Music therapy in progressive neurological disease: A neuropalliative rehabilitation perspective

Eleanor McNab  BMus  NMT  RMT
Calvary Health Care Bethlehem, Melbourne, Victoria, Australia

Abstract

The following paper describes the role of music therapy with patients with progressive neurological diseases (PND) within the context of neuropalliative rehabilitation. Neuropalliative rehabilitation is a construct which reflects the necessary interplay between neurology, rehabilitation and palliative care with long-term neurological conditions such as PND. The ultimate goal of care is best possible quality of life (QoL). Music therapy is highlighted as having a varied role in the treatment of people with PND, described by two case vignettes from the author’s work. The impact of PND on the individual is described and discussed in relation to both rehabilitative and palliative aspects of care as well as QoL literature. The concept of ‘centrality’ is raised as a key component of QoL, particularly in adjusting to chronic illness. It is proposed that music therapy is able to enhance QoL through assisting clients to gain new perspectives and providing opportunities to build coping resources and strategies. The music therapy literature highlights the use of music therapy to address psychosocial concerns of PND, however restorative needs are rarely discussed. It is concluded that the concept of neuropalliative rehabilitation may be useful to the music therapist working with PND to assist with collaboration with other health care professionals and clinical decision making.

Keywords: Progressive neurological disease, neuropalliative rehabilitation, palliative care, quality of life, music therapy

Introduction and literature review

Progressive neurological disease

Progressive neurological disease (PND) forms a complex set of illnesses which affect the nervous system, causing progressive and persistent deterioration to neural function for which there is no cure. The most common diseases include multiple sclerosis (MS), motor neurone disease (MND), Parkinson’s disease and Huntington’s disease. The estimated prevalence of MND Australia-wide for 2007 was 6.7 per 100,000 (Motor Neurone Disease Research Institute of Australia Inc., 2007).

For MS this was 63.8 per 100,000 in 2008 (Multiple Sclerosis Information Trust, 2008). Lastly, for Parkinson’s disease, an estimated
prevalence of 104 per 100,000 Australia-wide was based on data collected from 1992 to 2002 (Mehta et al., 2007).

These diseases, though varying in duration and symptoms, share the common attribute of increasing disability over time, leading to losses on many levels, including physical functioning, social role participation, personal skills, vocation, communication, independence (Perez et al., 2007; McNulty, 2007) and cognitive function (McNulty, 2007). According to American literature, the financial burden of PND on the patient and their loved ones is high, with out of pocket medical expenses, home and vehicle alterations, loss of earnings, and the need for domestic help (McNulty, 2007; Whetten-Goldstein, Cutson, Zhu, & Schenkenman, 2000). Physical symptoms may include pain, muscle-wasting, breathlessness, nausea, anxiety, spasticity, bladder and bowel issues, and seizures (Turner-Stokes, Sykes, Silber, & Sutton, 2008). In addition, disability may increase over many years, with disease progression unpredictable, and the future uncertain (McNulty, 2007). These challenges often lead to emotional strain (Khan, McPhail, Brand, Turner-Stokes, & Kilpatrick, 2006; Perez et al., 2007), stigma (Perez et al., 2007) and reduced quality of life (QoL) (Khan et al., 2006; McCabe, Stokes, & McDonald, 2009). MS literature has shown that life satisfaction, or QoL, is lower amongst people with MS than in individuals without illness (Beckerman et al., 2008; Benito-León, Morales, Rivera-Navarro, & Mitchell, 2003; D’Alisa, 2006; Khan et al., 2006; McCabe & McKern, 2002). In addition, QoL was found to be significantly lower in people with MS than in people with long-term chronic bowel disease and rheumatoid arthritis for several domains (Rudick, Miller, Clough, Dragg, & Farmer, 1992). It is reasonable to assume that this would apply to other PND. A recent Australian study with MS patients living in the community showed that a high 67% of participants experienced depression (Khan et al., 2006). In addition, suicide has been shown to be substantially increased in patients with MS, comprising up to 30% of deaths in MS patients (Weinshenker & Sibley, 1992). The combination of progressive and unpredictable disease creates an uncommonly stressful situation for people with PND (Benito-León et al., 2003).

The changes experienced by a person with PND threaten the individual’s sense of self or identity (Bishop, 2005; Schmid, 2005). Unlike congenital disease, where the individual can incorporate their disability into their identity from childhood, later-onset chronic illness causes the sense of self to be suddenly and dramatically altered (Bishop, 2005). In addition, this self perception requires continuous modification due to ongoing changes associated with progressive disease (McNulty, 2007; Schmid, 2005). The transition between the past identity and the new identity is known as adaptation, a process which is highly individual (Bishop, 2005; Chronster & Chan, 2007).
Neuropalliative rehabilitation

Treatment for PND requires input from a range of health care providers and specialists with skills across palliative care, neurology and rehabilitation. As such, the term neuropalliative rehabilitation has been used to describe the model of care employed with these patients and those with other long-term neurological conditions (Andrews, 2007; Turner-Stokes et al., 2008). Treatment may include symptom control, communication interventions, specialist and adapted equipment, counseling, psychological support, and welfare advice (Turner-Stokes et al., 2008). Neuropalliative rehabilitation is “an holistic approach to the care of neurological patients with significant disability, complex needs, and potentially shortened life span. It is patient-centred and involves diagnosis of clinical problems at all stages, rehabilitation to maintain function, care co-ordination and appropriate palliation to relieve symptoms” (National Council for Palliative Care, 2007, p. 23). It may be viewed as a continuum of care where these three specialist services are involved in the patient’s care to varying degrees throughout the different stages of the disease (Andrews, 2007; Turner-Stokes et al., 2008).

Traditionally, rehabilitation might be considered a task of recovery and physical improvement, which may appear to be inappropriate in the treatment of PND. However, Thompson (2007) posits that rehabilitation “aims to improve independence and quality of life by maximizing ability and participation...if a full recovery is not possible, [to] realize their optimal physical, mental and social potential” (Thompson, 2007, p. 28). This expanded definition of rehabilitation is governed by the ultimate goal to promote best possible QoL facilitated either by treatment to affect a process of change or to maintain the patient’s condition or social function (Thompson, 2007). On the continuum of neuropalliative rehabilitation, as the patient’s condition deteriorates beyond potential for recovery, ‘treatment to maintain’ takes a more prominent role, and furthermore evolves towards palliative care.

Palliative care

The World Health Organisation [WHO] (2010) defines palliative care as “an approach that improves the quality of life of patients and their families facing ... life-threatening illness, through the prevention and relief of suffering by ... treatment of pain and other problems, physical, psychosocial and spiritual”. Palliative care aims to provide relief from symptoms and affirm life, without aiming to postpone or hasten death (WHO, 2010).

Music therapy in PND and palliative care

Music therapy for people with PND and chronic neuro-disability is becoming increasingly prevalent in the literature. Daveson (2008) describes a
meta-model of music therapy for use in neuro-rehabilitation and neuro-disability which highlights the need for music therapists to draw from several frames of reference in setting goals and designing interventions. Three types of goals are presented, 1) restorative, 2) compensatory, and 3) psycho-social-emotional. Documented interventions for PND commonly focus on the psychosocial parameters of coping, identity, emotional expression (Aldridge, 2005; Magee, 1998, 1999, 2007; Magee & Davidson, 2004; Schmid, 2005; Steele, 2005) and social interaction (Aldridge, 2005; Magee, 2007), as restorative interventions may be inappropriate due to the progressive nature of these conditions (Daveson, 2008). Although music therapy is widely used to enhance functional and restorative outcomes in neuro-rehabilitation for patients with acquired brain injuries, there are few reports about the efficacy of such techniques with PND. Those available at the present time are the use of music and rhythm to improve motor function in patients with Parkinson’s and Huntington’s diseases (Thaut, 1999) and singing as a means to improve respiratory muscle strength in MS patients (Wiens, Reimer, & Guyn, 1999). In a study which aimed to identify the parameters that are subject to influence by music therapy in MS patients, Schmid & Aldridge (2004) found that creative music therapy had a moderate positive effect on self acceptance, depression and anxiety measures in patients with moderate MS, however there was no effect on motor and functional measures (Aldridge, Schmid, Kaeder, Schmidt, & Ostermann, 2005; Schmid & Aldridge, 2004). This evidence reiterates the efficacy of music therapy to address psychosocial needs in patients with PND, however further investigation into restorative benefits for this population is needed.

Ways in which music therapy assists psychosocial parameters of PND are well documented. These include: promoting a sense of control over life despite changes caused by the illness, through the experience of improvisation (Magee, 2007; Magee & Davidson, 2004); biographical work through sharing significant songs (Magee, 1998, 2007; Magee & Davidson, 2004); songs as coping strategies (Magee, 1998, 1999, 2007); providing a means of emotional expression (Aldridge, 2005; Magee & Davidson, 2004); redefining identity through facilitating awareness of living with a changed body, validating the client’s musical performance, and facilitating a new concept of wholeness (Aldridge, 2005; Magee, 1998, 2007; Magee & Davidson, 2004; Schmid, 2005); symbolic communication and interaction through music-making (Aldridge, 2005; Magee, 2007; Schmid, 2005).

Music therapy in palliative care is also discussed frequently in the literature regarding various terminal conditions including cancers, renal failure, dementia, cardiovascular disease, and heart failure, however rarely addresses neurological conditions specifically. Case reports as well as clinical studies have documented various effects of music therapy in addressing the holistic needs of patients in end-of-life care.
Case reports and qualitative research discuss positive effects of music therapy in addressing: emotional needs (Music Therapy Association of British Columbia [MTABC], 2004; Hilliard, 2001; Hogan, 1999; O’Kelly & Koffman, 2007); physical needs—including pain management and shortness of breath (MTABC, 2004; Gallagher, 2001; Hilliard, 2005; Hogan, 1999; O’Callaghan, 1996; O’Kelly & Koffman, 2007; Weber, 1999); agitation (Gallagher, 2001); social needs (O’Kelly & Koffman, 2007); environmental milieu (O’Callaghan, 2001; O’Kelly & Koffman, 2007); spiritual needs (Gilbert, 1977; Hilliard, 2005; Hogan, 1999; O’Kelly & Koffman, 2007); communication difficulties between the patient and family members (Gallagher, 2001; Gilbert, 1977; Hilliard, 2001, 2003, 2005; Krout, 2003; O’Callaghan, 2001; Weber, 1999); the need for family members to celebrate and farewell the imminently dying patient (Krou, 2003); low mood (Gallagher, 2001; Hilliard, 2005); fatigue (Hilliard, 2005); tension and anxiety (Gallagher, 2001; Hilliard, 2005); reduced self-expression (Gallagher, 2001); and reduced quality of life (MTABC, 2004; Hilliard, 2003, 2005).

Experimental research has shown varied support for the efficacy of these goals due to limited random control trials and small sample sizes. A recent review of empirical research in end-of-life care concluded that there is currently insufficient evidence to conclude or refute that music therapy has beneficial effects for QoL and that there is no strong evidence that music therapy affects pain and anxiety (Bradt & Dileo, 2010). Horne-Thompson & Grocke (2008) observed a moderate effect for music therapy on tiredness and drowsiness, although no significant improvement on nausea, appetite or shortness of breath. Two recent studies showed significant benefits of music therapy on QoL in end-of-life care (Hilliard, 2003; Nguyen, 2003). Using single-session music therapy interventions, Krout (2001) investigated the observed and self-reported effects of music therapy on pain, physical comfort and relaxation, and found significant differences between pre and post session measures. However, there was no control group in the study. Finally, Wlodarczyk (2007) identified music therapy as more effective than non-music visits in enhancing spiritual well-being in hospice patients and reported that patients and families perceived music therapy as being highly beneficial to them and their loved ones and greatly contributed to bringing end-of-life closure.

A variety of active and passive methods are used by music therapists in palliative care. The most recurrent are song choice, music listening, musical life review, music assisted counseling and relaxation with music (Hogan, 1999; O’Callaghan, 2001). Music is highlighted as an excellent catalyst for verbal and non-verbal communication, particularly where thoughts and emotions are difficult to express, and promotes a supportive, non-threatening environment for the expression of emotions (MTABC, 2004; O’Callaghan, 2001). O’Callaghan (2001) reports that even patients who are
barely responsive to most interaction, may respond to music by singing or crying.

Quality of life

Underpinning both palliative and neuropalliative rehabilitation models is the core objective of quality of life (QoL). QoL is a complex construct which may be defined in many ways in different contexts (Bishop, 2005; Murrell, 1999). Researchers have struggled to effectively and consistently measure QoL in people with PND due to confounding factors such as cognitive impairment and reduced communication (Murrell, 1999). Bishop (2005) defines QoL as the “subjective and personally derived assessment of overall well-being that results from evaluation of satisfaction across an aggregate of personally or clinically important domains” (Bishop, 2005, p. 7). Research has demonstrated a fairly consistent set of core domains on which individuals base this assessment: 1) psychosocial well-being; 2) physical well-being; 3) social and interpersonal well-being; 4) financial and material well-being; 5) employment and productivity; and 6) functional ability (Bishop, 2005; Perez et al., 2007). These domains are rated according to their importance to the individual in a concept known as centrality. By this concept, people may report high QoL despite dissatisfaction with some domains (Bishop, 2005). Bishop (2005) posits that when chronic illness influences a negative assessment of QoL, the individual may cope with the situation either by altering the importance of the domain; altering the perception of control they have over the domain; or making no change and continuing to live with reduced QoL. He suggests that interventions to assist this process should focus on helping clients to experience increased control and exploring avenues for increasing satisfaction in currently peripheral domains or areas that may be ‘new interests’ to the client. The author proposes that music therapy interventions are able to assist clients in both of these areas. This may occur through opportunities to engage in rewarding music experiences where these may not have been a focus in the past, or opportunities to control aspects of the music and their level of involvement in the session.

According to the coping literature, maintaining QoL or coping with stress such as PND involves several key factors. McNulty (2007) defines these as: 1) the individual’s appraisal of their situation; 2) the coping resources of the individual; and 3) coping strategies used. Coping resources may be internal such as sense of self, mastery, control, self efficacy, and interpersonal skills, or external such social support and material goods (Chronster & Chan, 2007). The author considers the promotion and maintenance of coping to be an important aspect of rehabilitation with PND.

Several authors have demonstrated the use of music therapy to improve both coping resources and coping strategies in people with PND.
Opportunities for increased control may include directing content of sessions such as preferred music or musical activities. Specific song requests may align also with elements of the individual’s identity (Magee, 1999) and allow the experience of emotional states which the task of coping may not usually allow (Magee, 1998). The choice of activity may also allow patients to take control of their own symptoms and perceived needs (e.g. relaxation to manage agitation or anxiety) (Steele, 2005). Regarding the sense of self, patients reported feeling “professional” and “successful” through music therapy improvisation, which facilitated a more able identity, challenging their ‘illness identity’ (Magee, 1999). As for coping strategies, Magee (1998, 1999) found these to be reflected in the way people used and responded to music. Songs were often used as coping strategies such as to present a more acceptable image of the client’s situation (Magee, 1999; Magee & Davidson, 2004). In addition to these, music therapy may support a variety of other coping strategies, such as turning to religion and using humour (Steele, 2005).

Hilliard’s (2003) study on the effects of music therapy on QoL in palliative care patients showed that QoL measures were significantly higher for subjects receiving music therapy than those receiving family support counseling, with an effect that increased over time. Interestingly, QoL in these patients improved despite their decreasing health, whereas QoL deteriorated in the control group. It is feasible to assume similar outcomes in PND.

Overview of the role of music therapy in PND

Through the lens of neuropalliative rehabilitation, we may view music therapy interventions as part of a continuum of care with the ultimate goal being QoL. Here, the continuum is broken down into three components:

1) Rehabilitative care which aims to influence change over aspects of the individual’s condition (e.g. adjusting to the illness, improving lung function in MS);

2) Rehabilitative care which aims to maintain aspects of the individual’s condition (e.g. maintaining the individual’s coping resources, cognitive ability and expressive outlets);

3) Palliative care which aims to provide comfort and affirmation when no further change or maintenance is possible (e.g. reducing pain perception, supporting family interactions).

Restorative, compensatory and psychosocial frames of reference may guide goal setting at various points throughout this continuum. Whilst for some PND there is a clear disease trajectory, for others such as MS, it can be difficult to know when the patient is nearing death. For this reason maintenance and palliative interventions may overlap and goals change...
suddenly as rapid deterioration occurs. As Magee (1999) describes, this work can span over many years and fluctuate at different points throughout the disease.

The remainder of this paper uses two case vignettes from the author’s clinical work with this population to highlight the varying role of music therapy throughout the continuum of Neuropalliative Rehabilitation. Both cases were clients living at home and receiving music therapy through home-based services connected to a specialised palliative and neuropalliative care hospital in Metropolitan Melbourne.

Vignette one

Nadia

Nadia\(^1\) was a lady in her early 60s who had emigrated from Europe in her 30s with her husband and son, but was now separated and living on her own. Nadia was diagnosed with MND soon after a battle with cancer and had assumed that she would undergo rapid deterioration and die within 12 months. For this reason she had given away many of her belongings to family overseas and chosen to cut ties with all friends and relatives other than her son and ex-husband. She became extremely depressed, and spent much of her time crying and planning to end her life before she became dependent on others.

Nadia was referred for music therapy about four months after her diagnosis. At this point, she chose to listen to what she felt were sad songs and used this as an opportunity to grieve. The music therapist also introduced music and relaxation techniques to assist Nadia to refocus and calm herself down when feeling distressed. This continued for several months during which time there was a change in therapist and the author began working with Nadia. Although her disease showed little progression, Nadia’s unwillingness to accept and adapt to her illness showed little change. This was evident in her participation in music therapy which was very passive. She would allow the author to play live music for her, but appeared fairly indifferent about the music and showed little interest in song choices and related discussion. Occasionally, she recalled memories of her youth as these were elicited by songs. This would usually upset her and she would state that she did not want to remember. She did not wish to engage in anything potentially fun or challenging, such as playing musical instruments or using music and drawing or collage to explore her feelings. She found this idea preposterous: “how could anyone waiting to die do something like that!” In addition she found music and relaxation overly confronting as it brought back memories and reminded her that she could not control her muscles anymore.

\(^1\) All identifying information and social backgrounds have been altered to protect clients’ confidentiality.
She described herself as “waiting to die” and in fact “already dead”. She did not feel that she could ever enjoy life again.

Contrary to her expectation, over a year after her diagnosis, Nadia’s disease remained fairly unchanged, however she remained as emotionally disjointed as before. Searching for a means to influence change to her perception, the author proposed the idea of songwriting. Sceptical at first, Nadia began to brainstorm with the author about what she felt was her main issue. She quickly stated that this issue was that she was not able to walk anymore. The author was intrigued by the meaning of this as Nadia could actually walk unassisted with a frame. Through the brainstorming process and structuring her ideas into lyrics and chorus, a continual flow of thoughts and emotions emerged. It was found that Nadia’s sense of self was very much connected to walking and what this meant for her. Walking was going to her special park on her own, it was skipping, laughing, dancing, singing and talking to the animals when no-one was looking. Walking represented pleasure, freedom, and joy. It was a joy that had come as a surprise but had become the one thing that she truly found enjoyment in, and now it had been marred by her disability.

After the ideas were collated into lyrics and set to music, Nadia was extremely surprised by how well the song had captured her thoughts and how easy it was. She showed a sense of relief in being able to articulate and share what had been troubling her for so long. She showed a sense of pride that she was able to impart some wisdom that one could discover joy unexpectedly. This led the author to suggest to Nadia that she could once again be surprised by joy.

The experience of song writing at that moment in time led to an immediate shift in Nadia’s disposition and following this, things began to change. Nadia agreed to recommence playing the keyboard, having learned as a child but not played for 40 years. She acquired a dog, and showed a more lighthearted and humorous perspective towards life events.

**Reflections**

Nadia’s journey is an example of rehabilitative work with PND where there was a need for intervention to influence change regarding her self concept. Her initial responses to music therapy showed a distinct separation between her pre-illness self, her current self and her future self. This was evidenced by not wanting to remember the past when memories were prompted by musical experiences, and not allowing herself to be alive but defining her present and future as waiting to die. This might be referred to as a fragmented sense of self as described by Chronister and Chan (2007).

From the perspective of Bishop’s (2005) model of QoL and adaptation, the author perceived that Nadia’s QoL was poor as the domain that she regarded as most important in life was threatened by her disability.
The main issue of the loss of her preferred leisure activity and her restricted independence outweighed other areas that remained intact. Walking had become her special place where she could be truly herself.

Songwriting played a significant role in the process of adaptation for Nadia in integrating her illness into an acceptable self-concept on several levels. Firstly, she was able to clarify her ideas and feelings about walking and view them from a different perspective. Secondly, she was able to discover something positive within herself, that was still alive, and thirdly, she was able to grieve the loss of her special place and the freedom, independence and ability that were closely linked to it. This method is supported by Baker, Kennelly & Tamplin (2005) as they describe the use of songwriting to assist with adjustment to identity change following traumatic brain injury. In their practice, song lyrics were used to explore concerns about the individual’s impairments and body image as well as positive experiences, which assisted them to grieve their losses (Baker, Kennelly, & Tamplin, 2005). Songwriting has been noted to provide an alternative way to approach reality which encourages growth and self awareness as well as a change in thinking (Glassman, 1991).

Following a growth in self awareness, Nadia was able to see potential to enjoy life in other ways and begin to accept the loss of to her beloved walking. The author’s encouragement to engage in playing keyboard is supported by Bishop’s (2005) suggestion for interventions that promote involvement in peripheral activities and provide a new, more accessible ways to find enjoyment and a sense of independence. Nadia was once again able to experience joy and connect with her true self. From this point, the goal of therapy changed from an intention to influence change to an intention to maintain her ability to cope and provide ongoing resources for self expression and creativity.

Vignette two

Marg

Marg was a lady in her mid 70s with long-standing MS which had progressed over many years to approximately 8.5 on the Kurtzke Expanded Disability Status Scale (EDSS) (Kurtzke, 1983) by the time the author met her. This meant that she could sit out of bed, communicate and eat, but required assistance for all activities of daily living and had minimal use of her limbs. She had notable cognitive deterioration regarding short term memory, attention and executive planning, but remained able to converse effectively and maintained a contented disposition. Due to her level of dependence, Marg was confined to the house most of the time, aside from occasional outings to a day centre and was cared for by her husband and in-home carers.
Marg had been receiving music therapy at home for several years prior to the author commencing work with her. The focus of music therapy was to maintain Marg's QoL and optimal functional ability across several areas. These were to increase effective social interaction, stimulate her existing cognitive function and promote effective self expression and creativity. In addition, music had been a significant interest in Marg's life. Sessions involved singing familiar songs and reading song lyrics, attention and memory recall tasks, music-facilitated discussion and lyric substitution. Attention tasks included call-and-response singing and Marg reading song lyrics for the duration of a song. Memory tasks included fill in the blanks during singing and song-recognition. Marg frequently reflected on her childhood as prompted by familiar songs, and was able to contribute insightful ideas about life during reflection on song lyrics. Marg responded enthusiastically to music therapy sessions and these continued on a regular basis for a period of three years with minimal change.

After a stressful event, Marg's condition deteriorated rapidly and she was admitted to the hospital for management and assessment. She became increasingly drowsy, unable to speak or communicate effectively. Her lung function was much weaker and she appeared to have reduced awareness of her environment. At this time, the multidisciplinary team felt that Marg's condition had become palliative and was entering a stage of decline in her illness. This was not considered end-stage-care however. The team felt that Marg would need to remain at the hospital indefinitely.

The author and other music therapy staff continued to provide music therapy sessions for Marg throughout her hospital admission, often with her family members present. Sessions aimed to provide non-verbal support and comfort for Marg as well as improved interaction with her family members. Despite the deterioration of her speech, Marg continued to mouth the words to well-known songs and her husband reported that she was more engaged and interactive during music therapy than at any other time. With these positive responses and potential for improvement, music therapy interventions became more focused on increasing Marg's active participation in singing and song-related discussion, as well as stimulating word production and an increased awareness of her environment.

Over several weeks, Marg showed gradual improvement and her condition began to stabilize. After much discussion within the multidisciplinary team, it was decided that she was able to return home. Music therapy sessions at home resumed and were provided more frequently than prior to her admission. Marg continued to improve steadily, returning over time to her previous level of ability at which point music therapy sessions once again focused on maintenance of Marg's functional ability and expressive outlets.
Reflections

This vignette demonstrates the changeability of PND and the resulting change in the individual’s needs, highlighting the interplay between rehabilitation and palliative care and the uncertain future for these patients. In this example, the predominant intention for music therapy was a rehabilitative aim to maintain Marg’s overall QoL on both functional and psychosocial levels, however there was a clear point at which the role of palliative care and rehabilitation overlapped.

The methods described during the maintenance phase focus on the use of songs and active singing which are observed frequently in the literature with MS patients (Magee, 1998, 1999, 2007; Magee & Davidson, 2004; Steele, 2005), particularly as a means of access after significant physical deterioration has occurred (Magee, 1999, 2007). Marg’s ability to engage in social activities was limited by her disability and music therapy provided a vehicle of successful shared activity. It is suggested that Marg’s QoL was supported by enabling her to maintain an area of her life that was important to her and that was unaffected by her disease progression (Bishop, 2005). The biographical work which resulted from song sharing may have also played a significant role in maintaining Marg’s sense of self (Magee, 1998, 2007; Magee & Davidson, 2004). Although there was no found literature on the efficacy of music therapy for cognitive stimulation in MS specifically, the author applied concepts from the neuro-rehabilitation literature in using modified attention-training and memory tasks (Thaut, 1999).

During the palliative and rehabilitative overlap period, there was an immediate change in focus for music therapy session. This became focused towards comfort and support for family relationships whilst promoting self expression, as indicated by the palliative care literature (Gallagher, 2001; Gilbert, 1977; Hilliard, 2001, 2003, 2005; Krout, 2003; O’Callaghan, 2001; Weber, 1999). As O’Callaghan (2001) observed, despite her deterioration and unresponsiveness to most interaction, Marg continued to respond to music by mouthing the words of songs. However, whilst these palliative intentions were held, the potential for improvement led the author to keep in mind simultaneously the potential for restorative rehabilitation. In this area here is a need for sensitivity to the both the momentary (palliative) needs and the potential future (rehabilitative) needs of the individual.

Despite sensitive intentions and intervention planning, it is difficult to determine the degree to which maintenance and restorative/change interventions played a tangible role in Marg’s condition. It may not be realistic to assume that the positive changes observed were due to stimulation provided by music therapy. Empirical investigation is needed to avoid assumptions. Nevertheless, music therapy was able to encourage positive interactive responses and support Marg throughout the various stages.
described. As Schmid (2005) encourages, music therapy interventions may develop and strengthen individual and unique creative resources within the client, which may have underestimated value.

Summary and conclusions

These case vignettes provide a snapshot of the varied role of music therapy in the construct of neuropalliative rehabilitation. From a rehabilitation perspective, music therapy aims to influence change or maintain the individual’s physical or psycho-social functions. From a palliative perspective, it aims to ameliorate symptoms and promote overall QoL.

The varied role of music therapy described in the author’s approach uses elements of both neuro-rehabilitation and psychodynamic therapy. As PND clients present with various levels of functioning, individual experiences and potentials for change, a person-centred approach is important. The music therapy methods described incorporate the use songs, songwriting and music-based cognitive tasks. In addition to those mentioned, the author has employed many different methods in PND, including improvisation, music and relaxation and musical life review. Although improvisation is emphasised in the PND literature (Magee, 1998, 1999, 2007; Magee & Davidson, 2004; Schmid, 2005; Schmid & Aldridge, 2004), the author has found this to be appropriate with only a few clients, perhaps due advanced disease progression. Song and project-based interventions have been used most commonly in the author’s practice.

Neuropalliative rehabilitation as a frame of reference is most useful within context of the multidisciplinary team. The ability to perceive the specialist needs of the patient throughout their illness trajectory will assist music therapists and other health care professionals to speak a common language. This may promote timely and appropriate referrals and lead to improved outcomes for the patient through interdisciplinary collaboration. In addition, it offers therapists a reference point for making decisions regarding appropriate goals and the need for ongoing therapy.

The present discussion on music therapy in neuropalliative rehabilitation is limited to two examples out of numerous psycho-social and functional applications. As there are different needs and trajectories within PND, there may be a need for disease-specific investigation. This is particularly pertinent regarding the efficacy of music therapy for functional rehabilitation in PND, where there is minimal evidence. Similarly, despite detailed discussion here about music therapy and QoL, no empirical evidence was located for the effect of music therapy on QoL in PND specifically. Even with significant outcomes in palliative care, it has not been confirmed that music therapy definitely improves QoL. This requires additional research.
Overall, music therapy with patients with PND aims to promote best possible QoL. For many clients, it will considerably impact their self-concept and/or physical condition. For others it will be more peripheral. Nevertheless, music therapy is able to meet the person with PND at their own perceived point of need. It facilitates change where possible, and assists patients to maintain their ability to cope and function at an optimal level despite the changes and challenges they experience.

Acknowledgements

The author would like to thank the patients who gave consent for their stories to be shared this is paper and the Neuropalliative Rehabilitation team at Calvary Health Care Bethlehem for their hard work in the development and promotion of this approach. Thanks to Dr. Katrina McFerran for her guidance during the writing process.

References


neurology, rehabilitation and palliative care. London: Royal College of Physicians, National Council for Palliative Care, British Society of Rehabilitation.


