributing to her poor adherence. The clinicians involved in her care may have been unaware of how these cultural beliefs may have influenced adherence.

The clinicians' culture

Patients diagnosed with ALS receive news of a 3.9 years mean life expectancy (Kim et al. 2018), which could be perceived as bad news. Bad news being any information which adversely or seriously affects an individual's view of one's future (Buckman 1992). Sikhs generally accept illness and death are that of God's will (Singh 2009; FHDS 2013) which differs from western culture whereby there is a belief that medical intervention prevails over death (Young et al. 1996). This may mean that Sikhs are not inclined to fight illness as western clinicians may expect. This difference between a patients and clinician's worldview may have led to the clinicians being unable to understand the reasons for poor adherence as the patient's actions potentially did not coincide with a westerner's world view. This may have led to ineffective communication and delivery of pertinent information that the patient desired.

Culture and decision making

Previous literature has defined the decision-making process in ALS as a framework through which patients and clinicians interact with consciously (Hogden et al. 2015). Despite this the patient continued to have poor adherence. Traindis (2007 as cited in Alden et al. 2014) highlighted culturally congruent situations tend to feel right and make sense to an individual, while those that are culturally incompatible may feel wrong and uncomfortable. This 'feeling' towards using the ventilatory support systems could explain reasons behind poor adherence that the patient was unaware of herself and thus unable to discuss with the team, as earlier highlighted. Even if the patient was to recognise the potential deeper cultural influence, it may be unwise to explore or challenge her worldview with styles like motivational interviewing or shared decision making as they are what define her as an individual, and to do so may feel like a personal attack. And so, professionals should be

understanding and sensitive to other cultural worldviews whilst remaining vigilant to factual incorrectness.

Bridging the gap

If a patient's culture does influence decision making, be it conscious or unconscious, there is no guidance on how clinicians bridge the gap between their worldview and the people for which they provide care. Psychological theories have developed decision aids that focus on targeting and tailoring decisions based on the individual's culture (Miscel 2004; Higgins 2006; Kitayama et al. 2009; Oyeserman et al. 2009). These predict that when information is culturally congruent with the individual it could result in deeper thinking and thus improve important decision outcomes. These include knowledge gained, improved accuracy regarding possible benefits and harms, choices that are more consistent with informed values, and increased participation in decision making (Stacey et al. 2017). Although the majority of the research to date pertains to Hispanic American and African American populations, Alden et al. (2014) developed a framework which may be a starting point for other populations. This is not within the scope of this article, however, may be relevant for future research.

Conclusion

Although guidelines advocate for patient-centred care there is little high-quality research pertaining to Sikh culture's influence on adherence; therefore, the robustness of the discussion, conclusion and key points are limited. However, this study outlines the potential influence of the patient's and clinician's culture when dialoguing to promote adherence to ventilatory support systems in order to build a 'good death'. Ultimately the clinician's role is to inform patients with information about ventilatory support systems in a way that can be understood and is meaningful to that individual so they can make informed decisions, culturally congruent messages may bridge the gap.

Key points

- A difference between the clinician's culture and the patient's culture may lead to poor understanding of adherence and thus ineffective communication of pertinent information.
- Sikh culture may influence decision-making subconsciously, for a clinician to attempt to challenge this rooted cultural worldview for adherence to interventions may be unwise.
- The use of targeted and tailored decision aids may have the potential to bridge the gap for culturally diverse populations more effectively than current decision-making frameworks.

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The use of high-flow oxygen therapy delivered via Airvo™ in the acute setting over a six-month period: A clinical perspective

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Abstract

Since 2010 the benefits of high-flow oxygen therapy (HFOT) have been realised both in the acute clinical setting and for chronic long-term conditions. Independent control of flow, inspired oxygen and humidification, and reports of good patient tolerance, makes it a favourable treatment option.

A service review looking at the use of HFOT delivered via Airvo™ (Fisher and Paykel) was completed over a six-month period in the acute clinical environment in a small tertiary hospital in New Zealand. It was used on the critical care unit, but its use focused primarily at ward level to determine which patients could benefit from it and to indicate where it could be safely delivered. Data was collected on patient diagnosis, clinical indications, respiratory rate, oxygen percentage and mode of delivery prior to using high-flow, initial HFOT settings and highest settings throughout treatment, number of HFOT treatment days and clinical outcome.

In this report, clinical observations showed that for those patients who have secretion retention, atelectasis, increased work of breathing, and increasing oxygen requirements, HFOT is an appropriate treatment option especially in those patients who are not reliant on high levels of positive end expiratory pressure (PEEP). It also demonstrated that HFOT via Airvo™ can be safely implemented in ward settings for a variety of clinical conditions.

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High flow, oxygenation, humidification, positive end expiratory pressure (PEEP).

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Recommendations for future work includes the collection of qualitative data on patient comfort and compliance with HFOT in addition to information on clinician confidence in setting up and weaning patients from the device.

Introduction

Oxygen delivery via nasal cannula was first implemented in the early 1940s in order to direct flow into the nose. The advantages of this were soon recognised, enabling the patient to eat, drink and speak, as well as limiting the feelings of claustrophobia often felt with a tight-fitting face mask. However, limitations were also recognised in terms of nasal discomfort, dryness and the provision of only lower levels of inspired oxygen to the patient's minute ventilation (Ward 2016).

It is widely accepted that caution should be exercised when using nasal cannula with oxygen flow rates over 5–6ℓ/minute due to the risk of mucosal dryness and damage. Additionally, in current clinical practice when using nasal cannula with low flow rates, this is not used in conjunction with humidification (Nishimura 2015).

In adults, HFOT was initially recognised using flows of up to 40ℓ/minute, showing that a higher fraction of inspired oxygen (FiO_2) could be achieved with higher flows compared to the same flows with other interfaces due to the nasopharynx and oropharynx acting as internal anatomic reservoirs that increase the volume of inhaled oxygen as well as a wash out of dead space in the nasal passage. With higher flow rates there appears to be even greater washout of anatomical dead space (Ward 2016).

Over ten years ago HFOT devices were introduced with heated humidification systems allowing higher flow rates and oxygen concentrations, whilst minimising the effects of mucosal dryness and damage, enhancing patient comfort and tolerance (Ward 2016).

Landmark studies also report the ability for higher flows to generate distending pressures similar to those achieved with continuous positive airway pressure (CPAP) (Groves 2007; Park et al. 2009). In clinical practice CPAP has the effect of 'splinting open' alveoli, improving ventilation/perfusion matching and subsequent oxygenation whilst also decreasing work of breathing and can stabilise the chest wall in the presence of chest wall trauma. However, traditional CPAP is administered using either a tight-fitting face, nasal mask or the CPAP hood, and positive end expiratory pressure (PEEP) is achieved by placing a PEEP valve within the circuit. These interfaces can be uncomfortable for the patient and can impact on patient tolerance of the device and subsequent compliance. Care is needed to maintain skin integrity, particularly at the bridge of the nose, and often the patient can only tolerate wearing the mask for short periods of time, decreasing its overall benefit.