

VOLUME II

APPENDICES

Table of Contents - Volume II

<u>SECTION.</u>	<u>TITLE.</u>	<u>PAGE.</u>
<u>Introduction:</u>	Table of Contents.	ii
<u>Appendix 1:</u>	<u>Rancho Los Amigos Scale</u>	1
<u>Appendix 2:</u>	<u>A Description of Multiple Sclerosis - Biological, Psychological and Social Implications.</u>	3
2.1:	Biological Factors.	3
2.1.1:	Definition and aetiology.	3
2.1.2:	Demographic features.	3
2.1.3:	Symptoms.	3
2.1.4:	The disease process and its effect on the central nervous system.	4
2.1.5:	Diagnosis and treatment.	6
2.1.6:	Disease course and prognosis.	7
2.2:	Psychosocial factors.	9
2.2.1:	Neuropsychological effects.	9
2.2.2:	Emotional responses and mood disorders.	12
2.2.3:	The social consequences of MS.	14
2.3:	Summary.	17
<u>Appendix 3:</u>	<u>Mental State Questionnaire.</u>	18
<u>Appendix 4:</u>	<u>Criteria for inclusion to the pilot study.</u>	19
<u>Appendix 5:</u>	<u>Music Therapy Questionnaire.</u>	20

<u>Appendix 6:</u>	<u>Post session questions.</u>	22
<u>Appendix 7:</u>	<u>Session evaluation form.</u>	23
<u>Appendix 8:</u>	<u>Background to the research participants.</u>	25
8.1:	Introduction.	25
8.2:	Background to participant 'Francesca'.	25
8.3:	Background to participant 'Tracey'.	26
8.4:	Background to participant 'Elaine'.	27
<u>Appendix 9:</u>	<u>Consent form.</u>	29
<u>Appendix 10:</u>	<u>Words to song 'All cried out'.</u>	31
<u>Appendix 11:</u>	<u>Background information to participant 'Jack'.</u>	32
<u>Appendix 12:</u>	<u>The therapeutic process of participant 'Jack': Musical, behavioural and verbal responses and changes in these over time.</u>	35
<u>Appendix 13:</u>	<u>Guide to reading the analytical diagrams.</u>	45
13.1:	Introduction.	45
13.2:	The phenomenon under investigation and its concepts and properties.	45
13.3:	Intervening conditions.	47
13.4:	Actions and interactional strategies.	48
13.5:	Consequences and outcomes.	48
13.6:	The overall diagram.	48

<u>Appendix 14:</u>	<u>Background information to participant 'Jessie'.</u>	50
<u>Appendix 15:</u>	<u>The therapeutic process of participant 'Jessie': Musical, behavioural and verbal responses and changes in these over time.</u>	53
<u>Appendix 16:</u>	<u>Background information to participant 'Guy'.</u>	64
<u>Appendix 17:</u>	<u>The therapeutic process of participant 'Guy': Musical, behavioural and verbal responses and changes in these over time.</u>	66

1
APPENDIX 1

Rancho Los Amigos Scale

Research Foundation of the State University of New York at Buffalo.
(1993). *Guide for the Uniform Data Set for Medical Rehabilitation*. Buffalo, NY:
Uniform Data Set-Data Management Service.

Levels of cognitive functioning

Behaviours Typically Demonstrated

Level.

I. No response.

Patient appears to be in a deep sleep and is completely unresponsive to any stimuli.

II. Generalised response.

Patient reacts inconsistently and non-purposefully to stimuli in a nonspecific manner. Responses are limited and often the same, regardless of stimuli presented. Responses may be physiological changes, gross body movement, and/or vocalisation.

III. Localised.

Patient reacts specifically but inconsistently to stimuli. Responses are directly related to the type of a stimulus presented. May follow simple commands in an inconsistent, delayed manner, such as closing eyes or squeezing hand.

IV. Confused-Behavioural.

Patient is in heightened state of activity. Is bizarre and non-purposeful relative to immediate environment. Does not discriminate among persons or objects; is unable to co-operate to direction with treatment efforts. Verbalisations frequently are incoherent and/or inappropriate to the environment; confabulation may be present. Gross attention to environment is very brief; selective attention often nonexistent. Patient lacks short-term and long-term recall.

V. Confused.

Patient is able to respond to simple commands fairly consistently. However, with increased complexity of commands or lack of any external structure, responses are non-purposeful, random or fragmented. Demonstrates gross attention to the environment, but is highly distractible and lacks ability to focus attention to a specific task. With structure, may be able to converse on a social-automatic level for short periods of time. Verbalisation is often inappropriate and confabulatory. Memory is severely impaired, often shows inappropriate use of objects; may perform previously learned tasks with structure but is unable to learn new information.

VII. Confused-appropriate.

Patient shows goal-directed behaviour, but is dependent on external input for direction. Follows simple directions consistently and shows carry-over for new tasks. Responses may be incorrect due to memory problems but appropriate to the situation; past memories show more depth and detail than recent memory.

VIII. Automatic-appropriate.

Patient appears appropriate and oriented within hospital and home settings; goes through daily routine automatically, but frequently robot-like with minimal-to-absent confusion, but has shallow recall of activities. Shows carry-over for new learning but at a decreased rate. With structure is able to initiate social or recreational activities; judgment remains impaired.

VIII. Purposeful and appropriate.

Patient is able to recall and integrate past and recent events and is aware of and responsive to environment. Shows carry-over for new learning and needs no supervision once activities are learned. May continue to show a decreased ability relative to premorbid abilities, abstract reasoning, tolerance for stress, and judgment in emergencies or unusual circumstances.

APPENDIX 2

A description of Multiple Sclerosis - biological, psychological and social implications.

Appendix 2.1: Biological Factors.

2.1.1: Definition and aetiology.

Multiple Sclerosis (MS) is a disease which progressively causes damage to the central nervous system (CNS). It is characterised by the widespread and seemingly indiscriminate patches of breakdown of the myelin covering of the axons throughout the brain and spinal cord, which causes progressive degeneration. This process is known as 'demyelination' (Walton, 1977). The disease is of unknown aetiology, but it is now widely accepted as being linked to a combination of environmental, genetic, viral and immunological factors.

2.1.2: Demographic features.

MS is the most common nontraumatic neurological illness affecting young and middle aged adults (Rao, 1986). It affects approximately 100 per 100 000, with a higher rate of occurrence in temperate zones, and a low prevalence rate in those of non-Caucasian origin (McCarthy, 1996). It accounts for around 80% of residents in Young Disabled Units in the Britain, and within a typical health district there will be approximately 300 - 400 individuals with MS, with 2 - 3 on a typical general practice list (Barnes, 1993).

2.1.3: Symptoms.

Demyelination of the nerve fibre results in confused and distorted messages being transmitted to and from the brain via the CNS. A conglomeration of

symptoms follow which may affect cognitive, motor and sensory skills. For example, demyelination of the nerve cells in the cerebral cortex involved in leg movement is likely to result in poor conduction of impulses to the leg muscles, resulting in a limp or affected walking pattern. The more common symptoms include weakness in one or more limbs (40%); optic neuritis (22%); paraesthesia (21%); diplopia (12%); vertigo (5%); disturbance in urinary and bowel continence (5%); and less commonly reported symptoms such as epilepsy, deafness, dysphasia, respiratory failure, psychosis and schizophrenia (Barnes, 1993).

2.1.4: The disease process and its effect on the central nervous system.

'Gliosis' is the scarring of the supporting cells and fibres of the CNS, which causes shrinkage, in turn implicating healthy tissue surrounding the demyelinated patch. This further helps to distort messages transmitted along that nerve fibre. Therefore, gliosis may result in a slowly progressive disabling condition, without any further acute attacks. Before describing the implications of the demyelinating process further, it is important to understand the function and purpose of the CNS within the human body.

It may be helpful to think of the CNS as a motorway, acting as a passage for the transport of all messages to and from the brain via the spinal cord, by means of electrical impulses. Branching out from this main route are other smaller routes, which carry the nerves out to the limbs or other areas not within the CNS. The 'vehicles' which transport the messages are called 'neurons,' which are the basic unit of the nervous system. The neuron is made up of a cell with an attached nerve fibre known as the 'axon'. It is the axon which conducts nerve impulses away from the cell.

The axon is covered in a white substance called 'myelin' which acts as an insulator to the neuron, and allows impulses to be transmitted effectively. The nerve cells however are greyish in colour, causing the distribution and concentration of myelin and nerve cells to give the appearance of white and grey matter throughout the brain and nervous system. There are many different types of neurons, but the two which are affected in MS are the motor neurons, which control movement and transmit messages to muscles or glands, and sensory neurons, which transmit sensory impulses and affect sensation. Messages to do with sensation, particularly sensations of pain, light touch and temperature, are picked up by sensory nerve endings in the skin, muscles and around the joints, and transported inwards to the sensory centres in the CNS.

The CNS involves the brain, the cerebellum and the spinal cord, which all act as pathways on which messages are transported. The two hemispheres of the brain, known as the cerebral cortex, are responsible for motor activity, sensation, behaviour, memory, perception, speech, organisation of incoming messages, and primitive functions such as swallowing, breathing and action of the heart. The cerebellum at the base of the brain controls balance, muscle tone, and co-ordination of all muscle activity.

The spinal cord runs like a long cylinder from the brain down the spinal canal, and is responsible for transmitting 'incoming' messages from sensory nerves to the brain, and the 'outgoing' messages coming from the brain via motor 'neurons' to the particular muscle or organ involved. Neurons which serve similar purposes are bundled together in the brain stem or spinal cord in tracts.

In the cerebral cortex there are thousands of motor neurons, responsible for controlling all movement. Movement involves a complex sequence within the

CNS, activated by electrical impulses. A particular neuron will give an electrical discharge, which then travels along the axon, activating other discharges in connecting nerve cells, until finally it activates the muscle or organ causing it to contract or relax. It is not, however, a simple matter of a chain of impulses being activated, but also having the entire message coordinated with other axons, so that the muscle contracts or relaxes smoothly, and to the appropriate amount, and that opposing muscles respond appropriately so as to ensure coordinated and balanced movement.

The CNS, therefore, is a complex network of pathways for transmitting incoming and outgoing messages to and from the brain, and is responsible for cognitive function and all voluntary and intentional motor activity and its coordination. It is this functioning which is affected by the degenerative process of MS.

2.1.5: Diagnosis and treatment.

There is, as yet, no single test which will solely diagnose MS. The person with presenting symptoms must undergo a combination of tests in order to confirm the suspicion of MS. Diagnostic tests at present include blood tests, a test entitled 'visual evoked response' which measures the responses to various visual stimuli, 'auditory evoked response' which measures similarly auditory responses, examination of the cerebrospinal fluid involving a lumbar puncture, CAT scanning, and magnetic resonance imaging (MRI), which can locate plaques of demyelination within the brain.

Diagnosis often follows a period of presenting symptoms which have mystified the person involved, and perhaps their GP as well. Depression is a common reaction to the strange symptoms, unknown quality of their illness, and

constant tests, particularly if the diagnostic period has been drawn out over a period of months or even years.

At present, only symptomatic treatments are available. These are mostly immunosuppressive medications, based on the belief that MS is an autoimmune disease triggered by an environmental factor (Barnes, 1993). Medications include steroids to reduce swelling and reduce spasticity, tremor and rigidity, and antidepressants to address affective changes. Regular and adequate rest is strongly advised to reduce the occurrence of fatigue, and physiotherapy exercises and stretches are recommended for short periods each day. Diet is seen to be an important factor as dietary intake of fat has been found to affect symptoms, and there are differing opinions about suggested gluten free and animal fat free diets. Similarly, herbal treatment involving evening primrose oil has been recommended, but not clinically proven to make any difference. Overall, it is recommended to lead a healthy lifestyle and to avoid stress.

2.1.6: Disease course and prognosis.

MS is characterised by periods of 'relapse' - an attack of demyelination, and 'remission' - periods when there appears to be no further degeneration. During remission, the myelin sheaths may regenerate, so that afterwards function may be restored to that nerve fibre for a period of time. However, if the nerve fibre remains damaged after an attack, regeneration is less likely.

Disease course is variable. Although no strict definitions exist, disease course has been loosely classified to follow two streams (McCarthy, 1996). These are a chronic progressive or malignant course which affects approximately 10 % of individuals diagnosed. This course is devoid of any significant remission of

symptoms. Death occurs in approximately 5 years from diagnosis. The second course is the relapsing remitting course, which is characterised by periods of successive attacks and improvements. Those who show severe cerebellar ataxia and progressively deteriorate over a short time span have a poorer prognosis than those who have long periods of remission with little degeneration (Capildeo, 1982). There is no set course for the illness, and individuals are affected very differently. Someone diagnosed with MS can be told that relapses and remissions are likely, that they may live many years with very few symptoms, or progressively become more disabled within a short span of time. The severity of each attack depends on the position and size of the plaque, and the amount of damage caused to the neurone.

Common onset features of the illness include episodes of weakness in a leg or hand, altered sensation such as tingling, numbness or cold, a feeling of urgency when needing to urinate, loss of balance, double vision, and most commonly fatigue. Any of these symptoms may be experienced on their own, or in any combination with other symptoms. After an initial attack, which may last weeks to months, a period of remission may follow when no new symptoms appear. Remission may last a period of years, with no new severe symptoms ever occurring. A relapse may involve previous symptoms, as well as new symptoms which are more severe. Symptoms of greater severity can include speech disturbances, incontinence of bladder and bowel, spasticity of limbs, increasing tremor when attempting movement known as 'intention tremor', inability to co-ordinate movement of the legs and arms known as 'ataxia', acute eye pain and loss of vision, sexual impotence, and extreme fatigue.

Prognosis is greatly variable, as it is most commonly determined from the time of diagnosis, which in itself may have dragged out over some years. In 1970

the median survival time was estimated at 35 years, but more recently this has increased to 40 years (Barnes, 1993). This may indicate improved diagnostic procedures rather than increased survival times, however.

In the later stages, the severest symptoms of MS may involve cognitive problems, behavioural and personality changes, severe ataxia impairing all voluntary movement, loss of speech, the inability to swallow, and extreme, nearly constant, fatigue. Care of the person with MS in this later stage entails use of a wheelchair, and often special dietary, communication, and environmental aids to ensure any quality of life. Institutional care may become necessary as demands on the family outgrow their energy and facilities within the home. It is important to note however that few people with MS develop such severe disability, and approximately fewer than 10% will require wheelchair care (Capildeo, 1982). Many will be able to lead fully active lives within the community for much of their natural life span. The leading cause of death in MS is from bronchopneumonia (Barnes, 1993; Bauer & Hanefield, 1993).

Appendix 2.2: Psychosocial factors.

2.2.1: Neuropsychological effects.

In recent years there has been more research and a developing awareness of the neuropsychological damage that may occur when there is demyelination within the brain, and the resulting cognitive and psychological changes. Early neuropsychological investigation found that features most commonly presenting in MS included memory impairment, particularly with short term memory; decreased insight; poor motivation; poor concentration; perseverative behaviour; poor planning and problem solving; personality

changes and mood swings; and a reduction in flexibility of thinking and attitude (Vowells & Gates, 1984). More recent research has examined the underlying processes of these deficits in greater detail. This has revealed more specifically memory disturbance, difficulties with conceptual reasoning, visuo-spatial problems, and an inability to rapidly process information (McCarthy, 1996). Although differences between verbal IQ and performance IQ have been most commonly found, it is suggested that this results from problems with fine motor control and a combination of other cognitive abilities. Memory impairment has been most commonly reported, however research suggests that it is retrieval processes which reveal such problems, whereas encoding and storage capacity is preserved (Rao, 1986). Near normal recognition memory has also been found to be preserved in patients with white matter diseases (Rao, 1996). The implication of depression in these problems has also been questioned, but one comparative study found deficits in areas of attention, verbal fluency and visuomotor search independently of depressive symptoms (Krupp et al, 1994). The conceptual and abstract reasoning deficits which occur stem from a combination of defective self monitoring, distractibility, impulsiveness, carelessness and low motivation (Rao, 1986).

Rao (1996) reports that of those patients presenting with cognitive impairments, severe dementia is observed in 20-30%. Dementia of this type affects social functioning in all aspects of life, including employment, social and environmental. The type of dementia stemming from MS has been labelled 'sub-cortical dementia'. This has led to comparisons with other neurological conditions such as Huntington's Disease, Parkinson's Disease, closed head injury and AIDS related dementia (Rao, 1996). Subcortical dementia differs from cortical dementias, such as the Alzheimer's type, based on relative differences in the location of the neuropathology and the pattern of

neuropsychological deficits observed. Subcortical dementia is characterised by the relative preservation of intelligence and language in conjunction with problems of forgetfulness, slower mental processing speed, difficulties with conceptual reasoning, sustained attention and visuospatial processing. This results in primary presenting deficits in attention, memory and conceptual reasoning in the absence of signs of aphasia or apraxia. Subcortical dementias have also been identified to involve disturbances to fundamental functions, including arousal, timing and sequencing, motor programming, motivation and mood, all of which underlie the performance of many other processes (Mahler & Benson, 1990).

The combination of different deficits has ramifications on a practical approach with cognitively impaired patients. For example, disruption of dynamic, novel and conceptual problem-solving abilities may exist whilst static, over-learned, routine skills remain relatively well-preserved (Rao, 1986). The correlation between the brain damage and the resulting behaviour has great implications for therapy treatment, and by being aware of the cognitive problems that may be involved, a therapist can be helped in designing realistic programmes and utilising techniques to overcome them. For example, it would be helpful to understand that: the client is not lazy or resistant to trying something, but may actually lack the ability to initiate a task; that although the client persists in a behaviour or discussion topic they are not necessarily showing obsessive tendencies, but are perseverative in their behaviour, and are unable to move on from that point; that someone with impaired insight may benefit more from gentle directive intervention from the therapist rather than insight oriented techniques.

2.2.2: Emotional responses and mood disorders.

Emotional responses which emerge as the illness progresses may include anxiety, denial, fear and anger at the uncertainty of future symptoms, prognosis and treatment, and a sense of having no control. Mood disorders associated with MS are widely reported including depression, and also other organically caused disorders. In the Gottingen study which sampled 660 MS patients, Bauer and Hanefield (1993) found that 54% had mood disturbances, 22% were emotionally unstable, and 19% were depressed. This study found that the variables of greatest correlation with high depressive symptoms were increasing severity of the illness, frustration and mounting life problems. Furthermore, depressive reactions were seen to reduce with increasing cognitive impairments and also resignation to the realities of chronic illness.

Depression in response to the illness may be due to a variety of factors, such as medication, a reactive grief in response to loss, a result of brain damage caused by demyelination, or personal predisposition to an affective disorder (Whitlock, 1984). Apart from reacting to the loss already experienced, there may also be a 'preparatory' depression in considering the impending losses (Simons, 1984). Much of the research into the cause of depression in MS is conflicting, but there appears to be a correlation between depressive symptoms with progressive disability and lack of social support, i.e. reactive depression, whilst major depressive episodes appear to result more from the structural lesions caused by the demyelination within the brain (Garland & Zis, 1991). Rao (1996), however, states that depression is more commonly found in MS when there are no major cognitive deficits, supporting the findings of the Gottingen study. It is also interesting to note that one study comparing the incidence of depression in people with MS to that of a matched neurologically disabled population found a significantly higher level of depression in the MS

population (Whitlock & Siskind, 1980). This was supported by a review of epidemiologic research concerning depressive disorders and MS, which found that most controlled studies have indicated a greater prevalence of depressive features amongst MS patients than other neurological control groups (Schiffer, 1990). This suggests that in addition to the normal emotional reactions experienced by people confronting their own mortality and coping with chronic degenerative disability, there are additional factors or more complex responses for those with MS. In case studies given throughout the literature, it is commonly expressed that chronic feelings of low self-esteem, self-blame, denial, and grief are all reactions to the diagnosis. Research from health sociology drawing on qualitative analysis sheds greater light on these concepts, as reviewed in the following section.

Psychotic symptoms and suicidal tendencies have also been reported. In the Gottingen study already cited, 8% of the 660 sample presented with neurotic reactions, and the authors report that the suicide rate of the MS population may be up to 7.5 times higher than in the general population. Indications for suicide have been linked to feelings of helplessness, hopelessness and persistent pain, mental distress and despair, feelings of desolation, failure and personal disappointment, and submerged fear with psychiatric complications (Bauer & Hanefield, 1993). These findings offer invaluable insight into individual experiences and emotional responses which may be masked by larger group studies.

In one study examining the emotional responses to MS, a classification system of emotional reactions to MS was developed (Baretz & Stephenson, 1981). These include overt depression, concealed depression, neutral mood and elevated mood. Relevant to this study are the behaviours defined under these classification headings. For example, 'concealed depression' was

defined as marked by a conscious or unconscious effort to control the outward expression of symptoms, indicated by inconsistencies in behaviour. The authors used terms such as 'dismiss' and 'avoid' to describe how patients dealt with negative feelings about areas of concern. 'Neutral mood' included behaviour classified as 'an outward deceptive cloak for underlying feelings that are not readily accepted'. Such classifications might indicate subjective impressions on the part of the researchers, however, when considered with findings of much greater depth from qualitative research, these classifications are valid and highly accurate.

Early and ongoing descriptions of mood disorders in MS have commonly included 'euphoria', which is defined as an inappropriate cheerfulness of elation in mood, having been categorised as a psychiatric symptom of the illness (Whitlock, 1984). More recently, however, this has been discredited as largely unfounded in research, and more aptly described as a defence mechanism that provides psychological stability (Rabins, 1990)

Regardless of the causes of depression in people with MS, it needs to be a major consideration when working with these clients. It is important however, that causal factors of mood disorders are thought about when planning appropriate treatment interventions; reactive grief needs an entirely different approach than depression caused by organic brain damage, and any apparently 'euphoric' behaviour must be recognised as such so as not to mask an underlying depression.

2.2.3: The social consequences of MS.

The literature reviewed so far has involved largely controlled group studies and trials which have examined trends in disease course, symptomology, and

medication effects. These studies have attempted to improve the medical community's understanding of MS. Such studies also fail, however, to give any clear picture of the individual's experience, or of larger psychosocial responses to illness. Qualitative research studies from health sociology are starting to redress this balance, and to provide valuable insights from the individual's perspective and view the chronically ill person in social contexts. This in turn helps health professionals to improve their understanding of fundamental issues of living with chronic neurological illness.

The impact of chronic illness affects the individual's life in every way: increasing loss of health, changes in personal relationships, loss of employment, and changes to living environments. Such changes can lead to poverty, isolation, and institutionalisation. Hospitalisation may be the only option for the individual to meet particularly complex medical needs, but this results in a loss of individuality and loss of privacy. Opportunities for communication in a hospital setting may often be kept only to that of basic needs, particularly in the current climate of staffing shortages. Opportunities for communication of fears, anxieties, hopes, frustrations, grief and joy may be limited, just at a time when the affected person is having to face many difficult issues. Contact with family and friends may become more difficult or less frequent as the person becomes more impaired, further increasing feelings of isolation.

The consequences of all of these aspects accumulate to result in the emotional responses outlined previously, particularly despair and hopelessness. The individual living with such enormous changes in their life needs to find ways to continue coping. Such mechanisms are much more complex than simply 'denial' or 'acceptance'. Increasingly within the health care literature, the role of coping mechanisms are being identified, and the

need for psychotherapeutic treatments.

Accompanying progressive disability are changes in self-concept, stigma, and decreased opportunities to get out into the community independently. This serves to reduce existing ties and increase isolation. Personal identity which is formed through concepts of the self have been identified as central to the experience of living with chronic disability (Corbin & Strauss, 1987; Charmaz, 1987&1991). Charmaz (1991) identified that the struggle for control over illness and control over time reflect an individual trying to control the defining images of the self and making sense of their illness. Hence distinct phenomena emerge which combine in complex ways to form the individual's experience, particularly control, time and self. Research indicates that as individuals experience increasing disability, they experience a loss of self, a loss of wholeness, and are forced to opt for the identity of a 'salvaged self' (Charmaz, 1987). Isolation and immersion in illness increase the likelihood of damaged self concepts and a damaged identity. These issues are central to the individual living with chronic illness.

Differing prognoses and treatment options given by medical specialists may reinforce the affected person's difficulty in accepting their diagnosis. Furthermore, the individual operates as part of a social network. The existing relationships with partners and family prior to diagnosis have been found to affect the family's coping strategies and acceptance of the illness. As the mean age of onset is 29-33 years of age, relationships with partners are not necessarily well established, and there may also be a young family. An individual's reactions to the symptoms will be strongly influenced by their background, personality, general coping styles, and existing support network (Simons, 1984). Further complexity of the social/familial network can occur if the person diagnosed with MS has become estranged from family or partners.

In this instance, ameliorating or reforming connections with significant others can be difficult due to ill health and increasing disability, or complicated by inappropriate behaviours caused by organic psychotic symptoms.

2.3: Summary.

The person who is diagnosed as having MS, therefore, experiences a complicated diagnostic process, is given an undefinable prognosis, and cannot be offered curative treatment. The social and emotional adjustments needed for such uncertainty and the possibility of a severely disabled future are enormous. A person whose life is increasingly affected may have to face the challenge of leaving their work, changing their role in the family and society, and even hospitalisation. On top of this, the individual is likely to experience increasing physical symptoms and disability, with possibly cognitive difficulties as well. The combination of all these factors has an overwhelming impact on self concept and identity.

APPENDIX 3

Mental State Questionnaire (Aberdeen Version)

- 1 Name**
- 2 Age**
- 3 Date of birth - month**
- 4 Date of year - year**
- 5 Present location (e.g. hospital)**
- 6 City (lived in)**
- 7 Day of week today**
- 8 Month**
- 9 Present Prime Minister**
- 10 Previous Prime Minister**

APPENIDX 4.**Criteria for inclusion to the pilot study**

1. Had a severe neurological disability stemming from brain damage caused by traumatic or anoxic brain injury, Multiple Sclerosis or stroke, and were resident for rehabilitation or residential care at the facility at the time of data collection
2. Music had a significant meaning in their lives, either by having had a background in music associated activities, or being an avid listener of music. For the purposes of this study, participants needed to readily engage in and relate to music within the two treatment sessions, and those with an active background in music had been observed to relate and respond to music therapy more immediately
3. Were physically able to play the instruments involved in the study as outlined in the section 'Equipment' in order to participate in improvisatory activities
4. Were able to communicate effectively using speech or communication aids
5. Functioned at a cognitive level which enabled the individual to answer the questions included in the measurement tool accurately and reliably. This level was set at a score of 7 and above on the Mental State Questionnaire (Appendix 3)
6. Agreed to be included in the study, by giving written consent
7. Did not display inappropriate affect or labile behaviour caused by their brain damage, which would render mood scores collected as invalid.

20
APPENDIX 5

**Music Therapy questionnaire to be used as part of project
'Comparing two methods of Music Therapy within a neurological
population - improvisatory versus song based activities with six
participants with Multiple Sclerosis'.**

The attached form is to be administered by an independent person, and is to be answered in the post session testing immediately after the Bipolar Profile of Mood States (POMS-BI) form has been answered.

Participants are to state their answer to each question in one of the four categories given: much like this, slightly like this, slightly unlike this, and much unlike this. Each of these categories is scored differently and results in a total score out of 30, with a minimum score of 0. A higher score indicates a more positive result for the method being evaluated.

This form is only to be used in conjunction with the POMS-BI measure, as a back-up measurement tool.

cont...

Participant's name
Date
Time
Session no.

1. I felt stimulated by the music in the Music Therapy session

Much like this Slightly like this Slightly unlike this Much unlike this
3 2 1 0

2. I found it difficult to talk about myself or my feelings in the Music Therapy session

Much like this Slightly like this Slightly unlike this Much unlike this
0 1 2 3

3. I feel better about myself after the Music Therapy session than before

Much like this Slightly like this Slightly unlike this Much unlike this
3 2 1 0

4. I felt confused by the music in the Music Therapy session

Much like this Slightly like this Slightly unlike this Much unlike this
0 1 2 3

5. I felt bored in the Music Therapy session

Much like this Slightly like this Slightly unlike this Much unlike this
0 1 2 3

6. I feel I experienced something new in Music Therapy

Much like this Slightly like this Slightly unlike this Much unlike this
3 2 1 0

7. The music in the Music Therapy session brought up memories and/or feelings for me

Much like this Slightly like this Slightly unlike this Much unlike this
3 2 1 0

8. I found the Music Therapy session a waste of time

Much like this Slightly like this Slightly unlike this Much unlike this
0 1 2 3

9. The music played in the Music Therapy session tended to reflect what I was feeling

Much like this Slightly like this Slightly unlike this Much unlike this
3 2 1 0

10. I felt pretty useless during the Music Therapy session

Much like this Slightly like this Slightly unlike this Much unlike this
0 1 2 3

Interviewer's Initials.....

22
APPENDIX 6

Post session questions.
Initial model for focussed interviews

How are you feeling after all that?

If you were to describe to someone what you've just done in the MT session, how would you put it in your own words?

Prompt: So did you play instruments, or sing ..?

Which part did you enjoy the most?

Was there any part you found harder, or where you felt like you weren't sure what you were supposed to do?

What sort of music did you play in the session?

P: Had you ever heard the music before?

P: Did we play a song you knew?

P: So we played a song you knew / So it was unfamiliar

What were you thinking about when you were playing/singing?

P: I sort of felt at that moment; what did it feel like for you?

What's been the best thing about coming to MT today?

What sort of day were you having before you got here?

Other prompts:

(Immediate repeat of words with pause to suggest expansion)

So tell me more...

When you say

Try and tell me ...

Your mood seemed to change and I just wondered how it felt for you

You really seemed to be concentrating " " " " "

APPENDIX 8**Background to research participants.****8.1: Introduction.**

Following the recruitment and selection criteria outlined in Section 4.6, six participants were purposely selected for involvement in this study. Please refer to Appendices 11, 14 and 16 for the background information regarding Jack, Jessie and Guy respectively. Brief background information regarding the remaining three participants is included in this Appendix.

8.2: Background to participant 'Francesca'.

Francesca was a woman in her early 40's who was referred to music therapy due to emotional and behavioural problems. These problems were exacerbated by her cognitive deficits. She lived at home and attended the day-care facility at the hospital. She was only mildly physically affected by MS. She was still able to use both her hands functionally, and although she was able to walk, she needed a wheelchair to travel more than approximately ten metres due to the fatigue she experienced on all physical effort. Neuropsychological tests revealed that she was showing clear signs of moderate subcortical dementia, including severe short term memory deficits, verbal disinhibition, poor attention and concentration, difficulty with problem solving and reasoning ability, and impaired insight into her situation. She also had exhibited paranoid and occasionally aggressive behaviour. She presented as confused, and verbal interaction with her was difficult as she fired rapid questions with no pause for the listener to answer.

Francesca had not taken part in the pilot study. She was referred after the pilot study by her Occupational Therapist who felt Francesca needed a supportive

environment to explore emotional issues. It emerged in therapy that anxiety, loss and acceptance were key issues for her. She had lost both her parents and was isolated from people whose relationships she held as significant. Her living situation was becoming increasingly unstable as she had a series of live-in carers who rarely remained long enough for any sort of relationship to develop. This increased her isolation.

She continued with music therapy as part of this research project for only sixteen sessions. After this, she requested to withdraw for two reasons. The first reason was that she became suspicious of the questions asked by the therapist/researcher about her experience of the music in the therapy session, believing it to be some sort of test. Her cognitive difficulties caused any exploration of this with her to result in increased suspicion. Secondly, her need for acceptance and longing for intimacy had implications for therapeutic boundaries. This was emphasised by the contracted agreement that the therapy would be for a specified number of sessions. The impending loss of the therapist caused her considerable anxiety. It was believed by the clinical supervisor and the therapist that Francesca terminated therapy early due to fear of developing a relationship which she was in danger of 'losing'.

8.3: Background to participant 'Tracey'.

Tracey was a woman in her early thirties who had lived in the hospital for approximately eighteen months prior to her involvement in this study. She had not taken part in the pilot study. She was referred to music therapy by her Occupational Therapist to facilitate exploration of the emotional impact of becoming severely disabled at such a young age. Her particular illness trajectory had followed a path of sudden and extreme loss of all motor function and ability to communicate, followed by gradual improvement. She held on to this trajectory as an indication that she would regain all function and return to

a more independent lifestyle. At the time of this study, she was fully dependent for all aspects of care, such as eating, drinking, and personal care due to severe ataxia in both her arms. She was wheelchair dependent. Her mobility was further restricted as she was dependent on others for pushing her chair which she was physically unable to project herself. Neuropsychological tests revealed only minor cognitive deficits which rarely affected any aspect of her therapy.

As a highly pragmatic individual who took pride in supporting and providing for others, she did not respond immediately to the opportunity to explore her feelings. Instead, she focused solely on the physical gains she made in all her therapies, which were indicators for attaining her goal of moving back to the community. On occasion she did respond emotionally in an explicit way within therapy. This most often resulted in her cancelling following sessions to attend extra physiotherapy sessions instead. In clinical supervision these responses were explored from a psychodynamic angle, and interpreted to be coping strategies. At the end of the agreed period of therapy for this research, she made a decision not to continue with music therapy, although provision has been made for her to attend at a future date if she so wishes.

8.4: Background to participant 'Elaine'.

Elaine was a woman in her early 40's attending the day-care facility who lived at home with a parent who cared for her. She had not taken part in the pilot study. She was referred to music therapy by her Occupational Therapist as she had no individual therapy in her programme, and the multidisciplinary team felt that provision of individual therapy may provide an outlet for exploration of personal issues which were not provided for elsewhere. She was also experiencing increasing visual deficits which caused other 'activities' to become impossible. Elaine was fully dependent for all physical

tasks due to extreme muscle weakness and paralysis. She had some movement in one of her arms, but this movement was poorly controlled and very weak. However, she was able to use some lightweight instruments with this movement for very brief periods. She was wheelchair dependent and she relied on supervision in her mobility due to her visual problems. Neuropsychological tests did not reveal any cognitive changes.

Within music therapy it emerged that the nonchalant and easygoing appearance with which Elaine presented masked deeper concerns regarding her unknown future and more difficult feelings about her family. From these issues also emerged unresolved relationships from her past. Elaine was able to explore her feelings around each of her personal issues through music which she found a particularly emotional medium. She did benefit from having an individual therapy session as opposed to group sessions in which she felt more pressured to keep up her lively front so others would enjoy being with her. At the end of the research period, she chose to continue with music therapy for a period of time, and again at a later period. Within her most recent 'block' of music therapy, the technique of song-writing was used to compose with Elaine a song for a the family member who cared for her, and to whom she wished to express many sentiments.

29
APPENDIX 9

Consent form and information for research participants.¹

Information sheet for participants.

You have been invited to participate in a research project exploring two different types of Music Therapy activities. These are:

a - song based activities - involving singing, listening to or playing small percussion instruments to songs of your choice played by the Music Therapist.

b - instrumental activities - playing instruments or singing with the Music Therapist using 'improvised' music

The project will span 16-24 treatment sessions over approximately 4-6 months. You will be seen by the Music Therapist in the Music Therapy room on your own once weekly at a regular time, to fit in with the rest of your weekly activities.

Each week the sessions will alternate the activities outlined above i.e. song based activities in one session and improvised music in the next. After each session, you will be asked about the music in the session, and how it felt when you were playing the music, or what it meant to you. These questions will be asked by the Music Therapist.

***Your* participation in these activities will not be measured or judged, only the activities themselves.**All material from the sessions will be treated with utmost confidentiality, and you may withdraw at any time if you so choose.

¹ This consent form was used for the main research study. A slightly amended version was used for the pilot study.

Consent Form.

Royal Hospital for Neuro-disability,
West Hill,
London. SW15 3SW.

Title of study: Comparing two different Music Therapy methods in Multiple Sclerosis.

Investigator: Ms Wendy Magee
Head of Music Therapy

Supervisor: Dr Graham Beaumont
Head of Clinical Psychology

Purpose of study: To compare two different Music Therapy methods in people with Multiple Sclerosis. The two methods are song based activities using familiar well-known music, and instrumental activities using unfamiliar 'improvised' music. The results will help develop an understanding of which Music Therapy methods are most helpful in meeting the needs of people with Multiple Sclerosis.

Methods: The two Music Therapy methods being compared are:
a - song based activities - involving singing or listening to songs of your choice played by the Music Therapist, or writing words to set to well-known tunes.
b - instrumental activities - playing instruments with the Music Therapist using 'improvised' music

The project will span 16 - 24 treatment sessions over approximately 4-6 months. You will be seen by the Music Therapist in the Music Therapy room on your own once weekly at a regular time, to fit in with the rest of your weekly activities. Prior to and after each session, you will be required to answer a brief list of questions about how you are feeling.

.....

I.....of.....

.....
agree to take part in this study. I understand the procedures involved which have been explained to me. I understand that I can withdraw from the study at any time without giving a reason for doing so. I have been told that there are no risks involved and that the confidentiality normally applied to medical records will be maintained.

Signed(subject)

Signed.....(witness) Date.....

Signed.....(investigator)

31
APPENDIX 10.

Words to 'All Cried Out'

You took your time to come back this time
The grass has grown under your feet
In your absence I changed my mind
And someone else is sitting in your seat
I know that I said there'd be no-one else
I know that I said I'd be true -
But baby I'm burning Cupid's arrow
And here's the short and narrow
I've nothing left to offer you.

Chorus:

I'm all cried out,
You took a whole lot of lovin' for one handful of nothing.
All cried out,
It's hard to give you something when you're
Pushing and a'shoving me around.

So, don't look surprised there was no disguise
You knew where I stood from the start
So stop, look around you
You're right back where I found you,
Take back your cold and empty heart.

Chorus:

I'm all cried out,
You took a whole lot of lovin' for one handful of nothing.
All cried out,
It's hard to give you something when you're
Pushing and a'shoving me around.

Bridge:

You go your way, and I'll go mine,
I won't stay around here,
Don't you waste my time.

Words and music by
Tony Swain, Steve Jolley, Alison Moyet.

101 Pop Hits for Buskers, (1984). Scotland: Scotprint Ltd.

Background information to participant 'Jack'.

'Jack', a 59 year old Caucasian male, was diagnosed with Multiple Sclerosis nine years prior to the current investigation. He presented between the relapsing-remitting and chronic progressive classification of the illness. He was widowed with four children. Although Jack reported that he was 'very close' to his children, ward staff reported that he had in fact very limited contact with his children who lived at various distances throughout Britain. He had lived on a residential ward within the hospital for a period of approximately five years. Prior to this, he had lived all his life within a five mile radius of the hospital, and would have been familiar to the name of 'Home for the Incurables' which had existed until recent times. He had paralysis in his left arm and both legs, and weakness in his right arm which he was still able to use functionally to some extent, for example, to feed himself and manipulate objects once they were within reach. He was mobile in an electric wheelchair, therefore, had some semblance of independence within the confines of the hospital. For any external trips, he used a manual wheelchair which increased his dependence on others for mobility. He attended a spiritualist church, and expressed beliefs outside of music therapy sessions about faith healing. It was reported in medical notes that he had believed his Multiple Sclerosis may be cured through faith healing at his church. His medical records also revealed a history of depression, which had been treated pharmacologically, and underlying anxiety.

He presented as an extremely sociable, friendly, and very busy man, with an active social timetable including visitors within the hospital, and outings each week. Accompanying him around the hospital, he greeted all staff by name, and many of the other patients/residents and relatives similarly. He most often

appeared in a continuous lighthearted mood claiming that he'd 'never been better off'. In his verbal interactions within and outside of sessions he adopted many of the coping mechanisms already described in Chapter 7, particularly stating rules and beliefs, projecting, keeping busy, putting on a front and distracting. It was determined that the need for such coping mechanisms occurred due to contextual situations and conditions. For example, it has already been identified that individuals adopted a coping front when feeling threatened in some way, possibly of revealing feelings or emotional states which could be identified as 'not coping'. Other causal factors were low control and needing to make sense of the situation. For example, Jack stated his belief that people around him in the hospital who had sustained severe disabilities had done so for having led 'bad' lives. He also employed projection as a coping mechanism in every session, by referring to his increasing difficulty in controlling his vocalising for reasons of age or a passing cold or virus. He did not acknowledge his illness nor decreasing mobility which would have affected his vocal production. Such a mechanism indicated his confrontation with increasing inability and his need to find some way to continue coping. Jack often distracted within sessions when an emotional state categorised as 'not coping' related in some way to himself. In this way, he regained control of the situation distracting onto subjects unrelated to himself or mood. Within every session he referred to being 'happy', 'ecstatic', or 'joyful', such as the examples already given in the section describing coping strategies. In the ways described, his underlying anxieties slowly became evident during his music therapy. Through his incessant adoption of a coping front, it appeared that he was fearful of the unknown future of his illness, particularly considering he lived with so many others in very advanced stages of the illness. He was continually observing others' lives as they lived with complete physical dependence, no method of communicating with their environment, and day to day existence with Multiple Sclerosis.

Neuropsychological testing, using the Test of Everyday Attention, pointed to Jack having difficulty with the manipulation and sequencing of auditory-verbal information in working memory, in addition to auditory selective attention. His cognitive flexibility and attentional switching lay within normal range, which indicated that he had no difficulty moving his attention from one task to another. His learning ability relied on many repetitions of new material. His visual selective attention was severely impaired, although this would have had little relevance to music therapy tasks. Although within testing he was able to sustain attention for lengthy periods without distraction, within sessions he presented behaviourally as being highly distractible. Considering his neuropsychological measures, this may have been due to the amount and complexity of information being presented, as well as the information being unfamiliar and not clearly defined. His performance in tests revealed particular difficulty with auditory selective attention. In summary, his neuropsychological status suggested that novel, unfamiliar auditory material which was not well defined in task may have presented difficulties for him to learn or respond to.

Jack referred himself to music therapy, being very eager to find a place where he could sing the songs which were of particular importance to him. He therefore started the music therapy with a strong bias towards song-based activities, and his participation in the different activities reflected this bias throughout his therapy. Due to the unknown nature of improvising and his expressed preference for songs, it was mutually agreed that he would come for four initial sessions to see whether he liked it. Jack found being listened to when he sang such a profound experience that he was very keen to continue as part of the research project.

The therapeutic process of participant 'Jack': Musical, behavioural and verbal responses and changes in these over time.

Jack arrived at therapy each week carrying a bag full of song sheets, despite knowing that the session would be either improvisation or song-based. He could not read the music, however said that he needed the words to sing from. When given a choice of what to do in the session, he always chose to sing. He preferred to concentrate on his voice, although did show some interested and occasionally enthusiastic responses to the instruments presented in the sessions. His preferred songs included many from the Broadway shows and films, particularly sentimental or romantic ballads. Despite having a wide repertoire of songs, he increasingly narrowed his choice of songs to a small core from which he repeatedly chose in the song-based sessions. These included 'Ol' Man River', 'What a Wonderful World', 'Bless This House' and 'Some Enchanted Evening'. He usually insisted on needing the music whilst singing these songs, despite knowing them very well. On the occasions he did not have the music from which to read, he appeared anxious that he would forget the words. He usually became quite engaged whilst singing, although he tended to focus completely on the sheet music. At times he was not aware of the tempo or pitch at which the accompaniment was played, although he derived great pleasure from singing, and talking at length in nearly every session about how important music was to him in his life, particularly singing and using his voice.

Jack gave many varied verbal and mood responses to these songs. The words of each represent a different picture, with differing themes, although often the same song would elicit quite different responses on different weeks.

The two most chosen were 'Ol' Man River', with its theme of being weary of life, and 'What a Wonderful World', with its combination of wistful melody and words reflecting on a rosy, happy life. He would ask for these nearly every time, often juxtaposing them within the session. He revealed that the words of the songs gave them greater meaning to him, and that the words of a song related to a particular mood or feeling. The consequences of knowing the words to a song not only increased its meaning but enhanced other aspects such as increasing his sense of participation and feelings of ability. It also increased the enjoyment of a song. Unlike his general verbal indications of mood, the moods he related to songs sometimes extended to 'sad', a feeling he did not associate with himself. He indicated that the meaning within songs gave them their importance.

The experience of songs held strong associative qualities and temporal aspects for Jack. Through singing songs, or talking about them, he relayed his associations with the songs, usually referring to a previous time in his life. In relaying stories about his life, he talked of memories, unfulfilled hopes and ambitions, disappointments, relationships with significant others, and his feelings around these issues. In this way, the process of life review was often stimulated by the songs he requested to sing and share with the therapist.

Often, it appeared easier for him to discuss his feelings around past events than events in the 'here and now' such as his life in the hospital. Whilst it may be disputed that this focus on the past acted as a barrier for Jack to acknowledge his current feelings, the songs appeared to facilitate him getting in touch with more difficult feelings and being able to give these feelings a name. In this way, the emotional qualities of the songs came to play a crucial part in his therapy. In his own words, the songs held specific associations which improvisation did not hold. He chose to play and sing songs which helped him to get in touch with the sadder parts of his life, thereby

acknowledging those feelings. In this way, Jack was directly and non-verbally able to relate feeling states to himself rather than to others or the music. He could then explore such feelings verbally, or dismiss them altogether. The fact that, at times, he was able to acknowledge and share such feelings non-verbally through his songs was considered to be of prime importance within his therapeutic process, as it was one of the few times he dropped his superficial coping front. It also increased his control within a situation which could have been highly threatening for him.

Whereas a strong sense was gained of what place songs took in Jack's life and how they came to play this part, such a clear contextual picture could not be drawn for improvised music. He appeared to struggle with the abstract nature of the activity, having difficulty finding the language to describe his experience of it. He commonly used words such as 'noise' and 'vibration' in his attempts to describe the music within the session. The personal meaning held for him in songs by the words, temporal and associative aspects were absent in the improvised music. Through the temporal and associative properties, songs possessed a range of emotional properties and expressed a variety of feelings for him. As such properties were absent within the improvisations the experience engaged him less emotionally. Although in giving improvisations a theme their meaning could be increased, on the few occasions when Jack did such, he chose themes which were of no personal significance. In doing so he removed the personal and emotional experience even further away from himself and his pertinent issues. Also, whereas others within the study had found the experience of playing instruments a physical one which engaged them in the process of illness monitoring, Jack's focus of illness monitoring lay in his vocal production. Hence the experience of vocalising and singing songs engaged him more physically than did improvising with instruments. He did however clearly articulate his interactive experience of improvisation, which was a much stronger experience than

within the songs. Regardless of this aspect, he did not acknowledge improvising in facilitating his exploration of his feelings, and nor did it appear to aid in lowering his coping front. In many ways the experience of improvising maintained this front for him.

Concepts of skill and ability and the level of independence he felt in an activity affected his experience of each of the activities. This was triangulated between the analyses of the interviews and the behavioural and musical observations made in the session evaluations. It was clear from the analyses of the interviews that he felt better about himself when singing as this was something he felt he did well. He expressed not feeling able to play an instrument, despite the reassurance given by the therapist of no prior skill being needed, or there being no 'right or wrong'. The instruments he chose to play when improvising increased his feelings of inability and decreased his feelings of skill, as his chosen instrument was his voice, which could largely only be used in song-based activities. The ownership which he experienced with songs in the expression he put into them was also absent within the improvisations. Thus, he did not feel the expression to be a personal one within his improvisations, attributing expression to the 'tone' the instrument made.

He did not display the varied verbal and mood responses to improvising as he did with songs. Although he verbally expressed a polite interest in the instruments, he often adopted an amused expression when playing. At times he appeared to be playing the instruments more to comply with the therapist rather than out of any real interest. When this was discussed with him, he would openly admit that he would always rather be singing 'his songs' than anything else. When singing songs, Jack showed a variety of facial gestures as he appeared to take on the dramatic aspect of the words. In direct contrast,

within many of the improvisations he sat upright, looked at the therapist or out of the window with a smile which was fixed on his face. Such behavioural observations indicated little intent in his playing, as he rarely looked towards the instruments he was playing, and nearly always played with a 'flip-flopping' movement of his wrist i.e. dropping the beater wherever it fell, with little purposeful direction. Any comment on the therapist's part about him seeming not so interested in the playing met with comments about 'what fun' it was, and how much he 'enjoyed' it. Throughout his therapy he engaged more readily and more often in singing his songs although further on in his therapy he did start to engage in improvisation on some levels. This reflected a developing therapeutic process in both the music and his relationship with the therapist.

There were musical and behavioural differences noted in different activities using unfamiliar improvised musical material. For example, in structured turn-taking tasks, there was eye contact with the therapist, a range of facial gestures and expressions, and a given musical structure of call/question and response. Rhythms such as:



prevailed in Jack's material, and although he reflected other sorts of rhythmic patterns from the therapist's material and developed these slightly, the rhythm notated returned regularly towards the end of his phrases (refer to audio example 1). Generally within the turn taking activities Jack directly imitated the therapist's use of dynamic range, register of instrument played, method of playing, phrase lengths and duration of playing. In this way his novel musical material was limited and showed little development unless led by the therapist. He was aware of a feeling of being 'led' and in one of the early sessions requested that he 'lead' a turn-taking. Within such, however, he quickly reverted to repeating the therapist's sounds, and unless prompted by a silence, did not take the 'lead'. Although such turn-taking activities served to

explore a range of musical expressions, he was unable to develop or initiate these ideas within improvisation.

Within improvisations, he had difficulty initiating new material, tending to play well known and 'cliched' rhythmic patterns which varied little throughout the improvisation. Even within less structured improvisations, the musical material took the form of turn-taking, as he tended to either imitate the therapist's material or make literal representations of melodic material or musical registers i.e. using one instrument when the therapist played in a high register, and another when she moved into a lower register. He appeared to grapple with how to conceptualise the improvisations, unlike the turn-taking which he referred to as 'us talking to each other using the instruments'. Although this was interpreted on one level as possibly reflecting his neuropsychological problems, within clinical supervision an alternative interpretation was offered. His music was interpreted as 'latching onto' something familiar, in an attempt to try to give himself some structure and contain his emotional state. This was also the interpretation given for Jack's preference for songs, in which he could find 'safety'.

The music within his improvisations varied between sessions, as did his levels of engagement. In the fifth session he chose to play the bass xylophone which the therapist accompanied on the flute. His music was constant and rhythmic, although not formed into phrases, however he explored the full physical range of the instrument. He played softly and sensitively, with little dynamic range, and remained focussed on the instrument during the improvisation. His music reflected his apparent subdued mood, and Jack later acknowledged that he was feeling unhappy about a disagreement he had had with a staff member during the week. Taken to clinical supervision, the musical qualities of the sounds he made, which differed from those in previous turn-taking activities, were interpreted as a direct expression of his

feelings. The constancy and quiet dynamic of his music was interpreted as an attempt to control his 'anger' and 'sense of outrage' at how he had been treated.

In a joint improvisation with the therapist on the electric keyboard in session 7, Jack played in the treble section of the keyboard above a two chord ostinato in the bass, modally centred on E, given by the therapist (audio example 2). His material in this improvisation was musically formed into ascending phrases, paced at a tempo which followed the therapist's material and with rhythms reflecting the given pulse. Musically he showed a heightened awareness and greater interactivity, and his material was very different from that seen in other improvisations. In this one he allowed rests and silences in his own music, and his music was more original and less imitative of the therapist's, whilst being reflective of it. The ending of this improvisation was shaped by the rhythm and melodic shape of Jack's music, which again contrasted with other improvisations. In other sessions he often showed a reduced musical awareness of the overall structure of an improvisation, and at times seemed surprised that an improvisation had ended despite an extended 'winding down' section within the music.

The level of musical sensitivity described from session 7 was not observed again in his improvisations. In session 11 he verbally directed a story scene over sounds made on a selection of African instruments. There was little musical or behavioural engagement noted within this session. In session 13 he played with relentless rhythms and little dynamic variation, using his 'flip-flopping' wrist movement, and smiling at the therapist. It was far more difficult to gauge what he was expressing in this music. In session 15 Jack chose a conga drum and selection of chime bars. A more playful mood was evident by his musical 'sparring' with the therapist, when he responded to the therapist's music by using musical gestures (e.g. glissandi) to respond to a recurring

melody, or a particular instrument in response to her playing in the bass or treble on the keyboard. Within such energetic interactions the frequently heard: $\frac{4}{4}$ ♩ ♩ ♩ ♩ figure became shortened to: ♩ ♩ fragments. Even within such an interactive improvisation however, it was noted that he relied heavily on imitation and literal representations. As the therapist moved to heavier sustained chords in the bass, Jack took the lead in an energetic syncopated rhythmic section on the conga. This resulted in call response phrases of:

MT: $\frac{4}{4}$ ♩ - | ♩ - |
 Jack: $\frac{4}{4}$ - ♩ ♩ | - ♩ ♩ | etc.

In sessions 21 and 23 Jack was reaching a critical stage. His improvisations were more solemn, reflective and, in terms of the musical material adopted, less superficial. In both of these sessions he chose the metallophone which he had previously described as making a 'sad' sound (audio example 3). His music still included his $\frac{4}{4}$ ♩ ♩ ♩ ♩ pattern, however also included sounds of longer time values and occasional 'still' moments. The written session evaluations include the therapist's interpretive impressions of the music from these sessions as sounding 'sad' and 'searching', which were supported by the clinical supervisor's evaluations. This was a major shift for Jack from his usual, unceasing 'happy' front. In the final research session his music shifted to a different type of expression again, as he included a sudden energetic drum section within a wandering improvisation. His responses before this drum section suggested that he was not engaged, however, this changed during the drum playing. Afterwards he used the word 'anger' in relation to the 'noise' he had made, however quickly retracted this. This was the only reference he made in all his sessions to anger. Both the improvisation and the word 'anger' took place after he had discussed the loss of his mother and his wife. Although Jack's music therapy continued after this

final research session, such emotions did not emerge again in successive sessions.

Therefore despite his improvising showing strong interactive elements, it was somewhat limited in its initiation of varying musical components and tended to rely heavily on the therapist's musical material. The sounds within his music however did correspond to moods which he himself identified and which were supported by behavioural observations within the sessions. As he came to the final sessions, he started to explore a wider range of dynamic and energy levels, which corresponded with his verbal introduction of feelings such as 'anger'.

His engagement in activities was also monitored through his verbal behaviour and responses in sessions. Overall in the improvisation sessions, he tended to become more involved with non-verbal instrumental turn-taking activities rather than improvisations involving simultaneous playing with the therapist. For example, in his fourth session, Jack became engaged in an instrumental turn taking activity, reflecting rhythms and dynamics played by the therapist, with an animated facial expression. When the therapist brought the activity to an end, Jack appeared 'lost' for words, laughed awkwardly, and said "Aren't we funny...funny watching me, funny watching you", suggesting a heightened awareness of self consciousness. Despite jovial references to this activity being 'great fun', and claims such as "you would never find me late or absent from the music session, it's not possible", the week after this fourth session he double booked himself for his regular music therapy time. He also made various excuses to avoid attendance, and then delayed his arrival as much as he could. This avoidance behaviour also occurred after a much later session in many of his most personal issues emerged in discussing what his songs meant to him.

Beyond the associative and emotional qualities of the music, the experience of singing was an extremely physical one for him. Through singing within every session, regardless of what music was being used, he monitored his breath control, the quality of sound produced and any changes in his vocal production. When such monitoring occurred, the musical experience was a physical one rather than an emotional one. It also introduced temporal elements as he compared how he 'used to sing' compared with how he felt he was singing at the current time. This also linked into issues of identity, as he identified changes which had occurred over time in skill and ability. Such issues revealed how music therapy related to his experience of his illness. Furthermore, he revealed feelings of ownership in singing his songs, which increased his feelings of personal expression and enhanced his feelings of control.

It is difficult to understand the experience of living in close proximity with so many others with a similar diagnosis who had lost all ability to make vocal sounds, relying on augmentative communication aids for all types of communication. This was a part of daily life for Jack and his vocal monitoring indicated the enormous fear and anxiety he felt at any small changes detected.

After the research period, Jack continued with music therapy for a period of four months. In these sessions he chose to do his songs only, and the deeper emotions which started to emerge in the latter part of therapy did not emerge again. Jack stopped coming to music therapy on a regular basis, however came occasionally to sing some of his songs. Three years after his involvement in this study, he died suddenly from pneumonia and respiratory failure.

APPENDIX 13.**Guide to reading the analytical diagrams.****13.1: Introduction.**

The purpose of the analytical diagrams is to present an illustration which depicts the analysis of the text. The diagrams therefore break down a phenomenon into its component parts, show causal relationships between these component parts and how these component parts effect the individual's experience or behaviour. The consequences or outcomes of these events and relationships are also shown. Any intervening conditions which may have influenced a situation are also considered. Each of these aspects of the diagram is explained in turn. The diagrams read as flow diagrams. That is, the reader is to start at the top of the diagram and read downwards. Lines adjoining boxes vertically or horizontally indicate a relationship.

13.2: The phenomenon under investigation and its concepts and properties.

At the top of each diagram, the central phenomenon to which the diagram is pertaining is clearly identified in an individual cell. For example, this may be 'Experience of pre-composed music', or 'Identity', or 'Experience of clinical improvisation'. Stemming from this cell on a central trunk and placed below it in a separate box, is a breakdown of the component parts of that experience. These component parts are the concepts or conceptual groupings which have already been identified in the textual analysis.

For example, from the textual analysis of an individual's data the experience of pre-composed music may involve concepts pertaining to 'Personal Association' and 'Relationship over time'. If the individual has clearly stated that these are important in his or her experience, then these concepts are

given a 'high' value. That is, these concepts make up the individual's experience to a greater degree. Concepts which are specified to occur to a considerably lesser degree are given 'lower' values. For example, if the analysis of the verbal data indicates that the individual's experience of songs involves 'lower' values of 'Interaction' (for example, "I like to sing songs on my own, for myself"), then the concept 'Interaction' is also included in this box, but with a lower value.

Therefore, this box depicts concepts pertaining to the central phenomenon with values given as either 'high' or 'low', and can be called the 'concept property values' box. The phenomenon cell and the concept property values box are the basic building blocks to all diagrams. They are often identified early in the analysis. In identifying the experience in this way, it is possible to start to determine the conditions necessary for an event to occur.

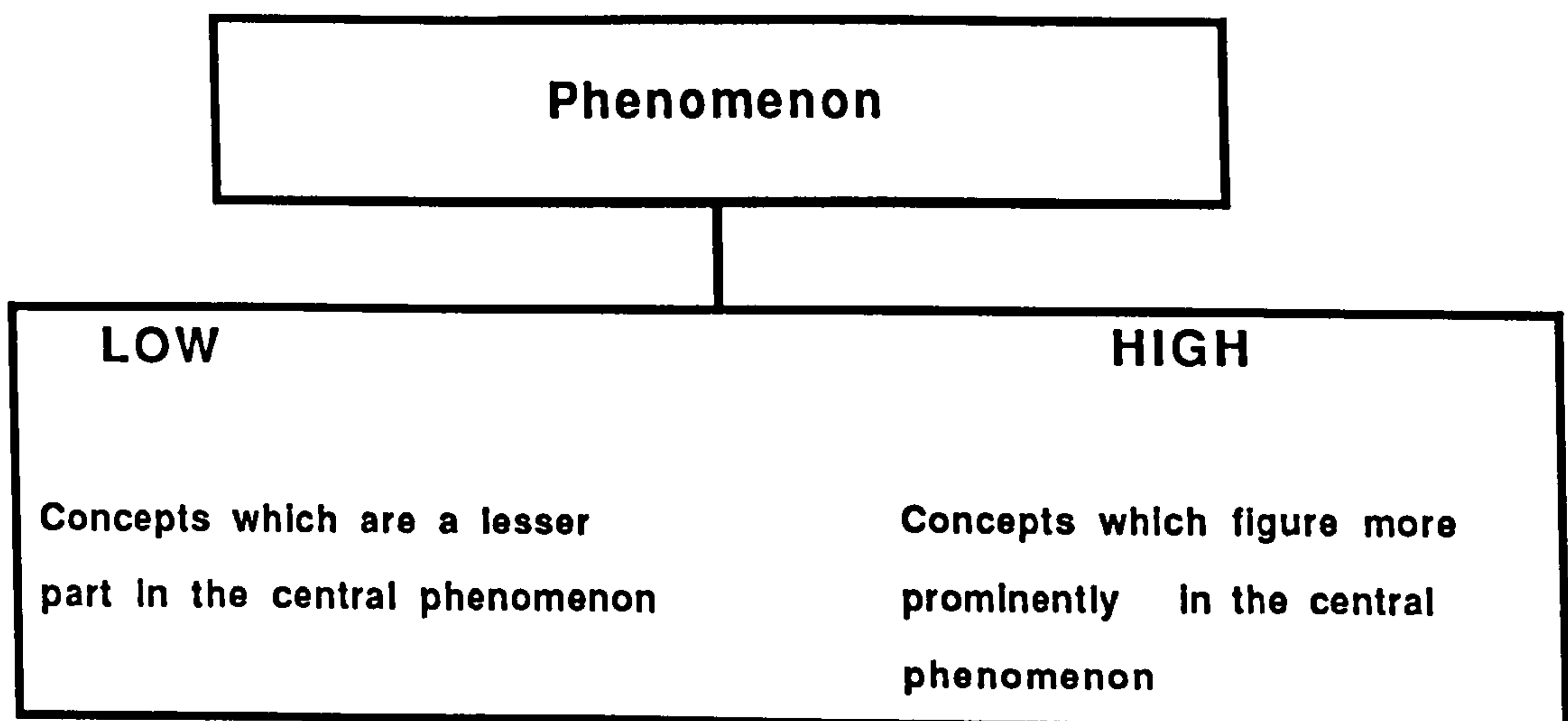


Figure 1: Central phenomenon cell with concept property value box.

Stemming from the concept property values, further concepts and their values may have resulted. For example, given that the experience of the music involved high association and high relationship over time, the individual may have identified that the music was therefore more meaningful or more

emotional for them. Any further consequences may also be identified at this stage in a separate box identified as 'Consequences'. This is then represented as in Figure 2.

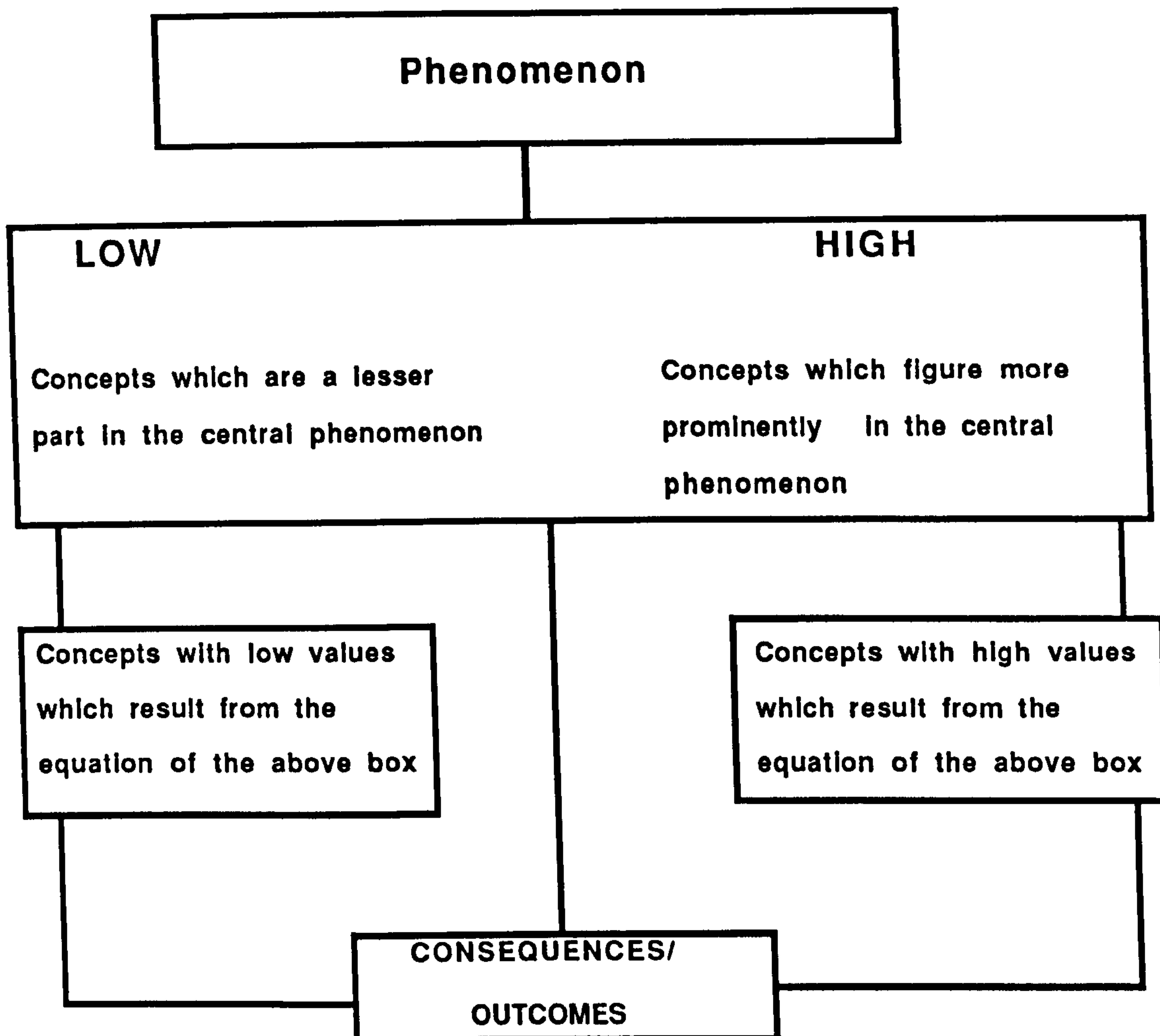


Figure 2: Diagram depicting the resulting concepts with high or low properties.

13.3: Intervening conditions.

Intervening conditions include any broader structural contexts pertaining to a phenomenon. These may include, for example, duration of therapy, current issues, mood state at start of session, or events before a session just to give a few examples. Intervening conditions are identified in a box to either side of the central trunk of the diagram, indicating that they influence the course of events, but are not necessarily a central part of the phenomenon. They may

occur at any part of the overall experience, and therefore at any part of the diagram.

13.4: Actions and interactional strategies.

As a consequence of the events already given in the diagram, an individual may adopt certain strategies or actions, such as physical monitoring, adopting a coping front, or relating the music to oneself. These strategies are identified in a box which most often occurs on the central trunk of the diagram.

At this point, depending on the strategies adopted, the central trunk may continue on a single course or may branch in two different directions. The diagram continues to be read in a downwards direction.

13.5: Consequences and outcomes.

Consequences and outcomes can occur at any point on the diagram. The box at the bottom of the diagram most commonly indicates what the overall outcome is. This may be a simple outcome such as 'Maintains coping front'. Alternatively, the outcome may be broken down into further concepts and properties. For example, the outcome 'Barriers Down' can be broken down into further variables such as longer or shorter durations of time. Each of these results in differing outcomes.

13.6: The overall diagram.

Understanding each part of the diagram should allow the reader to look at the diagram and follow the general flow of events. By glancing at the top of the diagram, the reader can understand the central phenomenon being illustrated, with its component parts and the degree to which these

components made up the central phenomenon. From the top boxes, the reader can understand the conditions under which the following events occurred. Any immediate consequences should be clearly defined. Following the central trunk downwards, processes, strategies or actions can be seen, with additional contexts or influential factors coming in from the side boxes. As the reader continues to move down the diagram, the process of events should unfold. The bottom boxes reveal the outcome of events stemming from the original conditions and influenced by the factors highlighted to the side of the diagram.

Background information to participant 'Jessie'.

'Jessie' was a 53 year old Jamaican born woman, who had resided in Britain for 34 years. Her first symptoms had shown 13 years prior to this study. Her diagnosis period stretched over several years as she was admitted and discharged continually from a string of hospitals for tests, which finally confirmed Multiple Sclerosis. Prior to her illness she had trained and worked as a paediatric nurse. She often referred to her professional past with a great sense of pride about how she had helped others, particularly those who were vulnerable.

At the time of this study she was unable to walk and was dependent on others to push her around in her wheelchair. Although she had functional use of her hands and arms, she had lost her vision entirely, which severely inhibited her independence. Although she was able to feed herself, she was fully dependent for all other activities of daily living. Jessie had altered olfactory and physical sensations, believing that she was constantly incontinent and offensive to be around. The isolation caused by being disabled and blind was exacerbated by such beliefs as she refused all offers of therapeutic group activities and even recreational events taking place in the hospital. Because her beliefs about being incontinent often contrasted with reality, nursing staff tended to ignore her requests for physical attendance, or even commented within hearing that she 'doesn't know what she is talking about'. She tended to be overlooked by most staff as her refusal of activities and withdrawal came to be expected. She spent most of her day sitting in her wheelchair by her bedside, not moving physically outside the limits of her wheelchair, listening to the radio. She was, in fact, never referred to music therapy, however was observed by the therapist by chance to respond to music during a recreational

event one day. After this, she was approached by the therapist and agreed to 'try' music therapy.

She had also had several periods of psychotic episodes of a persecutory nature in the years prior to this study, and commonly expressed persecutory thoughts. Such delusions were diagnosed to be psychiatric symptoms caused by sclerotic lesions within the brain. Thorough neuropsychological assessments to understand what brain damage may have occurred could not be completed, as the necessary tests required subjects to have vision. Hence any tests administered required verbal presentation. Neuropsychology reports estimated that due to her educational and occupational history, her premorbid intellectual ability would have measured within Average range. Tests of verbal intelligence (WAIS-R verbal) administered at the time of this project placed her in the Low Average range of intelligence scores, with particular deficits in the 'Similarities' category. This showed that she had difficulty in conceptual thought, tending to exhibit somewhat concrete thinking. Her results to a test of everyday memory (Rivermead Behavioural Memory Test) were in the impaired range, particularly in her immediate and delayed recall of 'ideas' presented within the test. Tests for verbal fluency and frontal lobe functions were within normal range. In response to standardised assessments of depression and anxiety (the Hospital Anxiety and Depression Scale and the Beck Depression Inventory) her scores were within a 'mild' level of anxiety and a 'moderate depression' range. In summary, assessments recommended that given her concrete thinking, verbal memory difficulties and her inability to reason in the abstract, verbal therapy was considered to offer little to counteract her emotional difficulties.

It was observed within music therapy sessions that she had insight into her situation, as she was able to relay the whole progress of her illness and the reasons for her hospitalisation. Also, she did not make unrealistic statements

which typify the verbal material of individuals who have difficulty reasoning through situations taking and into account their level of disability. Although having full insight could be considered positive, it certainly contributed to her periods of depression and low mood as she was fully aware of her devastating situation. It was observed behaviourally that when she was feeling brighter, she was talkative and aware of current affairs, however at other times she was low in mood, tending to question why her life was as it was, and complained of excessive pain and fatigue.

She had a son and daughter who were aged respectively 26 and 24 years at the time of this study. She had no contact with her son, but had regular visits from her daughter. There was no reference to a partner in any of her medical records, and Jessie made no mention of a partner at any stage of her treatment. She also had frail elderly parents who lived in another city in Britain. Although she had regular phone contact with her mother, she had not had personal contact with her for 12 years. She had no other friends or relatives who visited, and reported that she had lost contact with all of her friends due to having lost her sight and becoming unable to maintain any correspondence. At the time of this project, she had resided on the continuing care wards for seven years.

To summarise, Jessie was extremely isolated and severely restricted in her independence by visual impairment. Because she was mentally alert, she had insight into her situation which resulted in periods of low mood, combined with fatigue and pain. She had had psychotic episodes which involved persecutory thoughts and delusions, and mild cognitive deficits as a result of her illness. Despite her long residence in Britain, she still referred to Jamaica as 'home', and often expressed a wish to return there and experience the familiar things of the culture in which she had grown up.

APPENDIX 15.**The therapeutic process of participant 'Jessie': Musical, behavioural and verbal responses and changes in these over time.**

Jessie was severely isolated and emotionally distressed as a result of her blindness which had developed from her MS. Over all the other factors within her life, these were the overwhelming issues which emerged within her music therapy.

Jessie's mood varied every week, depending on what had been occurring around her or her physical state of health. She missed sessions when she was feeling too ill to stay out of bed. Such refusals to attend were noted to decrease over time as her relationship with the therapist developed. On the many occasions when Jessie presented as very low in mood, she spoke with a weak, high pitched voice and said she felt too tired to participate in any activity. The quality of her voice in both speech and singing were noted to change during nearly every session in terms of increasing in its range of pitch, increasing in volume and changing in timbral quality. When presenting with her weak voice, within verbal interactions there was noted to be either a considerable delay in her responses, or an absence altogether as she withdrew. Despite this, when she did choose to improvise music, her improvisations often did not reflect the depressed energy levels with which she had arrived, and she played with an enormous amount of energy, both in volume and in rhythm. Her voice therefore acted as an indicator of her immediate mood.

The behavioural observations made when Jessie was engaged in playing instruments, particularly within improvisation, were a significant change from

those made outside of musical activities. Often when playing instruments, her facial expression became very animated; her eyes opened wide staring upwards, and her mouth fell open in a slight smile. This facial expression was observed both during improvisations and during other activities when she was engaged in playing, such as during the welcome song. In contrast, her facial expression when singing songs often became calmer and less animated; her eyes nearly closing and her head dropping forwards and downwards. Overall, there was a considerable shift in mood noted within nearly every session. However, such development only occurred within sessions, and not across sessions over time. In this way it was difficult to show the therapy process, although this process could be shown in her increasing trust in the therapist and the development of the therapeutic relationship.

The one occasion when there was not a shift of mood within the session was when the usual welcome activity was omitted. This happened in response to Jessie arriving in a highly distressed emotional state. In order to focus on her immediate needs, a more passive music experience was offered to her rather than demands made on her to be actively involved and engage in the usual welcome. It is possible that the highly stimulating welcome activity caused initial changes in mood which were then developed further by following musical activities. It is also difficult to claim that mood change was solely due to the music as having individual contact for 45 minutes and getting away from the ward environment were likely to have affected her mood. Her active music making, however, did appear to give her an outlet for the feelings which she otherwise internalised.

Both activities enabled Jessie to actively participate, and when asked if she had a preference for either songs or improvisation, she mostly replied that she did not and would be 'happy to do either'. Although the therapist believed that the improvisation appeared to cause the greatest change for her, it was

difficult to clarify exactly how this occurred, until analysis of Jessie's own explanations revealed a deeper understanding of her experience. It appeared that the essence of her therapeutic process was to reach her 'most able' identity.

Due to the role of music in the culture in which she had grown up, neither improvisatory nor song-based activities played a more important role in stimulating reminiscences and associations. She stressed that the significance of music for her was for cultural reasons, stating on one occasion 'West Indians like music because they're all Africans and they're very musical'. Active music making had played an important role in Jessie's family life. Drum playing therefore stimulated reminiscences about her grandfather and aunts, whereas the guitar and autoharp stimulated memories about music played in her village. Similarly, the songs played resulted in reminiscences about her school days, her mother, or discussion around the song themes.

Her verbal material in the sessions included many reminiscences about life in Jamaica, but also often suddenly led onto topics which were completely unrelated to the music and to Jessie herself, such as world disasters or other current affairs topics. These nearly always had a tone of horror about them. In examining this within clinical supervision, the supervisor highlighted the emotional nature of Jessie's verbal material. It was questioned whether she was reflecting feelings about herself and her own situation when she focused on others' horror stories. The supervisor offered that this might be a more acceptable way of her expressing verbally the underlying sense of injustice and crisis in her own life. She often suddenly commented "What a life" at unexpected times, although when an attempt was made to explore this further, Jessie was dismissive of it, saying that it was a saying she had learnt from her mother. At other times she expressed distress at how she was not taken seriously or ignored by nursing staff because she was blind, and that staff lied

to her about her belongings and occurrences around her. Any verbal interaction which was held near her, but which she was unable to hear clearly, she felt to be about her, as she felt others saw her as 'daft'. She expressed many opinions she felt others held of her, all of which were negative and self deprecating. Any attempt to explore verbally this type of material caused her to withdraw or verbally distract onto other topics.

Jessie's improvised music was characterised by highly syncopated and complex rhythms, which gave her music a drive and continual energy. She gained enormous pleasure from exploring instruments, particularly the more unusual African ones, and expressed a wide preference in her instrumental choice. Although she had normal physical range with her arms, she was physically restricted by her wheelchair. Her physical use of the instruments was also impeded by her level of fatigue. At times she engaged for a duration of up to twenty minutes, reaching out and playing instruments at the distance of a full arm's extension. She would often suddenly stop an improvisation verbally, complaining of fatigue. Despite not being able to see the instruments, she explored most of those available in the therapy room. She tended to favour a small African cabassa for the welcome activity, which sometimes she would keep for accompanying within the songs. She also expressed great enjoyment in strumming the autoharp with the therapist playing the chords during the song-based activities. This often occurred during the goodbye section of the session. Jessie's reaction to this instrument was so strong that it became an aim to include it at some place in all sessions. This was in order to reduce any association it may have with either the improvisational or song-based activities, which may in turn have affected her overall experience of an activity. Often she chose the larger pitched percussion instruments during the improvisatory activities, such as the bass xylophone and alto metallophone, with a cymbal or drum as well. Although the pitched instruments allowed her melodic variation, she focussed on the

rhythmic elements and was most interactive within these, showing little awareness or development of her melodic fragments. The instruments she chose were placed within reach around her, and Jessie spent some time briefly becoming accustomed to the positioning of the instruments. In some sessions she chose the electric keyboard, exploring the range of timbres it offered. Jessie played this with both hands in 'clusters', using the rhythms which typified her playing.

Her participation in the song-based activities usually involved her accompanying the therapist using small percussion instruments, or strumming the autoharp and singing the words to the song. Although it was reported from other staff that she often sang to herself on the ward, she could not name a 'favourite' or special song, artist or even category of music, and preferred the therapist to choose a song. Her limited response in this way was just one indication of how she was unused or unable to make decisions for herself, showing an impoverishment of exploration or possibly motivation. Such a response has often been noted in people who have been institutionalised and had severely limited opportunities for decision making.¹ Over a period of time, the therapist gained a knowledge of a very small repertoire of songs that Jessie had sung during her school and teenage years and other songs to which she responded favourably. If she could not think of songs she wished to do in the session, broad categories of songs (e.g. Spirituals, Elvis) or moods (e.g. sadder or brighter) were suggested by the therapist, and she usually chose from these. On several occasions, Jessie started to sing songs spontaneously, with which the therapist joined in, accompanying on guitar. The song-based activities however most frequently stimulated feelings of failure, inability and loss in terms of not being able to 'remember the words'. In this way, it was observed that she appeared to use the songs to monitor her cognitive changes and 'prove' that others were right in thinking her 'daft'.

¹ Please refer to Goffman (1961) for a thorough discussion on this issue.

Often she stated she did not know the words to songs, but then sang the words once melodic cues were given. At times she responded to the suggestion of songs with an anxious comment about her failing memory. It was more difficult to engage her actively in songs, and at times she experienced the song-based activities passively.

It appeared that the experience of improvisation gave her a greater sense of closeness and communication with the therapist, which the songs did not seem to facilitate so readily. These feelings are expressed by Jessie in the examples given in the analysis, indicated by terms such as 'corresponding' and 'getting the sounds to match'. This experience reduced the isolation which so affected this woman's quality of life, in turn affecting her mood and motivation. The heightened senses of achievement, independence, ownership, and challenge were stimulated by participation in improvisation, as well as feelings of increased arousal. Accessing these feelings was a major aim within her music therapy sessions, and the ability to do so led repeatedly to positive statements of self worth. This was in opposition to the frequent negative statements she made about herself at other times, and her lack of confidence in any expression of opinion she made. As already noted, her mood shifted to a more positive one within nearly every session. Although it was not the aim of therapy merely to 'cheer her up', it must be acknowledged that the music therapy sessions may have been one of the few times during the week when she did experience a more positive sense of self, and also escaped the desperation which she described in her life, sitting on her own, by her bed, day after day. The role of the therapeutic relationship in shifting her mood can also not be ignored.

Her participation in the improvisatory activities was markedly different from that in the song-based activities, showing a greater willingness and motivation to explore instruments, respond in the music, and considerable shifts in mood.

In improvisations Jessie usually initiated her syncopated rhythmic motifs within improvisations, and these varied somewhat from week to week showing greater development over time. Examples of such rhythms are

(session 3): $\frac{4}{4}$ ♩ ♩ ♩ ♩ ♩ | and

(session 5): $\frac{4}{4}$ ♩ ♩ ♩ ♩ ♩ ♩ ♩ | etc.

with variations such as

(session 11): $\frac{4}{4}$ ♩ ♩ ♩ ♩ ♩ ♩ ♩ ♩ ♩ ♩ | etc. and

(session 21): $\frac{4}{4}$ ♩ ♩ ♩ ♩ ♩ ♩ ♩ ♩ ♩ ♩ | etc.

and in the latter sessions moving to triplet forms of

(session 25): $\frac{4}{4}$ ♩ ♩ ♩ ♩ ♩ ♩ ♩ ♩ ♩ ♩ | etc.

Her music was often in a fast, energetic tempo, and very often she ended the improvisation by speaking, apologising and saying that she was too tired to continue. This sudden verbal interruption occurred even though the different ways of winding down an improvisation were explored musically and discussed verbally. Even when musical components suggested 'winding down' within an improvisation, Jessie would take the lead and initiate an increase in tempi and dynamics. At other times she was able to respond to changes in musical elements, such as a decrease in tempo or dynamics, or sparser texture, and occasionally she added dramatic or formal touches such as 'tickling' the windchimes at the very end of an improvisation. At the end of many of the improvisation sessions, she chose to listen passively to the therapist play the autoharp and extemporise around the theme of the goodbye song, which fostered the nurturing air of a gentle lullaby.

In session 13, Jessie spoke with her 'weak' voice, and stated she did not care if she came to the music therapy session or not. On arrival at the session, her

mood was difficult to gauge, as she discussed issues around the theme of 'celebration', but in an apathetic and, at times, sarcastic tone of voice. Within the welcome chant used, she was noted to 'mouth' the words rather than sing them. Her music within her improvisation was tremendously energetic, playing a rapid and complicated version of one of her rhythms ($\frac{4}{4}$ ♩ ♪ ♪ ♪ ♩) on the rotary drum. Overall, the improvisation with the therapist was highly interactive in rhythmic and dynamic components. Jessie described the mood of this music as "jumpy and happy", and later suggested that the music may have been stimulated by "thinking how happy I am not". For the goodbye, she chose to listen passively to the therapist singing with the guitar.

On playing this improvisation within clinical supervision, the tempo and relentless rhythms were interpreted as having an 'angry' quality by the supervisor. Certainly her withdrawn and resistant mood within her behaviour and verbal material supported this observation. Although she was unable to verbalise any feelings of anger, or her often mentioned theme of 'injustice' within this session, the music did express such strong sentiments for her. This was despite her adoption of a passive and weak behaviour within the session. As Jessie's feelings centred around not being credible and being dismissed, it is certain that within her improvising she was able to express these feelings and have them met non-verbally. This was a much safer medium for her to do so, and one which facilitated support and reflection of her emotional expression through the interactive elements of clinical improvisation. Within clinical supervision, the therapist's musical role was examined in terms of providing support for her expression, rather than simply meeting it with equally 'driven' music. Techniques were discussed for providing sustained 'holding' harmonies to support Jessie's musical utterances. Although this was attempted in future sessions, Jessie became anxious if she could not hear continuous musical interaction from the therapist. When she was playing such rhythmically driven music, she needed continual rhythmic feedback. In

response to any longer sustained chords, she would suddenly stop her own playing, and ask for reassurance i.e. 'Have we stopped? Am I doing the right thing?'. Allowing her own musical voice to be given greater prominence was an aspect of the clinical improvisations which took Jessie many months to develop the confidence in. This process in fact took much longer than this research project itself.

In session 17 Jessie arrived in a lethargic mood, and was compliant with anything the therapist suggested, making few active decisions herself. She did however choose to play the electric keyboard, using both hands with a slow ascending pulse in the left hand and more syncopated melodic clusters in the right. In analysing the improvisation, her spontaneity and level of interaction can be seen to increase during the improvisation. Early on in the music, she played longer clusters in both hands, as the therapist gave shorter interjections to which she did not respond in her usual rhythmic way:

Jessie : $\frac{4}{4}$ $\text{d} \quad - \quad | \quad \text{d} \quad - \quad | \quad \text{etc.}$
 M.T. : $\frac{4}{4}$ $\text{z} \text{ d } \text{d } \text{d } \quad | \quad \text{z} \text{ d } \text{d } \text{d } \quad | \quad \text{largo}$

As the improvisation continued, call and response figures emerged, with much more rapid responses from Jessie. For example, the therapist's rhythmic figures were reflected and developed into a phrase by Jessie as follows:

M.T. : $\frac{4}{4}$ $\text{d } \text{d } \text{d } \text{d } \quad | \quad \text{z } \text{d } \text{d } \text{d } \quad | \quad \text{etc.}$
 Jessie : $\frac{4}{4}$ $\text{z } \text{d } \text{d } \text{d } \text{d } \quad | \quad \text{z } \text{d } \text{d } \text{d } \text{d } \quad | \quad \text{etc.}$

Her mood was affected by any events which took place between sessions, however as there were very few other activities and outings in her life, she had little in her life to affect her mood thus. One event which lifted her mood considerably was a holiday taken for two weeks between sessions 19 and 20. In session 20, she requested songs to 'cheer her up' and expressed great pleasure in the songs she chose (rock and roll songs from 50's and 60's),

although she did choose a more passive than active role. Her use of songs and accompaniment on instruments often expressed different moods simultaneously. Within session 24 she chose more reflective ballad songs such as 'Kum Ba Ya' and 'Danny Boy' although her accompaniment on the bongos was highly animated and rhythmic. In response to the songs, she reminisced about Jamaica, and a yearning to see it again. The drumming stimulated reminiscences about her grandfather who had been a drum maker. Hence although the mood and messages within the songs reflected one mood, the associations held with them stimulated another.

Essentially, the relevance of music therapy for Jessie appeared to be for her to participate in an experience where she did not have a continuing sense of inability, dependence, and lack of control. These were feelings she expressed having in many of her interactions with others on the ward and other daily experiences. Her inability to experience the world through visual images had enormous emotional consequences for her, particularly in her sense of loss and distrust of those around her. Such feelings were also exacerbated by her psychotic delusions. It also severely reduced her ability to place the events which occurred around her in a realistic context. Her physical disabilities compounded her sensory deprivation, as she was only able to experience what was placed immediately in front of her on her wheelchair tray, rarely reaching outside this boundary. Participating in music therapy activities therefore demanded that she extend this boundary in order to play the instruments, providing tactile stimulation and some type of positive reward for her effort. The non-verbal interactions within improvisations were very much in the present, and thereby focussed her on a relationship with another. In her descriptions of the improvisations, Jessie's introduction of the term 'corresponding' expressed for her the feeling of relating with the therapist using a non-verbal medium. Her attempts to impart verbally the feelings around this aspect of the improvisations reflected a closeness and mutual

effort which she perceived to be occurring within the music. It was speculated by the therapist that the relationship which was nurtured by the clinical improvisation may have been one of the most personal and possibly equal relationships Jessie was experiencing in her life at that time, and that the motivation and energy with which she improvised were a reflection of this. The support she experienced during an improvisation was absent in the way she talked about her interactions with staff which took place outside of her therapy sessions.

Changes indicating process within Jessie's music therapy were more notable within sessions rather than over a longer period of time, for example the dramatic mood shifts she made between arriving and leaving sessions. Change over time however needed much longer than the period of data collection for this project could allow. Although her research sessions continued until session 26, Jessie continued with music therapy long term after the project. Her ensuing music therapy used improvisation nearly exclusively.

Appendix 16.**Background information to participant 'Guy'.**

Guy was a 31 year old Caucasian male who had grown up in the north east of England, but moved to London in his twenties. He showed the first signs of MS approximately seven years prior to this study. Although he initially showed periods of relapses and remissions in his symptoms, his illness had become progressive in character. His physical function was considerably affected by his MS, with no voluntary movement in his legs and no functional movement in his left arm. Although he had normal strength in his right arm, ataxic tremor prevented this movement from being terribly functional. He was therefore fully dependent for all personal activities of daily living. He had been living in his own home with carers up until only 18 months prior to this study. Medical reports indicated however that due to poor insight into his condition and a lack of compliance with recommendations made, medical problems developed whilst he lived at home with carers and eventually caused hospitalisation to be necessary. Although Guy was determined to return home with carers, his poor insight did not indicate that this was advisable in case further medical complications developed. Reports from previous hospitals described him as 'disruptive and manipulative with staff'.

He had no children nor a partner. His mother had died seven years previously and his father, of whom he spoke often, lived in the far north of England. He managed to have a respite 'vacation' in a nursing home near to his family. Although he spoke of many 'friends', these were all hospital staff who had cared for him in some capacity since his admission to the hospital. There was no reference to having contact with friends outside of the hospital, although he made frequent references to a number of girlfriends from the past, none with whom he was currently in contact. He was not popular with many staff

because his behaviour was interpreted to be 'arrogant' and 'difficult'. He was also disliked by other residents, particularly those with whom he shared rooms or ward space.

Any personal behaviours however were not solely due to his personality, and certainly influenced by underlying neuropsychological deficits such as verbal disinhibition, poor short term memory, poor insight, and poor reasoning abilities. Such deficits exacerbated his emotional experience of increasing dependency and disability. General neuropsychological assessments showed that although he was well oriented, he was easily distractible and his information processing was slow. Learning and recall abilities were poor to very poor (Logical Memory subtest of the WMS-R and Rey Auditory Verbal Learning Test). His overall intellectual functioning was impaired in comparison to the expected normal level of someone with his educational standard which was at tertiary level (WAIS-R IQ: 86). Such cognitive deficits were typical of the early stages of subcortical dementia commonly seen in MS.

Guy self referred to music therapy, as he had a background of playing bass guitar in bands, and was generally keen on music. He was a creative individual whose other main interest in the hospital stemmed around creative writing. His first music therapy session was ten months after admission to the current hospital.

Guy's experience of each activity can be summarised thus. He used familiar songs as a way of expressing and exploring a wide variety of moods and themes. He used particular songs as a way of stimulating his more difficult and painful feelings, and then exploring such either overtly in verbal interaction with the therapist, or more covertly through the music alone. The relationship over time brought up memories which served to both stimulate life

review, as well as feelings of hope for the future. The improvised music however was experienced far more physically, particularly in the earlier part of therapy.

Appendix 17.

The therapeutic process of the participant 'Guy': Musical, behavioural and verbal responses and changes in these over time.

In nearly every session, Guy arrived in a highly agitated state due to the stressful experience of getting up, washed, dressed and having breakfast each morning. His behaviour when agitated comprised several factors. His ataxic movements would be visibly worse than usual, particularly in his right arm which he could still use functionally, and also in his head movements. When agitated his voice became louder, and the content of his speech was extremely tangential, jumping from one topic to another, or leaping from one question or command to another before the therapist had time to answer or act on the first. Furthermore his speech became more slurred and therefore more difficult to understand. Also, when he was stressed, he did not employ strategies to make his speech clearer, such as slowing down or repeating himself. In fact he only became more agitated and openly irate that others could not understand him. The emotional state underlying his agitation was reflected in both his manner and also the content of his verbal material. He would often be openly hostile about the nursing staff with whom he had dealt earlier in the morning, or challenging towards the therapist, or state a stream of abusive statements which were more rhetorical rather than specifically directed towards the therapist. He would often be particularly demanding and call out a series of commands. Such behaviour was nearly a weekly event en route to the session. Often, the long trip to the therapy room was broken briefly to stop for a cigarette if he requested to do so, which seemed to calm him somewhat.

On many occasions, as soon as he had entered the therapy room, he would exclaim 'What are we doing today?' and then dismiss any of the options offered. For the first fifteen minutes of many sessions, he continually challenged the therapist, either in dismissing the instruments presented or challenging her musical ability or critiquing her part in musical activities. At times his manner was openly patronising and critical. The purpose of his song selections within the early sessions appeared directed more towards testing the therapist's musical ability than to listen and sing to the songs that held personal meaning to him. In one session, he requested a pop song which comprised mainly synthesised percussive sound effects, which the therapist stated openly she would not be able to reproduce. In response to this, Guy replied with a mocking tone, 'You just can't do it, can you?'. It was important to acknowledge openly her own musical limitations candidly, as it became evident early on that challenges like this were a form of projection onto the therapist about Guy's own failing abilities. Guy's interpersonal manner in this way was typical of all his social interactions, not just his music therapy.

Within the first five sessions it was difficult to get past the challenging behaviour, which also reflected in Guy's use of music. Within the song sessions he requested 'punk rock' songs, and responded to improvisations in a robotic and emotionally removed manner. Within musical interactions he showed a poor awareness of any of the therapist's material and his own musical material consisted of a strong unfaltering pulse at a steady loud dynamic, usually on a drum. He preferred hard headed beaters rather than softer ones or brushes, because they gave him a louder sound. He began to refer to any playing with the word 'bash' which certainly described his own part. His physical behaviour during musical activities involved continual eye contact with the therapist, to the point of it seeming like a glare. Within the welcome activity and improvisations, however, it became evident that he was merely counting the number of times he hit an instrument, as he would

suddenly yell '100!' during a musical interchange. Physical, musical and verbal responses considered, he was not engaging on an emotional level in any way with the music, and gave no indication that he was aware of the therapist's attempts to interact with him musically.

In the fifth session, Guy was dismissive of all the instruments tried, and again requested something to 'bash'. He made many references to familiar structures and music, and when improvisation was suggested, he gave the theme of a 'magic spell to make me walk'. He became focused on his own playing during this improvisation, looking at the instrument he was playing. As a result of momentary eye contact with the therapist however, he suddenly ended the improvisation abruptly by verbally requesting a rock song.

After the fifth session, the material to that point was taken to clinical supervision, particularly the therapist's own feelings of anger, frustration and questions about the validity of music therapy with someone who appeared to be battling so hard to avoid any sense of relationship both in the music and all verbal interactions. The supervisor's psychodynamic framework uncovered issues of transference and suggested Guy's coping 'bravado' front may also be stemming from a fear of developing a relationship, particularly employing a medium as intimate as music. As both client and therapist were of similar ages, the supervisor highlighted issues of sexuality and what this may have meant to Guy. As therapy progressed, intimate relationships emerged to be a significant issue, particularly one relationship from his early twenties which he had hoped would end in marriage. Although Guy may have been having private hopes for intimacy with the therapist, these were never brought up directly in music therapy. The therapist however realised the need for very clear boundaries in all aspects of interaction. This was particularly important as Guy often tested these by making comments about her appearance or other comments which could have been construed as 'flirting'. Similar

interactions were often responded to by other well-meaning female staff, but Guy believed their responses to be promises of greater intimacy. He therefore held the belief that he had several girlfriends, and also often expressed the belief that he was likely to marry any one of them in the near future. Working with music as a therapeutic medium created an intimate and emotional environment for Guy, stressing the importance of clear boundaries. This aspect of his interactions was just one indication of how deeper issues affected the front with which he presented.

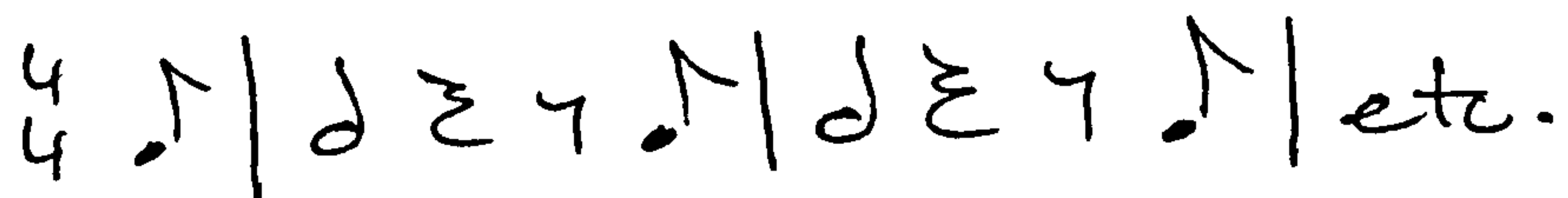
In sessions 6 and 7, the focus was upon trying to find an instrument which Guy could play with less difficulty. Because of his ataxic movements it was difficult to find an instrument on which he could control his movements enough to get the sound he wanted. In addition to this, he fatigued particularly quickly with instruments that involved reaching outside of the range of his wheelchair tray. In an attempt to find instruments which were sensitive enough as well as easily accessible, instruments synthesising electronic sounds were assessed, such as a small electric keyboard placed centrally on his tray, and a single switch linked up to a variety of drum sounds using Midigrd software and Atari computer. Although both gave him good quality percussive sounds with minimal movements, they failed to give him a range of dynamic levels or control over the timbre played at any one time. The resulting sounds therefore only emphasised the mechanical nature of his own playing and did not facilitate timbral and dynamic variations which could enhance the expressiveness of his playing. Despite the limited musical qualities of his playing however, there was a small shift noted in the musical interaction within session 6 in each of the two songs which were played and extemporised upon. Guy both sang and accompanied by tapping his unerring pulse. For the first time however, there was a sense of musically meeting each other, although Guy was also anxious about not knowing the right words to the song.

The types of physical problems described above had been encountered with other participants within this study, however there were added dimensions to Guy's particular experience. As therapy progressed, it emerged that his failing physical abilities were impacting on his life to such an extent that he was unable to do anything for himself. This in turn caused him immense frustration which underlay all his emotional behaviour. However his physical strength and ability generally were unable to sustain the expression of such intense emotional energy. Within his music, not only was he not strong enough to express these feelings, but it was nearly impossible to find instruments sensitive and yet expressive enough to reflect such feelings.

In session 9 the therapeutic relationship developed further, particularly within the music. When collected from the ward, Guy was angry and frustrated. He spoke continually although his speech was incomprehensible. His manner was non-interactive as he verbalised a stream of angry comments and claims, including that he might not be at the hospital for future sessions because he 'might be married by then' and living elsewhere. Immediately within the music he was more interactive. His regular loud pulse seen in previous sessions:



was replaced by a rhythm more reflective of the syncopated chant used for the welcome:



with a slight decrescendo at the end of the song. Although he requested 'drums to bash' for the first improvisation, the dynamic range of his playing was more varied, and also his manner of playing, including scratching and rubbing the surfaces of the drums chosen. His unfaltering pulse remained however. Behaviourally, his responses were also different, in that his usual continual eye contact did not occur. Instead, he closed his eyes and let his head rest back on his headrest. At one point during the improvisation the therapist started to vocalise quietly, which caused Guy to open his eyes and

look towards her. In earlier sessions, this musical change would have elicited a verbal comment from Guy, or caused him to stop playing altogether. In contrast however, he did not stop playing, but smiled and continued. The second improvisation within this session was also different from his usual music, with sections which were stiller and quieter. Guy's own verbal interpretations of the music were elaborated within the interview after the session. These interpretations differed markedly however from the therapist's observations and interpretations, in that he gave very concrete descriptions of his own part, such as counting to 100 and then changing instrument, and more surprisingly, that he had been singing several different songs to himself during the improvisations. Analysis presented in chapter 10 (see example 9) suggests that by drawing on a familiar structure, the meaning of the music was increased for Guy.

It was impossible to know whether Guy's own descriptions were influenced by emotional factors such as his underlying mood or reflected cognitive problems such as concrete thinking or difficulty describing abstract tasks. In taking this material to clinical supervision, however, Guy's ability or desire to acknowledge facets of the the musical relationship were questioned by the clinical supervisor, using a psychodynamic framework. The therapist, on the other hand, in using neurobehavioural interpretations, believed Guy's description reflected deficits in the ability to process abstract thoughts and concepts, which would explain why he described and experienced the task in such concrete terms. This difference in interpretative framework highlighted fundamental differences between the supervisor's theoretical stance and that of the therapist's. Despite such differences, the alternative perspective offered by the supervisor brought issues about social and human interaction to the therapist's attention, particularly around the therapeutic relationship.

Whatever the underlying causes or framework adopted to explain Guy's responses, the therapeutic relationship within the music had started to change within session 9.

In session 10, there were further developments. A song which Guy had specifically requested some sessions earlier ('Drive') was found and brought to the session for the first time. This song was played on the piano and sung by the therapist, during which behavioural changes were noted as within the previous session. Although Guy chose not to play, he was observed to tap his fingers quietly on his wheelchair tray to a prevalent rhythm within the song:

$\frac{4}{4}$ ♩. ♩. ♩ | ♩. ♩. ♩ | ♩. etc.

again being a departure from his regular pulse. He also sang the words, taking the direction of the song in an extended extemporised version, in which evidence of his listening was very clear through his anticipation of the words of verses and bridge sections. At the end of the song, he requested it to be played again, and again at the end of the second time. He commented after the third time that he felt moved to tears, and his physical appearance also indicated such emotional engagement. He was quickly dismissive of such sentiments, however, and then requested an energetic rock song used in an earlier session which he had previously described as 'violent' and 'raucous'.

Not only did the musical make-up of this song 'Drive' portray a sensitive mood, but the words to the song were also particularly poignant, concerning a vulnerable character needing help who would not acknowledge their difficulties. It was nearly impossible not to draw parallels with Guy's current situation and the theme of the song. However, his own interpretation differed from the therapist's, representing a strong, supportive male figure with emphasis on the romantic relationship in the song. He drew no parallels between himself and the vulnerable character.

In the following improvisation session, the emotional responses observed within this previous session were not repeated either in his music or his behaviour, and he reverted to his earlier behaviour seemingly to do with coping. In the successive session 12, however, when another of his special requested songs was brought to the session, he engaged on all levels, musically, emotionally and behaviourally in the ways already described, particularly showing a greater subtlety in his musical expression, despite having arrived at the session in a challenging mood. At the end of this session he requested 'Drive' again, the song which had been central to session 10. For the first time, within this session Guy's verbal material pertained to the difficulties he was having accepting his increasing disability and the ensuing dependence and changes in identity. In this session, a journey through different moods and behaviours was observed, which was triggered entirely by the music which Guy himself had chosen and directed musically. Within the following song sessions similar responses were noted as Guy alternated both the song 'Drive' and another song which was significant from this time in his life. This second song possessed similar musical qualities in tempo, harmonies and also theme of loss in love as did 'Drive'.

Guy's improvisation sessions, however, did not engage him on such a range of levels. His involvement in improvising was impeded by his physical fatigue and also an increased frustration as he could not play instruments in the way he wished due to limitations caused by his ataxia. His playing did, however, begin to become a little less organised, sparser, with less frequent occurrences of his relentless pulse. In his verbal material, he also started referring to large scale works of 19th and 20th century classical repertoire in relation to the mood of his own improvisations. In session 15 an improvisation on a guitar tuned to an open chord of D major stimulated many statements about his changed abilities, and significantly changed the hostile angry mood in which he had arrived. His musical material was different from that in

previous sessions in that it moved away from his usual 4/4 meter to a more lilting 6/8, which he plucked on individual strings. At the end of this session he requested 'Drive' once more, which was followed by a reflective silence. From this session on, Guy directed the use of improvisation and songs, as it was clear that he was starting to use each in his own way.

Session 16 was a mixed session in which Guy moved through a variety of moods initially stimulated by an improvisation and then using songs he requested either at random or from choices offered. The thematic content of all the music was the significant factor in this session. He gave the improvisation a theme which was becoming increasingly significant in his therapy material, which centred around a romantic story. He then requested unprompted the song 'Yesterday', which he associated predominantly with 'love gone wrong'. After this song, he quickly counteracted the mood with more uptempo rock songs. The moods and themes of the songs were not discussed with him as he wanted to focus on the music. Within the interview he spoke more intellectually about the music and themes than in any emotional way. This session highlighted how he was using both improvised and pre-composed music to express different moods and also focus on themes which were significant within his own life, without elaborating further verbally upon them.

In the final research session, Guy again arrived in a highly emotional state. Within this session he used improvisation to express extreme emotions, referring once more to large scale classical pre-composed works of music in terms of the emotion expressed within that music. This session revealed how involvement within improvisation helped to alter his own perceptions of his disabled identity to a more positive and independent one, thereby relieving the distressed feelings he had about his increasing disability. There were a further four sessions following this which have not been included within this analysis. For several reasons to do with holidays and outings which Guy had

booked and which were going to cause a long break in therapy, Guy decided to end therapy, with the possibility of review in the future. The remaining sessions focused on how Guy felt about the pending end of his music therapy, and the loss of the therapeutic relationship and the space he had found to 'play' how he was.