

Portfolio including Thesis

Volume 1 of 2

Volume 2 contains confidential information and is not available

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A portfolio submitted in partial fulfilment of the requirements of the  
University of Hertfordshire of the degree of Doctor of Clinical  
Psychology including a Thesis entitled:

**A Longitudinal Study of Bipolar Disordered Clients Going Through an  
Intensive Psycho-educational Intervention Programme.**

The programme of study was carried out in the Department of  
Psychology, University of Hertfordshire

November 2004

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People with dementia are PEOPLE with dementia and not people with DEMENTIA. Critically discuss how could the emphasis in such a statement might influence working with this group of people psychologically.

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Give an analysis of the rationale for, and important factors in, obtaining an effective and holistic psychological assessment of a child. Illustrate your analysis with clinical examples.

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## Written Exercise 1

People with dementia are PEOPLE with dementia and not people with DEMENTIA. Critically discuss how could the emphasis in such a statement might influence working with this group of people psychologically.

John Sørensen.  
DClinPsy. Year 1.  
October 2002

Word count: 4972

## Introduction.

The question posed in this essay is taken to ask how psychological work is influenced by a focus on either the person presenting with symptoms of dementia, or on these symptoms themselves. Further a *person* is understood to be a unique, holistic being with individual needs, desires and characteristics besides the generic symptoms of dementia. In the following, it is seen as self-evident that dementia is related to neurological erosion and the evidence supporting the biomedical model of dementia is not dealt with explicitly. Also, for reasons of space, the essay does not deal explicitly with ethical considerations or indirect work with carers.

The essay begins with a discussion showing that the biomedical model, with its focus on links between neurological changes and symptomatology, rather than the person displaying these symptoms, is an incomplete theory of dementia.

The following section discusses the social construction of dementia as a neurological disorder. A further deconstruction of the causal linearity between neurology and symptoms is attempted, and an understanding of dementia as a multi-causal process emerges. This in turn places psychological variables, such as individual perception of problems, in the aetiology of dementia, illustrating why a focus on the person with dementia should influence interventions.

The essay then moves on to consider the subjective experience of dementia in the context of potential loss of self-identity. This section also seeks to establish whether interventions aimed at the person behind the dementia can result in enhanced well-being.

After having considered the domains of bio-medicine, social construction and subjective experience, the essay deals with the only theory that draws these domains together in the field of psychosocial dementia care; *Dementia Care Theory* (DCT). DCT argues for the importance of supporting *personhood* and is of direct importance to the question posed in this essay. The theory is discussed and expanded upon, and finally it is suggested that DCT's conceptual structure hampers its translation into practical interventions. As a solution to this problem, the essay's final section proposes the nursing theory of *Modeling and Role-Modeling*. This theory relies on empathy within a person-centred framework and appears more readily taught and implemented than DCT.



### **The biomedical model of dementia.**

Within the biomedical model it is assumed that one or more unknown factors leads to neuropathological changes in the brain, which then causes the dementia to develop and progress (Kitwood, 1997). This model is an abstract account of a process that occurs in reality. However the model is routinely used as an objective explanation of the causes of specific cases of dementia (ibid.). The biomedical model, or in Kitwood's terminology, the *standard paradigm*, has survived a continuous debate surrounding the nature of dementia which started in 1907, when Alois Alzheimer published a case report "[A] bout a Peculiar Disease of the Cerebral Cortex" (Alzheimer in Snowden, 1997, p. 154). The trend throughout has been towards a separation between normal aging and dementia (Gubrium, 1986). However changes in the brain, such as those described by Alzheimer, are not necessary or sufficient for symptoms of dementia to occur.

That changes in the brain are not necessary for symptoms to present can be seen from post mortem studies of people with diagnosed dementia, where a proportion are without the pathological changes in brain tissue expected within the biomedical model (Kitwood, 1997; Burns, Jacoby, Philpot & Levy, 1991). The proportion varies from study to study and has been reported to be as high as 34% (Homer et al., 1988).

It could be argued that future technological developments might enable the detection of neurological change that is presently undetectable. However rather than support, this would in fact challenge the basic assumptions of the current medical model, as it would then have been shown that qualitatively, and/or quantitatively, very different types of neurological damage can lead to the same type of dementia. This would threaten the model's fundamental assumption of links between specific damage to specific brain structures and specific symptoms, and the predictive power of the model would be greatly diminished. Syndromes such as *frontotemporal dementia* would make little sense and lack reliability and validity if the symptoms usually ascribed to such constructs could also occur to an equal extent with a different, and as of yet undetectable, neurological basis.

On balance, and taking account of the empirical studies (Homer et al., 1988; Burns et al., 1991; Kitwood, 1997), the contention that changes in the brain are not necessary for symptoms to present, appears to be supported at the current stage of

scientific knowledge. Consequently the medical model needs to be complemented by psychosocial factors to give a complete picture of dementia aetiology.

That the changes in brain tissue are not sufficient for symptoms to present can be seen from findings of large neuropathological changes in the brains of people who did not show symptoms of dementia while alive (Kitwood, 1993). This was found by Snowdon in the so-called *Nun Study*; a longitudinal study assessing 678 nuns for cognitive impairment followed by post mortem examinations of brain tissue in 118 cases (Snowdon, 1997). The Nun Study was criticized by Weiner, Cullum, Rosenberg & Honig (1998) for using cognitive test results as evidence for the existence or non-existence of Alzheimer's disease in individual cases. Weiner et al. (ibid.) argued that an apparently non-impaired test score in an individual with neurological change detected post mortem, can be explained by a higher than assumed prevalence of dementia in the baseline sample used by Snowdon (1997). However Weiner et al. (1998) did not provide evidence as to why the 678 nuns who made up the sample would not show the variation in normal aging and pathology needed to get a baseline with high ecological validity. The Nun Study therefore gives support to the contention that neurological change is not sufficient for symptoms to appear.

Little doubt exists in the literature about the importance of neurological causes for the development of dementia. But the standard paradigm does not appear to explain all cases of dementia, nor does there seem to be a simple, causal relationship between the extent of neurological damage and the severity of symptoms observed (Burns et al., 1991; Nagy et al. 1995; Snowdon, 1997) As a result it is reasonable to look outside the biomedical paradigm and assume that it could be of value to work psychologically within a holistic personal paradigm, rather than staying solely within a model that tends to focus on dementia as a *disease entity* (Kitwood, 1997).

### **Dementia as a social construction.**

As can be seen from the above, much uncertainty exists about the "objective" nature of dementia and as a result the concept can, to a large degree, be shaped by social consensus within the scientific discourse (Gubrium, 1986). Social Constructivists such as

Hanson (1989, 1997) see neuropathology as one of many causal factors in the social and interpersonal process that plays itself out for the individual with dementia, as he or she goes from being a person with dementia to simply, and almost solely, being a patient. Hanson (ibid.) distinguishes between *symptoms* and *problems* and argues that symptoms often exist for long pre-clinical periods before problems develop in the internal workings of a family and the medical/social system is alerted. A pre-clinical or *pre-problem* period of between 5 and 7 years has been found in qualitative, interview studies (Swane, 1995. Keady & Gilliard, 1999).

Keady & Gilliard (1999) carried out qualitative interviews with 15 clients and their families in order to describe how the family construes the appearance of early symptoms. It was found that the dementia sufferer most often perceives the new situation as a battle with the family over whether the symptoms are problems or not. The person with dementia feels under suspicion and pressure to cover up the symptoms. On the other hand, allocation of help from external sources is often judged by the “gate keepers” to these resources as relevant, more on the basis of presence or absence of “drama”, than on the basis of professional assessment of objective family needs (Swane, 1995). Hence the carers are “pushed” towards creating the drama that will give them the help they believe is needed.

It follows that a set of conflicting interests are created, not just between the person with dementia and his or her family, but also within the family members. These carers will want to preserve the dementia sufferer from showing dramatic lack of coping capability, but on the other hand will also want professional help. It can be speculated that this set of conflicting interests can exacerbate the physical and mental abuse of dementia sufferers, known to be common within families (Carp, 2000), as the frustrations of irreconcilable interests are acted out.

In addition, it has been found that levels of *expressed emotion*, defined as communication of negative emotions in a family, is related to the likelihood that symptoms of dementia in a family member leads to problems, which in turn lead to the redefinition of that person as a patient (Hanson, 1989; Vitaliano, Becker, Russo, Magana-Amato & Maiuro, 1989).



This illustrates how dementia cannot be well described as a linear relationship between single causes, such as neurological erosion, and symptomatology. Dementia is a neuro-psycho-social process without a discreet starting point and one that only ends with death. It follows that all involved in the psychological well-being of dementia sufferers must think in terms of *complexity* and *process*, rather than *symptoms* and *irreversible* decline, in order to devise interventions aimed at actual *problems* as these are subjectively experienced by the person with dementia.

### **The subjective experience of dementia.**

The focus on the person with dementia is a relatively recent development, partly because dementia's inherent challenge to memory based identity makes it difficult to study the *self* by standard question and answer approaches. However a shift occurred in the early 1990's when a number of researchers began to interview individuals with dementia, rather than only carers as had been usual until that time (Keady, 1996). Combined with more sophisticated observational methods (Kitwood & Bredin, 1992. Kitwood, 1997) this elevation to interviewee status meant that the dementia sufferer became less of an object and more of a subject in the research. As a result large individual variation in the experience of dementia was shown to exist and to be related to pre-morbid personality (Swane, 1995; Magai, Cohen, Culver, Gomberg & Malatesta, 1997). This variation indicates that the dementia process can have varied consequences for different clients. It has even been suggested that, as the person ceases excessive conformity to social convention, dementia can act as "a genuine form of personal growth" (Kitwood, 1995, p. 139). Again, it is clear that every person is unique and psychological work must take account of the subjective experiences of individual clients as they change over time.

Nevertheless, a desire to maintain involvement in one's own life is a common feature of the dementia sufferer's attempt at adaptation to his or her changing world. There are two main strategies used in succession to stay involved; *Taking stock* refers to a period with anxiety, low mood and possible depression while the client becomes ready to speak and thereby move to a stage characterised by *sharing the load* with carers (Keady & Nolan, 1995; Keady, 1996; Keady & Gillard, 1999). These stages overlap and have individual expressions in different people, a feature that any psychological intervention

must take account of to support the individual adequately. That is, it would be disrespectful and counterproductive to offer a *sharing of the load* if the client is clearly *taking stock*. It is important however, to be aware that some clients move quickly between stages and that a minority may even skip either stage (Keady & Gillard, 1999).

As it is now established that desire to maintain involvement in ones' own life is common for the person with dementia, it becomes important to support a coherent narrative about self-identity or *personhood*. This contention is underlined by Woods, Portnoy, Head & Jones (1992), Funkenstein (1993), Gearing & Coleman (1996), Haight, Coleman & Lord (1995) and Mills (1997), all of which refer to improved quality of life when narrative identity is supported.

Mills (ibid.) reported that all participants (n = 8, interviews = 141) in her in-depth interview study focussing on life history, showed improved life satisfaction as measured by the indicators of well-being defined by Kitwood and Bredin (1992)<sup>1</sup>. An important finding by Mills (1997) was that all her participants put emphasis on conveying episodes from their personal history, in which their role had been central and their emotional involvement high. Mills takes this to mean that re-telling of such stories reiterates the link between emotions and episodic memory, which in turn is seen as a constant re-establishment of narrative identity. Mills (ibid.) describes how the participants slowly, and in tact with their memory decline, "*transferred*" their personal narrative to the interviewer who was then able to feed it back in order to help retain a feeling of narrative identity in the client. Crucially, Mills (ibid.) found that even at the most severe stages of dementia, all participants had retained at least fragments of narrative identity as indicated by the ability to react with recognition to verbal clues of personal and emotional significance.

Mills' findings illustrate the central importance of recognizing the person behind the dementia even in the most advanced cases. Clients at this end of the dementia spectrum rely heavily on others to supply them with a sense of identity and therefore well-being (ibid; Haight et al., 1995; Gearing & Coleman, 1996).

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<sup>1</sup> These indicators are: The assertion of desires, ability to experience and express a range of emotions, initiation of social contact, affectional warmth, social sensitivity, self-respect, acceptance of other dementia sufferers, humour, creativity and self-expression, showing evident pleasure, helpfulness and relaxation.

Further Mills' (1997) findings point to the importance of early diagnosis and staff consistency over time. Clients can convey their personal narrative better in the early stages of dementia, and staff who have dealt with a person over time will be better able to vicariously hold, and then feed back, the salient features of the narrative in a way that can sustain self-identity for that person in the advanced stages of dementia.

### **Dementia Care Theory.**

The most influential theory in the field of psychosocial dementia care is the Dementia Care Theory of Tom Kitwood. DCT incorporates many of the insights already described in this essay. Kitwood and Bredin (1992, 1992a) argue that society's emphasis on neurological causes of dementia, and the resulting neglect of the individual's unique perspective on his or her psychosocial situation, causes the greatest loss encountered by the dementia sufferer: the loss of personhood. Personhood means that an individual has a certain status in society and that he or she is worthy of respect on the basis of being human.

In contrast to Mills (1997), who believes that carers should recognize the client's inherent personhood *despite* his or her lack of cognitive ability and other problems, Kitwood does not see personhood as something inherent, or as being dependent on the individual's characteristics or abilities. Kitwood sees personhood as a status allocated at birth and one that continues to develop through mutual social interactions (Kitwood, 1997). Thus "personhood is not, at first, a property of the individual; rather, it is provided or guaranteed by the presence of others" (Kitwood & Bredin, 1992, p. 275). As such personhood can be given - and taken away - by others within social inter-relationships and the question of whether an individual has personhood is under continual renegotiation.

According to Kitwood (1997) loss of personhood may occur with the continual encounter of depersonalising in the form of: treachery, disempowerment, infantilization, intimidation, labelling, stigmatisation, outpacing, invalidation, banishment and objectification, ignoring, imposition, withholding, accusation, disruption, mockery and disparagement. Kitwood believes that such interactions form a *malignant social psychology*, characteristic of the standard paradigm or biomedical model of dementia and that the depersonalising interactions are common techniques used to promote compliance.



Carers justify the need for compliance by construing the person with dementia as “defective” (ibid.). Thus a vicious circle is created as a “defective” person with greater ease can be treated as a non-person, confirming his or her lack of personhood and the split into “them” and “us” is strengthened within the carers.

Furthermore Kitwood (1997; Kitwood & Bredin, 1992) argues that this process of undermining personhood, results in negative effects on four global sentient states: diminished *self-esteem*, a reduced sense of *agency* and control over one’s life, a sense of *hopelessness* and reduced *social confidence* defined as a feeling of being at ease with others. Taken together these aspects of the malignant social psychology will, according to Kitwood (1997), lead to a reduction in level of functioning, perhaps even increase the rate of decline and neurological impairment and will promote a persistent vegetative state in the person with dementia. However, Kitwood believes that a different outcome is possible if an empathetic care regime is implemented. Under such conditions the dementia sufferer is thought to have an opportunity to “‘expand’ again, perhaps in new and unexpected ways; becoming part of the action and having both a place and a role” (Kitwood, 1997a, p. 20). Thus a state of relative well-being, not possible under the malignant social psychology of the standard paradigm, can be facilitated if the dementia sufferer’s personhood is acknowledged.

### **Interventions in Dementia Care Theory.**

In order to bring about the mentioned “expansion” it must first be established which malignant elements exist in the social psychology between carer and client. It was with this in mind that *Dementia Care Mapping* (DCM) was developed (Kitwood & Bredin, 1992a; Innes, Capstick & Surr, 2000). DCM is an assessment method designed to evaluate quality of care as a whole, but can also be used to pin-point areas in need of further development with regards to the process of care for individuals. DCM uses registration of both qualitative and quantitative variables to find correlations between activities engaged in and apparent well-being, and has been found to be valid and effective in a number of studies (Brooker, Foster, Banner, Payne & Jackson, 1998; Williams & Rees, 1997). The DCM approach forms a natural starting point for DCT interventions.

The psychological work carried out within a DCT framework assumes that well-being follows from having physical and psychological needs met through an intersubjectivity that supports personhood (Kitwood, 1990). It follows that psychological interventions must focus on the person behind the dementia symptoms to aid well-being. Also, the interventions must promote an empowering intersubjectivity and require an empathetic caregiver who is able to facilitate interactions at the zone of proximal development, which in this context means to perform only those components of an activity that the client is no longer able to master (Vygotsky, 1990). For example, if a person is no longer able to set the dinner table correctly but can perform this task if given step-by-step instructions. A caregiver working within a DCT framework could provide the needed items but let the client place them on the table, thereby enhancing the client's feeling of mastery and connection to the carer as they solve the problem together. The underlying rationale is that intersubjectivity maintains personhood, which strengthens self-esteem, agency, hope and social confidence, whereby well-being is facilitated and the withdrawal into a persistent vegetative state is possibly prevented or delayed (Kitwood, 1997).

### **Dementia Care Theory extended.**

In general Kitwood (1990; 1997) suggests a dialectic model that gives both neurological and psychosocial factors an interactional, causal role in dementia. The more practical recommendations, as formulated under the heading of *Person-Centred Care* (PCC), are however targeted solely at the social psychology between caregivers and the person with dementia.

The primary aim of PCC is that the client retains personhood in the face of failing mental powers. This is sought through the development of high quality social interactions, designed to improve the following variables: *comfort, inclusion in social activities, attachment needs* (understood as a reduction in "strangeness" of a situation), *occupation with what is subjectively significant* and the *feeling of identity*. It can be argued that Kitwood falls into a tautological trap when he defines a high quality interaction by the presence of the above-mentioned variables, and then argues that the presence of these variables, in specific cases, proves that the observed interaction was of

a high quality (Kitwood, 1997). In addition, this aspect of the theory seems to go against the overall aim of putting the person with dementia centre stage in his or her life, as it objectifies what can be considered a high quality interaction, thereby subtracting from what must be an inherently subjective judgement.

This view is supported by Lawton (1983) who asserted that the only true measure of well-being is the person's idiosyncratic perception. Lawton (1983a) suggested a two-dimensional model of psychological well-being, based on the finding that negative affect is more strongly related to engagement with inner aspects such as a memory, a thought or a physical symptom, while positive affect is more strongly related to engagement in external, interactive aspects of the person's world. The two-dimensional model has received some support in Lawton's later work (Lawton, Moss, Kleban, Glicksman & Rovine, 1991; Lawton, Haitsma & Klapper, 1996).

By combining Lawton's research (ibid.) with results showing that: "[A] high proportion [77.5% n = 213] of elderly people can answer questions about their quality of life, even in the presence of significant cognitive deficits" (Mozley et al. 1999, p. 776), a case can be made for extending Kitwood's concept and DCM-measurement of well-being to encompass a variable reflecting degree of felt congruence between desired and obtained goals. This would give a more complete and valid estimate of felt well-being, because it takes account of the balance between inner wishes and actual possibilities in the environment.

DCT stands almost unchallenged in the psychological literature but has been criticized on methodological grounds by Adams (1996). Adams argues, in line with the above-mentioned desirability of a subjective aspect to the measurement of well-being, that Kitwood's research relies too heavily on information supplied by relatives, information Adams considers unreliable. Adams (ibid.) goes on to say that the low correlation between the number of crucial life events reported by relatives, and subsequent development of dementia, does not lend support to the general idea that psychosocial life conditions and dementia are related.

However it appears untenable to first develop a criticism of DCT based on the unreliability of relatives as informants, only to develop another criticism based on a



correlation that is entirely dependent on the validity of information about clients lives supplied by these same relatives.

The comprehensive nature of DCT reflects Kitwood's varied background, which includes a natural science degree and training as a priest in the Church of England (ibid.). While comprehensiveness is part of the theory's attraction, it can also remove its recommendations from the day-to-day psychosocial work with clients, as caregivers struggle with the implementation of a theory encompassing aspects such as society's ideological and socio-political discourse on attitudes towards dementia (Packer, 2000; Pool, 2000). Studies show difficulties with implementation even when extensive training is undertaken (Lintern, Woods & Phair, 2000; 2000a).

A way to implement Kitwood's central ideas of sustaining personhood in a manner less reliant on understanding theory, and therefore easier to teach and supervise, exists in the nursing theory of Modeling and Role-Modeling (Rogers, 1996).

### **Modeling and Role-Modeling; a nursing theory.**

*Modeling and Role-Modeling* theory (MRM) originated in practical nursing and synthesised the theories of Rogers, Maslow, Erikson, Piaget, Selye, Engel and Bowlby to explain the observations made in this practice (Erickson, Tomlin & Swain, 1983). MRM holds that all interventions should be based on the client's subjective understanding of the environment (ibid.).

*Modeling* refers to understanding a person's resources, needs and expectations and facilitating meaningful interventions for the individual.

*Role-Modeling* entails formulating and implementing interventions from a client-centred perspective designed to enhance and maintain health and well-being in all aspects of the individual's experience, or in Erickson et al.'s terminology; it is the promotion of *holistic health* (ibid.).

In MRM signs and symptoms of dementia are seen as indicators of need status rather than as problems to be treated, and attention is constantly paid to any incongruence between desired and obtained goals (Kinney & Erickson, 1990). As argued in the above section of this essay, this in turn implies a promotion of well-being through the focus on the person with dementia rather than on an assumed disease entity.

The concepts of facilitative affiliation, nurturance and unconditional acceptance, are of primary importance in MRM's application to dementia care (Erickson et al., 1983; Rogers, 1996). Facilitative affiliation is defined as: "any nurse-client interaction in which the nurse assesses the client's needs based on that individual's self-care knowledge and perceived resources and creates individualized interventions based on those identified needs" (Rogers, 1996, p. 175). The relationship between nurse and client is furthermore characterised by availability, advocacy and nurture on the part of the nurse, and the overall nurturing approach is designed to install mutual trust, so that the client can move towards holistic well-being with help but also with the least possible dependence on carers (Erickson et al., 1983). There is no apparent reason why this general attitude and approach should not be readily generalized to professionals, other than nurses, when working psychologically with dementia sufferers.

Unconditional acceptance assumes an empathetic approach, giving insight into the client's perception of the world whereby a unique opportunity to identify needs arises. It also opens a cognitively low-demanding "channel" through which the client can be told that he or she is a valued person with whom one can relate (Rogers, 1958).

It is an explicit assumption of MRM that all humans are endowed with a need to fulfil their potential and that this need is responsible for lifetime growth. This is assumed even when the growth is expressed as a "slowing down" adaptation to a stressor, such as the cognitive decline experienced in dementia (Erickson et al., 1983). Related to this is the idea that humans possess an inherent need for both dependence and independence from others. This dual need is thought to be present from birth, and only the degree of dependence and independence fluctuates over the lifetime of an individual. Again, the caregiver must take an empathic stance in order to find the balance that will give the highest sense of well-being for the dementia sufferer (ibid.).

MRM offers a practical operationalization of many recommendations coming out of the theories and studies related earlier in this essay as it is person-centred and promotes an empowering intersubjectivity. Furthermore it does so in a more pragmatic way, without losing track of the central importance of the person behind the dementia.

MRM is based on empathic relations between caregiver and client. This emphatic and “non-technical” feature means that the theory is more likely to be implemented in day-to-day work with clients as it is, in principle, easily taught and has obvious face value.

Although it has been shown that MRM can be beneficial for both clients and those caring for them (Acton and Miller, 1996), the empirical base is not as strong as that of DCT. However, in practical terms, the two theories will have similar expressions when working with clients, and when taking account of the difficulties with the implementation of DCT a case for the promotion of MRM as a practical extension of DCT can be made. This may not be optimal from a scientific perspective, but could represent a step closer to *best practice* in settings where one is struggling to implement DCT.

### **Conclusion.**

This essay initially argued that neurological change is not necessary or sufficient for symptoms of dementia to occur. This supports the idea that various paradigms could be of value when working psychologically with clients, as not all variation in symptomatology is fully accounted for by the medical model. Also, seeing a *person* with dementia rather than generic symptomatology will influence psychological work as it entails taking account of relevant information typically disregarded by the medical model.

The social construction of dementia was considered in more detail and it was discussed how families often experience conflicting interests that can cause problems for all involved. Psychological interventions are best suited to deal with these problems and it was argued that a prerequisite for this work is to acknowledge the person with dementia and not exclusively focus on symptoms. The reason being that problems are partly cognitive and social constructions, and as such can only be understood if one attempts to take the position of the individuals in question. A feat not easily achieved if one is only seeing a disease entity.

Empirical studies showed that, even at the most severe stages of dementia, clients can retain at least fragments of narrative identity if supported correctly. This illustrates the influence on psychological work of recognizing the person behind the dementia, as such recognition is necessary for support to be carried out effectively. Further this has



added importance as it was shown that recognition of personhood is linked with improved well-being.

The domains of biomedicine, social construction and subjective experience are incorporated in the only comprehensive theory in this field; the Dementia Care Theory. DCT argues that care based on the biomedical model of dementia results in a malignant social psychology that ultimately promotes a persistent vegetative state in the dementia sufferer. However, it is also believed that a more positive outcome is possible if empathetic care, supporting personhood, is implemented. DCT highlights how psychological work is influenced by the ability to see the person behind the dementia and thereby move away from a malignant social psychology. It is concluded that the theory is an important tool in this regard, but also that it would benefit from including a variable measuring felt congruence between desired and obtained goals. This would give a more complete and valid estimate of subjective well-being. Furthermore it is suggested that DCT's practical implementation could be hampered by its relatively complex conceptual nature and as a solution to this problem the nursing theory of Modeling and Role-Modeling was introduced.

MRM uses a client-centred and emphatic approach with emphasis on the individual with dementia and does so in a non-technical manner that makes it more likely to be taken up and used in the busy day-to-day psychological work in settings such as the NHS.

In sum, psychological work in this field is heavily influenced by whether one sees persons with dementia or only symptomatology. It is clear that a narrow biomedical approach has detrimental effects on well-being and it should therefore be challenged whenever encountered.

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## **Written Exercise 2**

Give an analysis of the rationale for, and important factors in, obtaining an effective and holistic psychological assessment of a child. Illustrate your analysis with clinical examples.

John Sørensen.  
DClinPsy. Year 2.  
November 2003.

Word count: 4989

## **Introduction.**

According to The Penguin Dictionary of Psychology, the basic axiom of a holistic position is that a complex phenomenon cannot be understood by an analysis of the constitute parts alone (Reber, 1995). As such the analysis put forward in this essay will assume that an effective and holistic psychological assessment of a child must keep the child in the centre of attention while assessing the impact that multiple factors in the environment may have on the child. This means that a 'tick the box' approach, which can assess many environmental factors will not be considered a holistic assessment until the information obtained has been related specifically to a particular child.

The essay utilizes Urie Bronfenbrenner's *Ecological Systems Theory* and argues that this developmental theory provides a terminology and a way of thinking about children that can guide holistic assessment. The case for using Bronfenbrenner's thinking in this manner is analysed using empirical evidence. This is done to show how all the different levels of the environment, as defined by the theory, impact on the child's development and psychological status.

The essay then argues that when all levels of the environment can be shown to effect the child's development and psychological wellbeing in a complex and interactional way, it follows that a 'non-holistic' assessment is incomplete and at risk of missing important factors and potential opportunities for effective intervention.

As a result, it is concluded that the analysis of the rationale for holistic assessment has provided a compelling argument for the contention that effective assessment of children must be holistic in nature.

Ecological Systems Theory formed the background to the now well-established view that a child's development happens within a complex web of relationships affected by multiple levels of the environment. The theory thereby challenged the traditional understanding of the relevant environment as being limited to events and conditions immediately surrounding the child. The theory is however phrased in mainly abstract and theoretical terms and as a result the essay will use clinical examples to illustrate the

analysis of how different levels of the environment can impact on the child. It is hoped that these examples will illustrate important aspects and also help keep the focus on the child as a unique individual, a fact easily lost in the scientific language within this particular field.

Together with clinical examples and the empirical evidence cited below, Ecological Systems Theory provides a rationale for holistic assessment and a general framework for thinking about children as interconnected with various aspects of the environment. However it lacks the necessary conciseness in the establishment of important factors for an effective assessment in clinical practise.

A more concise model for effective assessment has been provided by the Government's Assessment Framework which had to be implemented across all services by March 2001 (Department of Health, 2000).

While broadly based on holistic thinking the assessment framework provides a list of important factors in the assessment of children in need. The essay attempts to place the Government's framework factors within Ecological Systems Theory. This is done in order to establish whether the provided list of important factors assesses all levels of the environment and their impact on the child.

Furthermore the essay analyses the framework's main factors separately in order to determine whether the existing empirical evidence constitutes a rationale for this approach as the assessment strategy of choice.

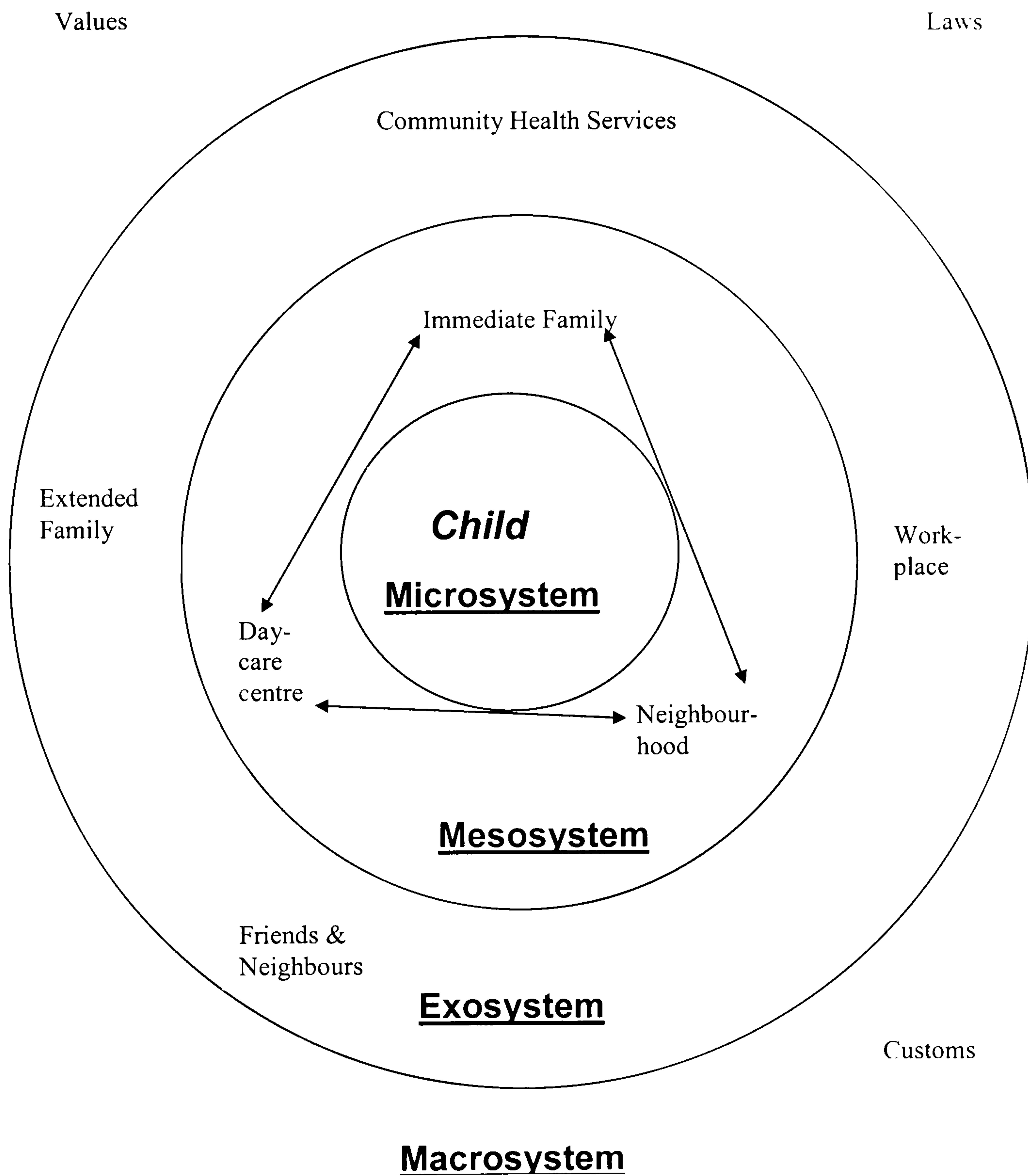
### **The rationale for holistic assessment.**

Since Bronfenbrenner (1979) published his Ecological Systems Theory, the assumption that children develop within a complex system of relationships affected by multiple levels of the surrounding environment, from immediate settings to broad cultural values, laws and customs, has become widely accepted (Berk, 1994; Department of Health, 2000)<sup>2</sup>.

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<sup>2</sup> Please see Figure 1 for Bronfenbrenner's model and general terminology.

This acceptance is based on sound empirical evidence at all levels. Figure 1 Ecological systems theory (Adapted from Berk, 1994, p.26)





At the microsystem level, which refers to activities and interaction patterns in the child's immediate surroundings, it has been shown that a child's temperament (friendly or unfriendly as seen by its mother) is a strong determinant of whether the parenting is characterized mainly by positive and patient attitudes or by restriction and punitiveness (Henker and Whalen, 1989).

Similarly the mother-infant dyad's "fit" or reciprocal communication pattern, in which the optimal mother reacts to her baby's signals in a well-timed way, has been reliably correlated with attachment style, which in turn has been linked to various psychological and behavioural problems in later childhood and adolescence (Carlson, Cicchetti, Barnett and Braunwald, 1989; Elicker, Egelund and Sroufe, 1992; Jones, 1998; Suess, Grossmann and Sroufe, 1992; Stern, 1985).

Within the microsystem any interaction is effected by the activities of other individuals present. This can be illustrated with the clinical example of a mother who resents the lack of child rearing support received from the child's father, and who therefore reacts to her child's demanding temperament by using inconsistent discipline and by becoming hostile towards her child. This pattern was regularly found in Hetherington and Clingempeel's (1992) study of the relationship between marital conflict and parental child rearing style (see also Simons, Lorenz, Conger and Wu, (1992) in further support of this finding).

As illustrated by the clinical example given above, factors at the microsystem level, such as the child's temperament, marital conflict between carers and the parenting style to which the child is exposed, interact in complex ways and can have an impact on the development and psychological wellbeing of the child. This strengthens the rationale for paying attention to factors at microsystem level in the psychological assessment of children.

At the Mesosystem level, which consists of connections between Microsystems (such as day-care centre, school, home, neighbourhood etc.) that influences the child's development, it has been shown that a child's academic success is not solely determined



by what goes on in the classroom. Rather, academic progress is influenced by parental involvement in school and by the extent to which schoolwork is supported and engaged with by the parents at home (Stevenson and Baker, 1987).

Similarly the strong correlations found between neighbourhood characteristics (such as the presence of overhead walkways or the number of interconnected exits) and increased levels of burglary, theft and assault (Coleman, 1991), are in accordance with data that suggests that the physical environment has an impact on children's deviancy rates because of increased difficulties in parental supervision (Loeber and Stouthamer-Loeber, 1986).

A clinical illustration of the interconnection between Mesosystem factors can be seen when a mother presents with a son who is falling behind at school, not as a result of learning difficulties, but rather because the mother is not valuing schoolwork and has difficulties keeping him away from crime on a deprived estate where the physical environment allows him to go about his activities unsupervised.

Again, the cited research and the clinical example illustrate how factors at Mesosystem level can impact on the child's behaviour and development. As a result, the rationale for including Mesosystem factors in the psychological assessment of children has been supported.

The Exosystem consists of social environments that do not include children but nevertheless have an impact on their lives. Examples of factors in the Exosystem are parent's workplace, parent's friends and neighbours, the extended family and community health services (Berk, 1994).

Apart from the common sense view that workplaces that aid flexible work hours and extended families with supportive characteristics can enhance the adaptive development of children, the breakdown of factors at Exosystem level has been extensively researched and found to be important in children's development and psychological well-being.

In relation to this it has been shown that not only do factors such as social isolation, lack of employment, lack of social support and limited access to community services, often

lead to reduced wellbeing and sense of control over life amongst parents (Aldgate and Bradley, 1999), these factors are also positively correlated with rates of conflict with children, failure to thrive amongst children and child abuse (Emery, 1989; McLoyd, 1989; Utting, 1995). As a consequence it is clear that an assessment that neglects the Exosystem runs the risk of missing factors that can have very important effects on the child's life and hence the intervention that is most appropriate.

An example of Exosystem importance from the clinic is the single mother who cannot afford child care, who has no network of friends around her and who has an employer who does not allow flexible hours. In this case it becomes important to look for other Exosystem factors that can compensate, and it would be important to determine whether the extended family or social services could help with the provision of childcare, so that the mother can continue work and not slip further into social isolation.

This example also illustrates the more general point that assessment at all levels should include protective as well as challenging factors in the child's environment.

The Macrosystem is not a particular context but refers to laws, values and customary practices of the surrounding culture (Bronfenbrenner, 1989).

Again it is important to relate information at this level to the individual child. As an example it can be noted that while black and white children share large parts of their culture, it is noticeable that black children are much more likely to be taken into care (Barn, 1999), are less likely to be included in a family support program (Butt and Box, 1998) and are significantly more likely to experience the type of stress frequently associated with people who need the services of social care agencies (Butt and Mirza, 1996).

This example, dealing with 'institutional racism', illustrates how factors at macrosystem level can have direct effects on individual children's lives and psychological wellbeing and as such the rationale for including this level in psychological assessment has been made. Other factors at this level include exposure to religious intolerance, employment

law determining when parents return to work after having had a child, particular customs such as sending children to boarding school at an early age etc.

### **Summary of Ecological Systems Theory in relation to assessment.**

According to Bronfenbrenner (1979; 1989) children create and select parts of their environment and experiences according to their developmental stage, their physical, intellectual and personality related characteristics and according to the opportunities afforded by the environment. As such development and psychological well-being is not seen as determined by inner forces or by external/environmental conditions, but rather children are seen as producers and products of a complex network of interdependent effects.

As shown above, this general point of view has been well supported by empirical evidence and it is clear that intervention at any level of the environment can have an impact on the immediate experience of a child. It follows that an effective assessment must be holistic in nature and that an approach to assessment which is solely focused on the complaint or symptoms a child is referred for, is likely to miss opportunities for helpful intervention.

To illustrate this point, intervention at the exosystem level for socially isolated parents who abuse their children may be appropriate if, for instance, a parenting group can supply gratifying social relationships that relieve the frustration currently leading to abusive behaviour towards the children.

In a revision of his original theory, Bronfenbrenner (1989) gave prime importance to the macrosystem as a determinant of children's well-being and development, thereby illustrating how the influences traditionally seen as furthest removed from the child should be assessed in relation to the individual because influences at this level impact on all the other levels.

An important strength of Ecological Systems Theory is that it supplies a terminology for holistic thinking and communication about children. As a result of this, the theory is able



to capture all the numerous potentially important factors in an effective assessment within a few levels or “systems”. However this strength is also a weakness when it comes to actual, clinical practise.

This follows because the general nature or “over-inclusiveness” of the subsystems does not provide an operational guide to assessment nor a specification of which particular factors should be considered important in obtaining an effective assessment of a given child.

### **Operational guidelines and governmental demands.**

Updated versions of Bronfenbrenner’s model (Jack, 1997; Garbarino and Collins, 1999; Department of Health, 2000) form the basis of the requirements for *children in need* assessments that came into force across all services in March 2001 (Department of Health, 2000).

These requirements locate the task of promoting and ensuring the child’s welfare at the centre of a so-called *domain triangle*, bounded by the child’s developmental needs, parenting capacity and family and environmental factors, thereby offering an operationalized guide to the important factors in an effective and holistic assessment, while still attempting to capture the ecological completeness of Bronfenbrenner’s model (See figure 2).

As can be seen from figure 2 this is an ambitious framework that is further complicated by the fact that the maximum timescale for completion of an indepth assessment is 35 working days from referral, and by the requirement that appropriate services should be provided whilst awaiting the completion of this specialist assessment (Gray, 2001). While social services have the lead responsibility for assessment of children in need, section 27 of the Children Act 1989 specifies that other local health services (including mental health) have a duty to assist in carrying out this function (ibid.).

In the following I will analyse the important factors in obtaining an effective psychological assessment under the framework illustrated in figure 2.



Figure 2. The Assessment Framework (Department of Health, 2000, p. 2).

**Dimensions of the child’s developmental needs domain.**

This aspect of the guidance is based on earlier work in the looked after children system (Department of Health, 1991) which found seven main developmental dimensions along which children must progress if they are to achieve desired outcomes and enter adulthood successfully.

The dimensions are: Health, Education, Emotional and Behavioural Development, Identity, Family and Social Relationships, Social Presentation and Self Care Skills.

These dimensions are set out in abridged form below, emphasising the internal aspects most relevant to psychological assessment.

**Health.**

Includes mental wellbeing and psychological difficulties as well as appropriate advice on health related issues such as sex and substance misuse, growth, diet, exercise, impact of genetic factors, immunisations etc.



### Education.

This concerns all aspects of a child's cognitive development starting from birth and also requires the assessment to obtain information about the opportunities for play and interaction with other children, the availability of adults who are interested in the child's educational activities and who takes account of any special educational needs.

### Emotional and Behavioural Development.

This includes an assessment of the appropriateness of the child's emotional and behavioural responses to caregivers and, as the child grows older, to others beyond the family. This dimension explicitly requires attention to the nature and quality of early attachment, responses to stress and change, degree of self control and temperament.

### Identity.

Concerns a child's sense of self as a valued and separate person and deals specifically with issues of self-esteem, degree of positive self image and the components that inform this in the shape of race, religion, age, gender, sexuality and disability etc. This dimension also requires an assessment of the child's feelings of belonging and acceptance by family, peer group and society in general, including other cultural groups.

### Family and Social Relationships

This dimension deals with the assessment of development of the capacity for empathy. Good development is assumed to include stable and affectionate relationships with parents or caregivers, good relationships with siblings, increasing importance given to age appropriate peer relations as the child grows older, and furthermore looks at the response of family members to these relationships.

### Social Presentation.

This concerns the child's ability to judge how its own appearance, cleanliness, behaviour and any impairment in these areas are perceived by others. This includes an assessment of age appropriateness of dress for age, gender, race, religion, culture and an assessment of the availability of advice on these matters from adults.

### Self Care Skills.

This relates to the assessment of a child's acquisition of practical, emotional and communication abilities required for progressively increasing independence. The dimension includes the available encouragement to acquire social problem solving skills and special attention is required with regards to impact on such skills from any impairment, vulnerability or social circumstance affecting the skill development.

### **Summary of the assessment framework's developmental domain.**

As mentioned above the guidance for assessment in this domain is built on earlier research which identified seven dimensions of important child development. The dimensions all have a child centred perspective and furthermore the guidance document for assessment (Department of Health, 2000) explicitly refers to Ecological Systems Theory as the inspiration and "blueprint" for the dimensions included.

In order to aide the analysis of whether the included factors or dimensions offer an adequate and effective operationalization of the holistic content of Ecological Systems Theory, for which a strong rationale was developed through empirical studies earlier in this essay, Figure 3A below has an outline of Bronfenbrenner's theory with the developmental dimensions of the assessment framework superimposed on it.

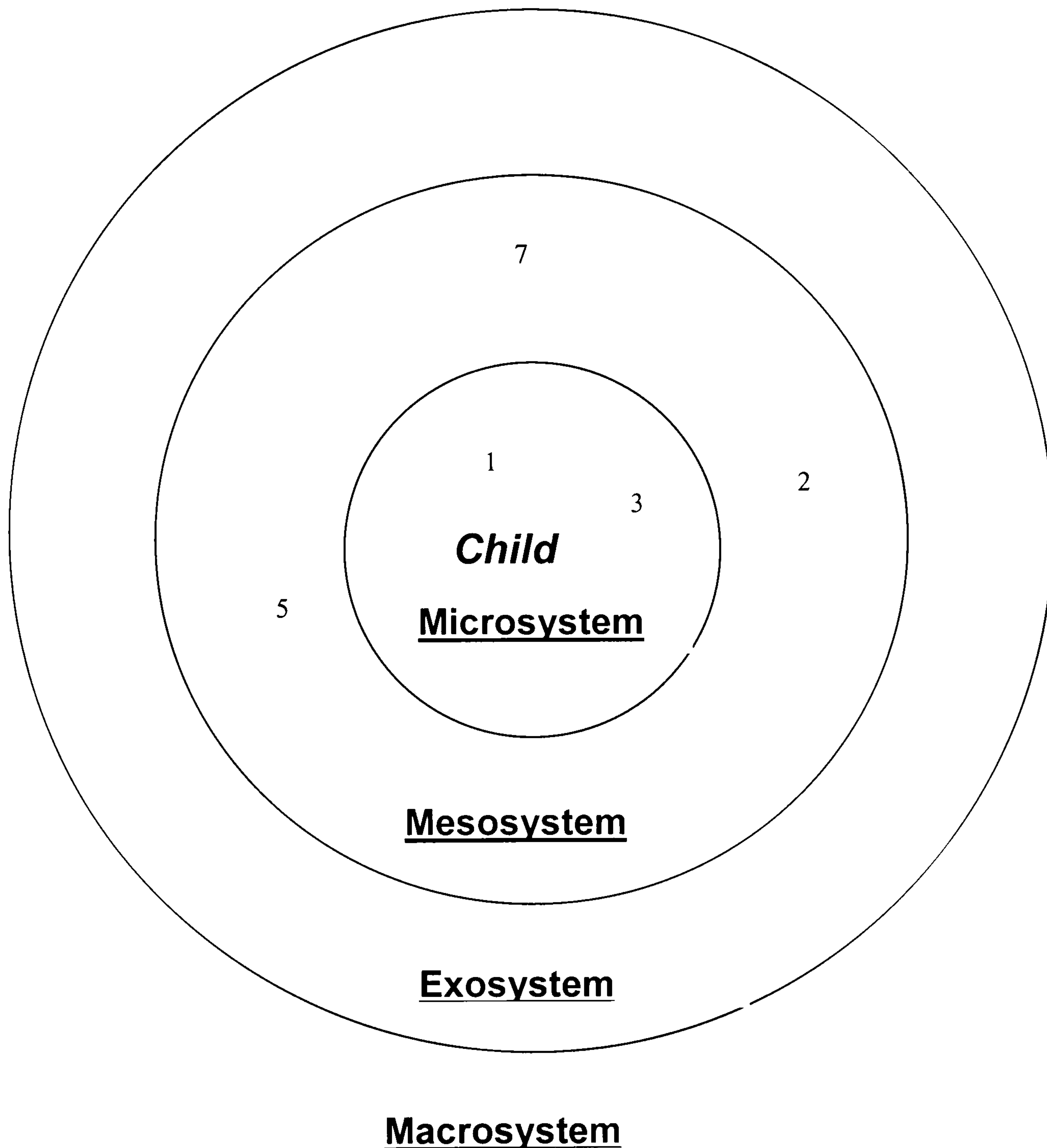
Figure 3A lacks information regarding the other domains of the assessment framework (Parenting Capacity + Family and environmental factors), which will be developed in subsequent sections of this essay, but it is already clear that the developmental dimensions spread across most aspects of the ecological model.

It should further be noted that the placement of individual dimensions in the ecological model is open to criticism, and that figure 3A is an expression of the author's subjective opinion of the best "fit" between the two models.

Figure 3A – Developmental needs assessment and the dimension's primary relation to an individual child's development as expressed in Ecological Systems Theory.

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- |  |                                    |
|--|------------------------------------|
| 1) Health                                | 5) Family and social relationships |
| 2) Education                             | 6) Social presentation             |
| 3) Emotional and behavioural development | 7) Self care skills                |
| 4) Identity                              |                                    |

### **Dimensions of parenting capacity.**

The second domain in the assessment framework deals with the areas in which it is known that adults who are responsible for parenting children, need to function well in order to help their children negotiate the developmental stages as they face them. It has been shown that some children are more resilient than others and that different parenting difficulties are particularly challenging for children at different ages (Cleaver, 2000).

The Department of Health (2000, p. 11) recognizes this and advocates a child-centred and context aware approach by pointing out that: “A two year old may be at risk of significant harm from a parent whose practical caring skills are diminished by a misuse of drugs...but a sixteen year old in a similar situation may be able to remain relatively unharmed”.

However the same Department of Health document also bases its guidelines on research findings that show how parenting influenced by mental illness, drug and alcohol abuse and domestic violence often has a damaging effect on children’s development and psychological wellbeing (Buchanan, 1994; Falkov, 1996; Thoburn, 2000). As such these areas of concern should be kept in mind in the required assessment of all the following dimensions.

#### **Basic care.**

Are the parents providing for the child’s physical needs? Includes food, drink, warmth, personal hygiene etc.

#### **Ensuring safety.**

This concerns the parents’ ability to keep the child from danger and from contact with unsafe adults/other children and furthermore looks at the parents’ ability to adequately protect the child from self-harm.



Emotional warmth.

Deals with parental ability to meet the child's emotional needs and supply the child with a sense of being specially valued. An aspect of this is the parents ability to give the child a positive sense of its own racial and cultural identity. Furthermore an assessment of appropriate physical contact and the parents' ability to ensure secure, stable and affectionate relationships with the child is required within the assessment framework.

Stimulation.

This relates to the promotion and encouragement of a child's learning and intellectual development at both cognitive and social levels. This includes an assessment of the parents ability to interact, communicate and facilitate educational opportunities in an age appropriate fashion and through joining the child's play.

Guidance and boundaries.

This dimension concerns the enabling of the child's ability to regulate his or her own emotions and behaviour. The key parental skills to be assessed are *demonstrating and modelling* appropriate behaviour, display of emotions and interaction with others and *guidance*, which involves setting boundaries so that a child is able to develop an internal model of moral values and social behaviour appropriate for the society in which they are growing up. More specific areas of concern in a psychological assessment are modelling of anger management, social problem solving, consideration for others and effective discipline and shaping of behaviour.

Stability.

This is concerned with the provision of a sufficiently stable family environment that allows the child to develop and maintain a secure attachment to the caregiver(s). This particular assessment dimension shows how the framework is influenced by the theories on development conceived by the psychoanalyst John Bowlby (1969), but also that Bowlby's model is not considered comprehensive enough. This is made clear when the framework goes on to require an assessment, not only of the stability of relationship

between parent and child, but also of the stability of relationships with important members of the extended family.

**Summary of the assessment framework's parenting capacity domain.**

The assessment guidelines are concerned with all aspects of parenting, from the most basic feeding, to the most general initiation into participation in the surrounding culture, with its specific demands for understanding of the prevailing values and moral codes for acceptable behaviour. As such it appears that the parenting capacity domain reflects the framework's ambition of being holistic in nature, while still being specific about the factors that are considered important in effective assessment of children.

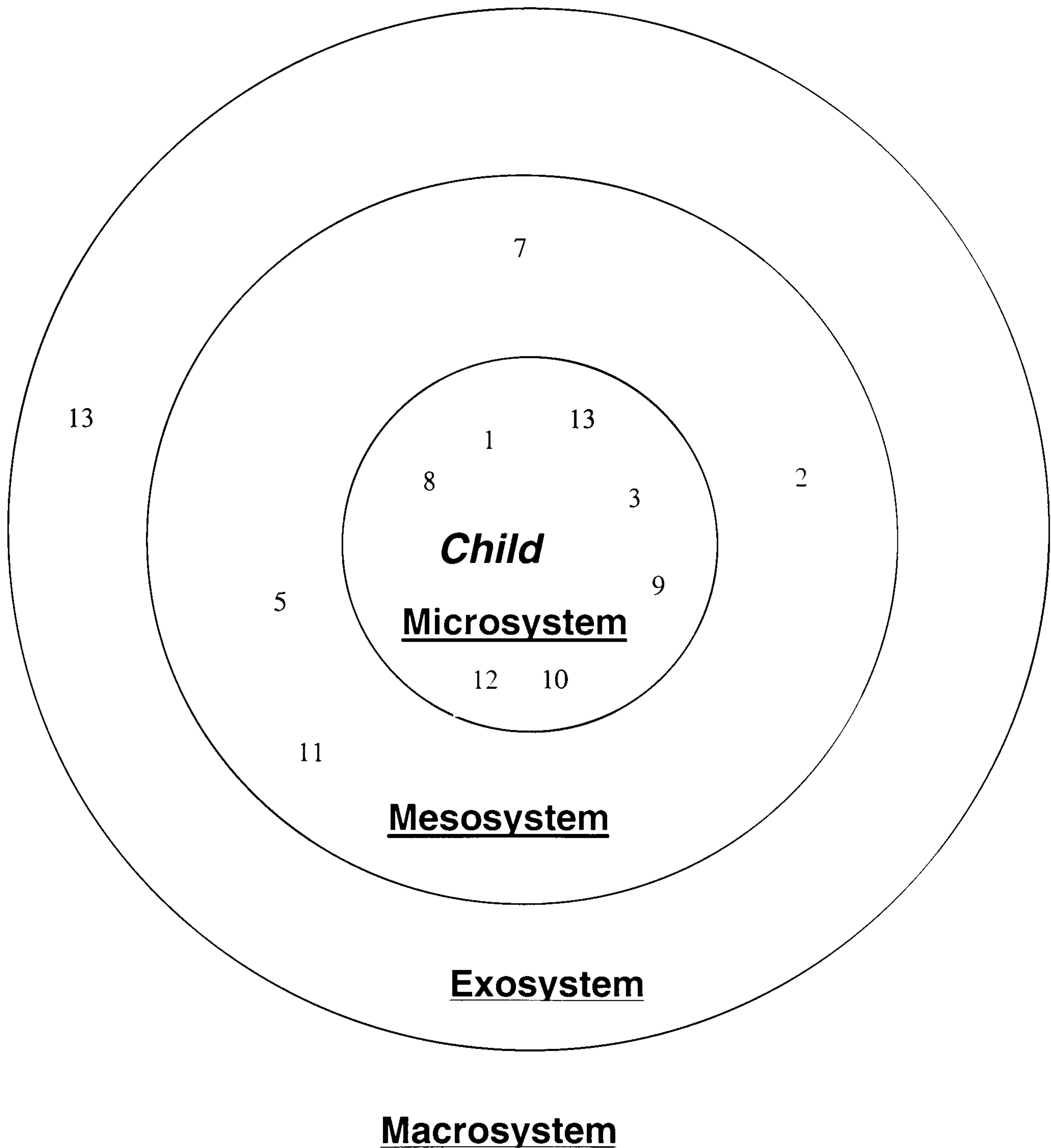
Figure 3B below is a revised version of figure 3A, with the addition of the dimensions of parenting capacity. The figure is meant to continue the analysis of whether the assessment framework offers an adequate operationalization of Bronfenbrenner's model, which this essay has argued provides an empirically supported rationale for holistic assessment of children.

As can be gauged from the model, it appears that the Government's assessment framework continues to spread across Bronfenbrenner's model, indicating that the framework's holistic ambitions may be fulfilled.

Figure 3B – (Figure 3A + Parental capacity dimensions)

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- 8) Basic Care
- 9) Ensuring safety
- 10) Emotional warmth
- 11) Stimulation
- 12) Guidance and boundaries

13) Stability

### **Family and environmental factors.**

The inclusion of this domain in the assessment framework is based on extensive evidence for the negative psychological and developmental consequences of poverty (Bebbington and Miles, 1989; McAuley, 1999), the potentially protective and damaging function of the community and extended family with regards to psychological adjustment and development (Brandon, Lewis, Thoburn and Way, 1999) and on the evidence for negative consequences when community resources fail (Hallett, 1995, Department of Health, 1995).

Generally speaking this domain includes factors in the wider family and community judged by the Department of Health (2000) to impact directly or indirectly on children's development and psychological wellbeing.

#### Family history and functioning.

This dimension includes both genetic and psycho-social factors. Family functioning is assumed to be influenced by who is living in the household, how they are related to the child and by any significant changes in household/family composition over time.

Furthermore, attention to parental strengths and weaknesses, the childhood experiences of parents, the relationships between separated parents and the child's relationship with siblings is required.

#### Wider family.

This deals with who the child and parents consider part of the wider family and looks at how these persons are important to the child. The people termed part of the wider family can be biologically unrelated to the child, but must be included if they are seen as important for the child's development.

#### Housing.

This dimension assesses whether the accommodation has basic amenities and facilities that are appropriate to the age, development and possible special needs of the child and other residents.



### Employment.

This concerns who is working in the household, their patterns of work and the impact this has on the child. Included in this part of the assessment is also attention to attitudes regarding work amongst family members and the child's experience of work.

### Income.

This looks at any gaps between needs and the financial resources available to breach this gap. In relation to psychological assessment this would be particularly interested in how a lack of money or the family's pattern of spending affects the child.

### Family's social integration.

This entails an exploration of the wider context of the local neighbourhood and community in order to ascertain its impact on the child. As part of this assessment attention must be given to the family's integration or isolation, their peer groups, friendships and social networks and the importance given to these contacts by the family.

### Community resources

This includes an assessment of the availability, accessibility and standard of primary health care, day care and schools, places of worship, transport, shops and leisure activities appropriate for all family members.

### **Summary of the assessment framework's family and environmental domain.**

As illustrated in earlier sections of this essays (see discussion of the Meso- and Exo-systems in the above) the family and environmental dimensions of the child's surrounding can have a dramatic impact on behaviour and psychological wellbeing and from this point of view the assessment framework's attentions to this aspect of an holistic assessment seem well founded.

### **The assessment framework as an effective and holistic psychological assessment.**

Considering Figure 3C below, which is Figure 3B revised to include the family and environmental factors, it is clear that the assessment framework has considered important

factors for children's development and psychological wellbeing across the ecological map developed by Bronfenbrenner (1979).

Furthermore it can be argued that the fact that some dimensions (such as housing and income) are difficult to place within the Ecological model indicate that the assessment framework contains aspects not covered by Bronfenbrenner's model. As such it appears that the Government's guide to what an holistic or ecologically valid assessment should contain, is comprehensive and adequate with regards to which factors such an assessment should contain in order to be effective.

However the fact that the dimensions included in the guidelines for assessing children in need can be seen to span the whole ecological system does not mean that the factors included constitute a complete list of important components in an assessment. It only indicates that many levels of the child's environment known to influence development and psychological wellbeing have been considered. As such it is entirely possible that time and future research will locate additions to the list of factors to consider in an effective and holistic assessment.

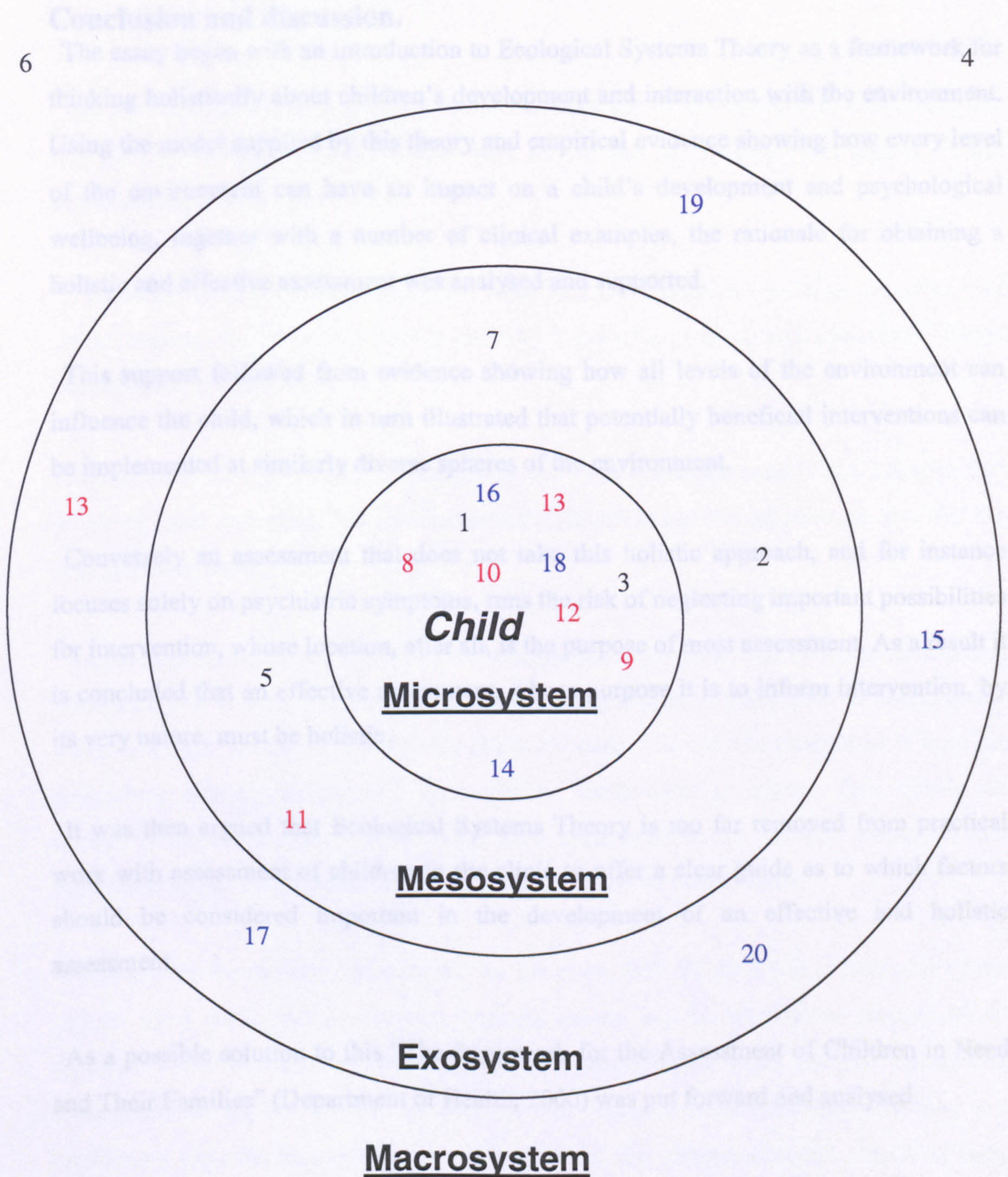
For now the assessment framework provides a comprehensive and useful conceptualisation of what should be considered in a psychological assessment of children.

Furthermore, while the assessment framework can appear to be an arbitrary list of factors and an example of a "tick the box" approach to assessment, it should be noted that all the included factors are closely linked to research that puts the child in the centre of attention.

As a result of this child centred approach, rooted in empirical evidence and well established knowledge of child development, the framework can be said to live up to the criteria for holistic assessment as defined at the outset of this essay.



Figure 3C – (Figure 3B + Family and Environmental dimension)



- 14) Family history and functioning
- 15) Wider family
- 16) Housing
- 17) Employment
- 18) Income
- 19) Family's social integration
- 20) Community resources



## **Conclusion and discussion.**

The essay began with an introduction to Ecological Systems Theory as a framework for thinking holistically about children's development and interaction with the environment. Using the model supplied by this theory and empirical evidence showing how every level of the environment can have an impact on a child's development and psychological wellbeing, together with a number of clinical examples, the rationale for obtaining a holistic and effective assessment was analysed and supported.

This support followed from evidence showing how all levels of the environment can influence the child, which in turn illustrated that potentially beneficial interventions can be implemented at similarly diverse spheres of the environment.

Conversely an assessment that does not take this holistic approach, and for instance focuses solely on psychiatric symptoms, runs the risk of neglecting important possibilities for intervention, whose location, after all, is the purpose of most assessment. As a result it is concluded that an effective assessment, whose purpose it is to inform intervention, by its very nature, must be holistic.

It was then argued that Ecological Systems Theory is too far removed from practical work with assessment of children in the clinic to offer a clear guide as to which factors should be considered important in the development of an effective and holistic assessment.

As a possible solution to this "The framework for the Assessment of Children in Need and Their Families" (Department of Health, 2000) was put forward and analysed.

This framework is based explicitly (ibid. p. 16-17) on Ecological Systems Theory and while not developed exclusively with psychological assessment in mind, the framework was found to provide an operationalization of holistic, psychological assessment that



includes clear guidelines for which factors should be considered important in such an undertaking.

The framework is closely related to empirical evidence of a child centred nature and it is entirely possible that future research will add to the list of important factors in the assessments of children<sup>3</sup>.

As a result of this, the essay does not argue that the framework provides an exhausted list of important factors, but does argue that it provides a good and empirically based starting point for such a list.

Furthermore the mapping of framework factors onto Bronfenbrenner's ecological model provided some indication that the framework manages to tap into all relevant levels of the child's environment.

An assessment following the described framework is an ambitious and time consuming undertaking. It is therefore essential that adequate resources are allocated to underpin the work. The high levels of professional skills required will only be developed if time for continuing study, training and high quality supervision is given. This entails an acknowledgement of the importance of such assessment at the level of managers and politicians and at the present time this appears unlikely to materialize.

Furthermore the multidisciplinary modus for work with children that is the order of the day in most child and adolescent services, means that psychological assessment of children often happens, at least partly, by professionals who do not necessarily understand all aspects of the framework. For instance some professionals may not understand the relevance of attachment theory and the intergenerational effects of early

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<sup>3</sup> The framework's child centred approach has caused some concern, and it has been suggested that a truly holistic approach should include factors that do not entirely centre on the vulnerability of the child, but also assess the possibility of harm to others. This is a procedure currently followed by Youth offending teams in their use of the "asset" form (Curtis, 2001).

childhood experiences when assessing parental capacity to meet the needs of a given child.

With a lack of resources for adequate training and supervision the danger is that the framework becomes the 'tick a box' approach that its holistic value base was an attempt to avoid. (White and Adcock, 2001).

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**Audit of user satisfaction and perceived need for developments of a Depot Clinic.**

Small Scale Service-Related Research Project completed in Year 1, placement 2 of the DClinPsy. Course University of Hertfordshire.

John Sørensen.

December 2003.

Word count: 4984



### **Summary:**

The following reports on an audit of user satisfaction with a Depot Clinic run within a Community Mental Health Team (CMHT), and includes an assessment of the users' perceived need for developments of the service provided. In order to answer the audit questions both questionnaires and interviews were used. It is concluded that user satisfaction with the clinic is moderate to high and that user perception of the treatment experience is highly individual. Despite this it is also concluded that psycho-education on a one-to-one basis could improve the satisfaction ratings of many users and that a person-centred, holistic and listening approach, which provides opportunities for regular feed-back on the workings of the clinic, is an important element for user satisfaction and reflects the most needed developments as seen by users.

## **Introduction.**

Developments in the provision of mental health services have, in recent years, been moving towards more user input and assessment of the service provided. "Outcome measurement" has become a central pillar of Department of Health policy (Department of Health, 2000. p. 110), in which outcome measurement is defined in terms of:

- a) mortality (suicide rate reduction).
- b) morbidity (reduction in mental illness).
- c) quality of life for service users and carers.

*And*

- d) service user and carer satisfaction.

This inclusion in the definition of central outcome measures illustrates the central importance given to service user satisfaction.

Further the National Service Framework (NSF) (Department of Health, 1999) sets out as a guiding value and principle that, "people with mental health problems can expect that services will: involve service users and their carers in planning and delivery of care" (ibid. p. 4) and that "specific arrangements should be in place to ensure: service user and carer involvement" (ibid. p. 10).

When looking specifically at the services provided to the severely mentally ill who are the users of the audited Depot Clinic, the NSF (ibid. p. 66) indicates that performance assessment should take account of the “experience of service users” and also measure “service user satisfaction with respect to a specific mental health service” (ibid. p. 125).

The present project fits well within the above mentioned policy trend as it attempts to gain information about the satisfaction and experiences of the clients using the Depot Clinic.

The project sprung from discussions with nurses, medical doctors and the CMHT Manager involved in the running of the Depot Clinic. In these discussions it quickly became clear that the satisfaction and attitudes amongst service users towards the Depot Clinic was unknown to the involved service providers and staff. It also became clear that both clinicians and management had an expressed interest in gaining information of the type sought here. This was partly because of the formal requirements described above, and partly because of the well-established fact that non-compliance (logically closely linked with dissatisfaction) with medication is a major factor in relapse for the severely mentally ill. (Basco & Rush, 1995; Robinson et al. 1999a, 1999b; Jamieson & Akiskal, 1983).

Also, the satisfaction, or otherwise, with the current service could point to possible service developments and as such form part of the future provision and assessment of treatment, as this is envisioned by the management of this particular clinical setting. Hence the current project can be seen as a possible initiating factor for a larger and more sustained effort in the local development and application of various practice improvement methods as recommended by the *Cape and Barkham pragmatic model of practice improvement methods* (see Figure 1).

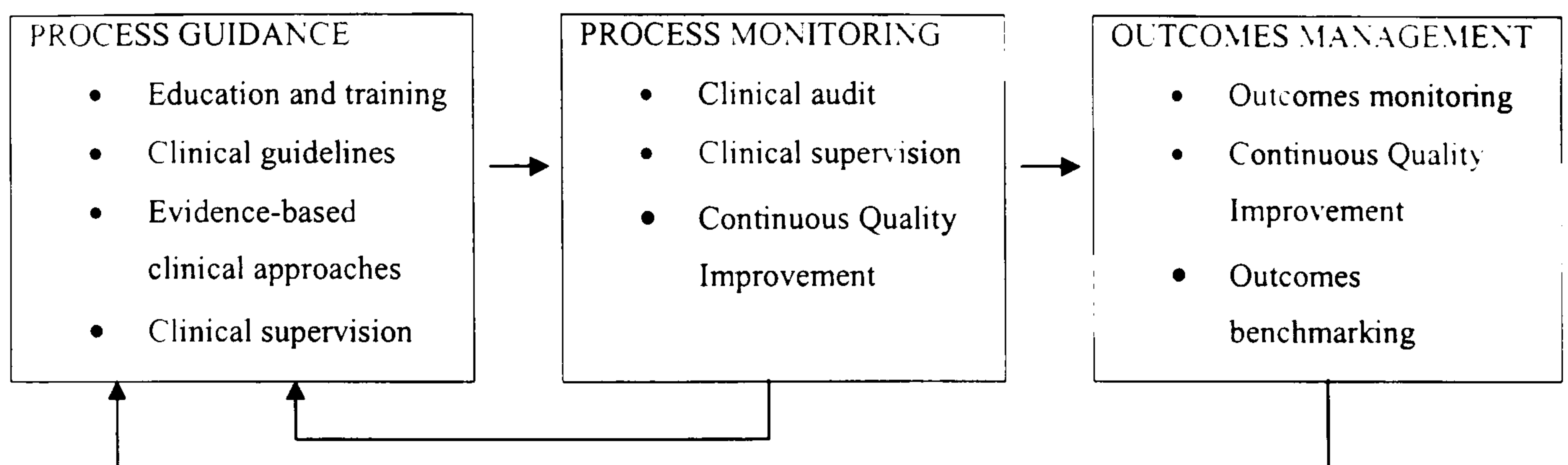


Figure 1. Cape & Barkham (2002, p. 287). Pragmatic model of practice improvement methods.

In sum, the rationale for the audit was an expressed local need for such audit in the fulfilment of government demands and as a result the project aims to gage satisfaction amongst users. Further the project aims to begin an assessment of the type of service developments wished for by the clinic's users in order to ensure adequate service user involvement in these developments.

The actual audit questions were based on the concerns expressed by staff regarding the unknown attitudes and wishes of clients<sup>4</sup>.

The audit aims to:

- 1) Assess user satisfaction with the service provided at the Depot Clinic.
- 2) Begin an assessment of user perceived need for developments of the service provided.

This type of audit is not without its inherent methodological problems and it has long been well-established that people say or report that they are satisfied when other indicators (such as what they do) strongly suggest otherwise (Gutek, 1978). However I believe with Kvale (1996) and Zachariae (1998) that this problem can be reduced somewhat by the inclusion of more than one data collection tool, and I therefore used

<sup>4</sup> Staff wondered specifically about user opinion regarding issues of privacy, degree of desired involvement in own treatment, the perceived quality of information given about treatment and whether psycho-educational programmes would be seen as desirable by users of the clinic.



both questionnaires and interviews in order to get a more complete picture of service user attitudes and needs.

### **Measures.**

For the purpose of this study a questionnaire was developed (Appendix 1). The questionnaire incorporated an adapted version of the Client Satisfaction Questionnaire (CSQ-8) (Larsen, Attkisson, Hargreaves & Nguyen, 1979). The adaptation consisted of the inclusion of the words “Depot Clinic” in the items, as it was anticipated that some users would need this concrete prompt and would have difficulties with the abstraction from their own experiences to the general questions on the CSQ-8. This adaptation is in accordance with guidelines given by Larsen et al. (ibid.).

The CSQ-8 has been used in a variety of studies as a global, or general measure of patient satisfaction and has proven to possess very high indices of internal consistency, with Alpha coefficients equalling .93, .93 and .87 in a series of studies (Attkisson & Zwick, 1982; Larsen, Attkisson, Hargreaves & Nguyen, 1979; Nguyen, Attkisson & Stegner, 1983). The CSQ-8 was chosen for the present study because of its established psychometric properties, its sensitivity, and its extensive application in previous studies which allows for direct comparisons between studies.

The CSQ-8 is a general measure of satisfaction and in order to obtain information specific to the audited clinic, further questions developed with this particular Depot Clinic in mind were included in section three of the questionnaire. This section takes account of what service users want and what clinicians should consider as set out in the NFS and further reflects what the CMHT manager and the clinic’s staff wanted to gain information about, as indicated in discussions with the author of this report.

The semi-structured interview (Appendix 2) was designed to expand upon and give qualitative information about the topics covered in the questionnaire. As such the interviews are meant to compensate for the inherent weakness of any questionnaire: the need for brevity and relatively simple questions and the lack of opportunity to correct misunderstandings.



## **Method.**

The three Consultant Psychiatrists responsible for the Depot Clinic were sent a letter (Appendix 3), summarizing the rationale for the project. Attached to this letter were a number of handouts to users (Appendix 4), explaining what was about to happen in the coming weeks. Hence, when data collection began, all potential participants had received written preparation for the project at their previous visit to the clinic.

The recruitment was done by a personal meeting with the researcher in the clinic's waiting room, where the questionnaire was handed out and explained. This recruitment took place at the twice weekly clinics over a six week period, as this is the longest interval between treatments for any user. The personal meeting procedure for recruitment was utilised in order to minimise the otherwise anticipated low return rate for the questionnaires in this client group.

At the end of the questionnaire, participants were asked to indicate whether they would be willing to take part in an interview centring on the issues covered in the questionnaire. An appointment for the interview was then offered to all who volunteered and interviews were carried out in the weeks following the initial contact.

Six participants volunteered for interviews, but only three actually showed up for their appointment despite the fact that a second appointment was offered to those who did not attend their first appointment. All interviews were tape recorded and a consent form was completed before commencement (Appendix 5).

## **Participants.**

It was attempted to offer all users of the Depot Clinic (N = 43, Male/Female: 28/15) inclusion in the study by filling in the questionnaire. 24 (17/7) completed the questionnaire, 15 (8/7) declined participation and 4 (3/1) did not attend the clinic or went undetected into the clinic without being seen in the waiting room. This gives a response rate of 56 per cent, which must be considered a good response in this population of the severely mentally ill. This assertion is backed by Gillham (2000 p. 9) who writes that "Over 50 per cent has to be accounted a good response" in any type of population. Only users of the Depot Clinic were invited to take part.

As shown by table 1 below, the age range is evenly distributed across the defined categories apart from the 46-55 years category which contains 41.7% of the participants.

The sample's educational level shown in table 2 is characterised by the fact that only two users have obtained education above GCSE level.

Table 3 shows that 62.5% had three or more years experience with the clinic and only 12.5% less than a year's worth of experience to base their assessment upon.

The diagnostic composition of the sample is illustrated in pie chart 1 below. It is noticeable that 25% did not know their diagnosis (please see discussion of this below).

**AGE**

|       |       | Frequency | Percent | Valid Percent | Cumulative Percent |
|-------|-------|-----------|---------|---------------|--------------------|
| Valid | 26-35 | 5         | 20.8    | 20.8          | 20.8               |
|       | 36-45 | 4         | 16.7    | 16.7          | 37.5               |
|       | 46-55 | 10        | 41.7    | 41.7          | 79.2               |
|       | 56+   | 5         | 20.8    | 20.8          | 100.0              |
|       | Total | 24        | 100.0   | 100.0         |                    |

**Table 1**

**EDUCATION**

|       |                | Frequency | Percent | Valid Percent | Cumulative Percent |
|-------|----------------|-----------|---------|---------------|--------------------|
| Valid | No Educa       | 15        | 62.5    | 62.5          | 62.5               |
|       | GCSE/"O"-level | 7         | 29.2    | 29.2          | 91.7               |
|       | A-level        | 1         | 4.2     | 4.2           | 95.8               |
|       | First degree   | 1         | 4.2     | 4.2           | 100.0              |
|       | Total          | 24        | 100.0   | 100.0         |                    |

**Table 2**



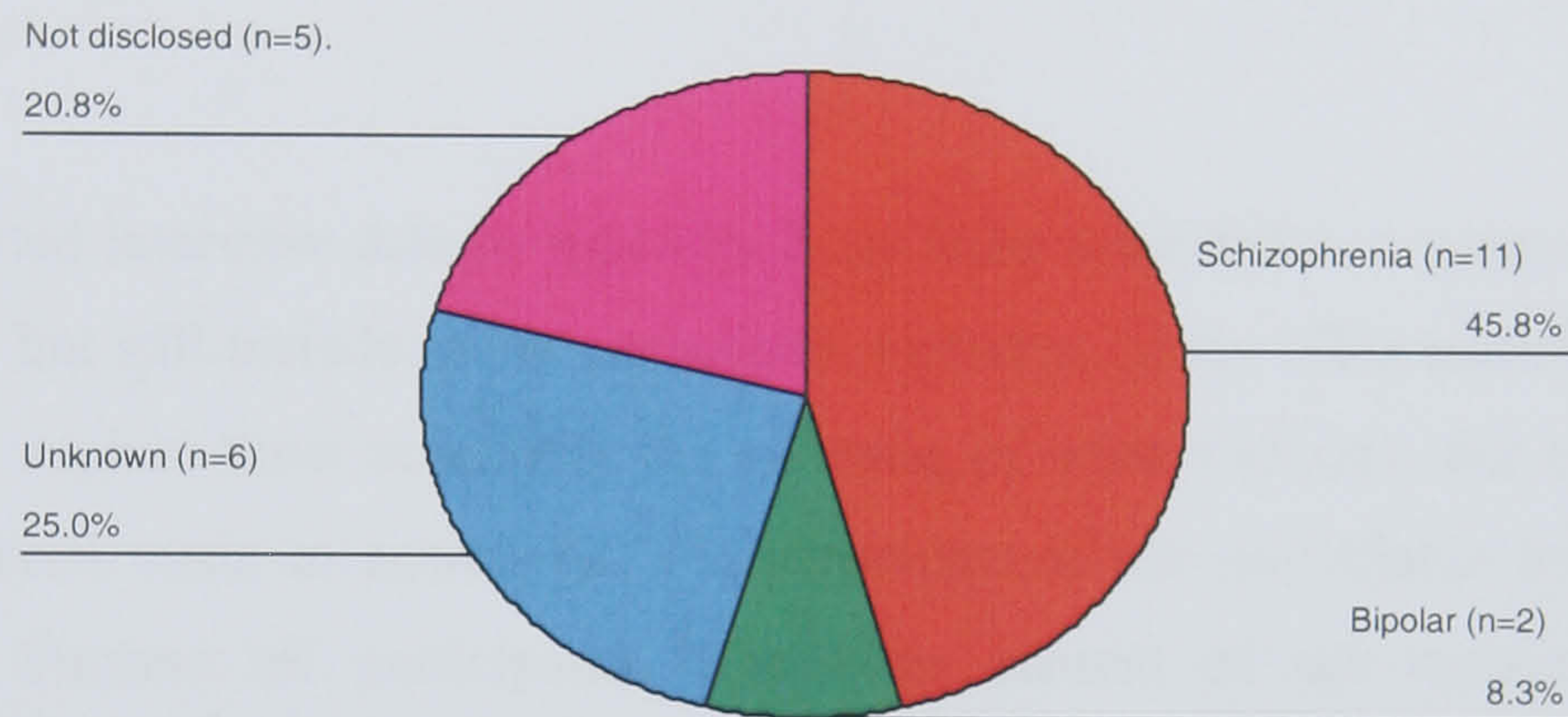
**TIME AT CLINIC**

|               | Frequency | Percent | Valid Percent | Cumulative Percent |
|---------------|-----------|---------|---------------|--------------------|
| Valid -1 year | 3         | 12.5    | 12.5          | 12.5               |
| 1-3 years     | 6         | 25.0    | 25.0          | 37.5               |
| 3+ years      | 15        | 62.5    | 62.5          | 100.0              |
| Total         | 24        | 100.0   | 100.0         |                    |

**Table 3**

Pie chart 1

Diagnostic composition of sample.



**Ethics.**

The project was discussed with the university research tutor who serves on relevant ethics committees, and the project was clearly considered an audit for which further, formal ethical approval was not needed.

Staff responsible for the Depot Clinic were asked for their permission to contact users in the manner described here, and the purpose of the study was explained in the initial handout to service users which they were given before data collection began. This explanation was repeated at the point of recruitment and again before the beginning of



interviews. At no point was any user put under pressure to take part and an initial “no” to participation was always respected without further inquiries, while the opportunity was given for any queries to be raised.

Participants were asked to sign on the last page of the questionnaire to say that they gave their consent to take part. During all stages of the project they were made aware of their right to decline further participation, and of the fact that this would have no impact on the treatment received. It was also made clear that any participation would be strictly confidential.

A further consent form was signed for the interview (Appendix 5) and time was built into the interview schedule for people to debrief and raise any difficulties resulting from taking part.

The reported interview data in appendix 6 has been subjected to a degree of ‘narrative smoothing’ but still includes some embedded, verbatim quotes. This material is included in order to capture most accurately the meaning of what was said, but every possible effort has been made to ensure that the participant is not identifiable by the reported utterances. Further, all participants have been assured of the destruction of tape recordings upon the conclusion of this project.

In both questionnaire and interview, questions about the wish for an extended service, i.e. further input from the psychology department etc., were included and this can potentially have raised hopes for more intensive psychological treatment amongst some participants. However it is not clear whether such services will in fact be made available to the Depot Clinic users and as such a “false hope” can have been installed. It is however clear that the CMHT found in this clinical setting is committed to the accommodation of service users’ wishes and that the current project will form part of the planning of future treatment provision.

## **Data analysis.**

The questionnaires were analysed with descriptive statistical methods using the SPSS computer package. This included a calculation of the CSQ-8 total sum as an overall expression of user satisfaction.

In the aid of further analysis, questionnaire items not in the CSQ-8 were clustered together according to content:

- Section 2, Q4: Privacy at the Clinic.
- Section 3, Q1-Q3: Involvement in treatment. Amount of knowledge held about own mental problem. Assessment of information given about treatment.
- Section 3, Q4: Perceived own ability to control mental state.
- Section 3, Q5-Q6: Interest in more information about mental problem.

The interviews were analysed using the qualitative method of *Phenomenological Meaning Condensation*. This entails an abridgement of the meaning expressed by the interviewees into shorter formulations (Kvale, 1996). As such the method's inherent end result is a narrative vignette or *descriptive statement* for each interviewee. This was seen as an attractive feature of the method because it offers an accessible and memorable format for the clinic's staff to engage with and was the reasoning behind choosing this particular method of analysis.

In practise five steps are involved in Phenomenological Meaning Condensation. First the tapes were listened to from beginning to end, in order to get an "phenomenological" sense of the whole. Then, the natural "meaning units" as expressed by the interviewee are determined by the researcher. Third, the theme that dominated a natural meaning unit is restated in as simple terms as possible, while attempting to understand the statements without prejudice and attempting to thematize from the interviewees' point of view as understood by the researcher. The fourth step consists of analysing the meaning units in terms of the specific audit questions. In this case the themes of the meaning units were addressed with the following questions: 1) "What does this statement tell me about

satisfaction or otherwise with the Depot Clinic?”. 2) “What does this statement tell me about the perceived need for developments in the service provided?”.

In the fifth step the essential and nonredundant themes of the entire interview were summarized into a descriptive statement. Thus the method involves a condensation of expressed meaning into still more central meanings about the satisfaction with the Depot Clinic and the perceived need for service developments.

Finally the extracted themes were compared across interviewees in order to determine agreement on what the important aspects regarding the Depot Clinic experience are.

## **Results.**

Larsen et al. (1979, p. 202) defines CSQ-8 levels of satisfaction with the following categories: Low satisfaction (8-20), Medium satisfaction (21-26) and High satisfaction (27-32).

As can be gauged by figure 2 below the vast majority of users (11 and 12) expressed medium and high satisfaction with the clinic as assessed by the CSQ-8.

Figure 3 makes it clear that while relatively more female users declined to take part in the audit (50% as compared with a male refusal rate of 32%) there are no noteworthy gender differences on CSQ-8 scores for the users who opted to take part. Similarly as can be seen from figures 4, 5 and 6, there are near equal CSQ-8 profiles across age, time at clinic and diagnostic groups, with the bi-polar group being too small (n=2) to warrant conclusions from its split satisfaction scores.

In general the overwhelming majority of Depot Clinic users expressed a moderate to high degree of satisfaction with their treatment experience as measured on the CSQ-8.



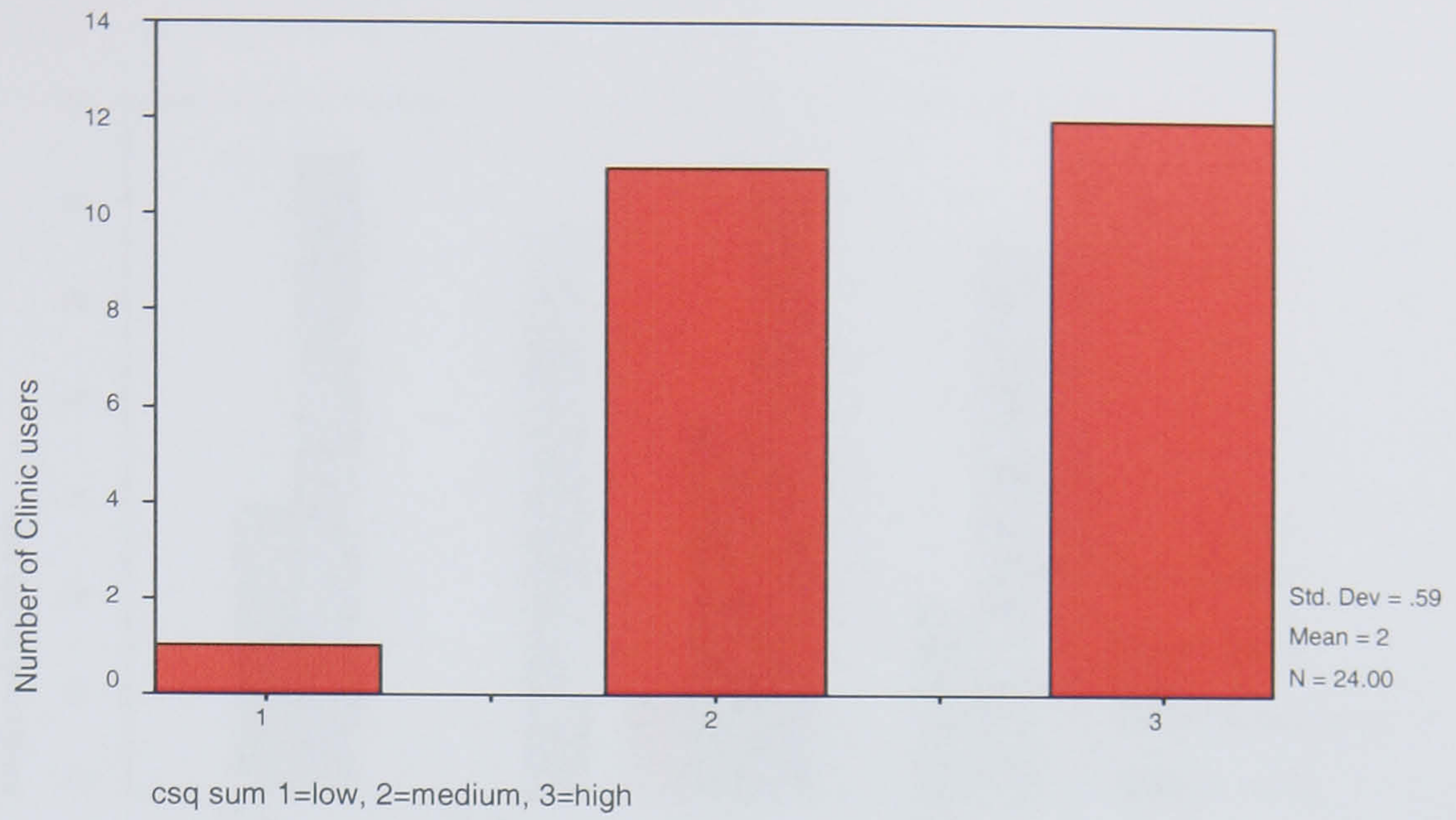


Figure 2.

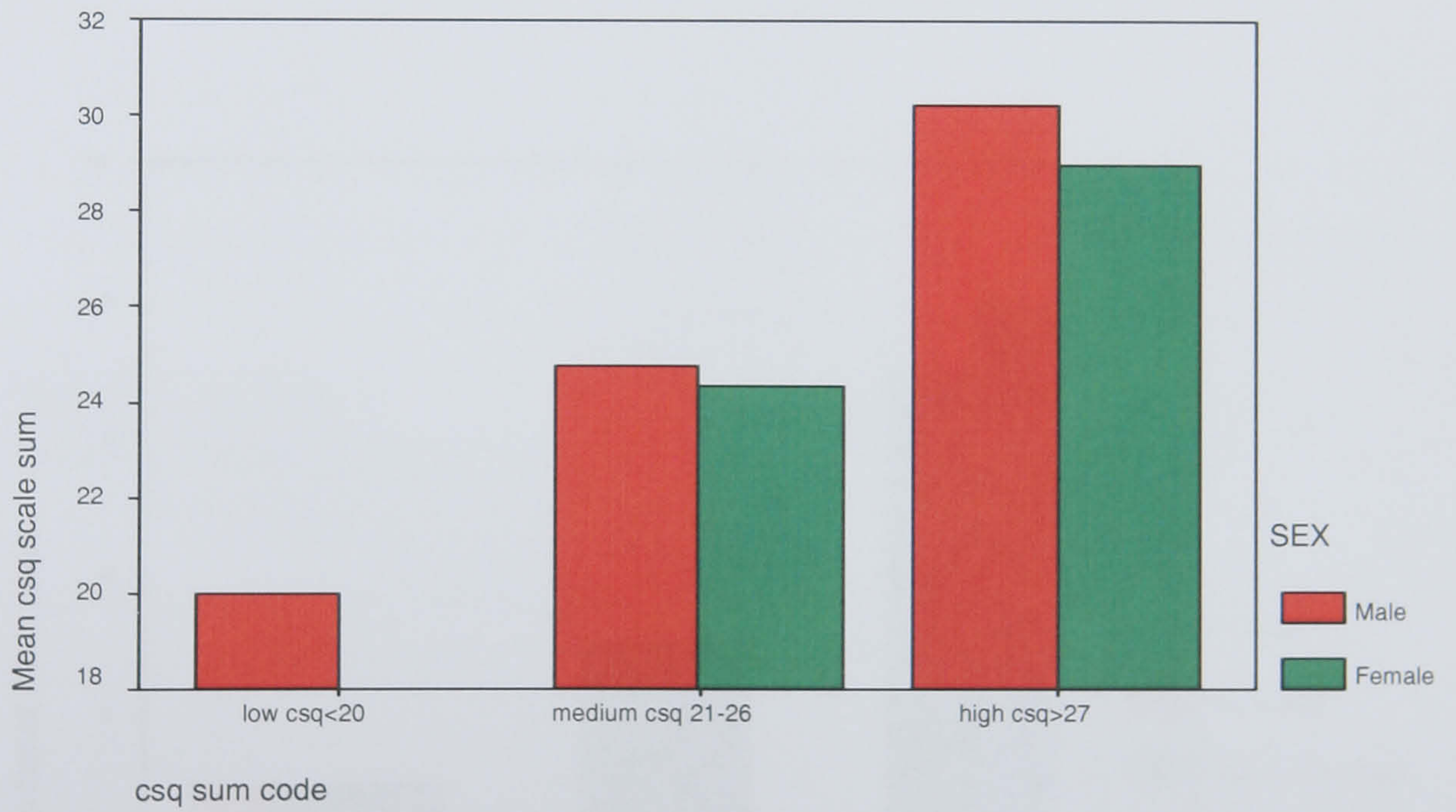


Figure 3.



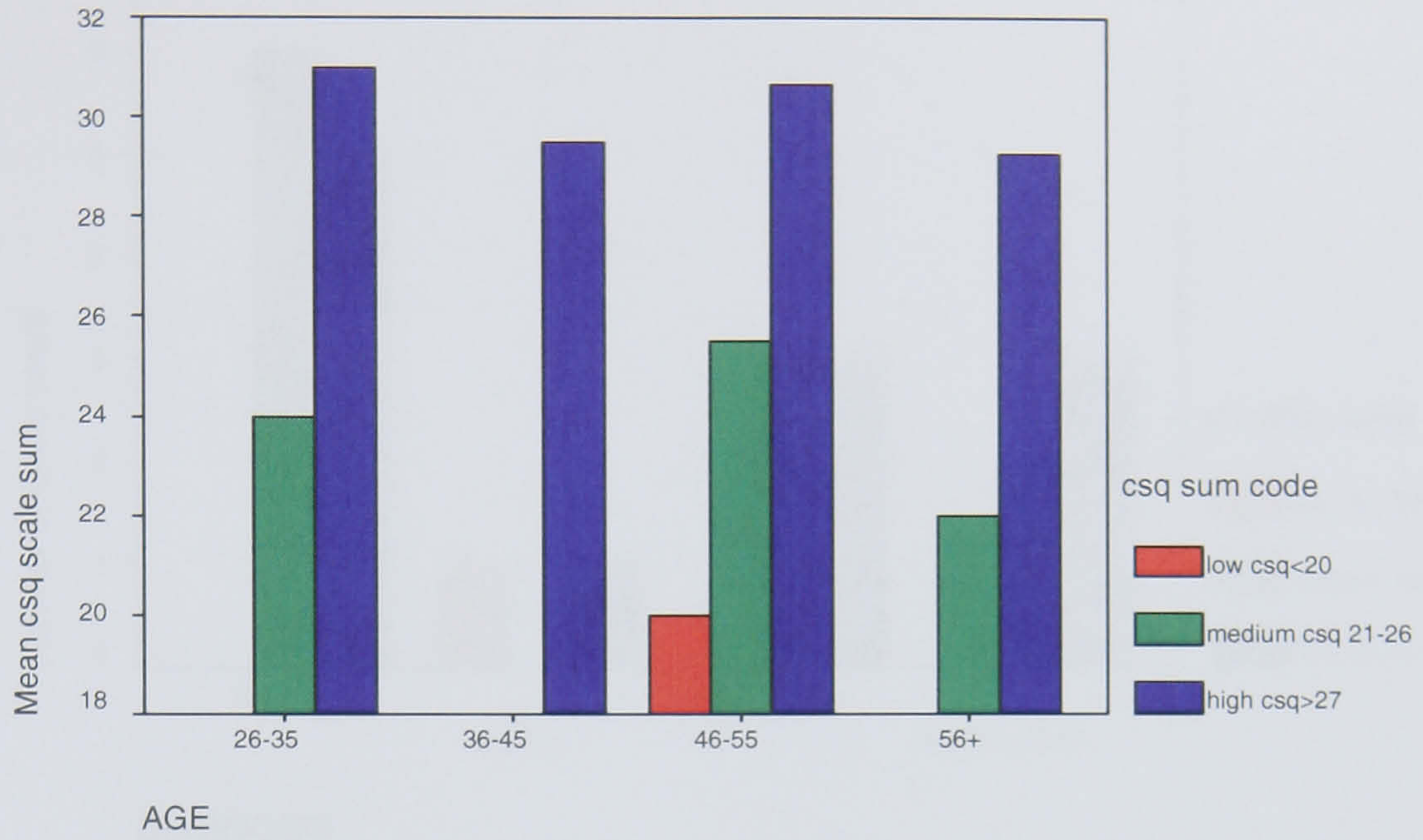


Figure 4.

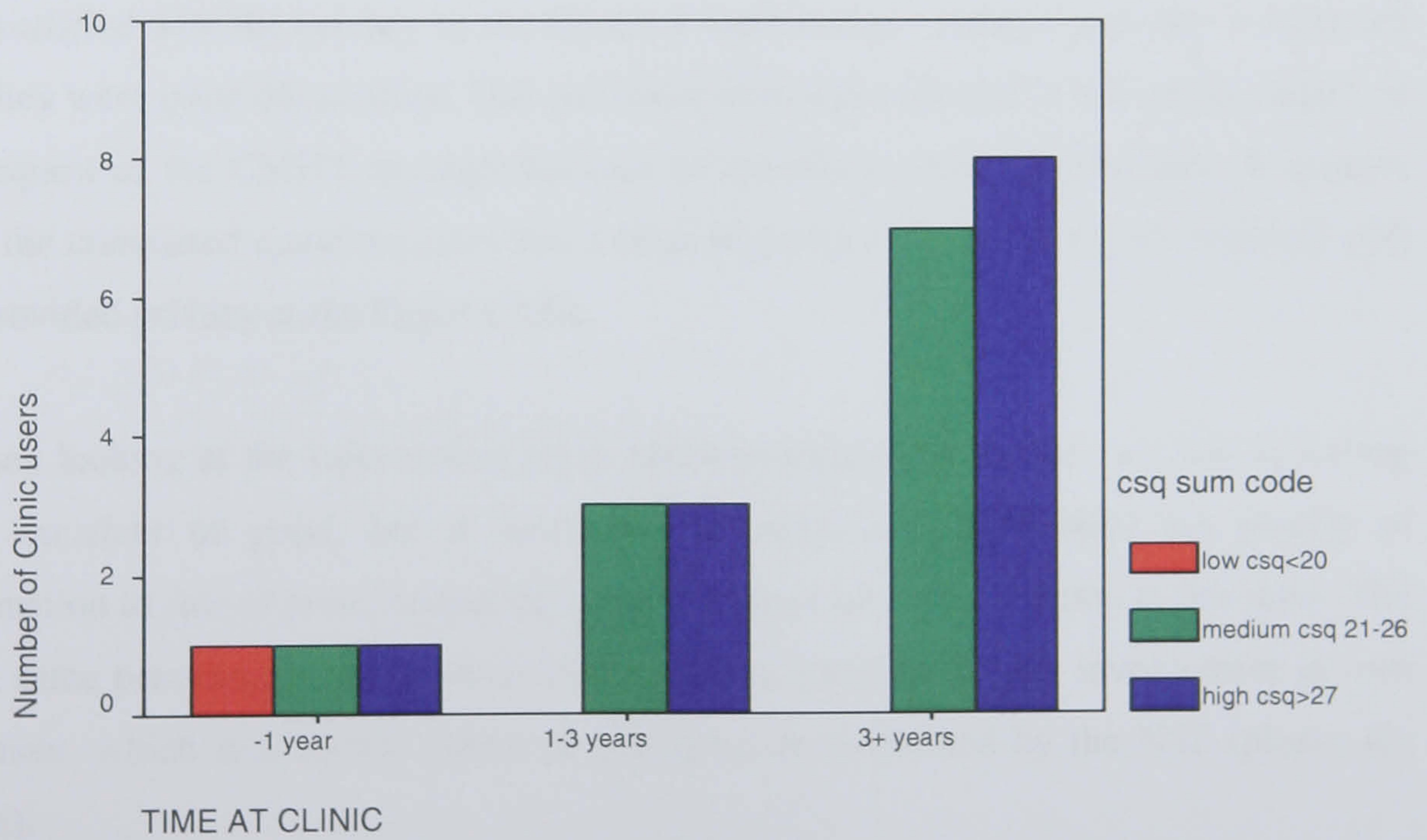


Figure 5.



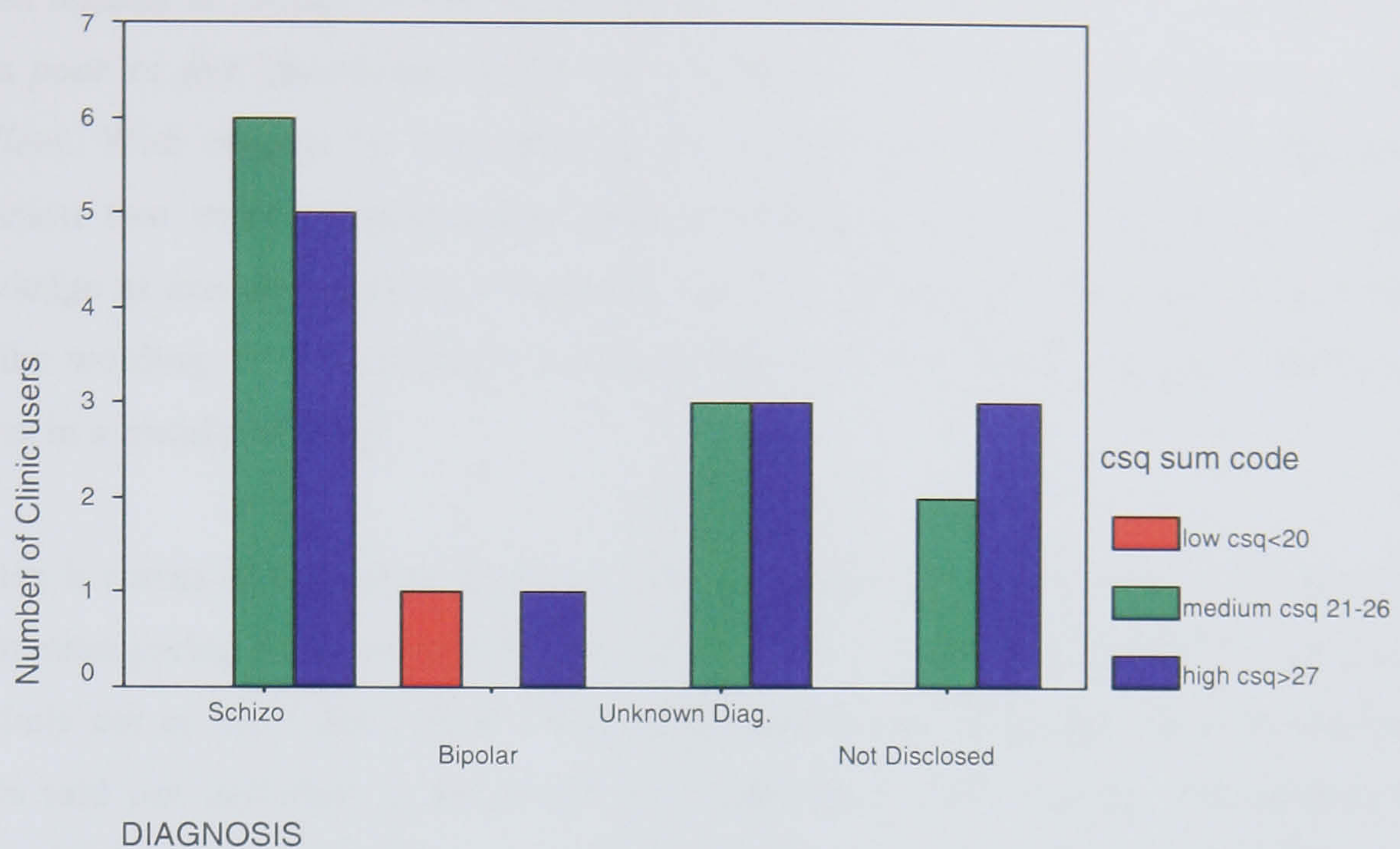


Figure 6.

When looking at sub-sections of the questionnaire it is noticeable that 17 users were *very satisfied* with the privacy in the Clinic, 3 were *mostly satisfied* and only 3 indicated that they were *quite dissatisfied*. This particular item was included in the questionnaire on the request of the CMHT manager because of specific concerns in this area. It appears from the completed questionnaires that a large majority of users are in fact satisfied with the provided privacy at the Depot Clinic.

When looking at the information given about treatment, most users see this as having been *excellent* or *good*, but a substantial minority of 29.0% rated the quality of information as *fair* or *poor*, indicating a possible need for further efforts in this area. The exact same percentages apply when looking at the question of user involvement in own treatment, which is a central aspect of best practice as defined by the NSF (please see above).

It is noticeable that only two users rated both quality of information and their involvement in treatment as *fair* or *poor*, showing that users have specific and individual concerns about these issues, rather than a consistently low opinion of the services offered.



With regards to ratings of own knowledge of mental difficulties 37.5% said that they had a *poor* or *fair* knowledge, while only 21.0% felt that their knowledge base was *excellent*. With regards to this result it should however be noted that during data collection two users spontaneously reported embarrassment with the rating of own knowledge as *excellent*, as they considered this to be “bragging”. As such it is possible that the wording of this particular item has had a negative impact on users ability to answer in a truthful manner.

When it comes to the desire for more information there is a noticeable preference for information giving on a one-to-one basis, rather than in a group format. 41.5% said *no, definitely not* or *no, I don't think so*, to having an interest in group psycho-education. 16.5% said *yes, definitely* to the prospect of inclusion in such a group. The equivalent figures for the information being given in a one-to-one format was 21.0% and 41.5%.

As might be expected there was a relationship between perceived, own knowledge of mental health problems and the wish for further information, even when given on a one-to-one basis. As such none of the five users who rated their knowledge as *excellent* said *yes, definitely* to having an interest in being given information about their particular mental health problem. In contrast, and as illustrated by Figure 7, below, most of the remaining users who rated their own knowledge *good, fair* or *poor* were quite keen to have more information if given to them on their own. In fact 89.5% of these users said either *yes, definitely* or *yes, I think so* to having an interest in attending psycho-education in this format. Further it is noted that all of the users who perceived their knowledge to be *poor* or *fair* indicated that they had a degree of interest in one-to-one psycho-education.



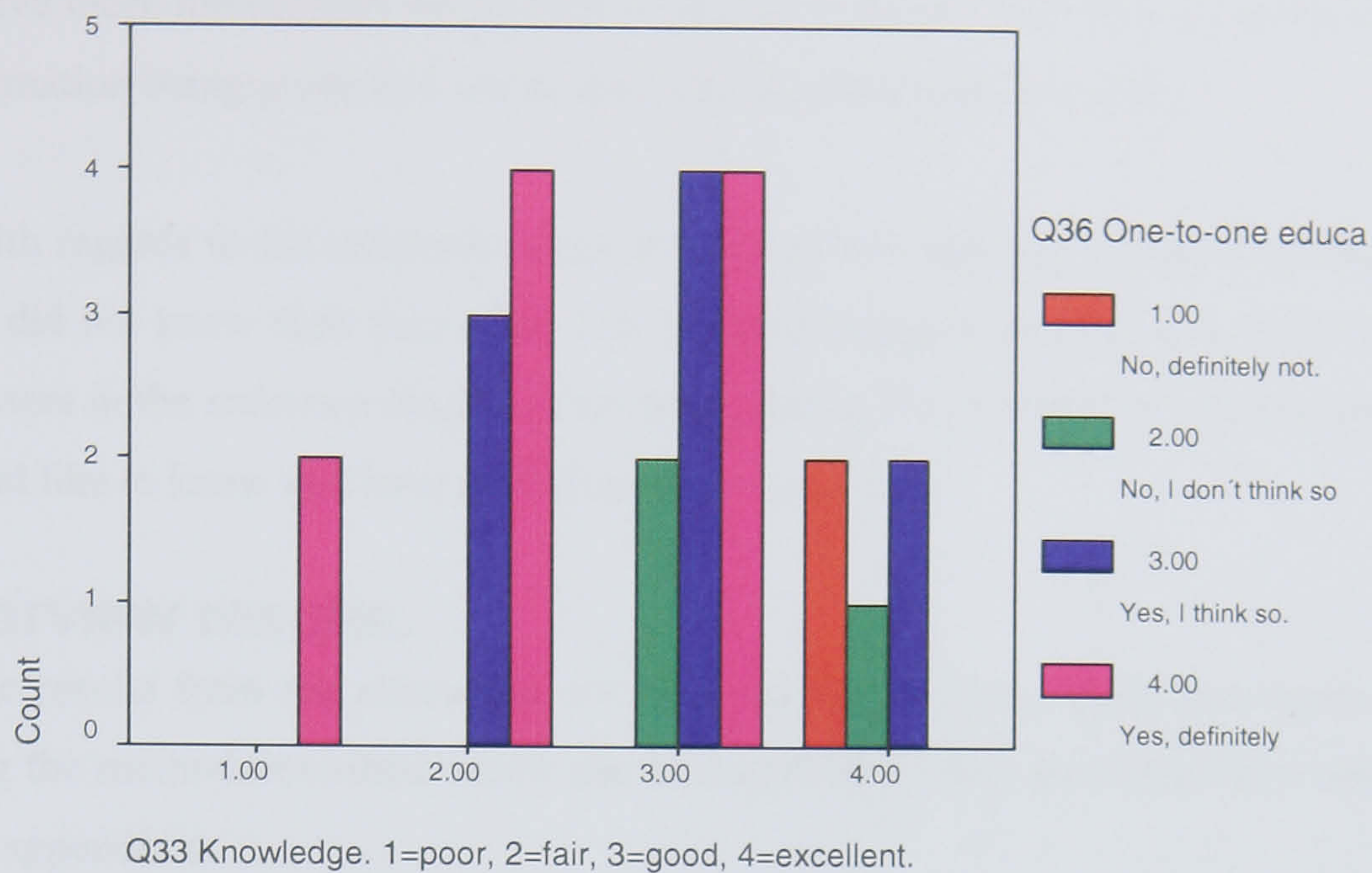


Figure 7.

### Summary of questionnaire results.

Data from the questionnaires indicate that the general user satisfaction with the clinic is moderate to high.

With regards to the specific question of privacy it is noted that most users are also quite satisfied with this aspect of the clinic.

Users are split on satisfaction with the information provided about treatment, with a substantive minority (29.0%) giving this aspect of treatment the lower ratings of *poor* or *fair*. This result is repeated for degree of user involvement, while it is noted that it is rarely the case that a specific user gives low ratings of both the information given about treatment *and* of user involvement. This shows a highly individual experience of the clinic, rather than general, objective problems with certain aspects of the clinic.

While there may have been specific wording problems with the relevant questionnaire item, a substantial minority of users (37.5%) gave their knowledge about their mental health problem the lower ratings of *fair* or *poor* and users would, generally speaking, like



to have more information about their problems. Further, there was a clear preference for information being given in a one-to-one format rather than in a group.

With regards to the information given to users it is noteworthy that 25% reported that they did not know their diagnosis. This has added importance because three out of these six users in the *unknown diagnosis* category, during data collection, volunteered that they would like to know and have their diagnosis explained.

## **Interview results.**

The results from the interviews are here reported as descriptive statements arrived at using the method described above and exemplified by data from the interview with user A in appendix 6.

### **Descriptive statement for user A:**

Please see appendix 6.

### **Descriptive statement for user B:**

Satisfaction for this user is closely linked to his sense of having a degree of control over the treatment he is receiving. He does not feel that he is being listened to by staff and he reports how several attempts at influencing his own treatment have all failed. He feels that the clinic is inflexible, because the staff do not reduce or increase his dose according to his ever changing life circumstances and psycho-pathogenic vulnerability factors. He would like to see more time allocated to the clinic, so that “on the spot” reflections on treatment could be made possible, but would prefer regular and frequent sessions with a psychiatrist who could make immediate changes in treatment.

He is very satisfied with the formal functioning of the clinic.

This user has no contact with other Depot Clinic users outside of the clinic and has no desire to change this, as he is not interested in giving or receiving support from other users.

It would increase his satisfaction to have more information about medication, including side-effects and he would like more opportunities to talk to staff about the impact of the medication, not just on his symptoms, but also on his life in general. He feels that he is



being treated as “a cluster of symptoms” rather than a whole person and is sometimes angry about this.

He would also like to give feed-back on his experiences with the clinic on a regular basis and in a formalized way, that does not lead to “heated” debates with staff.

Further he would like to be offered help with the development of non-medical coping strategies and would like to have regular sessions with a psychologist. He would not be interested in a psycho-educational group.

### **Descriptive statement for user C:**

This user is generally very satisfied with all aspects of the clinic and indicates that his high degree of satisfaction comes about from the client-centred approach taken by the staff. He feels that the staff generally take the time to talk to him about the relevant things, and he enjoys the atmosphere created for him by staff in the clinic. On the other hand, he does not feel that his interactions with other users has an impact on his satisfaction with the clinic, as he does not socialise, support or gain support from the other users. He does not see this as a negative aspect of the clinic because his experience from other settings is that users only want to discuss their illness.

This user would like to have access to a second opinion from a psychologist or a psychiatrist regarding his diagnosis. He believes that he has been given an inaccurate diagnosis and he wonders if another clinician might be able to correct this, or at least confirm and explain why the current diagnosis has been given. As a result of this he would like to see the development of more ongoing input from psychology and psychiatry in the daily running of the Depot Clinic. He does not, however, wish to participate in a psycho-educational group, as he feels that his coping strategies are adequate and he would only be interested in a limited number of psychology/psychiatry appointments, while he would like to see the development of easy access to such appointments for Depot Clinic users in general.

### **Summary of interview analysis.**

The three interviewees displayed much agreement on the question of which variables they saw as important for their satisfaction and also on the developments they would like to see, and not see, in the service provided. They may have had different experiences of

whether the clinic currently offered a person-centred, holistic and listening approach, but they all agreed that these are important aspects with regards to their satisfaction.

Similarly for the time allocated to the clinic, User A and B would like to see this increased and User C indicates that the time factor is important for his degree of satisfaction.

The attitude to personal involvement in treatment decisions is split, with User A seeing no rationale for this, User B sees it as essential to his satisfaction and User C does not commit either way. Related to this is the agreement between User A and B that arrangements for regular feed-back should be developed. User C feels that staff have enough time to listen to his concerns in the current set-up.

The three users agree that closer contact with other users is not desirable and they would not take part in a psycho-educational group, despite the fact that they all would like more information about issues such as medication, coping strategies and/or diagnosis. It is noticeable that they all would like this information provided through easier access to psychiatrists and/or psychologists.

## **Summary, discussion and recommendations.**

The interviews confirm the results obtained through the questionnaires to a large degree and it appears likely that the moderate to high degree of satisfaction could be improved further, if more information, with a focus on medication and its side-effects, coping strategies and diagnosis, were offered to users. Developments in the provision of psycho-educational information should take account of the clear preference for one-to-one sessions with a psychologist or a psychiatrist and the overall resistance to groups. Also, when planning psycho-educational interventions, attention should be given to the relatively low educational level of most users.

Further, improvement in satisfaction for the 29.0% of users who rated their involvement in treatment *poor* or *fair* in the questionnaire could possibly be achieved with a further development of the listening, holistic and person-centred approach. This



follows from the finding that these factors are seen as important by all interviewees and also from the interview finding that the optimal degree of involvement is a highly individual perception. Related to this is the wish for opportunities for regular feed-back on the workings of the clinic. This would be relatively easy to implement and was seen as an important factor for satisfaction across the three interviews, but was not specifically covered by the questionnaire.

The convergence of results from the two data collection tools gives me confidence that this audit has valid information about the satisfaction and self-perceived needs for service developments found amongst Depot Clinic users. However as described above, many users opted not to complete the questionnaire and many more could not be interviewed. Hence it is not possible to say that the users who took part accurately represent the views of all who use the service. It was considered unethical and intrusive to ask the often distressed decliners in the waiting room for their reasons not to take part. As a result it is not possible to speculate about the differences between users who took part and users who did not.

It is recommended that any further enquiries into users' experiences with the Depot Clinic attempt to motivate the decliners to take part in order to obtain a more complete picture. This could possibly be achieved if data collection was carried out by a member of staff whom the users know and trust from the outset.

Finally it is noted that audit of service users' satisfaction can be challenging for the staff involved, because they essentially have their ability to create this satisfaction scrutinized by an outsider, who they know will make the resulting report available to management and other colleagues. It was therefore a pleasant surprise that the audit was generally met with interest and enthusiasm by those staff members involved.

I attempted to develop a personal and trusting relationship with the clinic's staff and was available to answer any questions they had about the audit. Nevertheless, on several occasions during data collection a member of the clinic's staff would come into the waiting room, and with a smile and a humorous tone of voice, express the hope that the users engaged in filling in the questionnaire were being positive and complimentary

about the clinic. It is unclear what impact this may have had on the actual data, but as documented by Hart and Bond (1995)<sup>5</sup> such influences can be of non-trivial importance and should be kept in mind when considering the results in this report.

## **Dissemination.**

Regarding dissemination of the audit results it is noted that copies of this report has been made available to staff and that an oral presentation was given to all interested parties. This presentation was well attended and sparked an interesting debate.

Following this debate the Depot Clinic staff decided that they would immediately put up a “suggestion box” in the waiting room so that users now have a permanent route for feed-back on the running of the clinic. Furthermore it was decided by staff and management that they would form a “taskforce” with the objective of improving the running of the clinic. This taskforce would begin its work by discussing the descriptive statements developed in the analysis of interviews, as they found this part of the report most useful and closest to their own experiences of clients expressions of opinion. This course of action was supported and further input from the author of this report was offered if the taskforce believed this to be beneficial at any stage.

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<sup>5</sup> See also Firth-Cozens (1993) for a general discussion of this issue.



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## Appendix 1.

This is a questionnaire given to assess the satisfaction and demand for service development for the users of the Depot Clinic in xxxxxxxxxxx xxxxx, xxx xxxxxx. All personal information will be kept in confidence by the researcher; Trainee Clinical Psychologist xxxx xxxxxxxx. Also you are free to refuse to answer any question that you do not wish to answer. Please sign on the questionnaire's last page to consent to participation in this project.

### Demographic information

|   |                                |               |
|---|--------------------------------|---------------|
| Q1. Gender ( <i>please circle your answer</i> )                         | <b>Male</b>                    | <b>Female</b> |
| Q2. What is your age-range?   | <b>18-25</b>                   |               |
|   | <b>26-35</b>                   |               |
|   | <b>36-45</b>                   |               |
|   | <b>46-55</b>                   |               |
|   | <b>56 +</b>                    |               |
| Q3. Please circle the highest level of your educational qualifications: | <b>None</b>                    |               |
|   | <b>GCSE / 'O' level</b>        |               |
|   | <b>'A' level or equivalent</b> |               |
|   | <b>First degree</b>            |               |
|   | <b>Master's degree</b>         |               |
|   | <b>Doctorate</b>               |               |
| Q4. How long have you been coming to the Depot Clinic?                  | <b>Less than 1 year</b>        |               |
|   | <b>1-3 years</b>               |               |
|   | <b>3+ years</b>                |               |

Q5. If you are comfortable with disclosing your diagnosis, please indicate this in the space provided [A]. Otherwise circle one of the alternative answers [B] or [C]:

[A] **Diagnosis:** \_\_\_\_\_.

[B] **Diagnosis is unknown to me.**

[C] **I do not wish to disclose my diagnosis.**

**Section 2.**

Please help us improve our program by answering some questions about the services you have received at the Depot Clinic in xxxxxxxxx xxxxxx.

Circle your answer:

Q1. How would you rate the quality of service you received at the Depot Clinic?

|           |      |      |      |
|-----------|------|------|------|
| 4         | 3    | 2    | 1    |
| Excellent | Good | Fair | Poor |

Q2. Did you get the kind of service you wanted at the Depot Clinic?

|                    |                |                |                 |
|--------------------|----------------|----------------|-----------------|
| 1                  | 2              | 3              | 4               |
| No, definitely not | No, not really | Yes, generally | Yes, definitely |

Q3. To what extent has our program at the Depot Clinic met your needs?

|                                      |                                |                                      |                                |
|--------------------------------------|--------------------------------|--------------------------------------|--------------------------------|
| 4                                    | 3                              | 2                                    | 1                              |
| Almost all of my needs have been met | Most of my needs have been met | Only a few of my needs have been met | None of my needs have been met |



Q4. How satisfied are you with the amount of privacy in the Depot Clinic?

|                    |                                       |                  |                |
|--------------------|---------------------------------------|------------------|----------------|
| 1                  | 2                                     | 3                | 4              |
| Quite dissatisfied | Indifferent or mildly<br>dissatisfied | Mostly satisfied | Very satisfied |

Q5. If a friend were in need of similar help, would you recommend our program at the Depot Clinic to him/her?

|                    |                      |                 |                 |
|--------------------|----------------------|-----------------|-----------------|
| 1                  | 2                    | 3               | 4               |
| No, definitely not | No, I don't think so | Yes, I think so | Yes, definitely |

Q6. How satisfied are you with the amount of help you received at the Depot Clinic?

|                    |                                       |                  |                |
|--------------------|---------------------------------------|------------------|----------------|
| 1                  | 2                                     | 3                | 4              |
| Quite dissatisfied | Indifferent or mildly<br>dissatisfied | Mostly satisfied | Very satisfied |

Q7. Have the services you received helped you to deal more effectively with your problems?

|                                  |                              |                                |   |
|----------------------------------|------------------------------|--------------------------------|---|
| 4                                | 3                            | 2                              | 1                                       |
| Yes, they helped<br>a great deal | Yes, they helped<br>somewhat | No, they really<br>didn't help | No, they seemed to<br>make things worse |

Q8. In an overall, general sense, how satisfied are you with the service you received at the Depot Clinic?

|                |                  |                                       |                    |
|----------------|------------------|---------------------------------------|--------------------|
| 4              | 3                | 2                                     | 1                  |
| Very satisfied | Mostly satisfied | Indifferent or<br>mildly dissatisfied | Quite dissatisfied |

Q9. If you were to seek help again, would you come back to our Depot Clinic program?

|                    |                      |                 |                 |
|--------------------|----------------------|-----------------|-----------------|
| 1                  | 2                    | 3               | 4               |
| No, definitely not | No, I don't think so | Yes, I think so | Yes, definitely |

**Section 3.**

When answering the questions in this section please take account of **all** the mental health services you have received from xxxxxxxxx xxxxx, including the Depot Clinic.

Q1. How would you rate the quality of information about medication you have received from us in the Community Mental Health Team?

|           |      |      |      |
|-----------|------|------|------|
| 4         | 3    | 2    | 1    |
| Excellent | Good | Fair | Poor |

Q2. How would you rate the degree to which you are involved in your treatment ?

|           |      |      |      |
|-----------|------|------|------|
| 4         | 3    | 2    | 1    |
| Excellent | Good | Fair | Poor |

Q3. How would you rate your own knowledge of your particular mental health problem?

|           |      |      |      |
|-----------|------|------|------|
| 4         | 3    | 2    | 1    |
| Excellent | Good | Fair | Poor |

Q4. How would you rate your own ability to control your mental state?

|           |      |      |      |
|-----------|------|------|------|
| 4         | 3    | 2    | 1    |
| Excellent | Good | Fair | Poor |

Q5. Would you be interested in gaining more information about your particular mental health problem, if this information was given in a group consisting of people with the same diagnosis as you?

|                    |                      |                 |                 |
|--------------------|----------------------|-----------------|-----------------|
| 1                  | 2                    | 3               | 4               |
| No, definitely not | No, I don't think so | Yes, I think so | Yes, definitely |

Q6. Would you be interested in gaining more information about your particular mental health problem, if this information was given to you on your own?

|                    |                      |                 |                 |
|--------------------|----------------------|-----------------|-----------------|
| 1                  | 2                    | 3               | 4               |
| No, definitely not | No, I don't think so | Yes, I think so | Yes, definitely |

Thank you for completing this questionnaire.

Please indicate whether you would be willing to take part in an interview expanding on the topics covered:       **YES**       **NO**

**Name:**

**Address:**

**Phone:**

**I hereby consent to the use of the information given in the above questionnaire for the purpose of the ongoing user satisfaction audit at xxxxxxxxx xxxxx, xxx xxxx.**

**Sign.** \_\_\_\_\_.



## **Appendix 2.**

### **Interview.**

Intro.: You have kindly agreed to expand on the information you gave in the questionnaire, thank you for coming today. The questions I'll be asking today are about your experiences with the Depot Clinic, and also about possible developments of the treatment offered at xxxxxxxx xxxxx. The answers you give are part of a user satisfaction audit meant to help us improve the working of the department and it is important that you answer the questions as honestly as possible. You are free to refuse to answer any questions you do not feel comfortable with, and you can withdraw from the interview at any time. I would like to record this session on audio tape as it is difficult for me to write down everything. However I will be the only person who will listen to the recording and it will be erased as soon as I have a proper written record of everything that was said. Do you wish to proceed with the interview?

Q1. When you arrive for a Depot Clinic appointment, how long do you usually wait for your treatment?

Q2. What is your general experience of the Reception at the Depot Clinic?

Q3. How is your next appointment set up?

Q4. What sort of problem brings you to the Depot Clinic?

Q5. People have different views about the Depot Clinic. What in your opinion is good about the way the clinic works?

Q6. Can you give an example of something that has improved your experience of coming to the clinic?

Q7. What in your opinion is bad about the way the clinic works?

Q8. Can you give an example of something that has made your experience of coming to the clinic worse?

Q9. In your opinion what is the general atmosphere in the clinic?

Q10. Do you discuss your experiences with the clinic with other users of the clinic?

Q11. Do you gain support from other users of the clinic?

Q12. Do you give support to other users of the clinic?

Q13. Do you discuss your experiences with the clinic with the staff at the clinic?

Q14. Do you feel that your opinions of the clinic are being listened to?

Q15. Do you see the same members of staff every time you attend the clinic?

Q16. Do you feel that you have enough information about the treatment you are receiving at the clinic?

If no:

Q16A. What type of information do you lack?

Q17. Do you feel that your involvement in decisions regarding your treatment is adequate?

Q18. Do you have “techniques” or “strategies” which you feel give you increased control over your mental health problem?

If Yes:

Q18A. What are these “techniques” or “strategies”?

Q19. Would you like the opportunity to share your experiences with other users of the clinic on a regular basis?

Q20. Other services have set up projects to allow groups of people with similar mental health problems to meet, and for them to be given information by a psychologist which aid their understanding of the problem and suggest coping strategies. What do you think about this idea?

Q21. If that type of service was available at xxxxxxxxxx xxxxx, would you be interested in taking part?

Q22. Is there another type of service that you would like to see implemented at xxxxxxxxxx xxxxx?

Debrief.

That was the last question of the interview. How have you found taking part?

Is there anything else regarding the things we have talked about that you would like to discuss?



**Appendix 3.**

01-2003

Dear Dr. ....

I am writing to ask if you would kindly take a few minutes to help me with a piece of research that I hope to undertake here at xxxxxxxx xxxxx. Prior to this letter you will have received a phone call from XXXX XXXXX explaining the project in broad terms.

The research aims to establish the degree of satisfaction that patients have with the service they are currently receiving from the Depot Clinic. Also the research will attempt to establish whether there are any particular service developments that clients would like to see implemented. For instance, is there a general wish for more psycho-educational input from psychology in this group of patients?

The project has been discussed and agreed with Team Manager XXXX XXXXXX.

The research involves administering the enclosed questionnaire to patients. I hope to do this as patients attend their regular appointments with the clinic. Further I will ask four patients for an audio-taped, semi-structured interview to expand on the information given in the questionnaire. I have also enclosed the relevant interview schedule with this letter.

I hope that over the coming weeks, you will help me prepare the patients for the research by handing out the enclosed letter to patients, explaining who I am and why they are likely to be approached by me as they wait for their appointment with the Depot Clinic.

I hope that you will feel that this project is worthwhile and that you will get back to me with any comments, objections or concerns about the enclosed material or the research project per se. I hope to start administration of questionnaires in mid- to late- February 2003.

Thank you very much for you co-operation, it is much appreciated.

Yours Sincerely

xxx xxxxxxxx. Trainee Clinical Psychologist.

**Appendix 4.**

Dear User of the Depot Clinic at xxxxxxxxxxx xxxxx, xxxx xxxxx.

My name is xxxx xxxxxxxxxxx, and I am a Trainee Clinical Psychologist at xxxxxxxxxxx xxxxx. I write this to inform you that we are about to carry out a project looking at user satisfaction with the Depot Clinic.

As part of this project I will be in the clinic's waiting room during February with a questionnaire that I hope you will take the time to fill in. You naturally have the right to refuse to fill in the questionnaire, but I hope that you will help us to develop the clinic and the services we offer at xxxxxxxxxxx xxxxx, so that our services can be more helpful to its users.

If you have any questions about the project or the questionnaire please feel free to ask when we meet at the Clinic. I look forward to meeting you!

Yours Sincerely

Xxx xxxxxxx

Trainee Clinical Psychologist

**Appendix 5.**

**Consent Form**

**Title of Project:** User satisfaction with the Depot Clinic at xxxxxxxx xxxxx.

**Researcher:** xxxx xxxxxxxxxxxx (Trainee Clinical Psychologist).

I..... (Name) hereby agree to be interviewed. I am aware that this interview will be tape-recorded. The purpose of the study has been explained to me and any questions that I wish to ask, have been answered to my satisfaction.

The following information has also been explained to me:

- 1) That any information that I give is confidential unless I make statements which suggest that I or another person is at risk of harm.
- 2) That when this research is written up, no information will be printed which reveals my identity.
- 3) That on completion of this research, the tape recording of the interview will be erased.
- 4) That I am free to withdraw my consent to participate at any time.
- 5) That I am free to refuse to answer any questions that I do not wish to answer.
- 6) That any complaints that I wish to make regarding this research can be directed to XXXXX XXXXX (C.M.H.T. - Manager, xxxxxx xxxxxxxx) or XXXXXXXX XXXXXXXX (Clinical Psychologist, xxxxxxxx xxxxxxxx).

Sign..... Date.....  
(Participant).

Sign..... Date.....  
(Researcher).



**Appendix 6 (p. 1/4). (User A. Example of interview analysis).**

| <b>Natural meaning unit.</b>  | <b>Central theme.</b>   |
|---|---|
| 1. I usually arrive late for the clinic, and so I go straight in without waiting. The staff are always really friendly to me. It is nice to know that my appointments are planned well in advance and have a firm structure. This works well.   | Interviewee plans for himself and is satisfied with the clinic's formal functioning and its staff.  |
| 2. I like the fact that I know most of the staff and that they ask, not just about my problems and symptoms, but also about my life and that they care about other things apart from my illness. I remember several occasions where the nurses have asked me if I had plans for the day, or what I was doing that day. That makes me feel good about going to the clinic.   | Interviewee considers it an important aspect of the clinic that he knows the staff well and that they care about him as a person with various personal characteristics apart from his symptoms.   |
| 3. Some of the staff treat you like a piece of meat and don't care what you think. I have sometimes felt that all I got was an injection when what I wanted was to be treated like a real person. This does not happen very often, they are usually very good to me. The atmosphere is usually very good, and we often have a laugh together.   | Sometimes, but not often, the interviewee feels that staff do not take a person-centred approach and treat him without regard to his whole person.  |
| 4. I never talk to the other users. I see some in town, but I don't mind not talking to them. It's not a problem that I don't get support from the other users and I certainly don't need to feel that I should be supporting other people other than my own family and friends.  | Interviewee has no contact with other users and he likes this state of affairs.   |
| 5. I don't discuss my experience of the clinic with staff as such, but they know from our general chats that I'm quite happy with them [laughs]. I would like to tell them what I think and that's why I'm pleased to have this opportunity today. I have never expressed my opinions before, so I don't know if they will be listened to, but this sort of thing should be done on a regular basis, so that they know our opinions about the clinic. | Interviewee has not discussed experiences at, and opinions of, the clinic with staff so far. But he would like to let staff know his thoughts on a regular basis, and is happy to have the current interview for this reason.                         |
| 6. I would like more information about the medication, because I am not sure what are side-effects and what's my illness. I don't know much about medication so I don't see how I could be involved in the treatment, but if I asked for adjustments I'm sure they would listen. At this stage I don't think I should get involved in that way though.  | Interviewee would like more information about the effects of medication, but with his current level of knowledge, he does not feel qualified to be involved in the treatment. He feels confident that staff would listen if he asked for adjustments. |
| 7. I go for long walks to control the restlessness that I get, or sometimes I have a few drinks to calm me down but I usually try to stay off the drink. When I start to feel down or stressed out, I tend to manage with a chat with a friend or someone from my family. It would be good to learn more techniques to control things though.   | Interviewee uses walking, drink or conversation to control his symptoms. He would like to be taught more strategies.  |

Appendix 6 (p. 2/4).

|   |   |
|---|---|
| 8. I wouldn't take part in a group because I don't really have anything in common with most people at the clinic. But I would like to see a psychologist or a psychiatrist on a regular basis, there are so many things I would like to discuss. Monthly or even weekly appointments would be good.   | Interviewee does not want to take part in a psycho-educational group but would like to see a psychologist or psychiatrist for regular sessions. |
| 9. Before I started at the clinic I used to have a nurse come round and she would stay for a chat, and so she got to know me well and could spot if I was feeling down. I think that's what I really wanted to say, it's all about having the time to get to know people so that we are not just seen as someone who needs an injection. Most of the nurses are really good, but some just don't take the time to get to know you as a person. I often wish they had more time to chat. | It is important for the interviewee to be treated as a whole person, and that staff take/have the time to get to know him as a person.          |

Looking at the Central Theme section above, what do the statements contained within this section say about satisfaction or otherwise with the Depot Clinic and the users perceived need for further developments of the services provided?

Each central theme is analysed with these questions in mind and the result written out as follows:

Central theme 1: Formal functioning of the clinic is good and interviewee is satisfied with the status quo in this area.

Central theme 2: It is important for interviewee's satisfaction with the clinic to be seen as a whole person by staff and that the staff know him personally.

Central theme 3: *Same as Central theme 2.*

Central theme 4: Interviewee does not want more interdependence between users.

**Appendix 6 (p. 3/4).**

- Central theme 5: Interviewee would like to let staff know his thoughts on a regular basis and feels that opportunities such as the current audit should be a regular part of the clinic's workings.
- Central theme 6: Interviewee would be more satisfied if he had more information about medication, but is happy with his current, low level of involvement in his treatment. As such he would like to see developments in the information given about medication.
- Central theme 7: Interviewee would like to be offered help with the development of strategies to enhance coping.
- Central theme 8: Interviewee would like to be offered regular sessions with a psychiatrist or psychologist. He would not be interested in a psycho-educational group consisting of Depot Clinic users.
- Central theme 9: It is central to the interviewee's satisfaction with the Depot Clinic to be seen as a whole person and that staff know him personally. It is important for his satisfaction that staff have enough time to talk, and he would like to see more time allocated to his treatment.



**Appendix 6 (p. 4/4).**

**Descriptive statement:**

Satisfaction or otherwise with the Depot Clinic is, for this user, very much tied to being treated as a whole person. This means that it is important for his satisfaction that staff have time to talk to him, and he would like to see more time allocated to the clinic for this purpose. He is generally satisfied with the formal functioning of the clinic, and does not want closer contact with other users of the clinic. It would, however, enhance his satisfaction if he was given more information about medication, including side-effects. He would also like the opportunity to give regular feed-back on his experiences with the clinic, but is satisfied with his current, low-level involvement in actual decisions regarding the treatment received at the clinic. Further he would like to be offered help with the development of coping strategies, but would not agree to inclusion in a psycho-educational group. Rather this user would like to be offered regular sessions with a psychologist or a psychiatrist. Such developments in the intervention offered would increase his general satisfaction.

**A multiple case study of bipolar disordered patients going through an intensive psycho-educational intervention program.**

**Literature Review**

**John Sørensen**

**February 2004**

**Year 2 DClinPsy University of Hertfordshire**

**4981 words excluding references**

## **Introduction and diagnostic criteria**

The current review sets out the background and rationale for a research project that aims to examine the patient experience of going through a psychologically based intervention with Bipolar Disorder (BD) and to begin the evaluation of the particular intervention being implemented in the study.

BD is a serious mental illness characterized by dramatic mood swings, from the very high and energetic (Manic) to the low and unmotivated (Depressed). Although various sub-variations have been suggested, two major subtypes are defined in the DSM-IV-TR: Bipolar Disorder I and II (American Psychiatric Association, 2000).

The diagnosis of BD I requires a single lifetime manic or mixed episode and despite the name, diagnostic criteria does not list depression as a necessary feature. The main mood components include either euphoria and expansiveness or anger and irritability. A distinct change in mood must also be present and accompanied by a minimum of three of seven symptoms (four if irritability is the main mood feature). These symptoms must be present for one week or require hospital treatment and include: increased involvement in pleasurable activities with a high potential for negative consequences; increased goal-directed activity; decreased need for sleep; inflated self-esteem or grandiosity; over-talkative or pressured speech; distractibility and flight of ideas or racing thoughts. In addition to the symptom criteria, the patient must have experienced a marked functional impairment to be given the diagnosis (*ibid.*).

A mixed episode includes symptoms in fulfilment of diagnostic severity criteria for both depression and mania for a minimum of one week and a marked functional impairment needs to be present.

BD type II requires a single lifetime episode of hypomania, no history of full mania and at least one episode of major depression. The diagnostic criteria for hypomania are equal to the criteria described above for mania, but symptoms need only be present for four days. The patient does not display marked functional impairment as a result of the hypomanic mood state and the presence of delusions or hallucinations is ruled out.



In addition, DSM-IV-TR also describes a range of bipolar spectrum disorders such as cyclothymia (frequent but mild symptoms of hypomania and depression over at least two years) and substance-induced mood disorder, which includes the clinically important mania triggered by anti-depressant medication or other drugs. DSM-IV-TR also refers to other bipolar disorders that cannot otherwise be specified, for example short lived manic states and hypomanic states without the presence of depression. The latter condition may be relatively common in the population but is rarely seen in the clinic (ibid, Kessler, Rubinow, Holmes, Abelson, & Zhao, 1997).

In what follows, the focus will be on BD type I and II as these are the most common bipolar spectrum conditions in the clinic, and also because such patients constitute the usual recruits in the general research literature. But as boundaries between the different diagnoses are not always clear, (i.e. substance-induced mania or self-medication of a primary bipolar spectrum disorder?) the description of BD as a continuum from normal mood states to BD type I mania, should be kept in mind as a helpful conceptual model.

### **Epidemiology, onset and course of the disorder**

Estimates of lifetime prevalence vary but is conservatively estimated at around 8 cases per 1,000 adults in western societies (Johnson, 2004; Kessler et al., 1997; Weissman et al., 1996). This prevalence rises when bipolar spectrum disorders are included and, as sufferers are up to three times more likely to seek treatment for depression compared with (hypo)mania (Judd et al., 2002), the finding that 20-33% of people with diagnosed BD do not report any lifetime episodes of depression, illustrates how the above given prevalence rates must be considered a relatively loose and conservative estimate of actual rates in the population. This follows because people on the bipolar spectrum who do not experience depression are less likely to become known to services (Depue & Monroe, 1978; Johnson, 2004; Karkowski & Kendler, 1997; Kessler et al., 1997).

With regards to onset it had long been thought that this came about most often in the early to mid 20s (Kessler et al., 1997; Loranger & Levine, 1978), however recent research suggests that onset happens more frequently in adolescence than previously thought. Estimates of BD type I in adolescent populations range from 0 to 1.2%, again illustrating how it is difficult to establish a precise picture of the problem (Costello et al., 1996; Kessler, 1994; Kessler, Avenevoli & Merikangas, 2001; Lewinsohn, Klein & Seeley, 1995; Shaffer, Fisher, Lucas, Dulcan & Schwab-Stone, 2000; Wittchen, Nelson & Lachner, 1998; Youngstrom, Findling & Feeny, 2004).

The course of the disorder follows a highly individual pattern and many patients will not conform to the classic pattern of clearly defined episodes of mania and depression separated by full recovery. Rather, it is often the case that prodromal symptoms of both depression and mania can persist, and furthermore that they may develop into a full episode within a few days for one patient, whereas another might experience a slow, gradual onset despite comparable prodromal symptoms (Judd et al., 2002). In the long term, one large study (n = 20,350) has shown that hospitalisation rates become more frequent over the lifetime, but more research is needed before firm conclusions can be drawn in this area (Kessing, Andersen, Mortensen & Bolwig, 1998).

Generally BD is a significant problem for a substantial number of people. It is also problematic from an expenditure perspective, illustrated by the finding that in a population of Mental Health in-patients where 8% had a BD diagnosis, 45% of the care costs were spent on the BD subgroup of patients (Johnson, 2004).

These figures alone illustrate the importance of adequate intervention opportunities for this subsection of the population. It is further noted that with unipolar depression projected to become the sixth most common medical cause of disability-adjusted life years by 2020 (Murray & Lopez, 1996), BD, for which no specific projection is available but which has a high hospitalisation rate, is likely to contribute considerably to society's loss of productivity due to illness.

Furthermore the disorder has reliably been linked to significant increases in problematic behaviours that have traditionally been targets of psychosocial interventions. These include serious issues regarding substance abuse (Brown, Suppes, Adinoff & Thomas, 2001; Kessler, et al., 1997; Regier et al., 1990), violence (Jamison, 1999) and suicide. The latter problem being estimated between 15% (Simpson & Jamison, 1999) and 19% (Goodwin & Jamison, 1990) of the BD population, with para-suicide rates approaching 50% (ibid; Angst, 1990; Harris & Barraclough, 1997; Inskip, Harris, & Barraclough, 1998; Lam, Jones, Hayward & Bright, 1999).

As a result it appears likely that adequate treatment for this population will always include some form of psychological intervention.

### **Interventions, research strategies and the patient's perspective**

At the present time treatment and research into BD is dominated by the pharmacological approach and the disorder's symptoms can be ameliorated with variable success and sustainability using medication. However, the available medication has limitations at both symptomatic and functional levels as illustrated by incomplete long-term effectiveness and non-adherence (Greenhouse, Meyer & Johnson, 2000; Himmelhoch, 2003; Huxley, 2002; Keck, McElroy, Strakowski, Bourne & West, 1997; Kessler et al., 1997; Nilsson, 1999). This, combined with emerging support for an impact from environmental factors in the expression of the disorder, illustrates the need for a comprehensive and multimodal intervention strategy in order to optimize the programmes of treatment and rehabilitation (ibid.).

The issue of non-adherence is of major importance as it is well-established that non-compliance with medication is a reliable predictor of suicide as well as hospitalisation (Nilsson, 1999). Information about the patient's perspective on various treatments is therefore of paramount importance as it is logically linked to compliance with treatment, whether this is pharmacological or psychological in nature.

Exploring and describing patients' experiences of interventions is also consistent with the National Health Service objective of involving users in the planning and delivery of Mental Health services (Department of Health, 1999). Furthermore, it makes cost-benefit



sense to take account of patients' experiences of different aspects of disorder and treatment, both in order to minimise costly drop-out from psychosocial and medical treatment, and in order to begin an optimization of the psychosocial interventions offered in a manner that will minimise the use of interventions that are unwanted or ineffective from the patient's perspective.

It is therefore in both patients' and society's interest to gain information about the experience of both the disorder *per se*, as this is likely to influence the patient's attitude to different types of treatment, and also of going through a psychosocial intervention containing the elements currently recommended in the research literature.

There have been only a few exploratory studies into patients' experience of psychosocial interventions in general (cf. Kuehl, Newfield & Joanning, 1990; Lietaer, 1992; Rennie, 1992; Messari & Hallam, 2003) and the lack of such research in the area of BD is clear. As a result there is an argument for using qualitative and explorative case study designs to begin the development of a better understanding of patients' personal experience of the disorder and of the psychosocial intervention being evaluated. However, there is also a case for including more quantitative outcome measures as it is not viable to evaluate treatment components on the basis of how they are perceived by patients alone. The inclusion of more traditional outcome measures also allows a "triangulation" of information and assumes that firmer conclusions can be drawn if more than one type of data collection tool produces similar findings (Elliott, 2002). It is therefore important to track developments on established measures of such variables as hopelessness (Beck, Weissman, Lester & Trexler, 1974) and perceived ability to control internal states (Pallant, 2000), and further to combine qualitative data sources with quantitative measures of satisfaction with Mental Health services (Larsen, Attkisson, Hargreaves, & Nguyen, (1979).

The dual need for in-depth, phenomenological information and data of a more traditional quantitative nature leads to a research design in line with what has been proposed for evaluating psychological interventions by Elliott (2002; Elliott & Partyka, 2001; Elliott, Slatick & Urman, 2001). This so-called *hermeneutic single-case efficacy*

*design* combines the use of qualitative and quantitative data collection tools and is furthermore uniquely suited to generate hypotheses about processes of change. This aspect of the research design is considered an important quality at the current, relatively early stage of knowledge production regarding psychosocial treatment of BD.

As noted by Huxley (2002), and despite the increased attention given to psychosocial interventions in the research literature, “In evaluating what we know about these treatments, it is important to emphasize the very limited number of studies published on the topic of psychosocial interventions in bipolar disorder, which stand in marked contrast to the much more extensive research in depression, schizophrenia and anxiety disorders” (ibid. p. 347).

At the present stage of knowledge there is therefore a place for smaller research programmes or feasibility testing programmes that can function as ‘pilots’, guiding the direction of future research. This assertion is supported by the Medical Research Council in their considerations of best practice regarding development and evaluation of complex interventions (MRC, 2000).

The usual approach to alleviating lack of knowledge of the type described here, has been the randomized control trial (RCT), and as described above it is indeed the function of smaller research programmes to inform such endeavours (ibid). However while studies are under way (Scott, 2004) the RCT approach has produced very few results to date (ibid). Furthermore the traditional assumption that RCT is the ‘gold standard’ of research design in the area of efficacy of psychosocial intervention has come under increased criticism in recent years.

The criticism centres on three main difficulties. Firstly, difficulties obtaining sufficient statistical power because effect size is often, statistically speaking, small, even when clinical significance is substantial for the individual patient. Secondly, limited generalizability of causality to single cases as a result of restrictive sampling and lacking process data means that, even when overall outcome change can be reliably linked to an intervention, change for a specific patient may have been the result of non-intervention related factors. Thirdly, RCT designs have been criticized for so-called *causal emptiness*, because the traditional RCT simply establishes the conditions under which inferences

about causality can reasonably be made, but does not contain guidelines for understanding the nature of the causal relationship (Elliott, 2002).

The latter problem of the RCT design has led Haynes and O'Brien (2000) to argue that a plausible account, or a logical mechanism for the possible causal relation, should be added to the list of necessary conditions for confirming the existence of a causal link.

The logical consequence of the problems with the RCT design is to shift the causality seeking research attention from groups of patients to the single case methodology in which the processes of change and patients' experiences can be scrutinized and understood in detail. As a result there is a need for research projects that attempt to gauge patients' perception of different aspects of treatment and it follows that such studies can yield valuable information in their own right and not function solely as justification for later RCT, 'gold standard' research.

It is not suggested here that an RCT design cannot be modified to establish the processes or qualitative nature of the causal links for whose establishment this particular design has traditionally been used (Piper, 2001). It is merely postulated that the traditional RCT has inherent problems that need to be addressed for it to supply valid information about causality and that other research designs have something qualitatively different to add to the understanding being developed through the RCT strategy.

### **Components of psychosocial interventions**

It is now well-established that BD is a multifaceted condition that usually comes with a range of psychosocial problems that may act as precipitants of illness episodes. It is also recognized that these problems may be addressed by adding a psychologically based intervention to the pharmacological treatment (Huxley, 2002). Further, and despite the early stage of scientific knowledge within the field of bipolar research, there appears to be a consensus amongst the major psychosocial approaches that treatment should include: a) Education about the disorder, b) Collaboration with the therapist and c) Inclusion of the patient's social environment in attempts to stabilize mood (Bauer, 2002; Goodwin & Jamison, 1990; Leahy, 2004). However, far from all published treatment programs include all of these components.



Consequently it would be valuable to incorporate all three elements in a psycho-educational intervention based around the joint and collaborative development of an individualized relapse prevention handbook and to explore the usefulness of these elements from the patient's perspective as it is proposed in the study connected with this review.

However, the three components are, as they are described above, somewhat vague and non-specific, therefore, and in order to determine what the actual intervention components should be, it is necessary to have a biopsychosocial model with predictive power regarding relapse. The model must be able to describe how the psychosocial variables found to correlate with onset of illness episodes are related to such relapse. Also, in order to have face validity and to offer clinical utility, the model must be able to guide the choice of intervention based on circumstances particular to individual patients, i.e. only if drug abuse is taking place should the model guide the clinician to spend time on prevention of problems caused specifically by drugs.

With regards to depression there is sufficient empirical evidence to suggest that the predictors of uni- and bi-polar depression can be the same (Johnson & Meyer, 2004). For example negative life events, negative cognitive attribution style, neuroticism, lack of self-esteem and social support are all predictors of depression whether in the context of BD or not. It is therefore assumed here that one pathway to a depressive episode within a bipolar context is similar to that found in unipolar depression and that it is safe to apply well-known models of depression, such as, for instance, Beck's classic cognitive theory to BD depression (Beck, Rush, Shaw & Emery, 1979). This pathway to the development of depression is not elaborated on here and the reader is referred to texts such as Gilbert (1992) and Beck et al. (1979).

Knowledge regarding the prediction of mania and depressive episodes following a pathway unique to BD<sup>6</sup> is less well-established. However, a model which appears to offer helpful guidance of the type sought here, is the *instability model of bipolar disorder relapse* proposed by Ehlers, Frank and Kupfer (1988) and supported by Goodwin and Jamison (1990) (see also Scott (2004) and Frank & Swartz (2004) for more recent support of the model). As illustrated by figure 1 this model is comprised of several components all related to a basic problem of sleep dysregulation.

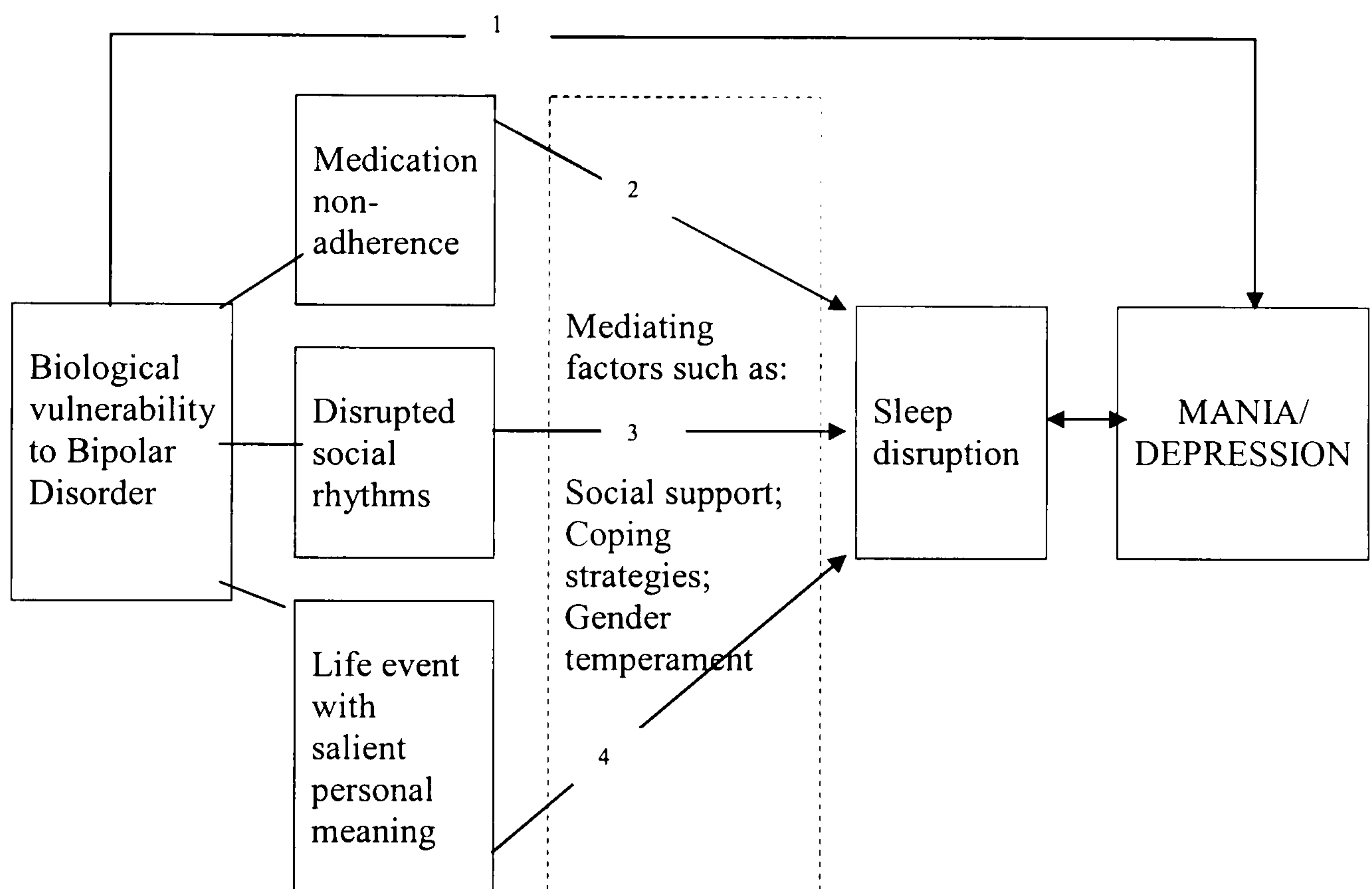


Fig. 1. The instability model of relapse adapted from Ehlers, Frank and Kupfer (1988) and Frank and Swartz (2004).

As illustrated by figure 1, the instability model hypothesises that there are four basic mechanisms of relapse in people with a biologically determined vulnerability to the disorder, and that these mechanisms are all mediated through a biological dysregulation at neurotransmitter level, causing onset of symptoms via the common pathway of

<sup>6</sup> More research is needed to determine the existence of such depression, but the model proposed here predicts depression on the basis of variables not usually given prominence in the classic psychosocial theories of unipolar depression. As such it is possible that separate pathways to bipolar depression exists.

biological rhythms disruption. This disruption happens particularly in the area of sleep regulation (Frank & Swartz, 2004). Firstly, an individual may experience a change in biological functioning of an internal nature. This can then result in somatic symptoms at prodromal levels, typically mediated by genetic/familial vulnerability, which in turn interacts with sleep disruption to produce a full relapse episode. Secondly, destabilization of physiological state may occur as a result of medication nonadherence. Third, irregularities in social routines (change to sleep-wake routine, weekly schedule and even regular television habits etc.) may cause disrupted social rhythms resulting in relapse. Finally, life events with a specific personal meaning for the patient can act as pathogenic stressors and ultimately cause biological dysregulation. This last mechanism of relapse is equal to Beck's cognitive model of depression and is assumed to be heavily loaded to dysfunctional assumptions and cognitive attitudes (ibid).

It is self-evident that multiple factors such as travel across time zones, family attitudes and communication, change of job etc. can all impact on an individual's biological system through any of the latter three pathways. Likewise, complex interaction patterns will exist between different pathways to relapse, e. g. an individual may disengage from medical treatment as a result of certain, negative assumptions about people who need long-term medication, or disrupted social rhythms may lead to forgetfulness regarding medical adherence. Nevertheless, the instability model is helpful when considering which specific treatment elements to include in the fulfilment of the above mentioned, somewhat vague and non-specific, recommendation found in the literature, that treatment should include: a) Education about the disorder, b) Collaboration with the therapist and c) Inclusion of the patient's social environment in attempts to stabilize mood (Bauer, 2002; Frank & Swartz, 2004; Goodwin & Jamison, 1990; Leahy, 2004).

Consequently, and regarding the model's first pathway to relapse, when no external stress factors can be identified, it may still be possible to teach the patient to recognize early signs of relapse and hence implement relapse prevention strategies. As a result the intervention attached to this review will include the development of an



individualized list of early warning signs and related strategies for reducing the risk of illness episode onset when such signs are encountered.

The second pathway to relapse, medical nonadherence, will be addressed through psychoeducation about the disorder and through the use of normalizing analogies between BD and illnesses such as diabetes, where a stress-vulnerability model provides an argument for continual medication by formulating the drug treatment as a protective factor (Scott & Tacchi, 2003; Zubin & Spring, 1977). Psychoeducational information about causes and influences on the disorder is included in the intervention in order to increase the understanding, and therefore possibly the satisfaction, with what Mental Health services are trying to achieve with treatments such as medication. This is of particular importance when addressing the second pathway because satisfaction with treatment is logically linked to adherence. The psychoeducational and the medicine adherence components of the intervention will happen in a collaborative development of a relapse prevention handbook, tailored to the individual patient. The handbook will, by its very nature, require information specific to the individual and will therefore stress the importance of empowerment and expertise of the patient on his or her own life and illness. By taking account of the instability model's second pathway to relapse in this manner, it is ensured that the general recommendations of collaboration and psychoeducational content to treatment mentioned above are adhered to. It is also thought that psychoeducation and the normalizing effect of the stress-vulnerability framework, can effect the fourth pathway to relapse as information and normalizing may have a modifying effect on the personal interpretations of life events related to the disorder.

The third pathway, consisting of disrupted social rhythms, will be addressed partly by educating patients about the importance of consistency in the way they live their lives and partly by stressing the importance of involving significant others who have an impact on the ability to uphold this consistency. The intervention will also give patients practice and practical skills in the area of adaptive communication about BD. These skills are designed for both home and work environments and have been inspired by work carried out primarily by Bauer & McBride (1996) and Copeland, (2001). In addition

patients will develop a specific plan for how to manage work situations, be it present or future, and for how to communicate with employers about the optimal management of the disorder. In practice, homework, initially rehearsed in treatment, and pre-written handouts to relatives included in the handbook, will address the third pathway to relapse and an inclusion of the patient's social environment will have taken place as it is recommended in the general research literature on the treatment of BD and in the wider literature on high expressed emotion<sup>7</sup> (Bauer, 2002; Frank & Swartz, 2004; Goodwin & Jamison, 1990; Hooley & Licht, 1997; Leahy, 2004; Leff & Vaughn, 1980; Liberman, Wallace, Falloon & Vaughn, 1981; Miklowitz, Goldstein & Nuechterlein, 1995; Vaughn & Leff, 1976).

In sum it transpires that the instability model can guide the decision making process regarding which particular elements to include in an intervention and that the recommendations arising from using the model in this manner are in accordance with what has been identified elsewhere in the research and therapy literature (Bauer, 2002; Frank & Swartz, 2004; Goodwin & Jamison, 1990; Leahy, 2004). However, a prerequisite for accepting the model is obviously that sleep patterns have a causal relation to the development of illness episodes, and judging by the current state of research evidence, this does indeed appear to be the case (Colombo, Benedetti, Barbini, Campori, & Smeraldi, 1999; Ehlers, Kupfer, Frank, & Monk, 1993; Thase et al., 1997; Wehr et al., 1998). As a consequence, the intervention linked to this literature review will also target the patients' sleep practises directly by providing information about good sleep habits.

Judging from the above given evidence for the instability model of relapse, this framework provides a good starting point when it comes to integrating the treatment recommendations found in different areas of bipolar intervention research. Through its multiple pathway to relapse conceptualization, the model supplies a rationale for the inclusion of specific treatment elements without bringing various research strands and related recommendations into conflict with each other. However, as argued in earlier

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<sup>7</sup> High Expressed Emotion (EE) is a term used to describe an attitude amongst caregivers characterized by being highly critical and hostile or very overprotective towards the diagnosed family member (Hooley & Licht, 1997).

sections of this review, the patients' point of view is paramount and a treatment that has a strong theoretical reasoning behind it may not pass the final and crucial test of patient perceived usefulness and therefore adherence. In other words, an intervention designed on the basis of research conducted in the pursuit of high efficacy, may not offer the effectiveness needed in everyday clinical practice. Consequently the patient's perspective on what is desirable to include in a given intervention must be given a high priority or the patient may simply opt out of treatment all together, as it currently often happens with pharmacological interventions. Consequently the study linked to this review focuses on obtaining information about the patient perspective on treatment components currently being recommended in the literature.

## **Conclusion**

After describing the diagnostic criteria for BD the above review of the relevant literature went on to establish that the illness is a significant problem for a considerable number of people. It was also established that in-patients with the diagnosis require a disproportionately large part of the total care cost when compared to other diagnostic categories (Johnson, 2004). As a result it is concluded that both patients and society as a whole has a vested interest in optimizing the treatment of these patients. This conclusion is further underscored by the reported findings of strong links between BD and problem behaviour, such as substance abuse, violence and suicide. These problems have traditionally been the targets of psychosocial interventions and the empirical evidence points to the conclusion that optimization of treatment for BD must include some form of psychological intervention. This conclusion is made all the more poignant by the persistent empirical finding that the available medication has limitations at both symptomatic and functional levels, as demonstrated by lacking long-term effectiveness and non-adherence amongst a significant number of patients.

A major problem in the treatment of BD is drop-out from treatment and it is therefore vitally important to gain information about the patients' experiences of different aspects of treatment and of the disorder *per se*. This aim is consistent with the National Health Service objective of involving users in the planning and delivery of Mental Health



services (Department of Health, 1999). Information of the type sought in the study linked to this review will help in the development of future treatments, by minimizing the use of intervention elements that are unwanted or ineffective from the patient's perspective, while also taking account of what is currently recommended in other parts of the research literature. In other words, knowledge of patients' perspective on treatment components is a necessary requirement for obtaining an adequate balance between efficacy and effectiveness in the design of any future intervention. This follows because an intervention that does not take account of patients' experiences and perspectives will be more likely to include treatment elements causing drop-out or non-engagement with the content of intervention on the part of patients.

There is currently a distinct lack of studies into patient experience of psychosocial interventions in general, and qualitative case study designs are needed to enable the development of a better understanding of patients' personal experience of the disorder and treatment. However when evaluating a treatment within a case study format it is also desirable to use a form of *triangulation* or inclusion of multiple sources of data. This method is used in order to enhance the likelihood that a reported benefit is linked to the intervention and not to extra-therapeutic influences. The inclusion of quantitative data collection tools can also strengthen the argument for the effectiveness of a treatment if these tools confirm the information obtained through qualitative data collection in the form of interviews. Hence there is a need for both in-depth, phenomenological information and for data of a more traditional quantitative nature. This dual need leads to a research design such as the hermeneutic single-case efficacy design which has been proposed for evaluating psychological interventions by Elliott (2002). The appropriateness of this study design is further strengthened by the general state of empirical knowledge regarding psychosocial interventions with BD, where only a very limited number of RCT studies are being produced. In such an empirical environment it has been noted, also by proponents of the *RCT Gold Standard Paradigm*, that so-called *phase II* or *Exploratory Trials* are the appropriate way to proceed, as pilot studies are needed to guide the direction of future, large scale research programmes (MRC, 2000, p. 3-4).

With regards to the intervention to be evaluated, it seems reasonable to gain a patient perspective on the type of treatment components currently being recommended in the research literature. As a result a) Education about the disorder, b) Collaboration with the therapist and c) Inclusion of the patient's social environment in attempts to stabilize mood, were chosen as the cornerstones for the intervention. The instability model of relapse was used to guide the choice of the particular content needed to fulfil the more general recommendation of including a, b and c in the treatment protocol.

As a result of the described treatment construction strategy, the outcome of the planned study will be an insight into the experience of receiving a psychosocial treatment comprised of commonly recommended intervention components. Further, the qualitative aspects of the study will be combined with data from traditional, quantitative outcome measures and will also be enriched by general information about the individual patient and his or her phenomenological experience of the disorder *per se*. This latter aspect allows the initiation of theory building or hypothesizing about what is effective for whom, i.e. are strategies designed to stabilize mood swings undesirable for patients who enjoy (hypo)mania but desirable for patients who do not enjoy any experience related to the disorder?

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**A Longitudinal Study of Bipolar Disordered Clients Going Through  
an Intensive Psycho-educational Intervention Programme.**

JOHN SØRENSEN

A Thesis submitted in partial fulfilment of the  
requirements of the University of Hertfordshire  
for the Degree of Doctor of Clinical Psychology

The programme of research was carried out in the Department of Psychology,  
University of Hertfordshire  
November 2004



## **Acknowledgements**

I would like to thank the participants who took part in the study and who all remained committed, not only to the treatment on offer, but also to the research effort during what, in some cases, was a challenging time with regards to their mental health. Special thanks go to Professor Chris Hawley and my supervisors Dr David Fewtrell and John Rhodes for their assistance and encouragement at every stage of the research process. Thanks also to the University of Hertfordshire Psychology Department and in particular Dr John Done and Joerg Schulz for advice and on-going interest in the study. Finally thanks to my partner Kathryn Smith for unwavering support and thought provoking conversations relating to the project.

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## **Abbreviations**

|        |  |
|--------|--|
| BHS    | Beck Hopelessness Scale                    |
| BAS    | Behavioural Activation System              |
| BPD    | Bipolar Disorder                           |
| CBT    | Cognitive Behavioural Therapy              |
| CSQ-8  | Client Satisfaction Questionnaire          |
| CI     | Confidence Intervals                       |
| PCOISS | Perceived Control of Internal States Scale |
| RCT    | Randomised Control Trial                   |
| TIM    | Therapeutic Instability Model              |
| VAS    | Visual Analogue Scales                     |



## **Abstract**

Although it is still possible to encounter the view that medication is the only method of treatment for bipolar disorder, research shows that there is a significant need for a comprehensive and integrative approach to this complex disorder.

The current thesis firstly describes the rationale and development of a new, psychological intervention specifically directed at bipolar disorder, and secondly reports on an evaluation of this approach to treatment.

Using a longitudinal design with replication across 13 participants, combined with the use of multiple case study methodology and qualitative data collection strategies, which allowed for triangulation between multiple data sources, it is concluded that the newly developed Therapeutic Instability Model approach to treatment had a significant and positive impact on factors of importance when treating bipolar disorder. These factors included hopelessness, known to be predictive of suicidal behaviour, and perceived control over internal states, a central aspect of bipolar disorder.

As part of the evaluation, insights into which factors are important for client satisfaction and perceived usefulness of a treatment were also gained and it is argued that these should be borne in mind when attempting to develop interventions with high effectiveness and low dropout from treatment.

The study furthermore found positive changes occurring as a result of the intervention in thoughts, feelings, behaviours and illness related knowledge, and began a mapping of the participants' understanding or subjective models of their disorder's aetiology and maintenance.

Further, two distinct patterns of change in important variables were observed during treatment and appear to be related to the participants' general attitude to having future episodes of mania. In relation to this, it was noted that specific interventions, such as behavioural experiments, may be more important for outcomes of treatment for individuals with a positive/ambivalent attitude to mania compared with individuals who do not share this attitude to manic experiences. It was argued that these findings could have potentially important clinical implications and a number of suggestions with regards to further research in this, and other, areas relating to the study were finally made.

## **1.0 Introduction**

The present study evaluates a treatment developed specifically for bipolar disorder (BPD) which, as set out by Sørensen (2004), is a serious mental illness affecting a substantial minority of the population with lifetime prevalence rates approaching 1%. As such it is important that our clinical services develop to provide for, and take account of, the views and needs of this client group (Johnson, 2004; Kessler et al., 1997; Weissman et al., 1996). Factors that may impact directly on the client's perspective and assessment of a given psychological therapy for BPD have not been addressed in the research literature. This introduction, which is divided into three sections, considers research and psychological theory relevant to this topic and will frequently refer to the literature review conducted by Sørensen (2004) to accompany the current research project.

The first section of the introduction provides the context for the current study and covers background information and a summary of the major psychological approaches to theory and intervention with BPD. This section also reviews the existing psychotherapy evaluation literature and introduces the instability model of relapse which has guided the development of the intervention being evaluated in the present study. In the second section, a description of the development and content of the current intervention is supplied. The connection between the reviewed studies and the current intervention will be highlighted throughout in order to draw attention to the rationale for both the development and the empirical evaluation of the present intervention. The third section will include an argument for the chosen methodological approach and a discussion of the use of the chosen methodology in the context of evaluation research. This will include a brief rationale for the inclusion of the chosen means of measurement and will also illustrate the importance of researching clients' perceptions and assessments of interventions as proposed here. This in turn will highlight the gaps in the research literature which gave the original impetus for the study. Finally, a statement of research aims will be developed on the basis of the preceding discussion.

## 1.1 Context and background to study

As summarised by Sørensen (2004), BPD is characterised by extreme mood swings often accompanied by serious secondary problems such as substance abuse, violence and suicidal behaviour.

It is therefore important that our clinical services reflect the need of this client group in an adequate manner, and that services are developed to take account of the typically recurrent nature of the disorder. Further, as set out in the National Service Framework (Department of Health, 1999), provision of quality services wanted by clients is in the interest of both the service user and society as a whole. This follows because both social and economic costs resulting from BPD are significant, with almost one-third of clients being unable to return to work for six months following an episode of the illness and with only one-fifth returning to work at their former skill level (Coryell et al. 1993; Dion, Tohen, Anthony & Waternaux, 1988). It is clear that even when symptom relief has been achieved for a given client, functional impairment often persists (Tohen et al., 2003). This lack of functional recovery amongst the bipolar population explains why the World Health Organisation (Murrey & Lopez, 1996, pp. 537-540) ranks BPD as the seventh most disabling condition globally with only unipolar major depression and alcohol abuse being ranked higher within the World Health Organisation's category of neuro-psychiatric conditions.

At the present time adequate service development can, to some degree, be said to have happened in the area of prophylactic pharmacological interventions and despite limitations at both symptomatic and functional levels, as illustrated by limited long-term effectiveness<sup>8</sup> and non-adherence (Greenhouse, Meyer & Johnson, 2000; Himmelhoch, 2003; Huxley, 2002; Keck, McElroy, Strakowski, Bourne & West, 1997; Kessler et al., 1997; Nilsson, 1999), medical interventions have proved to offer important progress for many patients with regards to stability of mood (Geddes, Burgess, Hawton, Jamison & Guy, 2004). The situation is much less well defined when it comes to theoretical understanding and therapeutic benefit of psychological interventions.

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<sup>8</sup> Gitlin, Swendsen, Heller, & Hammen (1995) provided a survival analysis indicating a five-year relapse risk of 73% despite what they termed *continual and aggressive* pharmacological maintenance treatment.



### **1.1.1 Major psychological approaches to intervention**

The poor adherence rates for pharmacological treatment (18-51%) reported in Ball et al's (2003) review of the research literature, combined with the same authors' assertion that only 25-50% of clients receiving Lithium prophylaxis are protected against relapse, illustrates the need for a more complete bio-psycho-social approach to relapse prevention. Despite this need it is only in the last two decades that substantial, empirically based psychological theories specifically addressing BPD have emerged and there have been surprisingly few studies published on either treatments or the validity of proposed theoretical models of the disorder.

Historically, psychological theories of mood disorders have focused their attention on depression, where the early, psychoanalytical considerations of BPD construed mania as essentially an escape or defence against underlying depression (Schwartz, 1961). Psychodynamic authors suggested that individuals with BPD experience greater emotional responses to failure and that such individuals typically display high levels of goal striving behaviour because success, as well as an overly enhanced sense of self-worth, is used by these individuals to ward off depression or feelings of insecurity (Pevin & Shulman, 1983). Interestingly, more recent cognitive theories are partly based on the empirical finding that, even outside of illness episodes, individuals with BPD set higher standards for goal attainment than normal control subjects (Lam, Wright & Smith, 2002; Meyer, Johnson & Winters, 2001) and that these individuals may strive harder for success as a result of having an increased sensitivity to reward (Johnson et al., 2000; Meyer, Beevers & Johnson, 2002). As such, the cognitive model, which is the only other major approach directly addressing BPD as opposed to unipolar depression from a theoretical perspective, is not incompatible with older, psychoanalytical theories on the same topic. However the bulk of cognitive theory centres on the subjective experiences of the person when actively manic or depressed (Lam et al., 2000; Leahy, 2004; Newman, Leahy, Beck, Reilly-Harrington & Gyulai, 2002). Thus the theory proposes that an existing genetic vulnerability to BPD is moderated by stressful life events and cognitive schemas or "styles" that, once activated, predisposes a person to seek out information from the environment in support of the already activated mood state. That is to say,

manic and depressed individuals display the same cognitive distortions but in different directions, with the depressed person showing a bias towards interpreting his or her experiences in a negative manner and the manic person being biased in the opposite direction (Leahy, 2004). Hence the selective cognitive style found in both phases of the illness enhances the existing mood state and a vicious cycle is created resulting in a progressive worsening of the symptom profile. This understanding of the development of depression is well-established for unipolar depression (Clark, Beck & Alford, 1999), whereas the nature of a cognitive vulnerability to mania is less well documented and researched.

In summary it is currently unclear whether mania springs from a defensive reaction to failure; is a reaction to excessively strong goal-directed behaviours combined with a strong belief in the ability to obtain a successful outcome and sensitivity to reward; or is better understood as a combination of the two.

It is clear that cognitive therapy for BPD is firmly rooted in Beck's (Beck, Rush, Shaw & Emery, 1979) therapy for depression and also that the theoretical understanding guiding cognitive interventions with the disorder, has strong links to Beck's original model for depression (*ibid.*). However it also transpires from outcome research conducted in recent years that interventions not informed by the cognitive framework can have positive effects for clients, suggesting that pathways to illness in BPD that are distinct from pathways to unipolar depression, are likely to exist.

### **1.1.2 Review of existing psychotherapy evaluation studies**

Traditionally, psychological therapy has not been offered to individuals with BPD as they were not considered able to benefit from such interventions (Scott, 1995). While changes to this practice have been slow coming, the wide acceptance of the stress-vulnerability model, which illustrates the interaction of biological, social and psychological factors in the development and recurrence of severe mental illness, has meant something of a turnaround in this thinking. It is now much more likely that a client with BPD will be considered appropriate for psychological treatment adjunct to medication, and despite there being "only limited research on the use of... [psychosocial] interventions in bipolar

disorder, there are encouraging reports from research groups exploring the ‘manualized’ therapies with this population” (Scott, 2004 p. 227).

It is apparent from the few large randomised controlled studies that have been published so far, that psychosocial interventions can have important benefits for clients. It also appears that short-term interventions, of a duration comparable to the one administered in the current study, can have significant, positive effects for clients. Both types of study are reviewed below.

Significant success, as measured by time between episodes, social/employment functioning and time in hospital, has been facilitated using a brief intervention lasting 3.5 – 6 hours in total with individual clients (Perry, TARRIER, Morriss, McCarthy & Limb, 1999, (n = 69)). These results were achieved through improvements of the clients’ abilities to detect early signs of relapse and through linking this with the development of relapse prevention strategies (ibid.).

Medicine adherence therapy and psycho-education within a group context have shown positive results in the form of a reduction in the number of illness episodes after only three hours of therapy (Colom, 2003, (n = 120), Morriss, 2004) and increases in medical adherence rates after six sessions (Cochran, 1984, (n = 28)).

So-called interpersonal social rhythms therapy has been shown to improve the stability of social rhythms (sleep-awake, work-rest etc.) and to have a positive effect on recovery time from depression compared with the control condition of intensive clinical management (Frank et al., 1999, (n = 82); Hlastala et al., 1997).

Addressing unhelpful thinking regarding medication, lifestyle etc., (Ball et al., 2003; Lam et al., 2000) standard cognitive therapy has been shown to have a positive effect on relapse frequency and severity of manic and depressive episodes (Lam et al., 2000, (n = 25); Lam et al., 2003 (n = 103)).

Other approaches that target the difficulties inherent in BPD in a less direct manner have also found some support in the research literature. Miklowitz et al. (2000, (n = 101)) found that family therapy reduced the rate of relapse and severity of symptoms for depression (but not for mania), in particular in families with high levels of expressed



emotion<sup>9</sup>. A number of smaller randomised control trials (RCT) have also shown that family and couple therapy can have positive effects by reducing expressed emotion in brief family therapy over six sessions (Honig, Hofman, Rozendaal & Dingemans, 1997 (n = 46), by increasing knowledge and medication adherence through couple therapy (Clarkin et al., 1998 (n = 33)), and by improving social and employment functioning more generally via family therapy (Glick, Burti, Okonogi & Sacks, 1994 (n = 19)).

From the reviewed studies it is clear that interventions of various types can lead to positive outcomes for clients. It also transpires that research into psychological interventions with BPD is still in its infancy, and despite the promise of larger cognitive therapy studies to be published within the next few years (Scott, 2004), it is still worth taking account of Huxley's (2002, p. 347) warning that "[I]n evaluating what we know about these treatments, it is important to emphasize the very limited number of studies published on the topic of psychosocial interventions in bipolar disorder, which stand in marked contrast to the much more extensive research in depression, schizophrenia and anxiety disorders". However it seems safe to draw the conclusion that clients with BPD can be helped using various approaches with different aims. This in turn suggests that relapses into illness, be it manic or depressive, may, at least partly, happen for reasons or through pathways, distinct from those leading to relapse in unipolar depression on which the cognitive understanding of relapse in BPD is based.

### **1.1.3 Neurological parallels to psychological theory and the instability model**

The assertion that unique pathways to bipolar episodes exist (distinct from those leading to unipolar depression) is backed by evidence that development of mania is linked to excessive activity in the so-called Behavioural Activation System (BAS) of the brain, whereas unipolar depression, but *not* bipolar depression (Johnson, et al., 2000; Meyer, Johnson & Winters, 2001), is linked to decreased activity in the system (ibid.; Johnson & Meyer, 2004; Gray, 1990; Depue & Zald, 1993; Depue & Iacono, 1989).

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<sup>9</sup> Communication with high levels of expressed emotion is characterized by emotional over-involvement and frequent critical comments (Birchwood, Hallett & Preston, 1989).

The BAS is believed to govern and facilitate the motivational and cognitive processes underlying goal-directed behaviour, and activation of the system has been shown to correlate, not only with typical components of mania such as inflated mood and self-esteem, but also with sensitivity to reward (Zinbarg & Mohlman, 1998; Carver & White, 1994). This is clearly in accordance with descriptions from both psychodynamic and cognitive theories, of the increased striving for success and enhanced sensitivity to rewards amongst people with BPD as set out above. Unfortunately the bio-behavioural model of BPD based on the activation level of the BAS system does not give any obvious or specific guidance for how the condition should be approached from a psychological treatment perspective. However it is interesting to note that both elevated BAS activity (Dupue & Iacono, 1989) and sleep deprivation (Ebert & Berger, 1998) have been linked to dopamine dysregulation, which in turn has been linked to both depression and mania (Anand & Charney, 2000). Furthermore, as set out by Sørensen (2004) it appears that a causal relation between irregular sleep patterns and the development of bipolar illness episodes does indeed exist for at least some individuals (Colombo, Benedetti, Barbini, Campori, & Smeraldi, 1999; Ehlers, Kupfer, Frank, & Monk, 1993; Thase et al., 1997; Wehr et al, 1998).

The link to sleep dysregulation provides a useful starting point for the development of psychosocial interventions, integrating all the theoretical insights and empirical findings cited above. This assumes that the cognitive style of interpreting environmental events and the individuals' tendencies towards enhanced responsiveness to rewards results in increased bipolar symptomatology through the mechanism of disrupting the regulation of biological rhythms in general, and sleep patterns in particular, as has been shown to be the case by Ehlers and co-workers (Ehlers, Frank & Kupfer, 1988; Ehlers et al., 1993). Based on this empirically tested assumption, Ehlers et al. (ibid.) proposed that any disruption to stability of daily routines (changes to sleep-wake routine, mealtimes, weekly schedule and even regular television habits etc.) and disruptions to sleep caused by emotionally salient psychosocial events or medical non-adherence in the vulnerable individual, can result in the development of instability and biological circadian

abnormalities (further sleep disruption), leading to the onset or worsening of bipolar mood symptoms, be they manic or depressive.

This so-called instability model of relapse, illustrated in figure 1, shows the four assumed pathways to relapse in BPD and clarifies that these (apart from pathway 1 which bypasses the mediating factors) are not independently assumed to lead to sleep disruption and subsequent illness episodes, but rather that progression through individual pathways is modified by a number of mediating factors. As described in more detail by Sørensen (2004) the four pathways to illness are:

- 1) Change in biological functioning of an internal nature.
- 2) Non-adherence to medication.
- 3) Irregularities in social routines (change to sleep-wake routine, work schedule etc.).
- 4) Life events with a specific personal meaning defined by dysfunctional assumptions and cognitive attitudes as set out in Beck's cognitive model of unipolar depression.

The concept of discrete pathways and mediating factors within the instability model makes it attractive as a guide to intervention design. This follows because modifying the mediating factors and disrupting progression through the pathways should, theoretically, have an impact on outcome in the form of enhanced mood stability.



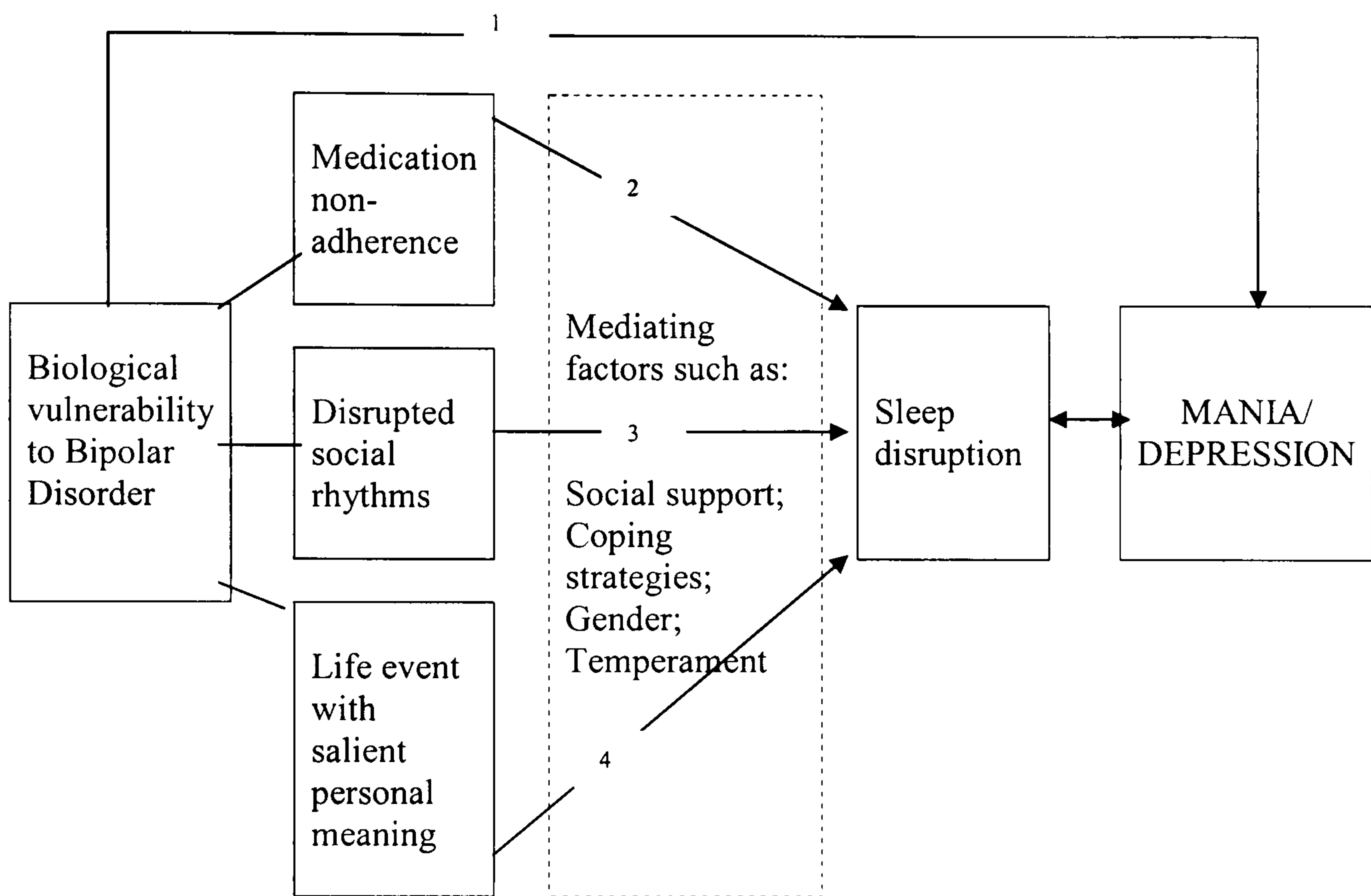


Figure 1. The instability model of relapse adapted from Ehlers, Frank and Kupfer (1988) and Frank and Swartz (2004).

### 1.2 The Therapeutic Instability Model (TIM)

Based on a reading of the psychosocial treatment literature on BPD and the general recommendation contained therein that treatment should include: a) Education about the disorder, b) Collaboration with the therapist and c) Inclusion of the patient's social environment in attempts to stabilize mood (Bauer, 2002; Frank & Swartz, 2004; Goodwin & Jamison, 1990; Leahy, 2004) the instability model was used by the author to develop the specific components of a psychological intervention (Sørensen, 2004). The general approach taken was to first ensure that the various studies shown to have beneficial outcome for clients as set out above, could be interpreted as having targeted one or more pathways to relapse within the instability model. This was found to be true. Secondly, the separate components or "active" elements of various treatments found in the research literature were integrated in a "hybrid" intervention targeting all pathways to illness

hypothesised by the instability model. As described in more detail by Sørensen (2004) and superimposed on the instability model in figure 2 below, this led to the inclusion in treatment of the joint and collaborative development of a personal handbook containing psycho-educational information and an individualized relapse prevention plan focusing on the identification of early warning signs and related strategies for reducing the risk of relapse. The intervention as defined by the treatment manual (Appendix A) is broadly psycho-educational in nature, but the development of the handbook requires an extensive consideration of the client's perspectives and experiences. This aspect of treatment is conducted within the framework of cognitive therapy with an emphasis on the collaborative working relationship and logical discourse.

In the first of four, one-hour sessions clients are presented with factual information about the BPD spectrum, from normal mood swings to bipolar type I. Causes and influences on the disorder are discussed and a conceptual model of the disorder, including stress and vulnerability factors introduced.

In session two, clients establish a personal list of signs and symptoms of depression, and a personal list of triggers for depression is created. Furthermore clients are helped to develop a personal depression profile (thoughts, behaviours and feelings characteristic of his/her particular depression) and to determine personal criteria for when to react to changes in the depressive profile and list the actions to take. This includes the development of new, relapse prevention/coping strategies (i.e. "when I feel and think in this way, I contact my GP and put on relaxing music while I take a long hot bath" etc.).

In session three, clients repeat the process described for session two regarding depression, only now the focus is on mania and the personal profile associated with this for the individual client.

In the fourth and final session, clients are educated about the importance of involving significant others in coping, and they are educated about the use of adaptive communication skills regarding BPD in both home and work environments. Furthermore clients develop a plan for how to manage work situations, be it present or future, including communication with their employer about the optimal management of the disorder.

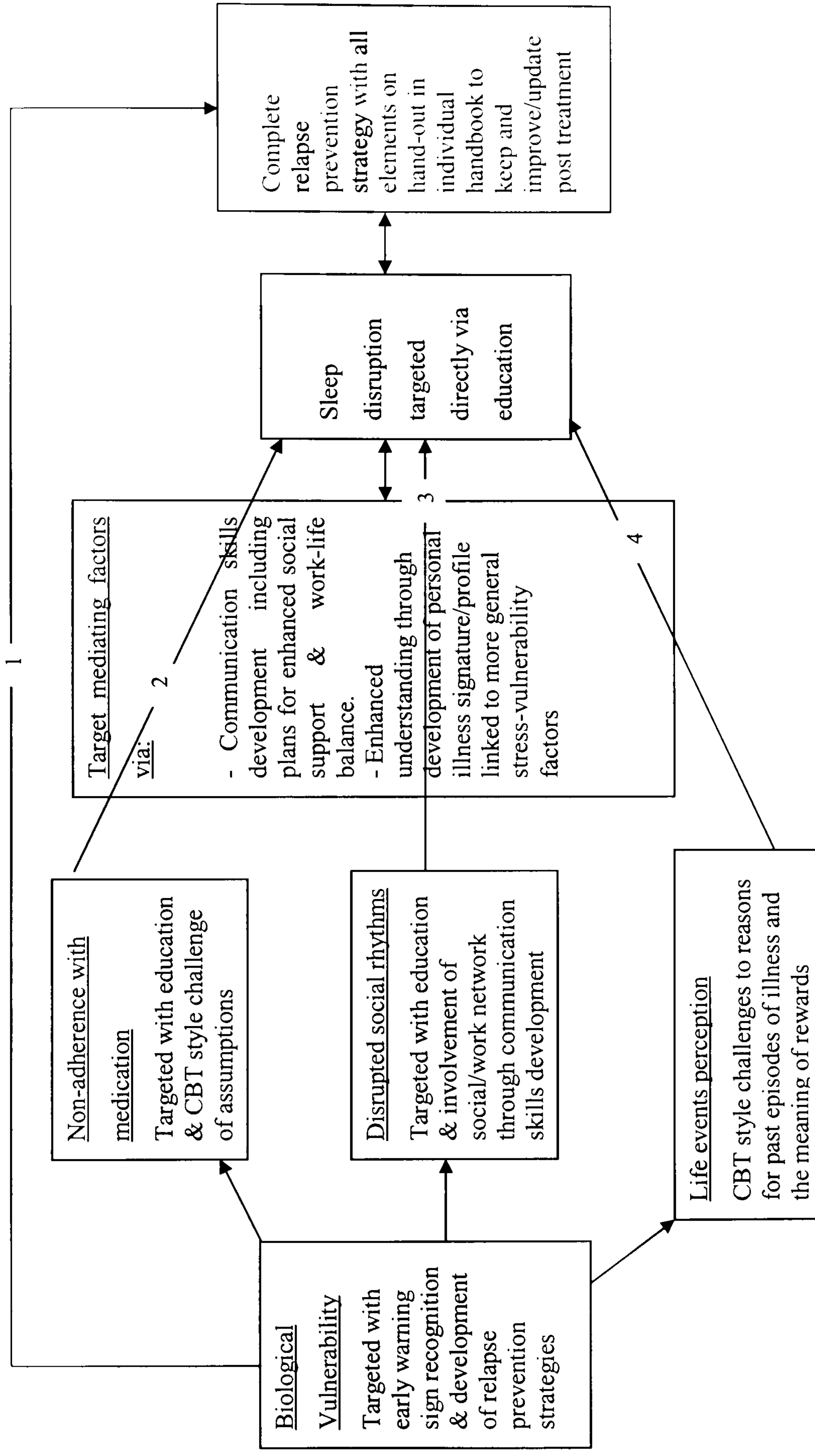


Figure 2. The Therapeutic Instability Model



Throughout the intervention, use of handouts (included in Appendix A) takes place, and at the end of the program clients have developed an individualized handbook containing information about stress factors, signs and triggers of illness episodes, adaptive action to take when at risk of relapse, communication skills and the major components of their particular disorder.

The handbook provides an individualized plan for active coping and living with the disorder, focusing on what actual actions, on the part of the client, are likely to be helpful for him or her.

In general the intervention and resulting handbook is designed to reduce hopelessness and enhance ability to control internal states, as it gives the client an ability to take more control, and to become proactive in managing the disorder.

While the TIM approach to treatment was devised prior to the publication of Scott's (2004) review of the literature, the shared characteristics of effective, brief therapies, noted by the author (*ibid.*, p. 237) to have particular importance when working with BPD, are in accordance with the content of the current intervention. However, no single therapy has previously paid specific attention to targeting all the instability models' pathways to illness within one intervention effort as has been done in the current study (Sørensen, 2004). Creating such a "hybrid-intervention" from treatment elements currently recommended elsewhere in the research literature, should not only result in direct benefit for clients, but also open up the possibility of gaining a client perspective on which common intervention strategies are wanted, or perceived to be useful from their point of view.

Considering the clients' perspective when planning interventions is important, not only because of the explicit National Health Service objective to do so (Department of Health, 1999; see also Sørensen, 2004), but also because it is essential for the effective delivery of treatment. It is becoming increasingly clear that the pattern of high levels of non-adherence to medical treatment, as set out above, may be repeated to some degree for psychological treatments. In relation to this it is noted that published trials have shown dropout rates of 31% and 21% (Scott, Garland & Moorhead, 2001; Clarkin, Carpenter, Hull, Wilner & Glick, 1998), and one can only speculate that these numbers may hide a higher "shadow" figure of dropout from

studies that did not reach publication precisely because of high dropout. It is therefore essential to gain an understanding of individual clients' perspectives and evaluations of the treatment being conducted, in order to begin an optimization of the psychosocial interventions offered in a manner that will minimise the use of interventions that are unwanted or ineffective from the clients' perspective, while also paying attention to the inclusion of treatment components shown in the studies reviewed above to have a positive effect on standard measures used in traditional psychotherapy evaluation.

### **1.3 Methodological issues**

The limited amount of research within this field means that a need for smaller feasibility testing programmes exists, because such studies can be used to guide the direction of future research and treatment design. This assertion is supported by the Medical Research Council in their considerations of best practice regarding development and evaluation of complex interventions (MRC, 2000). However, the current study is not merely a preparation for later RCT research. Having taken account of the criticisms of RCT designs emerging over recent years and which are set out below, the current study will attempt to add something qualitatively different to the understanding being developed through the "gold standard" of therapy research constituted by the RCT approach. This will be done by including an emphasis on the clients' perspective and experience of treatment (please see below).

As summarised in more detail by Sørensen (2004) the criticism of RCT design has centred on three main difficulties (Elliott, 2002):

- A. Difficulties obtaining sufficient statistical power because effect size is often, statistically speaking, small, even when clinical significance is substantial for individual patients.
- B. Limited generalizability of causality to single cases as a result of restrictive sampling and lacking process data, i.e. even when overall outcome change can be reliably linked to an intervention, change for a specific client may have been the result of non-intervention related factors.

- C. The problem of so-called *causal emptiness*, because the traditional RCT simply establishes the conditions under which inferences about causality can reasonably be made, but does not contain guidelines for understanding the nature of the causal relationship.

These general reservations regarding RCT as the “gold standard” of psychotherapy research can be expanded with concerns relating to the specific case of research into interventions with BPD. This follows because BPD is somewhat unique amongst disorders, in that some diagnosed individuals, also between episodes and when asymptomatic, are ambivalent regarding the desirability of controlling symptoms and in some cases even long for the experiences inherent in manic episodes of the disorder (Jamison, 1996).

This has important implications with regards to the choice of research strategy, as therapeutic outcomes and clients’ assessment of the usefulness of treatment are likely to be heavily influenced by a complex interplay between *how* they perceive the disorder (positive/negative) and *which* elements of treatment they found useful for *what* reason (e.g. “It helped me stay hypomanic safely” or “it helped me stop the hypomania” could both be plausible perspectives on the same aspect of treatment for individual clients).

Following these considerations the research method of choice became a longitudinal design with replication across participants, combined with the use of multiple case study methodology (Barlow, Hayes & Nelson, 1984).

The chosen research strategy allows a quantitative evaluation of the intervention *per se* but without neglecting questions related to the clients’ subjective evaluation of the intervention, which is likely to be of importance for the ability to design future interventions that minimise drop-out and that are perceived to be useful and effective from the clients’ perspective. An inclusion of multiple measures and data collection strategies as typically seen in case studies, address the main threat to internal validity of the current design, i.e. interfering life events that may occur at the same time as the intervention and therefore produce the illusion that the intervention has created a change when in fact the change was the result of factors external to the treatment. The construct validity of the study is also improved by using multiple sources of evidence in an attempt to corroborate or triangulate the conclusions drawn (Yin, 2003).



The current study used interviews, pre- and post-intervention questionnaires, standard quantitative scales administered throughout and questionnaires/pre-structured “diaries” which regularly collected data relating to extra-therapeutic aspects of clients’ lives, thereby enhancing the ability to rule out alternative, plausible sources of any change observed during, or after therapy (Elliott, 2002).

### **1.3.1 Data collecting instruments**

The reasoning behind the inclusion of particular quantitative measures in the study is developed in the methodology chapter and it suffices to mention here that the Beck Hopelessness Scale (BHS) (Beck, Weissman, Lester, & Trexler, 1974) is an important measure in the study. The BHS gives an indication of how the clients view their future prospects and has been shown to be a reliable predictor of suicidal behaviour which, as mentioned above, is a central concern with the bipolar population.

The Perceived Control of Internal States Scale (PCOISS) (Pallant, 2000) was adopted as a central measure because it assesses the client’s perceived control over internal states (emotions, thoughts and physical reactions) which is assumed to be a central aspect of the bipolar experience and one which is likely to change as coping strategies are developed in treatment.

The Client Satisfaction Questionnaire (CSQ-8) (Larsen, Attkisson, Hargreaves & Nguyen, 1979) supplies a quantitative measure of the clients’ satisfaction with previous and current treatment.

Apart from these standard measures, further information was obtained through weekly pre-structured “diaries” designed to capture information similar to that captured by the above data collection instruments, without the need for clients to dedicate prolonged periods of time to their completion. These weekly “diaries” (and the slightly altered Diary 2 version given at five week follow-up) also ask about the existence of any extra-therapeutic changes to clients’ lives in order to gain information for the development, or ruling out, of extra-therapeutic or alternative explanations for any change observed throughout, or following treatment. The clients were also asked to complete questionnaires containing questions of a factual and numerical nature in relation to relevant areas of their lives. Finally, semi-structured interviews before and after the intervention explored the study’s areas of interest with

each client. The probes developed for the interviews were inspired by the *Simplified Personal Questionnaire* (Elliott, Sharpiro & Mack, 1999), the *Change Interview* (Elliott, Slatick & Urman, 2001), and the *Helpful Aspects of Therapy Form* (Llewelyn, 1988) but have been adapted specifically for the current study.

An outline of the study with data collection points is given in figure 3 below.

| Baseline,<br>2 weeks<br>pre<br>session 1 | Baseline,<br>1 week<br>pre<br>session 1                     | Post<br>session<br>1 | Post<br>session<br>2              | Post<br>session<br>3 | Post<br>session<br>4              | Follow-up,<br>1 week<br>post<br>session 4                              | Follow-up,<br>5 weeks<br>post<br>session 4 |
|--|---|----------------------|-----------------------------------|----------------------|-----------------------------------|--|--|
| BHS<br>CSQ-8<br>PCOISS                   | BHS<br>CSQ-8<br>PCOISS<br>Interview<br>Question-<br>naire 1 | Diary 1              | BHS<br>CSQ-8<br>PCOISS<br>Diary 1 | Diary 1              | BHS<br>CSQ-8<br>PCOISS<br>Diary 1 | BHS<br>CSQ-8<br>PCOISS<br>Interview<br>Diary 1<br>Question-<br>naire 2 | BHS<br>CSQ-8<br>PCOISS<br>Diary 2          |

Figure 3. The structure of the study with data collection points.

### 1.3.2 Case study methodology and the clients' perspectives on the intervention

The current study partly employs explanatory case study methods to evaluate the intervention for its effectiveness and usefulness from clients' perspective as collaborated by standard or "objective" measures described above. However the complicated interplay between the individual's experience of mania and his or her subjective assessment of the usefulness of treatment components, necessitates the inclusion of a more exploratory stance to the research in the hope that this will allow the initiation of theory building regarding which of the treatment components works for whom. This aspect of the study begins to address the conclusion drawn by Gordon (2000) after an extensive review of the research literature on the client's perspective on psychological interventions generally: "research which attempts to examine the client's perspective tends, in fact, to examine client variables or the client *as a variable* rather than actually pay attention to the client's view" (ibid. p. 10). This assertion is backed by Mcleod (1998) who notes that very few researchers have conducted research which asks clients what they think about the treatment received. It is further noted that while researchers in other diagnostic domains have begun to address this gap in the literature (Kuehl, Newfield & Joanning, 1990; Lietaer, 1992;

Rennie, 1992; Messari & Hallam, 2003), the lack of such research in the area of BPD is total (Sørensen, 2004). It is hoped that the current study will begin to close this gap in the research literature and that insight gained will prove helpful when designing future interventions.

#### **1.4 Summary of Chapter 1**

The often disabling nature of BPD and its relatively frequent occurrence in the population highlights the need for adequate services for this group of clients. The present introduction has aimed to illustrate this need and to show that it is in the interest of both individual clients and society to optimise interventions that not only have high levels of efficacy but which are also effective and wanted by clients.

Despite the need for such services and interventions, it is only in recent years that sustained research and service provision of a psychosocial nature has been developed, and the knowledge base in this area is still rudimentary at best. From a theoretical perspective there appears to be a consensus between the two major approaches, psychodynamic and cognitive, that sensitivity to reward and a strong tendency for striving towards success is involved in the development of mania. Equally, research into unipolar depression has been generalised to the bipolar spectrum and it has been hypothesised that bipolar depression can be conceptualised in a similar way to other depressive states (Ball et al., 2003).

However, while generally supplying support for the psychological theories, research originating from the neurological sphere suggests that unique pathways to bipolar illness episodes exist. It appears that sleep regulation is of central importance for mood stability in the vulnerable individual and the so-called instability model of relapse was therefore used to inform the development of the intervention being evaluated in the current study.

It is assumed that there are four mechanisms or pathways to relapse, acting through the common mediator of sleep disruption. Consequently the TIM was developed to target all four pathways and can, as such, be construed as a hybrid drawing inspiration from various other approaches. Implementation of such a hybrid has not previously been attempted in the research literature despite emerging support for interventions



targeting separate pathways, as was illustrated by the conducted literature review of treatment evaluation studies.

The current study will attempt to gain information about the overall efficacy of the TIM and will also attempt to obtain information about the clients' perception of the intervention's usefulness both generally and also specifically regarding individual components of the treatment model.

Following these considerations the research design became a longitudinal design with replication across participants, utilising multiple case study methodology in the form of exploratory interviews. Triangulation of multiple data collection sources was used in the manner illustrated by figure 3 above.

### **1.5 Research aims**

The current study evaluates a newly constructed intervention with BPD targeting multiple pathways to episodes of illness and aims to gain information about the client perspective and assessment of the intervention. More specifically the study aims to determine:

1. The intervention's ability to effect change in hopelessness and perceived control over internal states.
2. Clients' satisfaction and assessment of the usefulness of treatment.
3. The possible links between the individually perceived desirability of future manic episodes and the subjective experiences of the current treatment.
4. Any additional changes in thoughts, feelings or behaviours experienced by clients and the connections that they describe between treatment and such changes.
5. The clients' personal explanations or cognitive models of their illness and any changes in these resulting from treatment.

It is hoped that information of the type summarised above will help in the development of future treatments by minimizing the use of intervention elements that are unwanted or ineffective from the client's perspective, while also taking account of what is currently recommended in other parts of the research literature. In other words, knowledge of clients' perspective on treatment components is a necessary requirement for obtaining an adequate balance between efficacy and effectiveness in the design of any future intervention. This follows because an intervention that does not take account of clients' experiences and perspectives will be more likely to include elements that cause drop-out or non-engagement.

## **2.0 Method**

### **2.1 Design**

As noted in the introduction to this thesis, the research design used is a longitudinal design with replication across participants, combined with the use of multiple case study methodology and qualitative data collection strategies (Barlow, Hayes & Nelson, 1984).

Apart from the standard quantitative element of the design, interviews, conducted one week pre- and post- treatment, together with a general use of multiple sources of information, allow for triangulation, a commonly cited advantage of the multiple method approach, which enables the object of study to be more richly described and more precisely defined (Robson, 1993; Yin, 2003). In the current study the advantages of qualitative research methods are not only important because of the criticisms of RCT designs set out in the introduction, but have added importance because of the aim of evaluating the intervention from the clients' perspective. This general research aim requires an exploration of questions to do with *what*, *why* and *how* elements of the treatment were useful or less so. These questions can only be answered using methods, such as interviews, which allow the researcher to gain an understanding of the client's subjective experiences and perspectives on given aspects of treatment. Further, this approach accommodates the capture of complexity and uniqueness between participants while also allowing model building through the identification of commonalities (ibid.; McLeod, 2001; Miles & Huberman, 1994).

### **2.2 Procedure and Participants**

As the study was conducted in two separate locations, ethical approval was obtained from both Barnet, Enfield & Haringey and East & North Hertfordshire Hospitals Local Research Ethics Committees (approval letters in Appendix B). Registration with the relevant research and development departments was also completed before the study commenced.

The majority of clients were recruited from existing waiting lists at two psychology departments in North London and Hertfordshire and a smaller number of clients were recruited by approaching local Consultant Psychiatrists and GPs in the recruitment areas (recruitment and information letters in Appendix B). In order to raise the



likelihood that the study would have ecological validity, i.e. reflect the client base that an average clinician would see in daily NHS practice, clients were approached in the order they had been referred to the psychology departments and, for clients specifically referred to the study, in the order the referrals were received.

Potential participants were sent a recruitment letter (Appendix B) offering them an initial assessment and information session and were invited to join the research if they:

1. Were fluent English speakers.
2. Indicated a willingness to do homework.
3. Had been given a diagnosis of bipolar affective disorder (type one or two).

Clients were to be excluded if they had:

1. Unstable medical problems.
2. Known or suspected substance intoxication or withdrawal.
3. A history of a major neurological problem.
4. An organic mental syndrome or seizures within the past year.

Further, clients who were in a manic state when the intervention began were to be excluded even if they were initially included in the study. None of the clients approached were excluded from the study.

Ten people found on existing waiting lists to psychology were approached and all opted to take part in the study. A further six people were referred from local Psychiatrists and GPs. Of these, five showed up for their initial information session and all opted to participate in the study. At the information session a written information sheet covering the information given verbally was given to the participants and written consent was sought (documents in Appendix B). Thirteen clients completed the treatment and the two who did not, dropped out after the pre-intervention interview, following several failed attempts at finding a time that would allow them to take part in the study. Hence, all thirteen clients who experienced the first treatment session completed the full treatment program.

### **2.3 Measures and Data Collection**

The data collection strategy is illustrated in figure 3 above and it suffices to say here that clients, at the initial session, were given information about the study and were then asked to complete the measures mentioned in figure 3. Similarly, clients were

asked to complete the measures at the end of the remaining weekly sessions. The five week follow-up was conducted by post, with participants receiving the relevant measures in the mail together with a stamped return envelope. The measures developed specifically for the study, the relevant cover letters and the client information sheets can all be found in Appendix B.

### **2.3.1 Standard Quantitative Measures**

The Beck Hopelessness Scale (BHS) (Beck, Weissman, Lester, & Trexler, 1974) has been shown to be a reliable measure of hopelessness, reflecting negative expectations for positive future outcomes. Beck, Rial & Rickels, (1974) reported a KR-20 coefficient of .93 amongst 294 hospitalized patients who had attempted suicide. This result has been replicated more recently by Steer & Beck (1997), who found KR-20 of .93 and .90 in two subgroups of psychiatric outpatients. Consequently the BHS constitutes a central measure in the current research because suicide is a serious problem within the bipolar population. The BHS manual further gives examples of test-retest correlations of .69 (1 week span) and .66 (6 week span), both of which are statistically significant results (Beck & Steer, 1993). Further evidence of reliability is provided by Hill, Gallagher, Thompson & Ishida (1988) who examined the internal consistency of the BHS and found a coefficient alpha of .84 and a Spearman-Brown split-half reliability of .82.

Construct validity has been confirmed by factor analytic methods in a number of studies (Beck, Rial & Rickels, 1974; Hill, Gallagher, Thompson & Ishida, 1988; Steer & Beck, 1997).

The Perceived Control of Internal States Scale (PCOISS) (Pallant, 2000) was developed to provide a measure of the degree to which people feel they have control of their internal states (emotions, thoughts and physical reactions). Across two studies (N=689 in total) carried out by Pallant (ibid.) the PCOISS showed good internal consistency, with a Cronbach's alpha of .90 and a mean inter-item correlation of .34. Factor analysis revealed two factors which appear to reflect that the scale mainly measures the client's belief that he or she has a set of appropriate self-control skills and the overall feeling of competency and control over internal states (ibid.). Any developments in these subjective assessments of control and appropriate skills during

treatment are of central concern in the current evaluation of the TIM and the PCOISS was therefore ideally suited to the study.

The Client Satisfaction Questionnaire (CSQ-8) (Larsen, Attkisson, Hargreaves & Nguyen, 1979) has been used in a variety of studies as a general measure of client satisfaction and has proven to possess high indices of internal consistency, with Alpha coefficients equalling .93, .93 and .87 in a series of studies (Attkisson & Zwick, 1982; Larsen, Attkisson, Hargreaves & Nguyen, 1979; Nguyen, Attkisson & Stegner, 1983). The CSQ-8 was chosen for the present study because of its established psychometric properties, its sensitivity, and its extensive application in previous studies, which allows for direct comparisons between studies. Furthermore, while it is of intrinsic interest to the research project to establish the level of satisfaction with the conducted treatment, the CSQ-8 also serves another purpose in the current study. When applied during treatment to measure satisfaction with past treatments received by clients, the CSQ-8 can function as a control of the manner in which clients approach the completion of measures generally, because major changes in clients' perception of previously received treatments, be they medical or otherwise, are assumed to be unlikely to occur during the present intervention. A significant improvement in satisfaction with past treatments as measured on the CSQ-8 could therefore be seen as an indication that clients are generally trying to express an overly positive or *please the scientist* attitude, which could also have influenced other measures in the study, rendering them invalid. In contrast, if clients are displaying stability on the CSQ-8 but changes on other measures, credence would be added to the assumption that the changes observed are genuine and accurate reflections of clients' actual experiences.

### **2.3.2 Self Complete Questionnaires**

The questionnaires given before and after treatment were developed with the research aims in mind, and obtain factual and numerical data about age, gender, relationship status, educational level, ethnic background, employment, housing and number of illness episodes. Furthermore, the questionnaires are designed to investigate the clients' experience and attitude to psychological and pharmacological treatments, their perceived knowledge about BPD, their degree of enjoyment of mania, usefulness of the current treatment and their wish to eliminate episodes of mania entirely (see Appendix B for the questionnaires).



### **2.3.3 Diary 1 and Diary 2**

These diaries were developed to supply a way to triangulate and track developments in the main areas of interest throughout the study, without requiring clients to use prolonged periods of time on completion of the standard measures described above. Apart from asking questions about extra-therapeutic events in clients' lives that could have an impact on outcomes (change in medication, substance use or general life circumstances), the diaries use Visual Analogue Scales (VAS) to measure ease of understanding of the information given in treatment, usefulness of treatment, hopelessness, satisfaction with past and current treatment and perceived control over symptoms (see Appendix B for diary sheets).

The VAS is a continuous measure depicted on a 100 mm. horizontal line with end-points in accordance with what is measured (ex. very hopeless – very hopeful). It has a zero end-point and equal ratios between any two consecutive numbers and is thus a ratio scale enabling the obtainment of percentages between different measurements taken from a group of clients or from an individual client over time (Price, McGrath, Rafii & Buckingham, 1983; Price & Harkins, 1992; Anastasi, 1997). The VAS approach to measurement has been extensively used in research areas where completing long measures is inconvenient, impractical or painful and has been shown to be fast and easy to administer and score (Jensen, Karoly & Braver, 1986), and also to supply reliable and valid information about complex constructs such as *impact of pain on daily living* and *subjective degree of pain experienced on a given day* (Jensen & McFarland, 1993; Anastasi, 1997).

### **2.3.4 Semi-structured Interviews**

The two interviews conducted with each client pre- and post- intervention explore the areas of interest for the study as defined by the research aims. The interview schedules were developed on the basis of a reading of the relevant literature as reviewed above, and also on the basis of theoretical assumptions about what is effective in treatment as predicted by the TIM, which targets the four pathways to illness set out in the instability model of relapse (Ehlers, Frank & Kupfer, 1988; Frank & Swartz, 2004). Furthermore, the probes developed for the interviews take their inspiration from the *Simplified Personal Questionnaire* (Elliott, Sharpiro & Mack, 1999), the *Change Interview* (Elliott, Slatick & Urman, 2001), and the *Helpful*

*Aspects of Therapy Form* (Llewelyn, 1988) in order to elicit information about the client's experience of BPD and the applied intervention (Interview schedules in Appendix B).

Within each interview section a broad, open-ended question was initially asked, followed by probes into relevant areas if the interviewee did not mention these spontaneously. The interview schedule suggests a number of probes but the general approach taken was to allow the interviewees to answer the questions in their own manner, while following up leads using clarifying, open questions that enabled illustrative points to be made in the interviewee's own words. The interviews were tape-recorded and later transcribed.

## **2.4 Analysis**

All data from diaries, self-complete and standardised questionnaires was transformed into variable data and entered into SPSS version 11.0. The interviews were transcribed and analysed using a content analysis approach as set out in the following (Kvale, 1996; Neuendorf, 2002; Robson, 1993).

The development of meaning categories for the content analysis was conducted via several re-readings of each transcript prompted by the determination of a new theme found through reading a particular transcript.

Initially, the conducted review of research studies, which was given concrete expression through the individual treatment components of the TIM, was used together with the research aims stated above to develop the main categories and some subcategories as illustrated in figure 4 below. Following the transcription of the 26 interviews, which came to 431 pages<sup>10</sup>, and a first meaning categorisation according to definitions of the main categories and their subcategories, further subcategories were added (represented by bold italics in figure 4) in order to make the categories used exhaustive. Finally, all interviews were coded according to the full range of subcategories in accordance with the definitions set out in the overview of meaning categories given in Appendix B.

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<sup>10</sup> Audiotapes are kept by the University of Hertfordshire subject to the data protection act. Transcripts are available from the author.

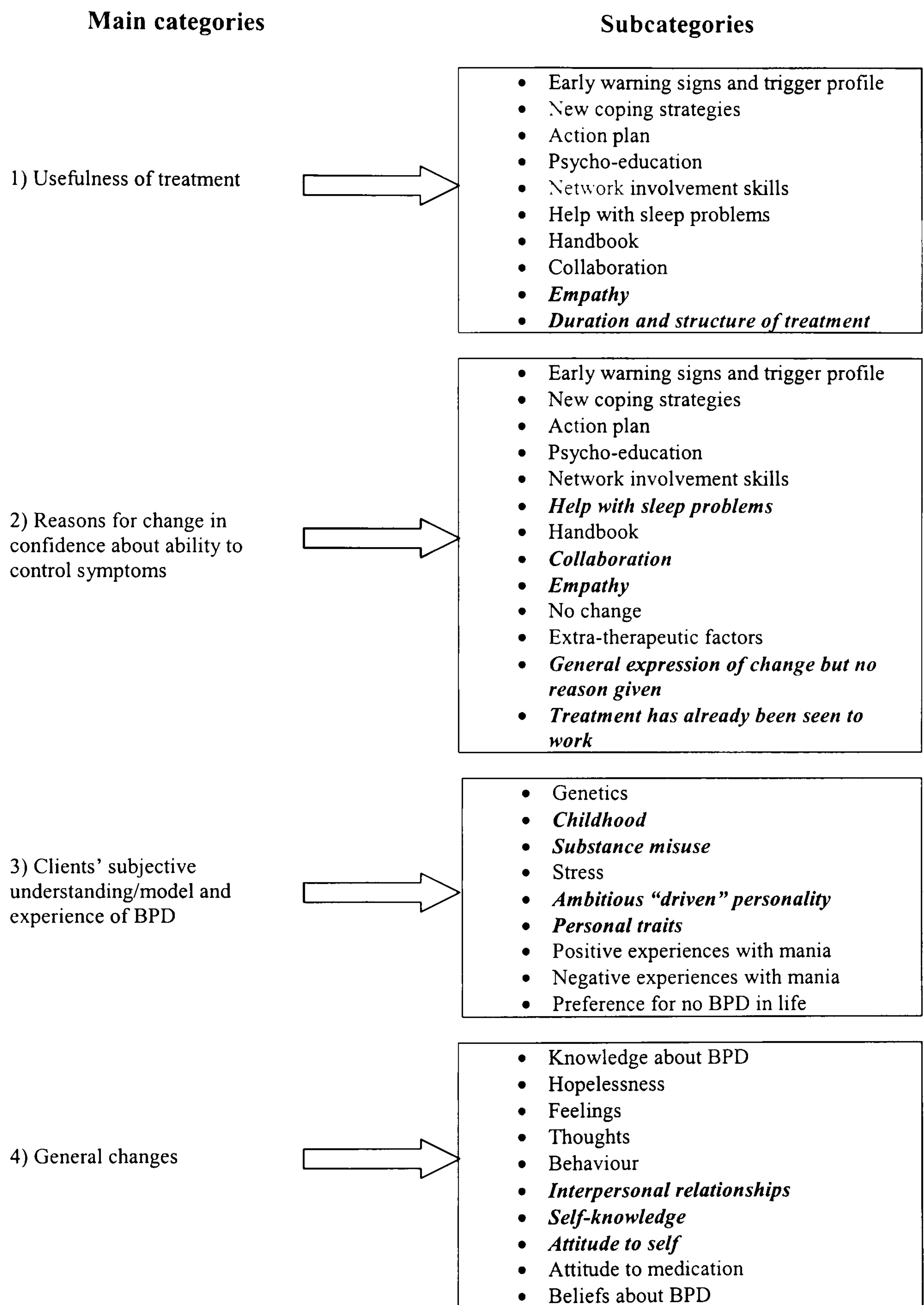


Figure 4. Main- and sub-categories for interview analysis. Categories added during analysis are represented by bold italics.

With regards to reliability of the coding it is noted that Robson, (1993) draws a distinction between *manifest* and *latent* content corresponding to the requirement of



the coder to classify low- and high-inference items respectively. Essentially, a latent content item requires more interpretation on the part of the coder, whereas a manifest item has a particular “physical” presence (e.g. a particular word) and is therefore not open to much interpretation. In the current study the items of interest are the experiences of individuals and the themes that are important in this regard. As a consequence the approach taken is that of *meaning categorisation* or *thematic content analysis* defined as, “the scoring of messages for content, style, or both for the purpose of assessing the characteristics or experiences of persons, groups, or historical periods” (Smith, (1992) reported in Neuendorf, (2002) p. 192). With this in mind the coding strategy needed was considered to be high in latency as defined by Robson (1993) and consequently a demand for rigorous checks on reliability was required. Robson (ibid.) recommends that this happens via the use of triangulation with data obtained through other sources or via the use of independent coders. Both of these strategies were employed in the current study.

The reliability of categorisation of themes was established in a manner equivalent to that outlined by Miles and Huberman (1994). Another psychologist, who was familiar with the study, agreed to act as a second coder on six randomly selected interviews. He was provided with the descriptions of each category as set out in Appendix B and categorised the interview statements already considered by the first coder (i.e. the researcher) accordingly. This second coder was also asked to add any other category of relevance when considering the whole interview material and the overall aims of the study. Inter-coder reliability was calculated as follows:

$$\text{Reliability} = \frac{\text{Number of agreements}}{\text{Total number of agreements and disagreements}}$$

Using this formula an inter-coder reliability of .84 was obtained. This figure constitutes a satisfactory level of agreement according to Miles and Huberman (ibid.) who defines agreement ratios of .80 and above as adequate. With regards to obtaining an expression of intra-coder reliability (i.e. internal consistency) this was computed in the same manner, using the author’s number of agreements and disagreements on two separate occasions, one week apart. This resulted in an intra-coder reliability ratio of .98, again showing an adequate level of agreement (ibid.).

With regards to validity, this was addressed through regular discussions with the second coder and the author's various supervisors, of which one is experienced in both severe mental health work and content analytic coding of interview material for research purposes.

### **3.0 Results**

The results will be divided into two main sections. Firstly, demographic data about the participants will be presented. Secondly, the outcome of statistical and other analytical techniques exploring the research aims will be reported together and presented according to the research aim they address. For instance, all data gathered about clients' hopelessness, be it via interviews, the BHS or VAS will be presented together in order to emphasise the triangulation approach taken and illustrate how different sources support, or cast doubt upon, the overall conclusions.

It is noted that a total of 11 measurement packages were returned at five-week follow-up and that of the two participants who did not return the measures, one was homeless at the time of last contact (post intervention interview) and the other was planning to relocate abroad. The data relating to these two participants was included in the analyses looking at areas of interest up until the post intervention interview collection point, one week after the final treatment session, but excluded from any analysis considering the five-week follow-up data.

#### **3.1 Description of the Participants**

The following section describes information obtained from the self-complete questionnaires regarding characteristics of the participants. As described above this includes age, gender, relationship status, educational level, ethnic background, employment, housing and number of illness episodes.

##### **3.1.1 Demographic Information**

6 participants were female and 7 male. The mean age was 42.6 years and the range 22-75 years. 9 participants described their ethnicity as White British, 2 as White Irish, 1 as White Other and 1 as Black British African. 1 participant had English as a second language. With regards to educational level, 2 participants had no educational qualifications, 5 had GCSE/ 'O-level' qualifications, 2 had A-levels or equivalent, 3 had a first university degree and 1 participant had a master's degree.

At the beginning of treatment 7 participants were in rented accommodation, 5 were home owners and 1 was living with parents. At the conclusion of treatment this housing status had changed for 1 person who had left rented accommodation and



become homeless. During treatment 2 participants had short spells on inpatient wards as a result of hypomanic and depressive episodes but all were able to attend for sessions and to complete the full treatment program on schedule.

9 participants were in employment and 6 were in a stable relationship with a partner. The participants reported having experienced on average 17.85 episodes of illness with a range of 3 - 54.

### **3.2 Research Aims Analysis**

The following sections contain analyses relating to the individual research aims as set out in section 1.5 above.

At the outset a statistical analysis was carried out on the CSQ-8 data as a “control variable” following the assumption that significant changes in satisfaction with previously received treatments were unlikely to be observed if participants generally approached self-completion measures with the aim of accurately reflecting their experiences and perceptions (please see section 2.3.1 for an explanation of this use of the CSQ-8).

A paired samples t-test<sup>11</sup> comparing the participants’ CSQ-8 scores for previously received treatment programs two weeks prior to beginning the current treatment (Mean (M) = 22.77, Standard Deviation (SD) = 5.00) and one week after completing this (M = 20.31, SD = 6.05), showed that no significant change had occurred ( $t(12) = 1.579$ ,  $p < .140$ ). Further, this result was largely replicated on the VAS for satisfaction with previous treatment comparing scores after session 1 (M = 55.62, SD = 30.64) with scores recorded at one-week follow-up (M = 58.77, SD = 26.07) ( $t(12) = -.301$ ,  $p < .769$ ).

While it is possible that participants may have completed the CSQ-8 and the VAS differently to the way they completed scales directly related to the current intervention and their general state of mind (BHS, PCOISS etc), the non-significant results reported above are taken as support for the validity of the statistically significant results found on the measures reported below. This follows because such differing results in the direction predicted (i.e. no difference between pre- and post treatment on

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<sup>11</sup> Due to the TIM’s nature as a newly designed treatment, it was conservatively decided to let all t-tests in this thesis be 2-tailed. Furthermore, while it is noted that “[W]hether to adjust P values for multiple comparisons is controversial” (Bacchetti, 2002, p. 1272), a *post hoc* Bonferroni analysis was conducted for reference purposes. This showed an adjusted significance level of  $p < 0.017$  for the research aims analyses.

the “control variables” but only on the measures assumed to tap into intervention related changes) shows a honest, deliberate and sophisticated completion of measures on the part of participants rather than a biased approach towards overly positive or negative completion of the measures.

### **3.2.1 Hopelessness**

Measures of hopelessness were obtained using the BHS, the relevant VAS and also through the conducted interviews.

It is noted that a baseline of the BHS was established using two measurement points, two and one week before the intervention began respectively, and that a high degree of stability was found between these pre-intervention measurements. This baseline stability can be shown by a paired samples t-test comparing the two-weeks pre-intervention scores ( $M = 8.77$ ,  $SD = 4.126$ ) and the one-week pre-intervention scores ( $M = 8.08$ ,  $SD = 4.481$ ). This t-test ( $t(12) = 1.426$ ,  $p < .179$ ) showed that no significant difference existed between the two baseline measurements and in the analyses below, the mean of the two baseline measurements will be used to get the most accurate basis for comparison with developments in the scores obtained on the BHS following treatment.

When comparing the mean baseline BHS score ( $M = 8.4231$ ,  $SD = 4.2173$ ) with the measurement taken one week post treatment ( $M = 2.77$ ,  $SD = 2.803$ ) a highly significant reduction in hopelessness is found ( $t(12) = -6.853$ ,  $p < .000$ ) leading to a large effect size (Cohen’s  $d \gg .80$ ).

Cohen’s  $d$  is calculated as the difference between means ( $8.4231 - 2.77$ ) divided by the pre-treatment  $SD$  ( $4.2173$ ):  $d = (8.4231 - 2.77) / 4.2173 = 1.34$ , which, according to Cohen’s (1992) definition, constitutes a large effect size as it is above  $.80$

This general result is sustained from baseline ( $M = 9.1364$ ,  $SD = 4.2017$ ) to 5-week follow-up ( $M = 3.09$ ,  $SD = 4.415$ ) for the 11 participants who could be contacted at that time ( $t(10) = -5.217$ ,  $p < .000$ ). Cohen’s  $d = 1.439$  and the results can be seen in figures 5A and 5B and in figures 6A and 6B below.



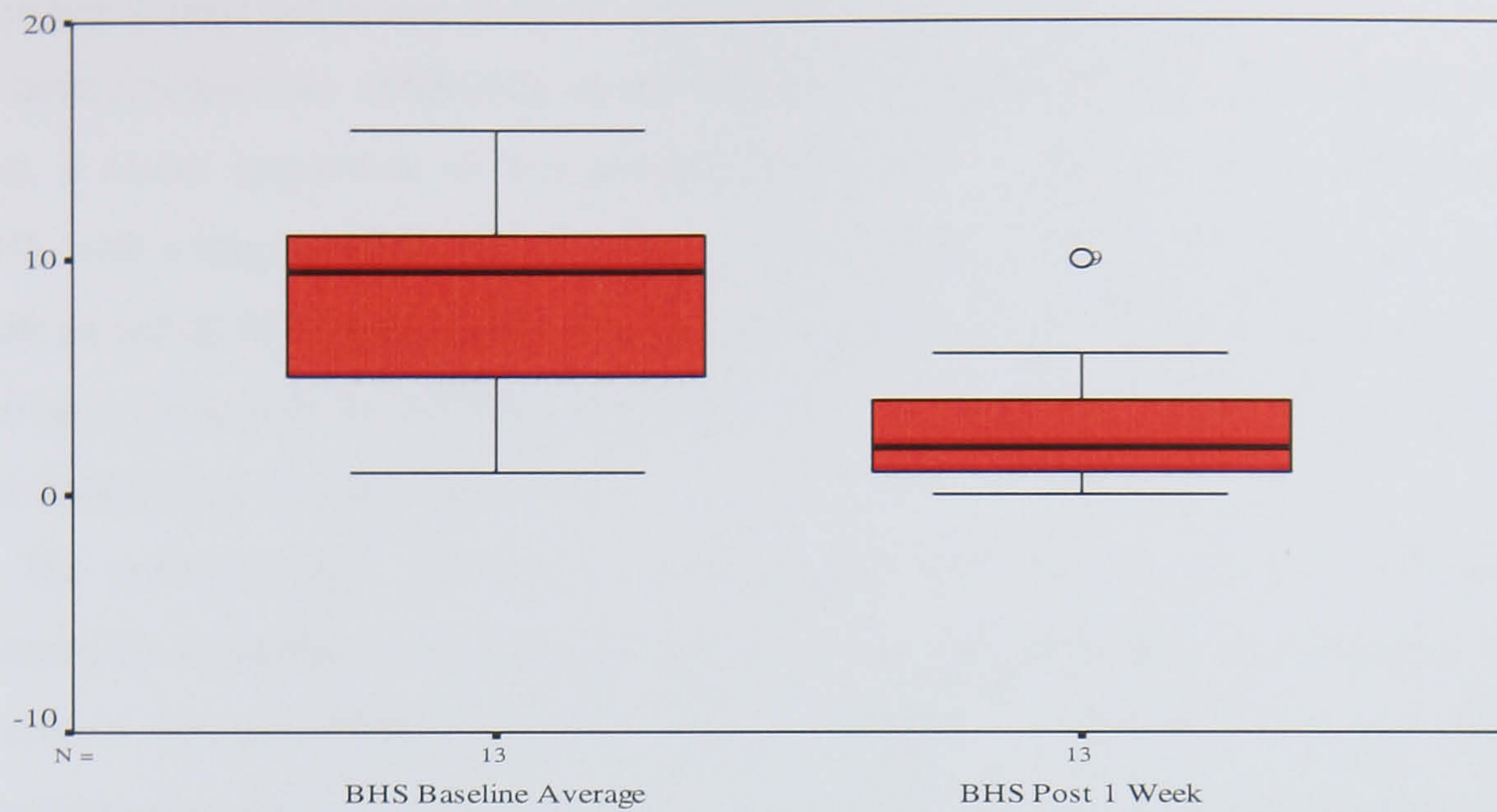


Figure 5A. BHS Baseline to 1 week follow-up (Mean at baseline = 8.4231, Median at baseline = 9.5, Mean post 1 week = 2.77, Median post 1 week = 2).

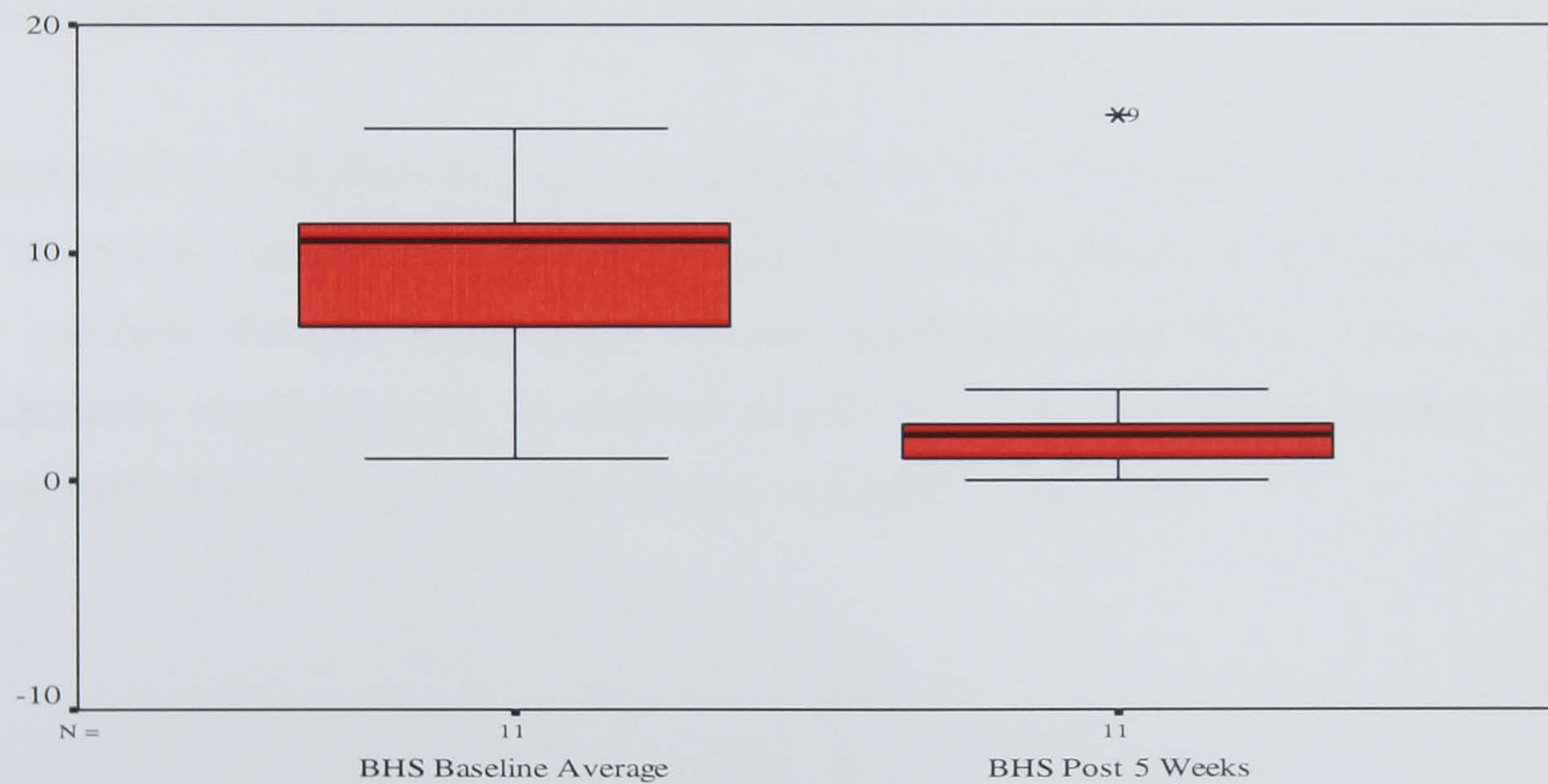


Figure 5B. BHS Baseline to 5-week follow-up (Mean at baseline = 9.1364, Median at baseline = 10.5, Mean at post 5 weeks = 3.09, Median at post 5 weeks = 2).

From figures 5A and 5B it is not only clear that a significant change in scores can be shown, as seen in the t-tests, but also that the variability has changed and reduced considerably post treatment. The length of the boxes containing 50 percent of scores become narrower and the whiskers reaching to the smallest and largest values become shorter over time. This indicates that the participants are giving progressively more similar estimations of their hopelessness as measured on the BHS.



One participant bucks this general trend (shown as an outlier in the figures) appearing to have reacted very differently to the treatment compared with other participants. In fact, a closer inspection of this participant's scores reveals that she completed the BHS with a large degree of consistency (i.e. no change) across the study, starting out with an initial BHS baseline of 16, then showing stability with three scores of 15 and a drop to 10 at one-week follow-up, followed by a return to her original score of 16 at the final follow-up after five weeks.

In the current study indications of change and no change are both considered potentially important pieces of information and while other study designs may have excluded this participant from the analysis because the reasons for the no change experience are specific to the particular participant<sup>12</sup>, her data will be kept here and in all analyses that follow. The reasoning behind this is the study's aim of retaining ecological validity, also testing the efficacy of the intervention with clients who reject medical intervention and who are faced with the consequences of limited resources in NHS departments, occurrences which are a common reality in daily, clinical practice.

Figures 6A and 6B illustrate the 95% confidence intervals (CI) and the fact that none of the two post-intervention CIs overlap with the pre-intervention CIs. This enables us to conclude that the mean scores of the hypothetical populations behind the empirically obtained scores are different at pre- and post- intervention and that the participants have changed in a significant way following treatment.

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<sup>12</sup> She refused medication during treatment and was told that the psychology department would not offer her further treatment after the current intervention. This caused her to launch a complaint against the department as she reported to feel unable to cope without psychology sessions.



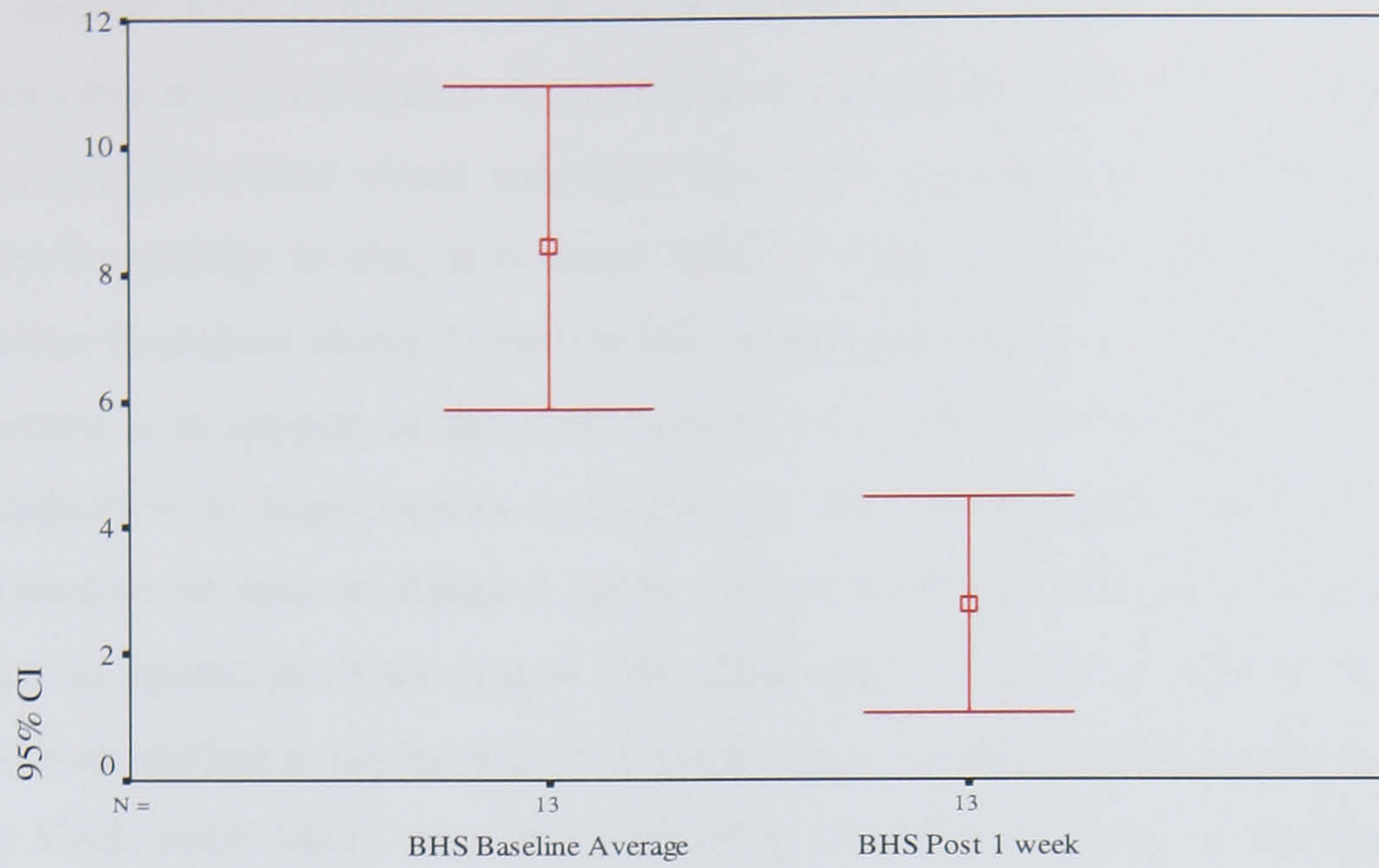


Figure 6A. BHS CI at baseline and 1 week follow-up.

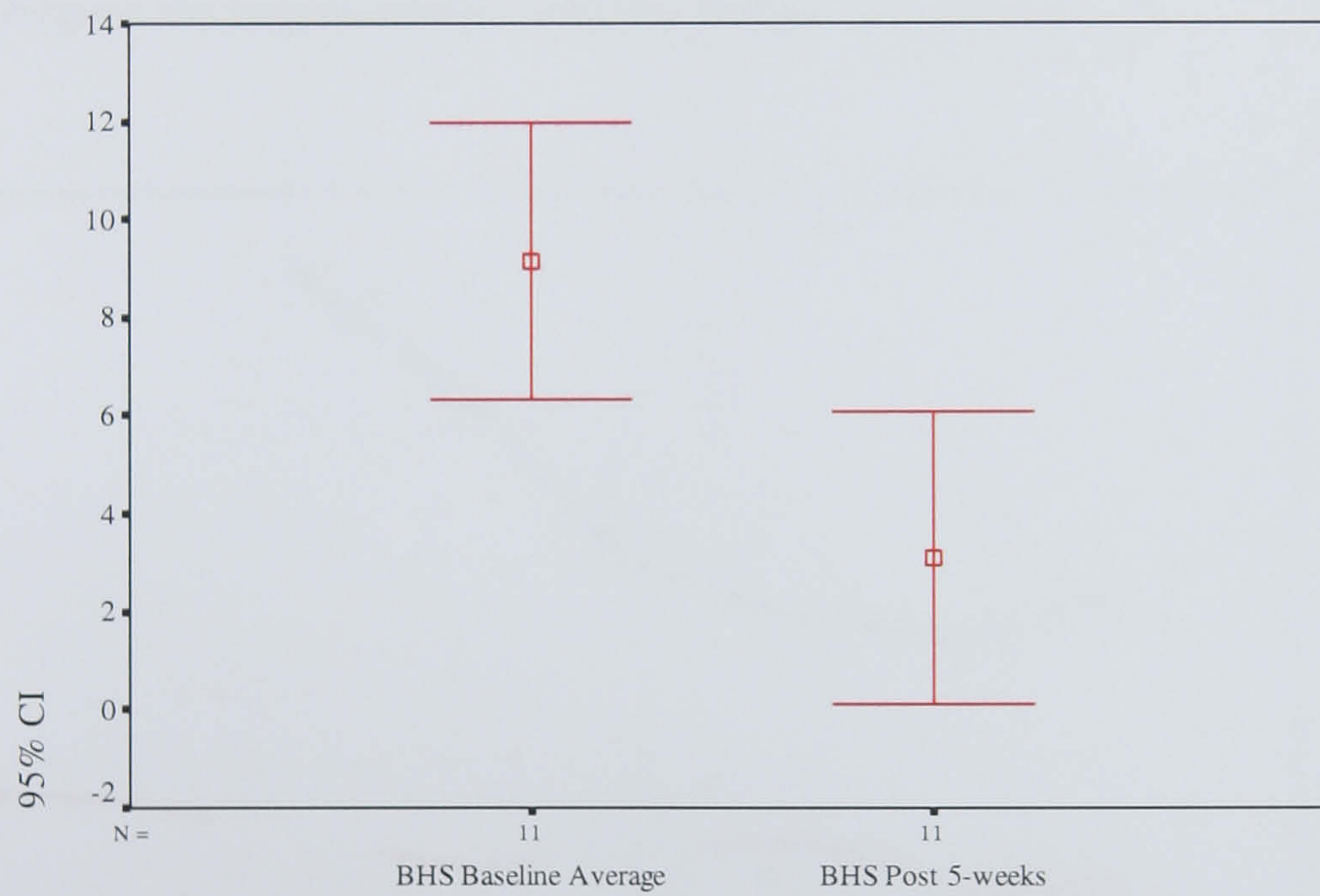


Figure 6B. BHS CI at baseline and 5 weeks follow-up.

The BHS scores are broadly replicated on the relevant VAS which, for presentational reasons, will be reported here by significance levels and effect sizes alone. When comparing VAS scores recorded at treatment session 1 ( $M = 40.31$ ,  $SD = 31.721$ ) with 1-week follow-up scores ( $M = 17.69$ ,  $SD = 19.687$ ), ( $t(12) = 2.732$ ,  $p < .018$ ) and when comparing session 1 scores ( $M = 42.18$ ,  $SD = 32.517$ ) with 5-weeks follow-up ( $M = 20.73$ ,  $SD = 18.183$ ), ( $t(10) = 2.512$ ,  $p < .031$ ) it is clear that the significance levels show a reduction in hopelessness as found on the BHS but to a somewhat



smaller degree. This is possibly reflecting that a drop in hopelessness had already happened after session 1 against which the post intervention scores are compared, or could be related to how visual analogue scales are completed by participants more generally. In relation to this, it is noted that the VAS approach did not register the BHS outlier described above. However the overall conclusion from the VAS data on hopelessness is in support of the results produced by the BHS as both scales show a stable reduction in hopelessness at follow-up. This concordance between the two scales can also be seen in figure 7 below, which illustrates that while two different scales are in operation (VAS max = 100, BHS max = 20), the general trend across, and post intervention is similar for the two measures. It can be gauged from the figure that the VAS, most likely as a result of being on a bigger scale, is showing what appears in the figure as a larger responsiveness. However the VAS scores broadly mirror the trend show by the BHS, which, in statistical terms, was shown above to have undergone the largest change from pre- to post intervention.

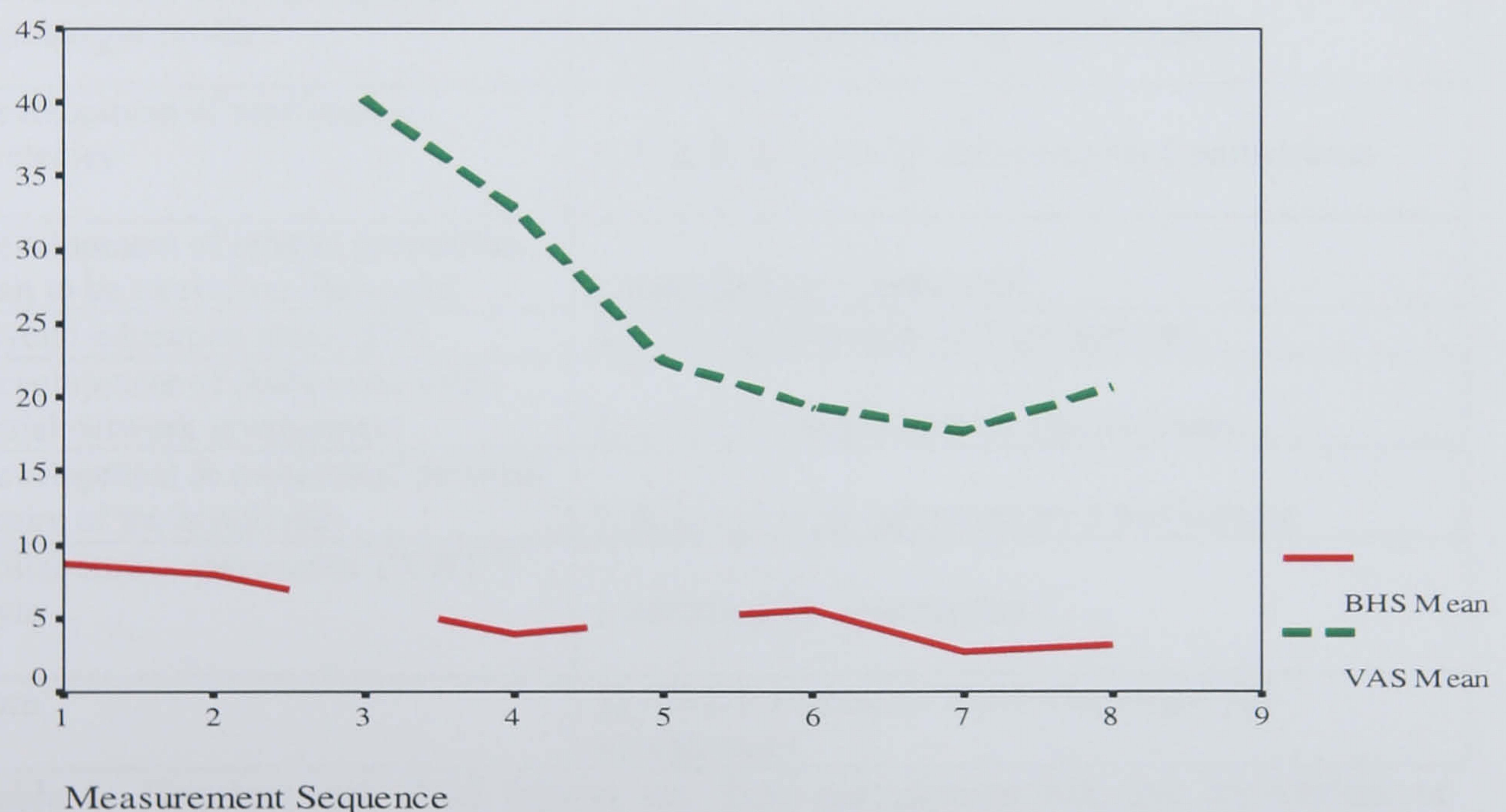


Figure 7. BHS and VAS for hopelessness with weekly measurement points except from point 7 to 8 which was 4 weeks. Gaps in BHS graph occurs as this scale was not administered weekly during intervention.

This trend of similarity between measures continues when considering the effect or size of the VAS results, as Cohen's *d* equals .71 at 1-week follow-up and .66 at 5-weeks follow-up, showing a medium (Cohen (1992) defines medium effect sizes as being above .50) to large effect (ibid. defines a large effect as being above .80). These



are not the extremely large changes seen in the BHS data but do represent a considerable improvement and it should be recognised that the post treatment scores are being compared here to scores obtained after participants had received some of the intervention (treatment session 1). As such the VAS results add general support to the conclusion that a reduction in hopelessness has happened.

When considering the semi-structured interviews, 43 statements indicating change in hopelessness were made by 11 of the 13 participants; the two remaining participants did not make clear statements relating to hopelessness. All statements made were expressions of increased hope for the future and all were related to treatment factors as opposed to extra-therapeutic factors or unnamed factors. Table 1 below shows how the participants related change in hopelessness to various treatments factors.

| <b>Reason for improvement in hopelessness identified by client</b> | <b>Number of statements identifying the component as causal in the improvement made</b> |
|--|---|
| Development of early warning sign/trigger profile                  | 1, 1, 2, 2 = <u>6</u> statements by 4 participants                                      |
| Development of new coping strategies                               | 1, 1, 2, 2, 3, 1, 3 = <u>13</u> statements by 6 participants                            |
| Development of relapse prevention plan to be carried on flash-card | <u>1</u> statement by 1 participant   |
| Psycho-education about BPD   | 2, 1, 3 = <u>6</u> statements by 3 participants   |
| Development of skills to do with social network involvement        | 2, 1, 1, 2 = <u>6</u> statements by 4 participants                                      |
| Development & ownership/ personal nature of the handbook           | 1, 4, 1, 1, 3 = <u>10</u> statements by 5 participants                                  |
| Collaborative therapeutic (“CBT”) style                            | <u>1</u> statement by 1 participant   |
| Sum  | <u>43</u> (19/24) statements identifying improved hopelessness                          |

Table 1. Hopelessness. Bold figures are from participants who are ambivalent or positive towards the idea of having future mania episodes.

As can be gauged from table 1 the 11 participants who indicated that a reduction in hopelessness had taken place, also broadly identified as causal in this improvement the components of the TIM (represented by the early warning sign/trigger profile, new coping strategies, psycho-education, social network involvement and the handbook) designed to target the four pathways to illness as predicted by the instability model of relapse (please see Chapter One).



It is also interesting to note that all five participants who were ambivalent (N = 3) or explicitly indicated that they were positive towards retaining the experience of manic episodes in their lives (N = 2)<sup>13</sup>, reported an improvement in hopelessness and that they all mentioned the development of new coping strategies as causal in this improvement. In contrast, the participants who were clearly negative about having manic episodes were more evenly spread across the categories of treatment components when considering what worked to reduce hopelessness.

Looking closer at the BHS and VAS data on hopelessness reported above, the possible difference between participants who are positive/ambivalent and negative towards mania respectively can be further supported as illustrated by figure 8 below.

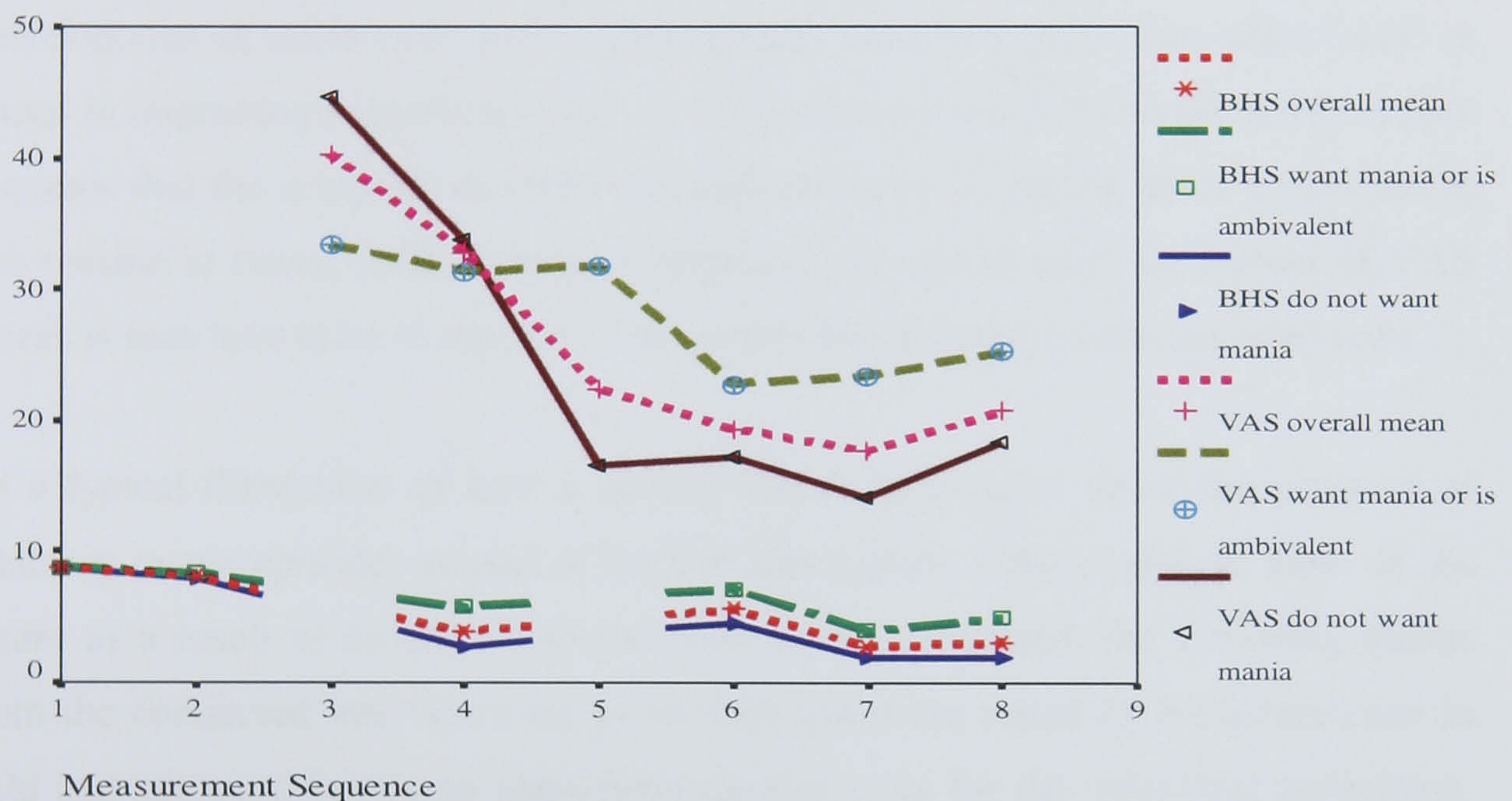


Figure 8. Sequence of BHS and VAS for hopelessness. Means with weekly measurement points except from point 7 to 8 which constitutes 4 weeks. Gaps in the BHS sequence occur because measurements were not taken weekly.

Figure 8 shows how the BHS patterns at the bottom of the display appear very similar and therefore independent of attitudes to having manic episodes in the future. However when considering the VAS graphs at the top of the display, it appears that reduction in hopelessness in one subgroup is mirrored by stability in the other and visa versa. The participants with a negative attitude to having future manic episodes show a steep drop in VAS hopelessness during the first three sessions after which they appear to hit a “floor-effect” and hopelessness remains largely unchanged until the

<sup>13</sup> The figures were confirmed in the questionnaire and did not change during treatment.



follow-up measurement points. This could be interpreted as an indication that treatment elements experienced in all intervention sessions can potentially help to reduce hopelessness and is in accordance with the interview material for this subgroup of participants as represented in table 1. For the positive/ambivalent group of participants the significant drop in hopelessness scores on the VAS did not occur until the measurement taken after session 4 (measurement point 6 in figure 8) and it appears that this group of participants either needed to have the full range of coping strategies in place, which occurred and was summarised in session 4, or that their degree of hopelessness was particularly effected by the remaining content of session 4.

As only one positive/ambivalent participant mentioned the main content of session 4 (development of skills to do with social network involvement and the action plan) as causal in improving hopelessness during the interviews, the most likely interpretation becomes that the complete development and summary of coping skills conducted in this session is causal in the improved hopelessness and as such the pattern of VAS scores is seen here to be in support of the results found in the conducted interviews.

As a typical illustration of how a person who is ambivalent about the prospect of retaining manic episodes as part of her life also reports a more positive view on the future as a result of having developed new coping strategies, the following quotes from the conducted interviews are given with questions posed by the interviewer in bold and accompanied by an identifying number code for the individual participant. As with all interview quotes in this thesis, some minor narrative smoothing has taken place to enhance the readability and italics are used to indicate an expression of emphasis.

From 61's pre-intervention interview:

**“If possible would you choose never to become manic again?”**

That's a really hard one.... I suppose it would be good if I was planning a family, then I definitely never want it to happen again, but if it turned out that I was always single then I wouldn't mind it [laughs], you know, it would be quite good... I don't know...

**It is quite difficult to decide?**



It is a bit hard, yes”.

From 61’s post intervention interview:

“On my first day [in treatment], I was so nervous about what I was going to find out about bipolar, I was just petrified, you know, because I thought “God I don’t know anything about it, I only know that it is bad”, you know, “and I know that Lithium is like a hardcore drug” [laughs], “and I don’t want to hear anything else” [laughs].

**Yeah.**

But now that I know... I don’t know, it is kind of like a softer approach, you know, you think “I’m getting a bit excited” or whatever “I will maybe listen to this type of music” or do something else, you can control it so much, you know, so much easier now.

**Yeah.**

And it’s just umm, not so scary to look ahead anymore”.

A greater number of treatment components are reported to have reduced hopelessness for the participants who did not want mania in their lives and the following quotes show how several elements of treatment were seen as causal in improving their hope for the future.

From 51’s post intervention interview when discussing which elements of treatment caused changes that may last into the future:

“I think just contemplating it with you... there has been quite a few useful things that I have thought “yeah”. Particularly doing the depression stuff where I have doubted control over having depression or not having depression in the past. Thinking about my limitations and about how I interact with people around me at that point in time and... I sort of... you made me consider it in a different way and I think that was useful, because now, should I be ill again, I should hope that I would be more equipped to deal with it, or I *would* deal with it differently now, and my partner would know how to deal with it.

**Yeah so do you feel that you have a better chance of coping with it?**

Yeah, well I don't know until I've tested it, but yeah I would say that's how I feel now, I would like to try some things that you suggested, like doing more physical exercise, and... I am being more aware and preparing myself sort of, where I am? and what I am doing? That is something I have never done in the past and it has led to extended periods of depression and hopefully if I were to be ill again, I will be able to deal with the depression side of it better.

**Ok... has anything happened in your life outside of therapy to make you rethink these things?**

Not really no, just normal, normal events”.

Similarly from 41's post-treatment interview:

“It has given me a bit of a kick start coming here in saying to myself “yep you *can* maintain wellness, you can obviously learn how to cope with it better”... I would have preferred if we had done these sessions when I initially became ill, all those years ago, but then it was “fair enough you have been in hospital right, now go out into the world, we are not going to give you any coping strategies for what you have just been through or things to look out for, but we are going to drug you up anyway so you will be ok”. I wish we could have done a course like this then, it would have given me the necessary tools and the skills to cope.

**So the coping strategies and the early signs stuff we have been doing here it might have improved your ability?**

Yeah, yeah and in just like planting the seed... and then when new contributing factors arise as I get older, then I can obviously tick more boxes [in handbook] and re-address which ones are now early signs and which aren't anymore and then you can know those things so well that you can spot them instantly”.

And when addressing the same area of interest at a different time of the interview:

“I recognised [in treatment] key areas which will obviously come into effect through building up of a sort of small portfolio, cards type thing that I can obviously carry around and that... that I can hopefully put into practice whenever things go awry”.

Finally it is noted that the only participant (22) who did not show improvement on the BHS and therefore showed up as an outlier in the post intervention data (but not on



the VAS) expressed her subjective take on developments in hope for the future in the following manner:

“Now [after treatment] I am sort of more positive, I am thinking “oh yes something is happening now” so I am looking forward more and not so negative. In a way I am thinking “I could possibly get something out of this [points to handbook], it is really, really going to help me” and I hope it will, and it has done so far”.

As such it appears that at least some hope that things could be different and better for her in future has been installed in this participant via treatment even if this does not register on the BHS.

### **3.2.1.1 Summary of hopelessness results**

The triangulation of various sources of information on developments in hopelessness across and following the intervention supports the overall conclusion that a reduction in hopelessness happened as a result of treatment. This was directly supported by data from interviews, the BHS and the relevant VAS. Further, none of the participants identified extra-therapeutic factors as causal in this improvement when asked but rather focused mainly on the treatment elements constituting the TIM as the factors involved in reducing hopelessness.

It is also noted that while two participants did not give any information on hopelessness in their interviews and one did not register any improvement on the BHS, no participant showed lack of progress in hopelessness on more than one data collection instrument (VAS, BHS or interviews). This firstly shows the inadequacy of using just one data source and secondly gives an indication that hopelessness may in fact have been reduced to some degree for all participants.

Finally it was noted that participants who were ambivalent or positive towards having manic episodes in future all mentioned the development of new coping strategies as causal in reducing their hopelessness, whereas participants who did not want to have manic episodes in future generally pointed to more elements of treatment as important for their improvements in hopelessness. This pattern of results was supported by the developments in VAS scores across treatment as illustrated in figure 8 above.

### 3.2.2 Perceived Control of Internal States

Measures of how much control participants perceive to have over their internal states were obtained using the PCOISS, the relevant VAS and were also explored in the conducted interviews.

As with the BHS, a baseline of the PCOISS was established using the two measurements obtained before the intervention began and a high degree of stability between these pre-intervention measurements was found. This stability can be shown by a paired samples t-test comparing the two-weeks pre-intervention scores ( $M = 42.54$ ,  $SD = 9.070$ ) and the one-week pre-intervention scores ( $M = 43.08$ ,  $SD = 9.332$ ). This t-test ( $t(12) = -1.620$ ,  $p < .131$ ) illustrates that no significant difference existed between the two baseline measurements and the mean of these two measurements will be used in the following analyses in order to get the most accurate basis for comparison with developments in the scores obtained post treatment.

When comparing the mean baseline PCOISS score ( $M = 42.808$ ,  $SD = 9.182$ ) with the measurement taken one week post treatment ( $M = 58.920$ ,  $SD = 10.428$ ) a highly significant increase in the perceived ability to control internal states is found ( $t(12) = 4.763$ ,  $p < .000$ ) leading to a large effect size (Cohen's  $d = 1.75$ ).

This general result is sustained from baseline ( $M = 42.318$ ,  $SD = 8.675$ ) to 5-week follow-up ( $M = 63.27$ ,  $SD = 9.414$ ) ( $t(10) = 6.372$ ,  $p < .000$ ) with Cohen's  $d$  increasing to 2.42. The results are illustrated by figures 9A and 9B below together with figures 10A and 10B.

From the boxplots in figures 9A and 9B it is clear that the participants' PCOISS scores, as a whole, have improved, while the variability is largely unchanged or slightly reduced from baseline to the two follow-up measurements.

The outlier<sup>14</sup> shown in figure 9A entered the research project two days after leaving an inpatient ward where she had received treatment for an episode of depression. During the second half of the current intervention she varied between hypomanic states and depressive states in a rapid cycling pattern and was assessed by the local Consultant Psychiatrist for a possible re-admittance to the psychiatric ward on two separate occasions. The participant managed to complete the treatment and, as will be

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<sup>14</sup> This is not the same participant who showed up as an outlier in the BHS data.



illustrated below, reported benefits in the form of absence of suicidal thoughts during the illness episode. Such thoughts had previously been a constant and repeated feature of her illness experience. It is further noted that she returned the 5-week follow-up pack and at that time did no longer register as an outlier in the data.

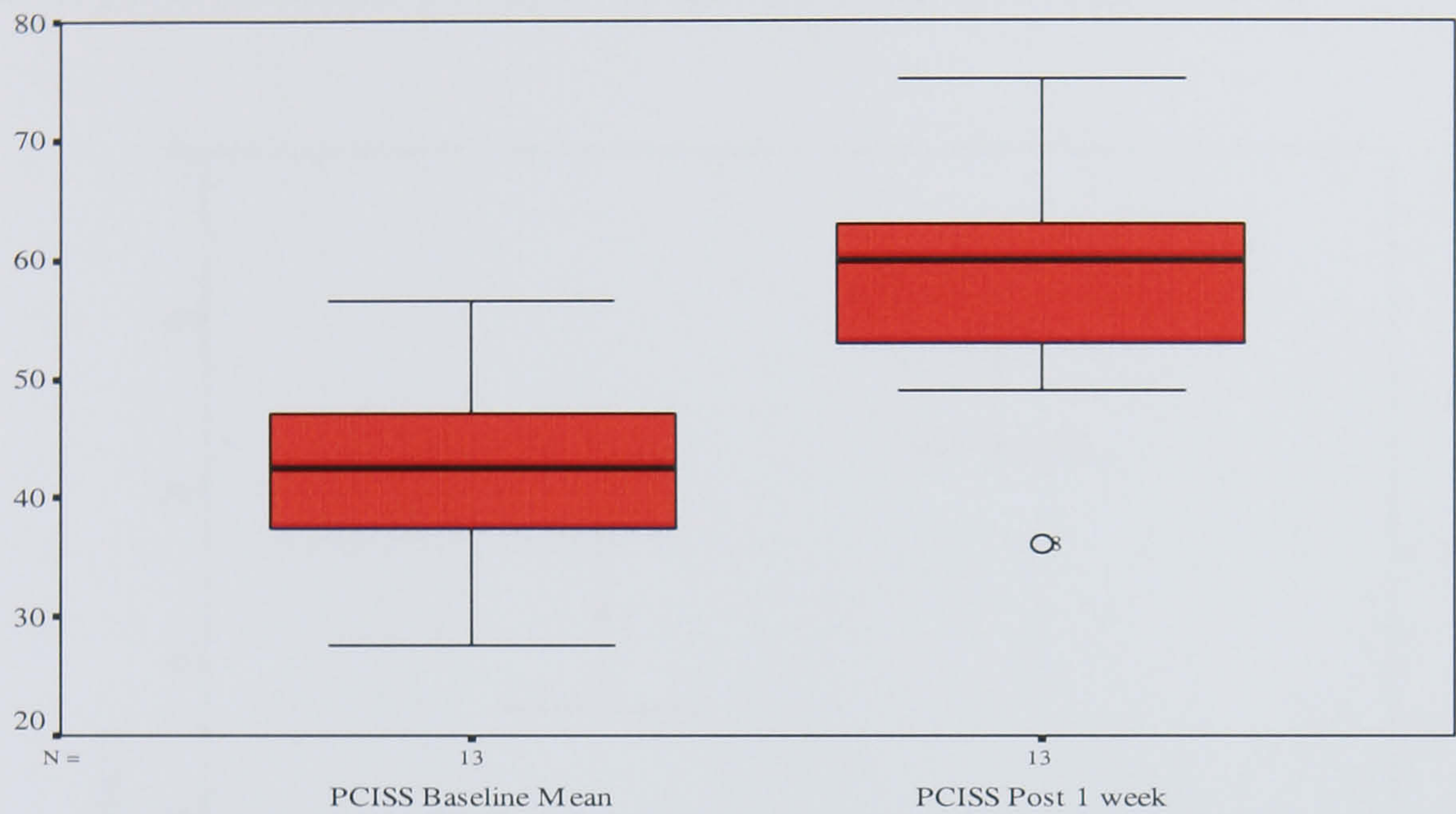


Figure 9A. PCOISS Baseline to 1-week follow-up (Mean at baseline = 42.808, Median at baseline = 42.5, Mean post 1 week = 58.92, Median post 1 week = 60).

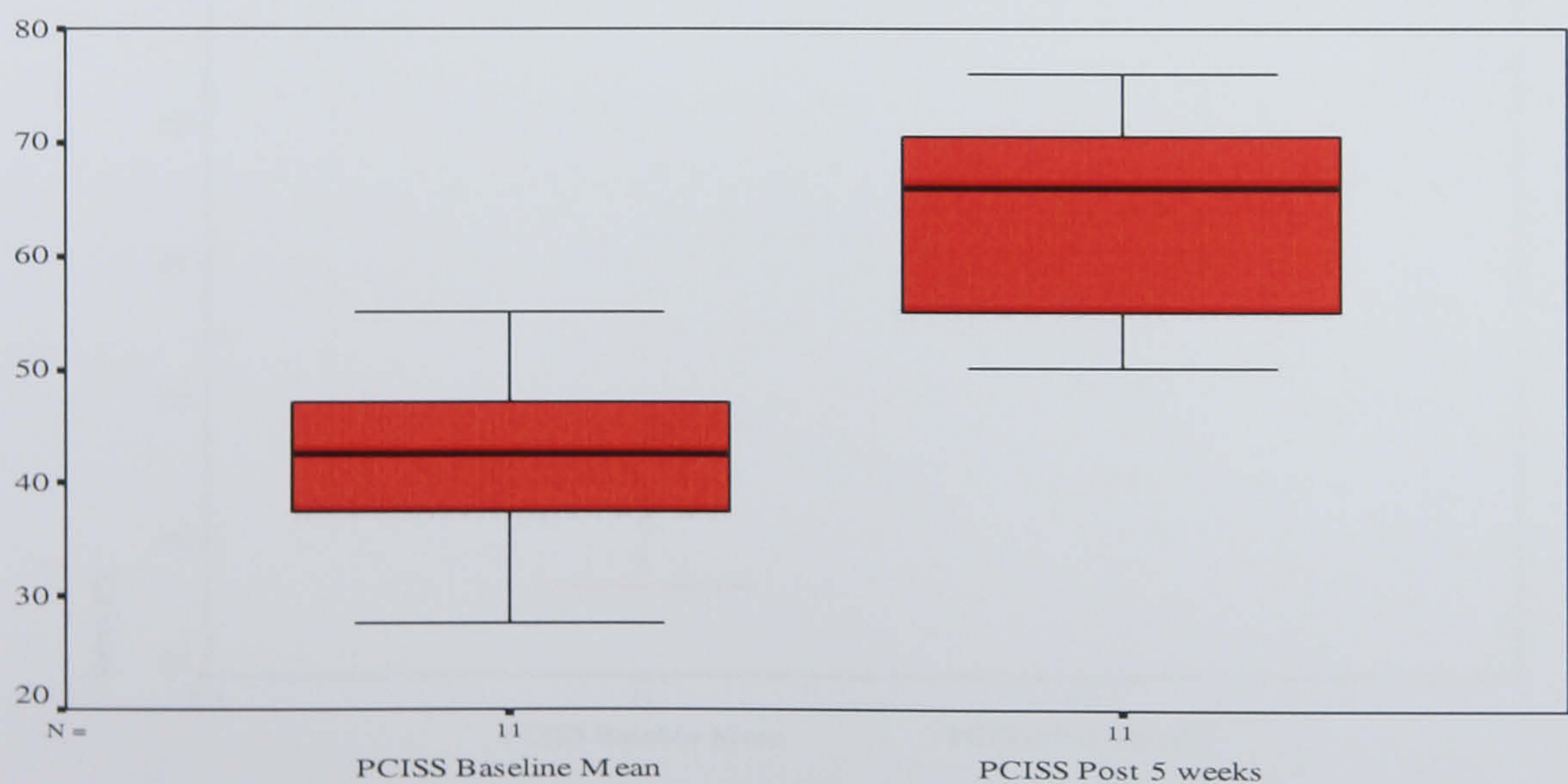


Figure 9B. PCOISS Baseline to 5-week follow-up (Mean at baseline = 42.32, Median at baseline = 42.50, Mean at post 5 weeks = 63.27, Median at post 5 weeks = 66.00).



Figures 10A and 10B below illustrate the 95% confidence intervals (CI) and the fact that none of the two post-intervention CIs overlap with the pre-intervention CIs. This enables us to conclude that the mean scores of the hypothetical populations behind the empirically obtained PCOISS scores are different at pre- and post- intervention and that the participants have changed in a significant way following treatment.

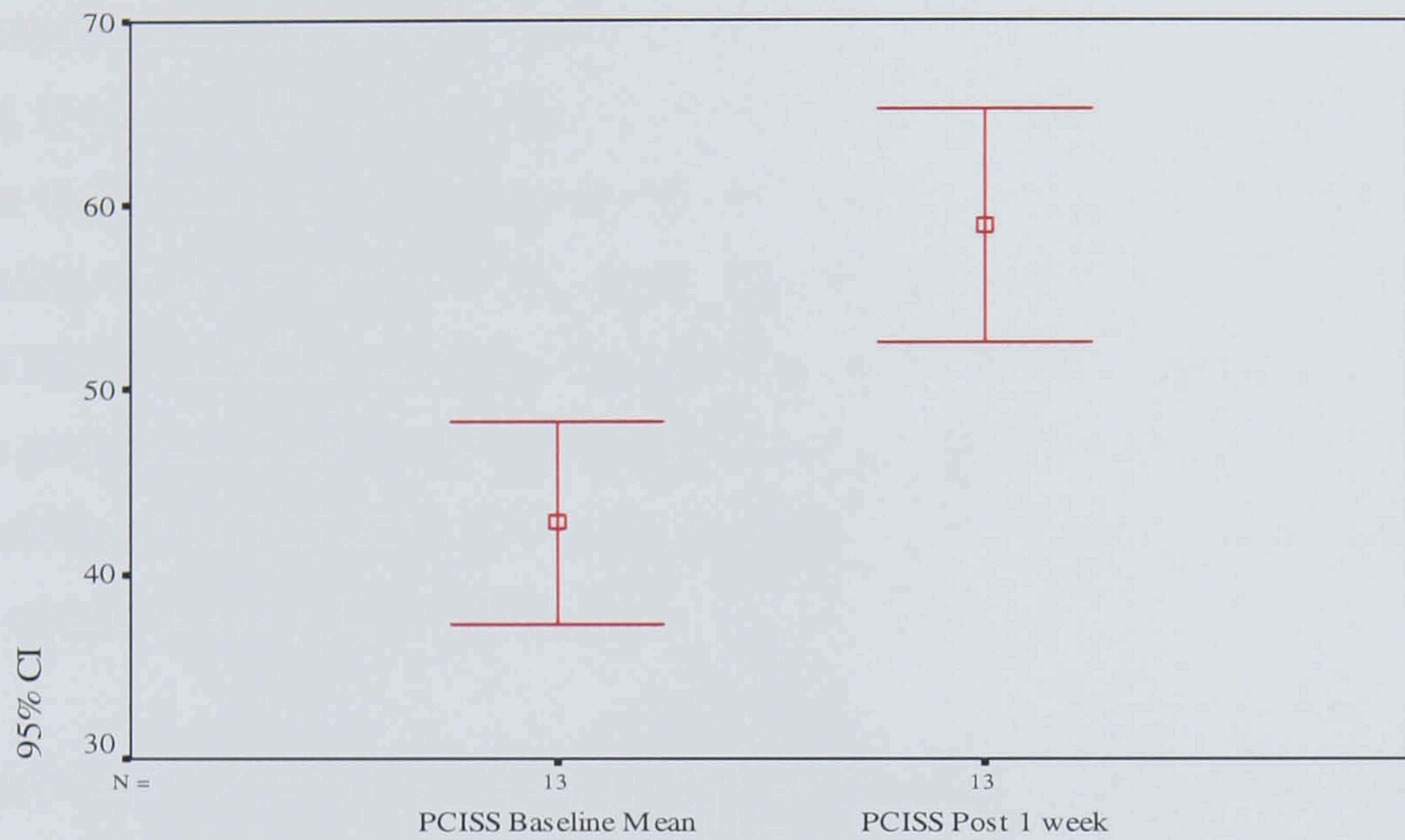


Figure 10A. CI at baseline and at 1 week follow-up.

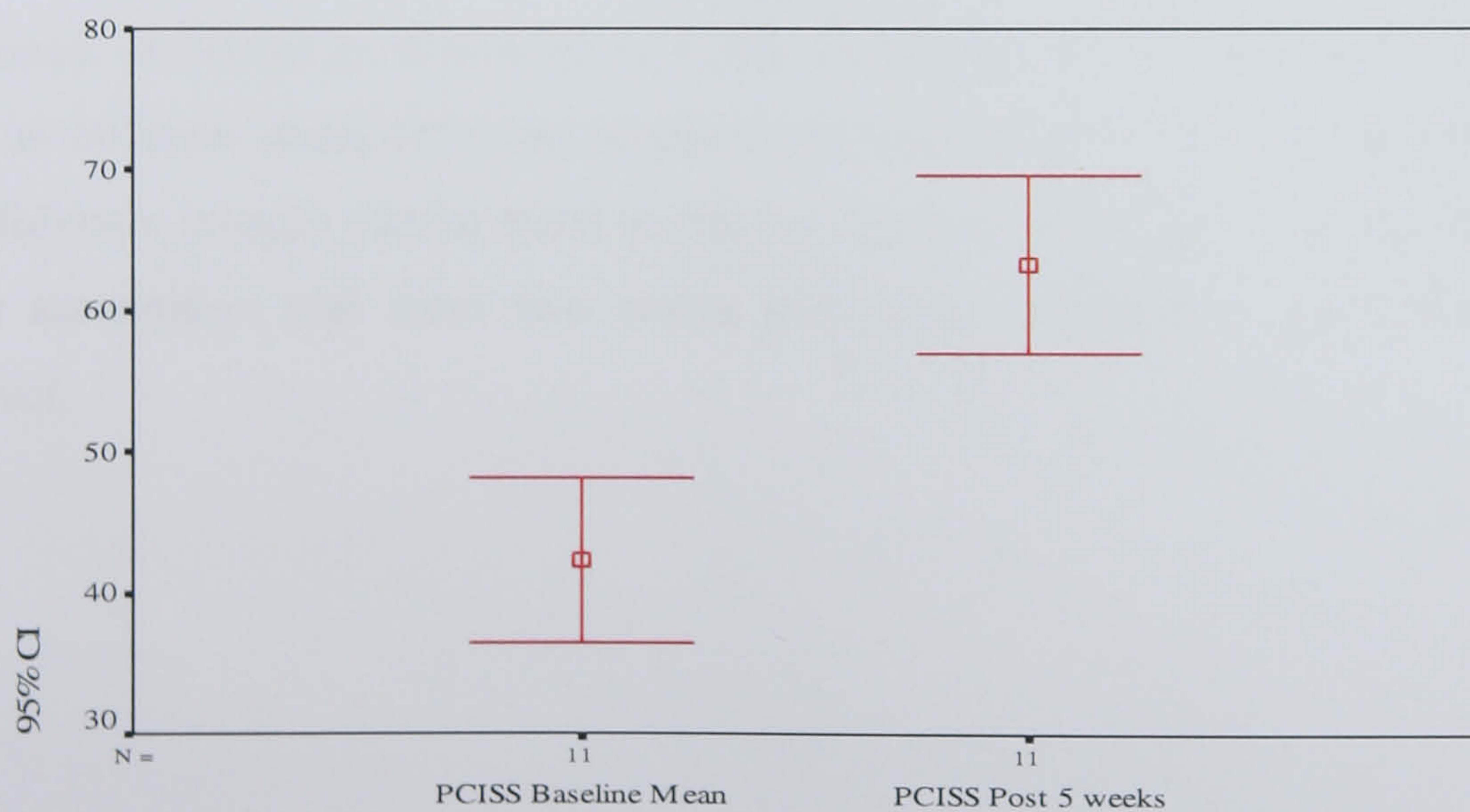


Figure 10B. CI at baseline and at 5 weeks follow-up.



The PCOISS results are broadly replicated on the relevant VAS, which, for presentational reasons, will be reported here by significance levels and effect sizes alone. When comparing VAS scores recorded at treatment session 1 ( $M = 46.00$ ,  $SD = 27.848$ ) with the 1-week follow-up scores ( $M = 73.54$ ,  $SD = 18.301$ ) a highly significant difference is recorded ( $t(12) = -3.986$ ,  $p < .002$ ) and a Cohen's  $d$  of .99 shows a large effect size. Similarly when comparing session 1 scores ( $M = 44.82$ ,  $SD = 30.334$ ) with 5-weeks follow-up scores ( $M = 72.00$ ,  $SD = 14.401$ ) the significance level remains roughly the same ( $t(10) = -3.800$ ,  $p < .003$ ) with an effect size of  $d = .90$  and it is clear that an increase, as found on the PCOISS, is also shown on the relevant VAS which is believed to tap into the participants' subjective assessment of their ability to control illness related states. It is also noted that the outlier observed in the PCOISS results reported above did not show up in the VAS data which indicated that the participant in question had experienced an increase in confidence with regards to her ability to control symptoms from 16 on the VAS at session 1, to 51 at 1-week follow-up and 68 at 5-weeks follow-up.

The VAS in question took the following form: "Please put a mark on the line below, marking how confident you feel in your ability to control the symptoms of Bipolar Disorder". In contrast to the construct measured by the PCOISS this is a specific question relating to BPD and the VAS's construct validity could reasonably be questioned. However as illustrated in figure 11 below, the PCOISS and the VAS, while on different scales (PCOISS scores range from 18 to 90, VAS range from 0 to 100), follow a broadly similar trend across the research period thus lending credence to the assumption that these two scales offer valid information about the same construct.



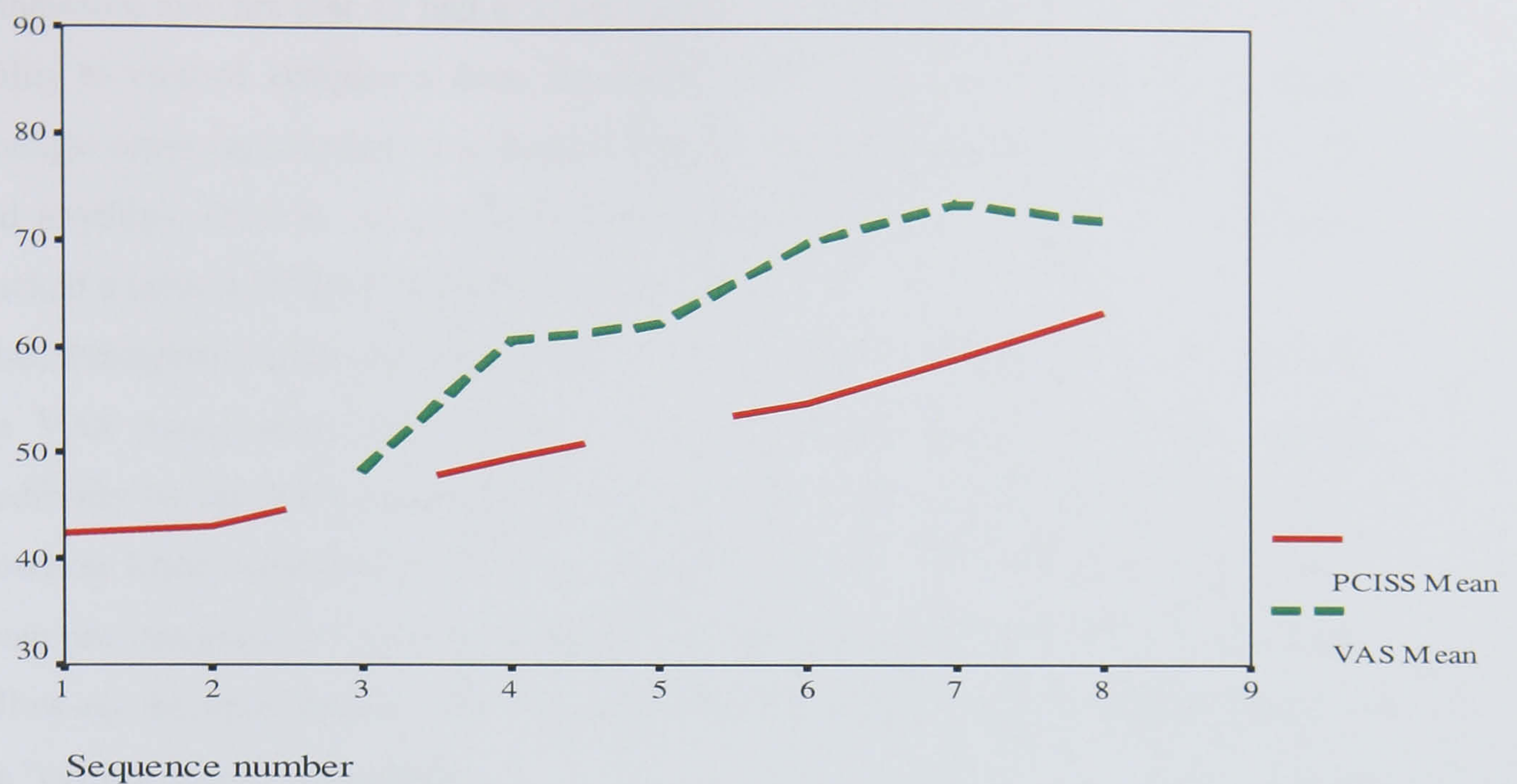


Figure 11. PCOISS and VAS for confidence in ability to control symptoms of BPD with weekly measurement points except from point 7 to 8 which was 4 weeks. Gaps in PCOISS graph occurs as this scale was not administered weekly during intervention.

When considering the semi-structured interviews, 105 statements indicating change in perceived ability to control symptoms were made by 12 of the 13 participants. The participant (42) who indicated that no change had taken place explained at her pre-intervention interview that she was already fairly confident in her ability to control symptoms:

**“So how confident are you that you will be able to keep the symptoms of bipolar disorder under control in the future?”**

Quite confident.

**Quite confident?**

Yeah”.

This had not changed at the post-intervention interview when asked:

**“How confident are you that you can control symptoms in the future?”**

Fairly confident”.



It therefore appears that 42 had a “quite” or “fairly” high degree of confidence in her ability to control symptoms from the outset, which was a characteristic not found amongst other participants. It is therefore possible that the current treatment does not add anything extra to the confidence of individuals whose confidence has already reached a certain “ceiling” before treatment commences.

Also, throughout the research period 42 showed a stable and high rating pattern across the VAS assessments of her own ability to control symptoms, thereby adding credibility to the interpretation that a ceiling effect had been observed in this case. However when considering 42’s PCOISS scores, which were gradually raised from a mean pre-treatment score of 55 to scores of 63 at 1-week follow-up and 76 at 5-weeks follow-up, an improvement does appear to have taken place and some doubt is cast on the “ceiling effect” explanation.

The collected data for 42 does not lead to any firm conclusions and the possibility of a ceiling effect for the ability to control symptoms/internal states may need to be answered in future research. At present it is unclear how an improvement in perceived control over internal states generally, as measured on the PCOISS, could have occurred within the timeframe of the current study without accompanying improvement in perceived control over internal states related to BPD as these were measured and explored on the VAS and in the conducted interviews. The main lesson from 42’s data is that more research is needed in relation to treatment efforts with people who report moderate or high degrees of confidence in their abilities to control symptoms prior to intervention.

The remaining 12 participants attributed 98 of 105 statements of enhanced confidence in ability to control symptoms to treatment factors (table 2 below) and the 7 remaining statements were not attributed to any particular cause. It is also noted that none of the participants described a reduced confidence level.



| <b>Reason for change in confidence about ability to control symptoms</b>                           | <b>Number of statements identifying the component as causal in the change a participant reports</b> |
|--|---|
| Development of early warning sign/trigger profile  | <b>1, 2, 2, 1, 1, 2, 4 = 13</b> statements by 7 participants  |
| Development of new coping strategies   | <b>1, 2, 3, 4, 5, 1, 2, 2, 2, 2, 3, 5 = 32</b> statements by 12 participants                        |
| Development of relapse prevention action plan to be carried on flash-card                          | <b>1, 1, 1, 2 = 5</b> statements by 4 participants  |
| Psycho-education about BPD   | <b>1, 3 = 4</b> statements by 2 participants  |
| Development of skills to do with social network involvement  | <b>1, 1, 1, 2 = 5</b> statements by 4 participants  |
| Development & ownership/personal nature of the handbook  | <b>1, 1, 3, 3, 5, 1, 1, 1, 2, 4 = 22</b> statements by 10 participants                              |
| Collaborative therapeutic (“CBT”) style  | <b>1</b> statement by 1 participant   |
| Skills developed in treatment has been seen to work at the time of the post intervention interview | <b>1, 1, 1, 2, 1, 1 = 7</b> statements by 6 participants  |
| Intervention component targeting sleep problems directly   | <b>2, 1, 3 = 6</b> statements by 3 participants   |
| General expressions of change in confidence without direct mention of cause for this               | <b>2, 1, 1, 1, 2 = 7</b> statements by 5 participants   |
| Sum  | <b>105 (46/59)</b> statements identifying improved confidence in ability to control symptoms of BPD |

Table 2. Confidence in ability to control symptoms. Bold figures are from participants who are ambivalent or positive towards the idea of having future mania episodes.

As can be gauged from table 2, the 12 participants who indicated that an increase in confidence about symptom control had taken place gave various reasons for this and all treatment elements contained in the TIM were mentioned in the interviews. However the participants focused their attention on three main factors; the development of new coping strategies (mentioned by all 12 participants), the handbook (10 participants mentioned this) and to a lesser degree the development of an early warning sign/trigger profile (mentioned by 7 participants). The remaining factors such as the action plan, the targeting of sleep problems and the development of



skills to do with increasing the social network involvement in coping, were seen as important by a smaller number of people without a definite pattern emerging. It is however noteworthy that the psycho-educational element of treatment was only mentioned by two participants and that this aspect of the intervention is generally not seen as important for the confidence with regards to symptom control by the majority of participants.

Further the table does not reveal any obvious difference between participants who were positive/ambivalent about future mania and those who categorically did not wish for such episodes. However considering figure 12 below a somewhat different trend for the VAS results is observed.

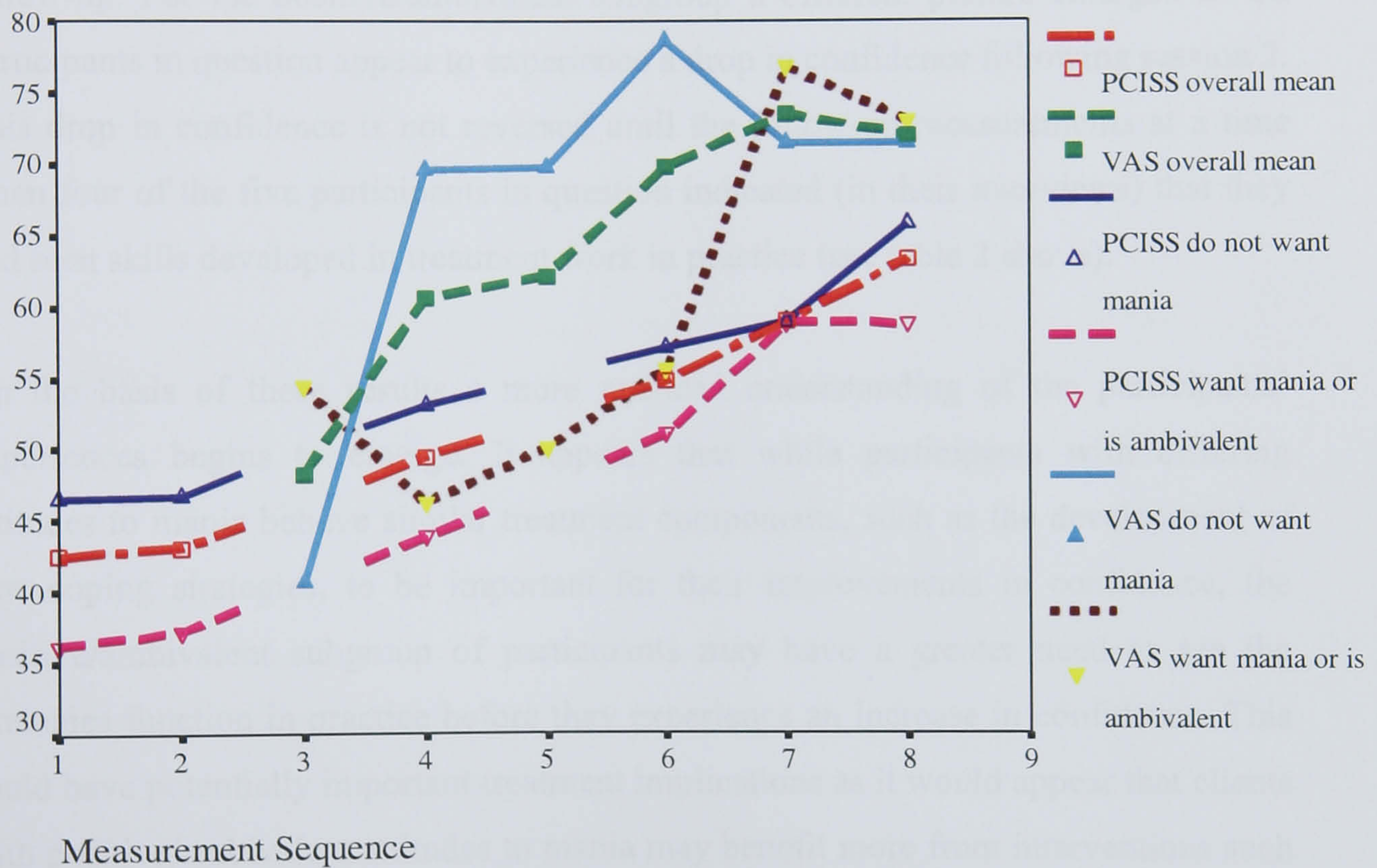


Figure 12. Sequence of means for PCOISS and VAS for confidence in ability to control symptoms with weekly measurement points except from point 7 to 8 which constitutes 4 weeks. Gaps in the PCOISS sequence occur because measurements were not taken weekly.

When considering the figure it is important to keep in mind that the two depicted measures are on different scales (PCOISS range from 18 to 90, VAS from 0 to 100) and that any direct comparison between them must be restricted to an assessment of general trends. As can be seen from the two overall means in the figure, a steady increase in perceived control over symptoms/internal states takes place across the



whole treatment period and is stabilized or still improving between follow-up measurements.

When considering the two subgroups defined by their attitude to future manic episodes, the PCOISS data does not give reason to think that a difference between the groups exists. However, as was the case for hopelessness, the VAS data suggests that the increase in confidence may have been achieved in somewhat different ways by the two subgroups of participants. For the participants who do not want mania in future the VAS graph illustrates a rapidly raising confidence after a comparatively low starting point immediately after session 1 (psycho-educational session), followed by a relatively small drop in confidence before stability in confidence is finally observed at follow-up. For the positive/ambivalent subgroup a different picture emerges as the participants in question appear to experience a drop in confidence following session 2. This drop in confidence is not reversed until the follow-up measurements at a time when four of the five participants in question indicated (in their interviews) that they had seen skills developed in treatment work in practice (see table 2 above).

On the basis of these results a more nuanced understanding of the participants' experiences begins to emerge. It appears that while participants with differing attitudes to mania believe similar treatment components, such as the development of new coping strategies, to be important for their improvements in confidence, the positive/ambivalent subgroup of participants may have a greater need to see the strategies function in practice before they experience an increase in confidence. This could have potentially important treatment implications as it would appear that clients with positive/ambivalent attitudes to mania may benefit more from interventions such as CBT-style behavioural experiments, compared to clients who are clearly negative towards experiencing mania and who do not appear to have the same requirement for "in vivo" experience of the treatment benefits in order to raise the confidence in their personal ability to control symptoms.

Further it is noted that both the results reported immediately above and the hopelessness results reported in section 3.2.1, show a tendency for improvements to come about later in the treatment process for the positive/ambivalent participants compared to the participants with a negative attitude to mania and it is clear that knowledge about this pattern may constitute a valuable insight informing the

expectations of clinicians who may otherwise come to a premature conclusion that treatment has been ineffective for a particular client.

When considering the interview material a more nuanced understanding of the PCOISS outlier (participant 12) reported above is also made possible and her post intervention interview enables an illustration of how she, despite having very recently experienced a lack of control over her internal states in the form of a rapid cycle of illness episodes, was able to look to elements of the treatment as tools that could potentially improve her ability to control future symptoms:

**“Have you experienced any change in your confidence about being able to cope with the symptoms?”**

Yes I think so”.

And further:

**“What about your confidence in being able to help yourself in the future? Not going down or going up?”**

Well I shall certainly try. By keeping this [touches handbook] and reading it quite often, I think I will recognise the signs”.

And a little later on the same topic:

“Well certainly the folder is very useful and I think I shall keep it by my chair and look at it from time to time, especially if I start feeling I’m going high.

**So to have something to take from treatment to use in the future that’s another important thing?**

Yeah, yeah and in the past I have tried to commit suicide twice, but funnily enough during this bad patch I would say that I was worse than I’ve ever been before, I never had any suicidal thoughts at all. Not at all”.

As can be seen from the quotes given above, 12 does not express in any direct manner how her confidence has changed but by mentioning the future use of the handbook and the importance of this, together with the observation that she has not been suicidal



despite going through a very difficult time with many bipolar symptoms, she does seem to hold out more hope for an improved ability to control symptoms in the future.

As previously mentioned the participants focused their attention on three main factors for the improvement of confidence in ability to control symptoms: the development of new coping strategies, the handbook and the development of an early warning sign/trigger profile. The expressions of individual participants are used below to illustrate the importance of these factors and it is noted that all the individual quotes have been selected because they are judged to represent the attitudes of the remaining participants who mentioned a particular treatment element as important.

From 31's post intervention interview when considering the development of new coping strategies and the impact this has had on his confidence with regards to symptom control:

“There are things I can do now I am aware of which symptoms could cause me to get worse... I can do a lot myself now that I never thought I could, I let it happen”.

And a few seconds later on the same topic:

“I feel different about it, I feel hopeful, really.

**That is good.**

Yeah really, very good... Yeah I am really pleased, I am feeling excited inside about it and the possibilities...I just used to hide, run away, sit in the house but I have started going out and doing things and I am planning on going to the gym”.

A somewhat different take on the same issues is represented by 61 below who, during treatment, had made many changes to the way he approached and coped with his highly demanding job:

“The act of making choices about cancelling trustee meetings, about leaving work early, about not caring if you are meeting deadlines touch on deeper issues of self-identity and inner being and how confident you are.

**So it is all connected?**

Yeah they are connected and I think, why I found this [treatment] particular useful is as a way to get to the deeper stuff, like you are making choices about things you can do, you can act on...I can make those choices.

**Ok, so are you confident that you will be able to control the manic-depression in future?**

Umm, fairly confident and... well, I am not a hundred percent confident, but I have learnt, exceptionally well in fact, to cope and to lead a largely normal life, but I wouldn't say that I am confident that it would never happen again".

This optimistic but also realistic assessment of future prospects with regards to symptom control is echoed by 22 when describing the handbook's impact on her confidence relating to symptom control:

**“Has anything happened with your confidence about your ability to control symptoms?**

Umm I suppose it has improved some, not completely, I wouldn't say completely, but I've got no fears or anxieties about it at all... I think now, because I've got the information written down for me and if I get a bit depressed and I can't remember what I said, I will look that up, pick something off my list and think “I will do that today” [laughs] “that will be my task...and I will feel better [laughs], hopefully”.

**Yeah, yeah so having that sort of...**

It's kind of a back-up system and I had nothing before”.

From 32's post intervention interview when considering the development of the early warning sign/trigger profile and the impact it has had on his confidence with regards to his ability to control symptoms:

“I feel a lot more confident.

**Ok.**

Yeah... I feel as if I'm quite a confident person all round really.

**And is that something that has changed?**

Yeah, yeah. A lot.

**How do you explain that?**



It's understanding it now, more... Someone's taken time out to explain it bit by bit, you know... and to know that when I start feeling something there is a reason behind that, and to delve a bit deeper and find out what the reason was in the first place. And then use the treatment to change it. I feel a lot more confident because I know a lot more".

Finally, the hypothesised greater need of people with a positive/ambivalent attitude to mania for experiencing the skills obtained in treatment to work in practice before a change in confidence occurs (as described above) is illustrated by the following quotation from 62's post intervention interview:

"I really liked that there was a week between sessions and a weekend as well, because it was a Friday we had the session and then you have the weekend, so time to relax and then put it to use for the whole week.

**You need time to test it out between sessions?**

Yeah, because I used to go home taking out all this stuff, you know, some weeks it would be on mania and I would be like "I wonder if I will get a bit manic and then I can test it out?" [laughs].

**Ok.**

But when I got depressed a couple of days ago I was like "cool how can I use this?"

[Both laugh]

It wasn't so bad, yeah.

**Yeah so you have used it already?**

Yeah and it worked wonders... It is very good.

**Do you think you will use it in the future?**

Yep, yeah I've got it in a file beside my bed.

**Ok.**

With all my other stuff... I do really think I will use it again, I think it is important to keep it because you just forget little things and it is the little things that count, like the sleep and you know...sometimes you just forget about it".

### **3.2.2.1 Summary of perceived control over internal states results**

The triangulation of various sources of information on change in perceived control over internal states and symptoms of BPD leads to the overall conclusion that the current treatment has had a highly significant positive impact on this aspect of the participants' experiences.

From data relating to the single participant who had a high degree of confidence about her ability to control symptoms before treatment began, it was hypothesised that the current intervention may not add significant benefits in the area of perceived symptom control when clients have a moderate or high perceived ability at the outset. However the various data sources were not in perfect concordance in relation to the participant in question and it was suggested that more research is needed in relation to treatment efforts with people who report moderate or high degrees of confidence in their abilities to control symptoms prior to intervention.

The 12 participants who indicated that an increase in confidence about symptom control had taken place, gave various reasons for this and all treatment elements contained in the TIM were mentioned in the interviews. However the participants focused their attention on three main factors; the development of new coping strategies, the handbook and to a lesser degree the development of an early warning sign/trigger profile, whereas the psycho-educational element of treatment was only mentioned by two participants and not generally considered important with regards to symptom control. The remaining factors such as the action plan, the targeting of sleep problems and the development of skills to do with increasing the social network involvement in coping were seen as important by a smaller number of people without a definite pattern emerging.

On the basis of results obtained in the interviews a reconsidering of the VAS data led to the interpretation that participants with a positive/ambivalent attitude to mania have a greater need to see strategies developed in treatment work in vivo compared to other participants before an effect in the form of improved confidence is seen. It also transpired that, as had been seen in the hopelessness results, the positive/ambivalent subgroup of participants had a tendency for improvements to come about later in treatment compared with the participants with a negative attitude to mania. Both of these findings are potentially important for the planning of interventions with



individual clients and for informing the expectations that clinicians should have when looking for progress in their clients.

### 3.2.3 Satisfaction and perceived usefulness of the intervention

The results reported previously in this chapter justify the conclusion that the applied treatment can effect positive change in hopelessness and perceived control over internal states, but in order to offer effectiveness and be a useful strategy in daily NHS practice, the treatment must also be resistant to high drop-out rates. This aspect of treatment is logically linked to client satisfaction and to the judgements about usefulness that clients make.

Data gained from the CSQ-8 and depicted in figure 13 below, illustrates the high level of satisfaction with the current treatment expressed by participants and that this satisfaction is largely stable and sustained from 1-week to 5-weeks follow-up. The CSQ-8 scores can range from 8 to 32 and Larsen, Attkisson, Hargreaves & Nguyen (1979, p. 202) defined CSQ-8 levels of satisfaction with the following categories: low satisfaction (8-20), medium satisfaction (21-26) and high satisfaction (27-32).

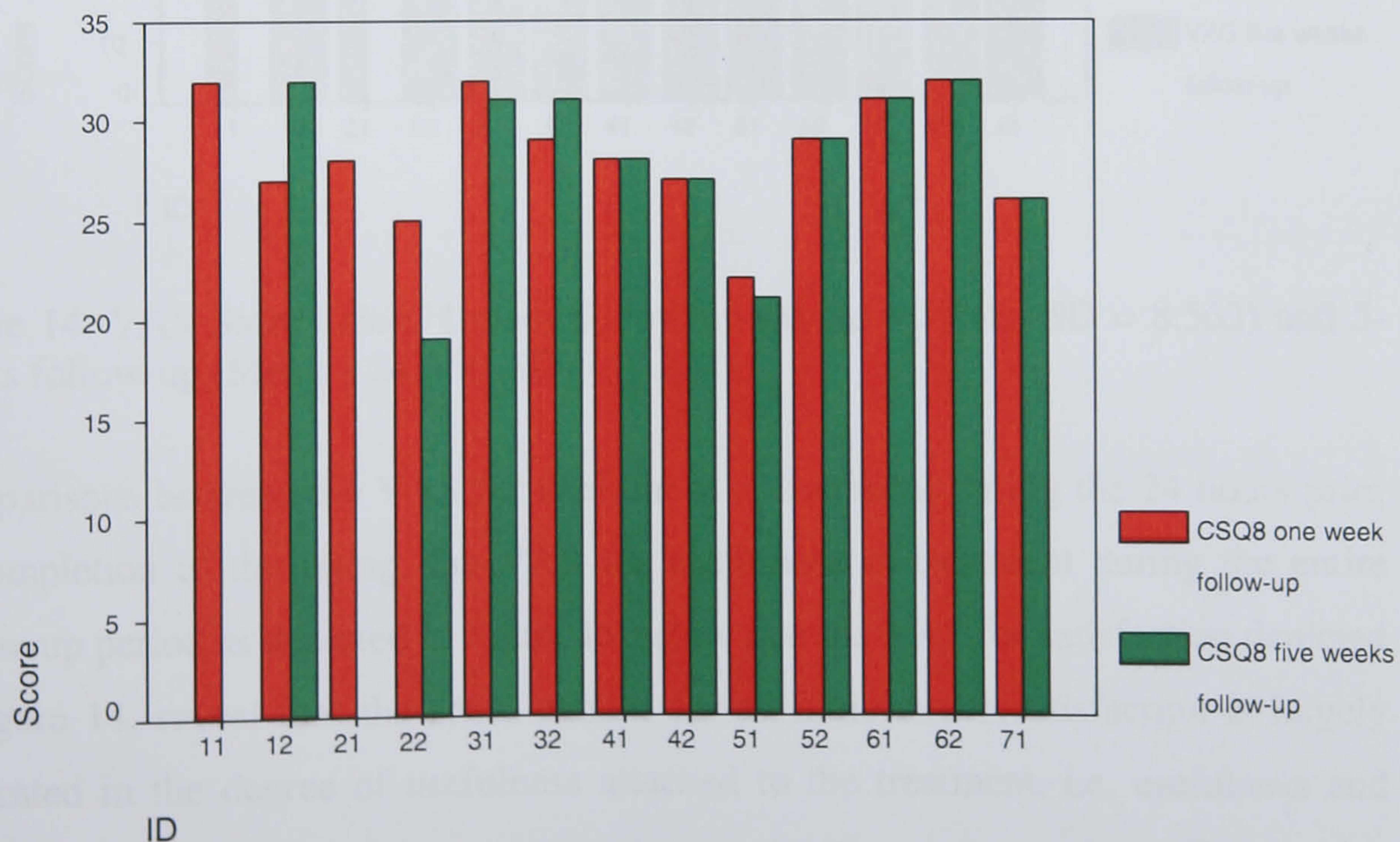


Figure 13. CSQ-8. 1-week follow-up (Mean = 28.31, SD = 3.011) and 5-weeks follow-up (Mean = 27.91, SD = 4.415).



It should be noted that the only participant (22) who produced a score below 20, is the outlier from the BHS data who had complained about the particular department in which the data was collected. It is possible that her 5-weeks follow-up rating of the current treatment was influenced by her general attitude or opinion of the department in which the intervention took place, as the 1-week follow-up score (collected before the perceived grounds to complain existed) was relatively high and as the ratings of the other participants were all fairly stable between follow-up measurements.

In general, the CSQ-8 show a high level of satisfaction with the current treatment and it is further noted that these results are closely mirrored by the VAS data for satisfaction with the treatment as represented in figure 14.

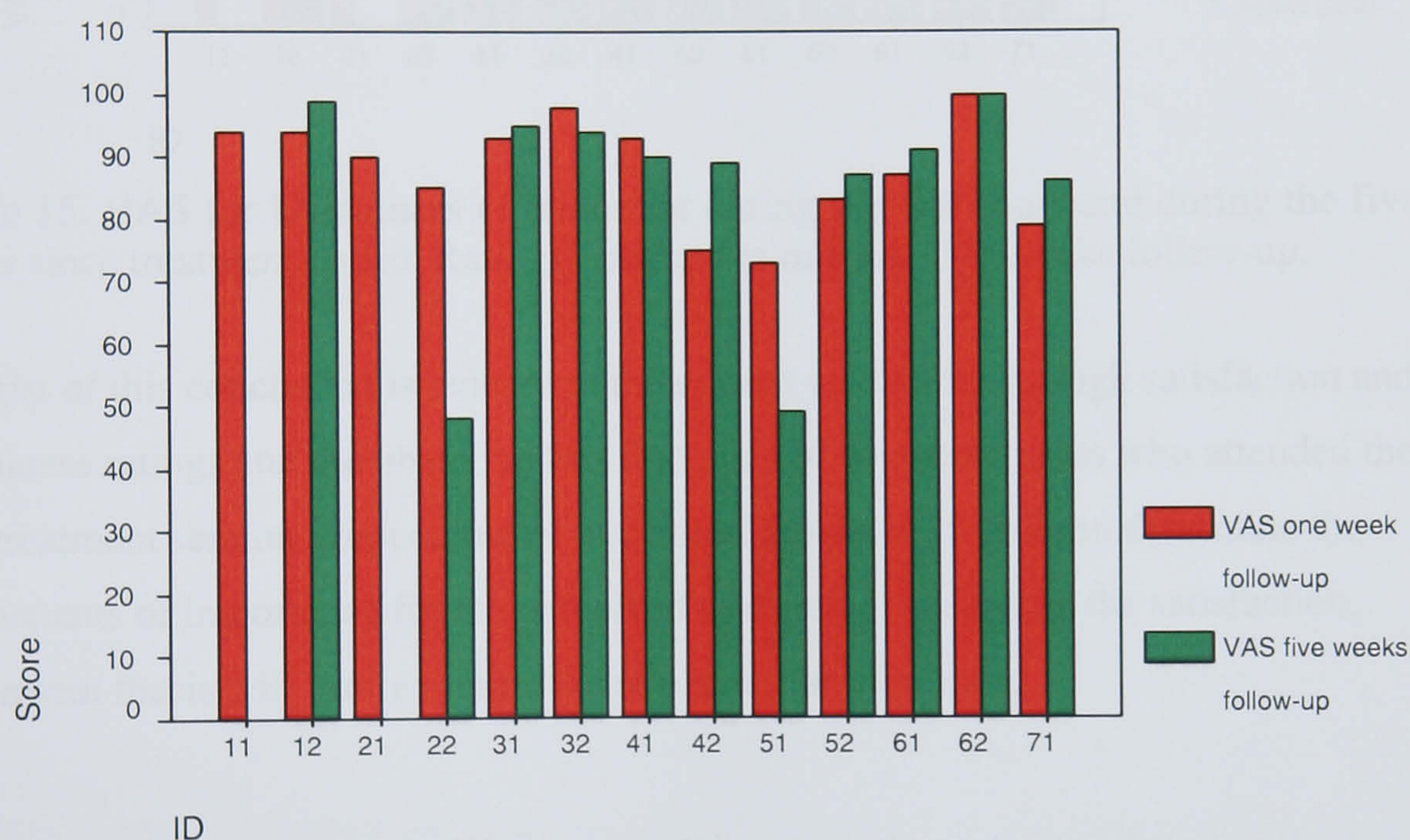


Figure 14. VAS Satisfaction. 1-week follow-up (Mean = 88.00, SD = 8.563) and 5-weeks follow-up (Mean = 84.364, SD = 18.228).

Comparisons between the VAS for usefulness of treatment during the 24 hours prior to completion of the rating, the VAS for usefulness of treatment during the entire follow-up period as depicted in figure 15 below and the VAS for satisfaction depicted in figure 14, reveal that the score pattern for an individual's satisfaction is largely replicated in the degree of usefulness attached to the treatment, i.e. usefulness and satisfaction with treatment are correlated to a significant degree (post five weeks: Spearman's rho = .717, N = 11, p < .05, two-tailed). Consequently it appears likely that a treatment perceived to be highly useful will also have high levels of satisfaction attached to it and hence have low dropout rates.



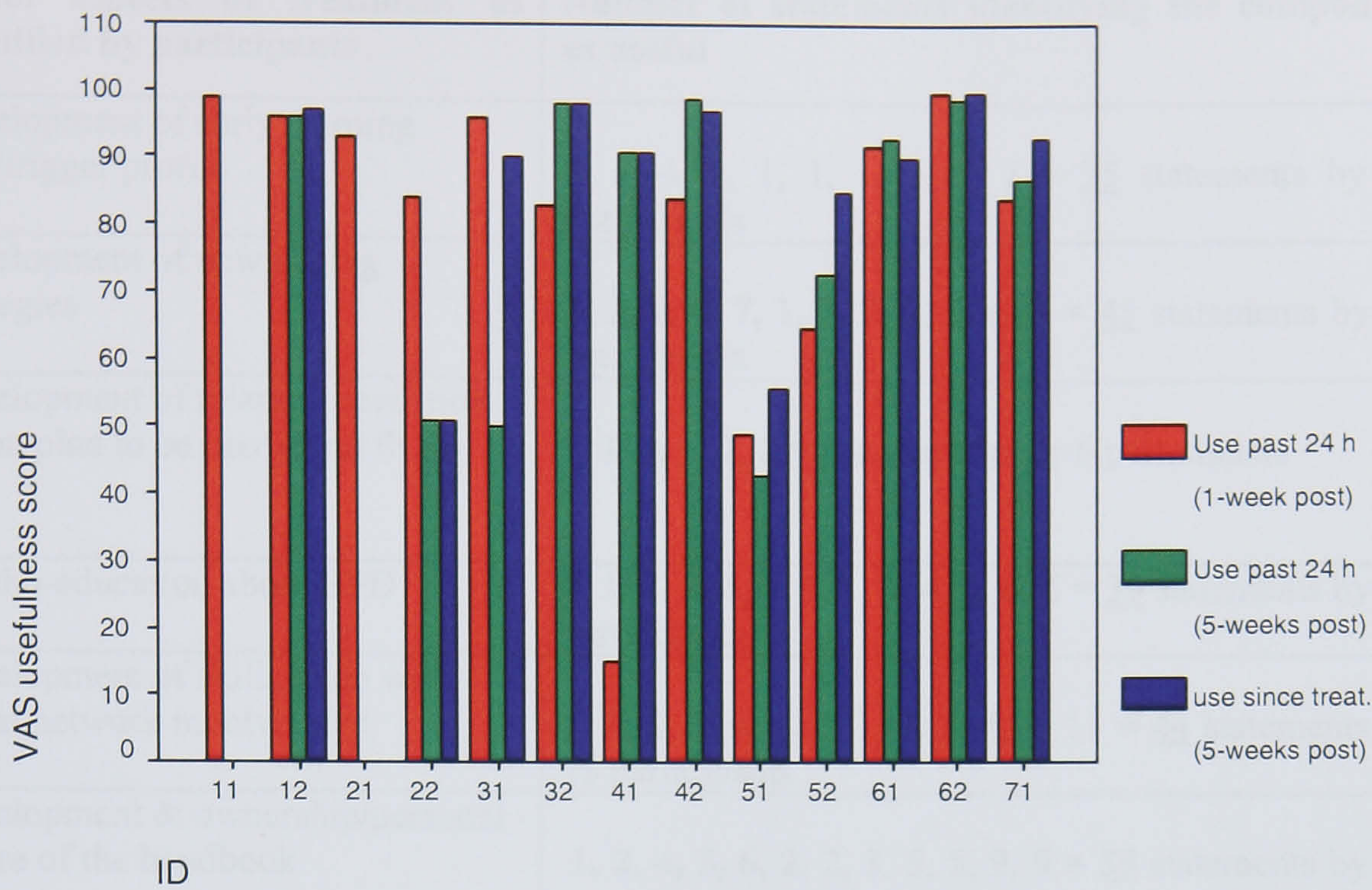


Figure 15. VAS for Usefulness of treatment during past 24 hours and during the five weeks since treatment ended. Ratings obtained at one and five weeks follow-up.

The gist of this conclusion is evident in the current study with its high satisfaction and usefulness ratings and the objective fact that none of the participants who attended the first treatment session dropped out of treatment. However in order to determine the components of importance for the perceived usefulness, and hence the satisfaction, the present thesis will now examine the relevant interview data.

As can be gauged from table 3 below, participants, independently of their attitude to mania, mentioned a broad range of useful aspects of the treatment but focused heavily on the main components of the TIM. This includes the psycho-educational component which did not feature strongly as a causal factor in any of the more specific research aims answered above (impact on hopelessness and perceived control over internal states) but is seen as useful in a general sense by all participants. Similarly, all involved identified the development of skills to do with social network involvement, which included training in communication skills, as useful. Furthermore, 8 participants mentioned the structure or duration of treatment as useful in a manner already illustrated in section 3.2.2 by 62 who explained how a weekly session taking place immediately before a weekend allowed her to practice the relevant skills at her own pace.



| Useful aspects of treatment as identified by participants  | Number of statements identifying the component as useful  |
|--|---|
| Development of early warning sign/trigger profile  | 1, 1, 4, 1, 1, 1, 1, 2, 6, 7 = <u>25</u> statements by 10 participants                              |
| Development of new coping strategies   | 2, 3, 4, 6, 7, 1, 2, 2, 2, 3, 6, 7 = <u>45</u> statements by 12 participants                        |
| Development of relapse prevention action plan to be carried on flash-card                                  | 1, 1, 1, 1, 2, 2 = <u>8</u> statements by 6 participants  |
| Psycho-education about BPD   | 1, 1, 2, 3, 6, 1, 1, 1, 2, 4, 5, 6, 6 = <u>39</u> statements by 13 participants                     |
| Development of skills to do with social network involvement  | 1, 2, 3, 3, 6, 1, 1, 1, 2, 3, 4, 6, 11 = <u>44</u> statements by 13 participants                    |
| Development & ownership/personal nature of the handbook  | 1, 2, 4, 5, 6, 2, 2, 3, 5, 5, 9, 9 = <u>53</u> statements by 12 participants                        |
| Collaborative therapeutic (“CBT”) style  | 1, 4, 4, 5, 1, 1, 3, 6, 11 = <u>36</u> statement by 9 participants                                  |
| Empathy and emotional atmosphere of therapy  | 4, 5, 5, 6, 7, 1, 2, 2, 2, 2, 3, 4, 6 = <u>49</u> statements by 13 participants                     |
| Duration and structure of treatment  | 1, 1, 2, 1, 1, 1, 2, 2 = <u>11</u> statements by 8 participants                                     |
| Intervention component targeting sleep problems directly   | 1, 2, 1, 1, 4 = <u>9</u> statements by 5 participants   |
| General expressions of usefulness of treatment without direct mention of a particular element of treatment | 1, 2, 2, 3, 5, 1, 1, 2, 3, 4, 5 = <u>29</u> statements by 11 participants                           |
| Sum  | <u>348</u> (137/211) statements made by 13 of 13 participants indicating that treatment was useful. |

Table 3. Usefulness. Bold figures are from participants who are ambivalent or positive towards the idea of having future mania episodes.

It is also noteworthy that 9 participants mentioned the collaborative therapeutic (“CBT”) style of treatment as useful. This can be exemplified with the following quotes from 51, obtained during a discussion of the general experience of attending therapy:

“It’s been very good natured... I never felt threatened, I just felt challenged and I think it has been a good one.



**Ok. You like being challenged?**

Yeah I don't think it would have been that productive... given I felt it gave cause to reflect, being asked "what do you do in this situation?" and "is it, would you, could it be this that leads to it?" and with a seriously damned picky type saying "well is it that, that does it?" and it's been a positive process and way you have done it... I expected a more prescriptive kind of "this is how you should do it" and it is not like that at all, it has not been like that.

**And that is good?**

That is good yeah".

And towards the end of the same interview:

**"So in general terms did this treatment meet your expectations?"**

I think it surpassed my expectations.

**Ok is that because your expectations were quite low?**

Yeah.

[Both laugh]

**Yeah?**

Yeah, they were quite low but more I had the assumption that there was nothing you could tell me which I didn't know and as it was presented in the first instance, it's almost like "I am going to tell you how to deal with your manic-depression" and in effect that is what you have done, but in a very good way and in a way that I hadn't expected it to happen.

**And the good thing about that is that I am not telling you what to do?**

No, you are not telling me what to do, you are just questioning, questioning my approach and making me decide how I want... but making me realise that there are certain approaches which are less helpful or that there are better approaches".

It is also interesting that all participants found empathy and the emotional atmosphere of therapy to be a useful component of the intervention as expressed by 11 when discussing the overall experience of coming to therapy:

**“What is important to have in this sort of treatment?”**

It is to listen.

**Listening is important?**

Yes and to be more understanding.

**More than I have been?**

No, not you, the others, in hospital.

**So to listen and try to understand...**

Yes.

**That’s important from the person doing the treatment?**

Yes that’s very important and it helped me a lot because they have made mistakes about my illness, they said that I was schizophrenic for so many years they made this mistake.

**So it’s important that someone tries to understand?**

Yes”.

And a few minutes later in the interview:

“You helped me a lot, I am grateful.

**OK, do you know what it is that I have done, can you pinpoint anything specific that was important?**

It was important to see what was going on around me because I was blind. People they act and tell you what to do, they treat you like you are a baby and you are a grown up person...

**So that has been important, that you have been treated like an adult here?**

Yes”.

This same general attitude was expressed in a somewhat different manner by 61:



“Aspects of the theory you put forward about depression I wouldn’t conform to or agree with, but that was ok, that can be accommodated within the work being done, that was great. I remember one of my worse experiences with therapy was going to see a doctor when I was feeling very anxious and being told that ‘no’ I was depressed and that I was Bipolar therefore... you know the guy wheeled out a prescription and wasn’t listening at all to what I thought my problem was and I just discounted him actually and told him so. But coming here I felt, although on the one hand there was a template, I could then say; “no mine doesn’t conform to that” and that wasn’t a problem”.

These quotes, which highlight empathy and the emotional atmosphere in treatment as useful, embody the common finding in psychotherapy research that non-specific factors, or common features of different therapies, are important for successful treatment and positive outcomes (Frank & Frank, 1991; Greenberg & Pinsoff, 1986).

Also contained in the interviews were a number of statements relating to the usefulness of treatment as a whole. These statements often captured the general sentiment surrounding treatment, conveyed by participants in their interviews and also expressed in the post intervention questionnaire item relating to usefulness of the intervention (measured on a 0 – 10 Likert scale,  $M = 8.70$ , range 7 - 10). Two examples of these more general statements are included here, as they reflect the views of most participants.

From 41’s post intervention interview:

“I mean it would be quite good to develop this service within the NHS and this approach remains better anyway, that’s definitely a thing I want to get down on this recording”.

And from 61’s summary of his experience with this, and one of several psychological interventions he had experienced in the past:

“I think it is probably, no it’s most definitely the most useful I’ve... I did a therapy which was about deep stuff a while ago, it was very interesting but it didn’t really apply it and this was definitely the most useful and applicable thing, so thank you”.

Finally it is noted that five participants made one statement each relating to developments that could improve the current treatment. These suggested improvements fell into two categories. Firstly three participants wanted more of the treatment as expressed by 61:

“You might want to do a review meeting later on, you might want to, two months later, have a brief review. That would be helpful”.

Secondly, two participants mentioned that the “look” of the handbook could be improved or in 51’s words:

“I think, to give out photocopied A-4 sheets of typed computer stuff is not going to inspire anybody is it?”

[Both laugh]”.

### **3.2.3.1 Summary of satisfaction and perceived usefulness results**

It was argued that in order to offer effectiveness and be a useful strategy in daily practice, the treatment evaluated must be resistant to drop-out and that this is logically linked to client satisfaction and perceived usefulness of the intervention.

When considering the CSQ-8 data completed for the current treatment and the corresponding VAS data, the levels of satisfaction reported were generally high, stable and sustained from 1-week to 5-weeks follow-up. This pattern of high ratings were repeated on the VAS for usefulness and using the interview data it was established that participants, independent of their attitude to mania, mentioned a broad range of useful aspects of the treatment but focused mainly on the components of the TIM, including the psycho-educational and social network involvement components which did not feature strongly as a causal factor in the research areas previously covered.

Further, the collaborative therapeutic style of treatment was mentioned frequently as being useful and it was also noted that all participants identified empathy and the emotional atmosphere of treatment as useful. This finding is a reminder that the technical aspects of an intervention should not overshadow the “softer”, relationship building components, which are well-established as important for the outcome of any therapy.



### 3.2.4 Perceived changes in thoughts, feeling and behaviours

When exploring the subjective models, or understanding, of the aetiology and development of the participants' BPD, these models were found to be remarkably resistant from pre- to post- intervention interview. In fact, none of the participants changed their models of the illness, possibly because their assumptions from the outset were, largely, in accordance with the stress-vulnerability model being presented in the current intervention. As such, all of the participants felt that stress, of various types, had, and did forthwith, play a major part in the development and maintenance of the illness.

| Participant ID | Stress | Genetics | Childhood experiences | “Driven” personality style | Other personality traits | Substance misuse |
|----------------|--------|----------|-----------------------|----------------------------|--------------------------|------------------|
| 11             | X      |          | X                     |                            |                          |                  |
| 21             | X      | X        |                       |                            |                          |                  |
| 31             | X      | X        |                       | X                          |                          |                  |
| 41             | X      |          |                       | X                          | X                        |                  |
| 51             | X      | X        |                       |                            |                          | X                |
| 61             | X      | X        | X                     | X                          | X                        |                  |
| 71             | X      | X        | X                     |                            |                          |                  |
| 12             | X      | X        | X                     | X                          |                          |                  |
| 22             | X      | X        |                       | X                          |                          |                  |
| 32             | X      |          | X                     |                            |                          |                  |
| 42             | X      |          |                       |                            | X                        |                  |
| 52             | X      | X        | X                     |                            |                          |                  |
| 62             | X      |          | X                     |                            |                          |                  |

Table 4. Causes and maintaining factors of BPD as reported by individual participants.

As can be seen from table 4 most participants believed that their illness is the result of at least one factor apart from the dominant stress factor and many believed it to be the result of several factors. It is interesting to note that 7 participants mentioned childhood experiences (sexual abuse, physical abuse, separation from parents etc.) as important factors in the development of the illness and while this finding can be incorporated into the stress component of the stress-vulnerability model, it is worth noting that a number of participants comparable with the figure for a genetic influence (8) hold this psychological/developmental interpretation of their illness. It is further noted that 6 participants identified personality traits as, partially, causal in the

emergence and maintenance of the disorder. 5 of these participants mentioned that the trait making them vulnerable to episodes of the disorder was a “driven” and ambitious personality style, which is in accordance with both Psychoanalytical and Cognitive theories as set out in Chapter One of this thesis. The belief that a “driven” personality is causal for the illness can be illustrated by 31 who explained:

“I don’t know when to stop. I think I’m a compulsive... And I think it’s the same with this illness. I don’t know when to stop.

**You just keep going until you become ill?**

I just go. I didn’t know when to stop ever. In anything I do. Sex too, I’m compulsive about that as well. Everything”.

Or as expressed by 41 when discussing why he behaves in a manner which he knows will result in an increased risk of relapse:

“It comes from a desire to succeed, be the best and always capitalise on opportunities and a lot may be risky but if you don’t try, then you’ll never know”.

And later on the same topic:

“I guess everybody has got this fear of failure, which is, I would imagine, inherent, I think we all got that in us, but some people can fail much greater than others, or some peoples’ failure could be another person’s success... I don’t know if it is a character fault, but I think there are certain people in this life, who will see their goals, and will try to push the boundaries so they achieve those goals”.

While the participants did not change their personal understanding of BPD other changes were identified as having taken place during treatment. This is set out in table 5 below which contains a summary of the changes mentioned in interviews separate from the issues of hopelessness and perceived control over symptoms.



| Categories identified as having changed  | Number of statements identifying a change in this category  | Sources of changes as identified by participants  |
|--|---|---|
| Improvement in knowledge about BPD       | <b>1, 2, 2, 3, 1, 1, 2, 3, 3, 4, 5 = 27</b> statements by 11 participants   | <u>Number of changes linked to treatment:</u><br><br><b>214</b> statements of change made by 13 participants  |
| Change in feelings/emotional status      | <b>1, 1, 1, 4, 5, 1, 1, 1, 5, 7 = 27</b> statements by 10 participants  |   |
| Change in thoughts generally             | <b>1, 1, 2, 5, 6, 1, 2, 2, 4, 6, 8 = 38</b> statements by 11 participants   | <u>Number of changes linked to extra-therapeutic factors:</u><br><br><b>3</b> statements made by 3 participants (1/2) (Bought a pet, received praise at work & improved relationship with partner). |
| Change in behaviours                     | <b>5, 5, 5, 6, 6, 4, 5, 5, 6, 7, 8 = 62</b> statements by 11 participants   |   |
| Change in self-knowledge/understanding   | <b>1, 1, 2, 3, 7, 2, 5, 7 = 28</b> statements by 8 participants   | <u>Number of changes not linked to any factor:</u><br><br><b>13</b> statements by 7 participants (3/4)  |
| Change in attitude or acceptance of self | <b>1, 3, 4, 6, 1, 1, 1, 4 = 21</b> statements by 8 participants   |   |
| Change in attitude to medication         | <b>1, 1, 2, 1, 1 = 6</b> statements by 5 participants   |   |
| Change in interpersonal relationships    | <b>1, 1, 5, 1, 2, 2, 3, 6 = 21</b> statements by 8 participants   |   |
| Sum                                      | <b>230 (101/129)</b> statements made by 13 of 13 participants indicating that change has occurred during treatment. |   |

Table 5. Change in therapy not considered elsewhere. Bold figures are from participants who are ambivalent or positive towards the idea of having future manic episodes.

All statements in table 5 regarding change refer to positive changes as no mention of negative change was made by participants and the table illustrates that most of the change experienced was ascribed to the conducted intervention.

The changes described fell into the eight categories highlighted in table 5:

- 1) Improvement in knowledge about BPD mentioned by 11 participants (e.g. 32: "I've gained a lot of knowledge through this, which has really helped me"). This result was supported by questionnaire results with improvement in knowledge as rated on a 0 – 10 Likert scale from pre- (M = 4.92, SD = 2.722) to post- intervention (M = 8.00, SD = 1.291) ( $t(12) = -3.385, p < .005$ ).

- 2) Change in feelings mentioned by 10 participants (e.g. 32: “I didn’t realise it would be this interesting, I am very surprised, yeah, of what I’ve learnt and the way I feel now compared to what I felt six weeks ago”).
- 3) Change in thoughts mentioned by 11 participants (e.g. 61: “[I] actually planned it [task at work] more beforehand and actively thought, ‘how can I avoid making myself worry about it’? That was very helpful”).
- 4) Change in behaviours mentioned by 11 participants (e.g. 11: “I talk to people now and I am more open to people, not so shy anymore”).
- 5) Change in attitude to medication mentioned by 5 participants (e.g. 62: “well I’m not scared of taking the medication. I was quite scared of it before... and you know, I’ve now been able to say ‘I have this [BPD] and I have to take this’ [medication]”). No significant change was found in the questionnaire results but the particular participants who reported a more positive attitude to medication in the interviews also reflected this in the completion of the questionnaires.

These five changes, which are the logical consequences of a psycho-educational and CBT-style intervention, are joined by positive, but from the outset unintentional, changes in self-perception and interpersonal relationships for a number of participants.

The changes in self-perception fall into two types; firstly, 8 participants (5/3) described an increase in self-knowledge and understanding exemplified by 31’s statements that:

“I never thought before, quite fully, about the different things that do trigger me off, and putting them down in black and white, I think “my God” I am quite surprised I found many affect me”.

And later in the same interview:

“It [the treatment] has helped me to look back and see the things I did in life... I haven’t done anything bad but I did leave my friend and I did go to Spain...”

**So things like that may...**



But I think now when I look back and with this [points to handbook] I can think, “No if I hadn’t gone then we wouldn’t have been together”.

Or as expressed by 52:

“It [the treatment] has broken down the illness into bite size, manageable pieces, that has allowed me to digest what it is to be ill like me”.

Secondly, 8 participants (4/4) (of which 5 (3/2) were identical with the participants who mentioned enhanced self-knowledge) noted a positive change in attitude or acceptance of self as described by 62:

“I didn’t have any support for myself at all before... I hated myself, I used to think that I was such an idiot for being depressed all the time, or manic or whatever, but now that I can pinpoint it, I am like “well... you know” [dismissive hand-gesture], now I know when I am being normal”.

Finally, positive changes to interpersonal relationships were noted by 8 (3/5) participants who related this to partners, work colleges and, in 32’s case, a parent:

“[M]y mother would know that something was up straight away but I could never talk to her. Whereas now, I have a brilliant relationship with my mother now. She’s read that [points to handbook], sat down and read that fact sheet. It’s helped her.

**And that has improved your relationship?**

Yeah. It has. Me and my mum get on really well now. I’m just quite surprised about that... But she has seen, since I’ve had this treatment, a completely different person come out.

**Ok. What has she seen do you think?**

I’m a lot happier. More chatty. I tend to spend time with her and her boyfriend now, chatting and talking with her or watching TV”.

#### **3.2.4.1 Summary of perceived changes in thoughts, feelings and behaviours**

It is clear that stress and various vulnerabilities combine to form the subjective models of BPD held by participants. This is consistent with the stress-vulnerability model informing the current treatment and can explain the unchanging beliefs

between the two interviews. It is also clear that beliefs about a “driven” personality as a vulnerability factor can be observed amongst several of the participants, none of whom expressed any knowledge of the theories promoting a concurring view as described in Chapter One of this thesis.

Furthermore, apart from changes in knowledge, feelings, thoughts and behaviours that are to be expected from a psycho-educational and CBT-style intervention, a number of participants described positive changes in self-perception and interpersonal relationships resulting from the intervention which, despite a few references to external factors, form the far greatest causal factor for change according to the participants.

### **3.3 Summary of results**

This section draws together the findings in relation to the research aims set out in section 1.5.

The intervention’s ability to effect change in hopelessness and perceived control over internal states was shown via highly significant changes at follow-up after one and five weeks and also via a high degree of concordance between the sources of data used as part of the triangulation approach. Further, the participants focused mainly on treatment elements from the TIM as the factors involved in producing improvements. It was also noted that participants with a positive/ambivalent attitude to future mania had a tendency for improvements to come about later in treatment and displayed a greater need for seeing the developed skills work in practice compared with those participants with a negative attitude to mania. Both of these findings are potentially important when planning interventions with individual clients and for informing the expectations that clinicians should have when looking for progress.

With regards to the participants’ overall assessment of the usefulness of the therapy, it was argued that this is closely linked to their treatment satisfaction and that a certain level of satisfaction is necessary if the treatment is to possess effectiveness in daily, clinical practice, as a low opinion of usefulness is logically linked to high dropout. None of the participants dropped out of treatment and they generally reported high levels of satisfaction. The usefulness was equally perceived to be high across the measurement tools used and participants, independent of their attitude to mania,



focused mainly on specific aspects of the TIM when explaining why the intervention had been useful to them. This included the psycho-educational component and the development of skills relating to social network involvement, which did not feature strongly as a causal factor in the analysis of the proposed reasons for the improvements in hopelessness and perceived control over internal states. However, participants also considered the relationship building or non-specific aspects of treatment to be useful, thereby highlighting a factor consistently found to be important in psychotherapy research generally. Finally, it is noted that the collaborative therapeutic style was frequently seen as useful and that suggested improvements of the treatment centred on extending the number of treatment sessions and on improving the visual impact or “attractiveness” of the handbook.

The subjective models of BPD held by participants did not change in therapy and it was speculated that this may be related to the similarity between the stress-vulnerability model presented in treatment and the models already held by participants. It is however interesting to note that childhood experiences and genetic vulnerability are seen as necessary factors for the development of BPD by an almost equal number of participants. This illustrates that developmental or psychological “trauma” theories are often important aspects of clients’ explanations for their experiences, even if such thinking is not at the forefront of the current research and academic theory trends which, until recently, have been dominated by a medical and genetic paradigm.

It was further noted that personality traits, and in particular being “driven” and ambitious, were mentioned by a number of participants as constituting a vulnerability factor and it was argued that this finding is in support of both Psychoanalytical and Cognitive theories on the subject of aetiology and risk of relapse.

Finally, it was shown, via data obtained in the research interviews, that participants generally ascribed the improvements and changes found in their knowledge, feelings, thoughts and behaviours to the intervention. It was further argued that such changes are the logical consequences of a psycho-educational and CBT-style treatment, but that the positive developments in self-knowledge and attitudes to self also established to have taken place were less easily predicted, but nonetheless important for the participants who experienced them. It appears that participants with a positive or

ambivalent attitude to having future manic episodes may be more likely to experience such personal benefits from the treatment but further research is needed before firm conclusions can be reached in this regard.



## **4.0 Discussion**

The current research project has evaluated the newly designed TIM and has, in the process, gained information on, not only the therapy's impact on hopelessness and the perceived ability to control internal states, but also more generally on the participants' subjective perception of the usefulness of the treatment. Following a summary of the rationale for the study, which includes a discussion of the research process with regards to the concurrent use of qualitative and quantitative data collection methods, the results are considered and it is concluded that the intervention can have a significant impact on important aspects of participants' experiences. In addition it is concluded that participants have given an important insight into what is likely to be seen as useful in treatment from a service user perspective. This has clinical implications that will be discussed within the context of theoretical models of BPD and their "fit" with the study's empirical findings. Finally, limitations of the study and suggestions for future research are considered.

### **4.1 Rationale for Research**

Although BPD is characterised by extreme mood swings and often by secondary problems such as unemployment, substance abuse and suicidal behaviour, sufferers do not form an entirely homogeneous group of people. In fact, despite the often serious consequences of the illness, people with the diagnosis frequently differ in their perception of the basic question of whether it is desirable to become symptom free with regards to the manic aspects of the illness. This is a unique feature of BPD amongst mental illness diagnoses and it is important that our clinical services and interventions reflect this characteristic of the illness in order for them to offer effectiveness and limit dropout from treatment. A way to approach these goals is simply to ask the individual carriers of the diagnosis what they believe has been useful in a given psychological treatment. This has not been done previously in the research literature and highlights the reasons behind the current study's interest in satisfaction and in what is considered useful from the client's perspective. This focus on the individual's perception and assessment of the intervention is also repeated in the actual treatment, with its flexible manual guiding the person towards creating an individualised relapse prevention handbook, unique in specific content, if not in format, for the particular user. The uniqueness of individual clients with BPD is also recognised in the research design applied, as the use of triangulation and case study

methodology aims to capture the uniqueness of individual participants without losing the ability to identify commonalities and the possibility for model building and generation of new hypotheses (Yin, 2003; McLeod, 2001; Miles & Huberman, 1994). It is however clear that perceived usefulness of a treatment is not sufficient when treating a disorder which often leads to drastic consequences such as suicide. The treatment must be able to produce change in constructs such as hopelessness known to predict suicidal behaviour, and to have an impact on the core feature of the disorder, i.e. lack of control over internal states, if it is to be considered for use in routine clinical practice. As a consequence, the current study looked at measures of hopelessness and perceived control over internal states/symptoms in order to determine the intervention's ability to improve measures of these. As the intervention has not previously been conducted or researched and its consequences therefore were largely unknown, it was further believed important to look for any other changes in thoughts, feelings, and behaviours that may follow from the treatment experience and to consider the subjective understanding or model of the illness held by participants. In light of the diverse research aims a longitudinal design with replication across participants utilising multiple case study methodology was seen as an ideal solution.

#### **4.2 Discussion of findings**

The conducted evaluation of the TIM partly followed a traditional longitudinal design and measured change before, during and after treatment, thus making it possible to determine whether statistically significant change took place on various measurement tools. The reliability and validity of the results were enhanced via a triangulation approach that examined the developments and changes observed, using different instruments and methods, thereby collectively building a more convincing picture than could otherwise have been achieved.

With regards to the overall results the first question must be, *can* the treatment evaluated have significant, positive effects for clients? This is in broad terms a question of efficacy and while this term is normally reserved for evaluations of an intervention's impact under ideal conditions, the question of whether the current intervention can effect important change will be dealt with as an issue of efficacy below. Secondly, in order to be useful in daily practice the intervention must have a degree of effectiveness which implies that it is shown to work well in normal clinical settings for a range of clients. This question will be seen here from the client's



perspective on what works well or is useful in the conducted treatment, as this is assumed to be closely linked to important variables such as drop-out or lack of treatment uptake.

#### **4.2.1 Background to treatment structure and overall efficacy**

As illustrated in section 1.1.2 of this thesis, evidence is beginning to emerge that different therapeutic approaches can have an impact on variables such as time to relapse (Perry, et al., 1999) and medical adherence rates (Cochran, 1984) etc. But little attention has been given to clients' experiences and the changes they perceive to have resulted from treatment. This is somewhat surprising when considering that the client group in question is known for its high suicide risk, which in turn is known to be linked to the subjective experience of hopelessness.

Hopelessness is likely to be learned<sup>15</sup> through the experience, central to the nature of BPD, of having no control over symptoms that repeatedly occur and wreck daily life. Hopelessness is thus linked to a lack of belief in one's future ability to control the various symptoms occurring and to the expectation that these symptoms will make life very difficult or "hopeless". The theory and empirical data collected on learned helplessness show that this state of mind causes passivity and prevents the individual from discovering that conditions may have changed, so that the perceived helplessness is just and only that; perceived (ibid.). Similarly for hopelessness, and in terms of treatment, an intervention that could increase the perceived control over internal states or symptoms is also likely to prompt renewed activity and actual attempts to control the unwanted states or symptoms. When this happens, it is important that clients have access to coping strategies that can disconfirm the perceived reasons to experience hopelessness which, according to basic behavioural principles, will otherwise be reinforced and even more entrenched. It is therefore important that clients are given an empowering and non-deterministic understanding of the nature of BPD relapse (this happened in session 1 of the current treatment) before developing the actual coping-strategies (which took place in sessions 2 and 3). Further, in order for the treatment to be consolidated and have long-term effects the social network, which will often have experienced many, seemingly unpredictable relapses, must also be moved to not reinforce or recreate the learned helplessness and

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<sup>15</sup> In the sense first described by Seligman (1974; 1975) with regards to learned helplessness.

hopelessness that they, themselves, may have internalised as a result of seeing past relapses occur outside of the client's or their control (network inclusion skills are developed in session 4). As such, it is not only the instability model's various pathways to illness, detailed in Chapter One, that give a rationale for the inclusion of elements from several other therapies in the current intervention. Rather, a rationale for this is given by the fact that a certain "empowering" form of psycho-education is, typically, necessary for a client to be open to learn relapse prevention and coping strategies, which in turn are less likely to survive over time if the social network is not included in the reinforcement of a new belief system which states that, at least some, control over symptoms can be achieved. Thus there is a logical argument for the inclusion, in a particular order and within a single treatment, of all the mentioned components which have separately formed the focus of the therapies reviewed in section 1.1.2 of this thesis and which the instability model predicts should have a relapse preventing impact.

The question was however; can the TIM achieve a significant reduction in hopelessness and perceived control over internal states/symptoms in the four sessions allocated to the intervention?

This question was answered positively in the results chapter of this thesis using both quantitative and qualitative methods in the triangulation of data, as recommended by, amongst others, Dey (1993) who argued for the mutual dependency of methods and stated that: "meanings cannot be ignored when we are dealing with numbers and numbers cannot be ignored when we are dealing with meanings" (ibid. p. 28).

The significant changes in hopelessness found across the different scales and interviews is perhaps best summarised by noting that the 11 participants who could be contacted at 5 weeks follow-up went from a mean baseline score of 9.15 (SD = 4.20) on the BHS which is defined as high risk of suicide (Beck et al., 1990) and "requires frequent, regular monitoring" (Williams, 1992, p. 105), to a mean score of 3.09 (SD = 4.42), which is comparable with the mean score of 4.45 (SD = 3.09) found in a normal population of 396 randomly selected adults (Greene, 1981).

Similarly, the improvements in perceived control over internal states/symptoms observed through all data collection instruments and strategies can be illustrated by the PCOISS scores which went from a mean of 42.32 (SD = 8.68) defined as in the low perceived control range (18-53) by Pallant (2000) to a mean of 63.27 (SD = 9.41)



in the medium range just below what is defined as high perceived control ( $\geq 65$ ) for a normal population sample of 439 adults (ibid.).

Taken together the statistically significant, quantitatively and qualitatively measured changes observed form a convincing picture in fulfilment of Kazdin's (1982) criteria for proven clinical significance, in that the problem areas have returned to the range defined as normal by reference to the background population.

On this basis and because no extra-therapeutic factors of importance were found, despite being actively sought after in the interviews and in the daily diaries, it is safe to say that the TIM has affected a significant and positive change in the four sessions allocated to treatment.

#### **4.2.2 Further on clinical significance and effectiveness**

A treatment that can have positive effects is only useful if it can obtain such results with the clients seen in daily practice and if it is seen by these clients as useful enough for them to stay in treatment once they have decided to join. It is therefore a positive result in itself that participants, who were mainly obtained through existing waiting lists to two different psychology departments, all completed the treatment. It is also important that the levels of satisfaction measured across the scales, in the questionnaires and in the interviews were generally high. These findings, together with the demographic composition of the participants, give hope that the TIM can engage and keep a range of clients in treatment when applied in other, normal clinical settings. This contention is further supported by the finding that the treatment can have a positive impact on, not only knowledge, thoughts, feelings and behaviours as is to be expected from a psycho-educational, CBT-style intervention, but also on self-knowledge and attitudes to self. This is likely to be an indication that the intervention was personally meaningful and important to participants, who would therefore be more likely to engage with the treatment and to return to the handbook in time of need.

When looking at the question of what participants believed to have instigated change and what they had found useful, it was noted that the elements of the TIM were frequently mentioned. It could be argued that this is based on a self-fulfilling prophesy in that these are the only treatment components that participants were exposed to. However this would be to underestimate the critical, "consumer" sense of

the participants, who were also able to identify other treatment elements as useful and as causal in positive change. Examples of this are the emotional atmosphere of treatment and the duration and structure of this. Further, it is not argued here that participants would not have found other types of treatment useful, only that the current treatment was considered useful enough to reduce drop-out and to supply the participants with a good treatment experience which may prompt them to return to the handbook in future.

#### **4.2.3 Service provision and clinical implications**

As outlined above it can reasonably be concluded that the evaluated intervention can offer both efficacy and effectiveness and it is further noted that the manual is written in an explicit manner that allows staff with very little or no training to apply it with clients. It is also a short-term and therefore cheap intervention to offer, which is likely to appeal to hard-pressed psychology departments in many areas. With the high satisfaction ratings and the various positive outcomes reported by participants in the study, this is not a controversial stance to take and application of the current treatment appears to be in the interest of both the individual service user and society as a whole (see section 1.1 for BPD's impact on society).

With regards to clinical implications, it was noted that differences may exist between clients who have a negative versus a positive/ambivalent attitude to the prospect of having manic episodes in future. It appears that the positive effects of treatment come about later in the treatment period for those clients who are positive/ambivalent about mania and that these clients may have a greater need to see skills developed in therapy working in practice before they experience reduced hopelessness and perceive their control over symptoms to have improved. These are potentially important insights for treatment planning, whether within or outside of the framework of the TIM, and should inform the expectations that a practitioner holds for a particular client's rate of improvement. That is, it may be reasonable to wait longer for improvements with a client who is positive/ambivalent about mania before a change in treatment strategy is considered, compared to someone who is clearly negative about having manic experiences. Also, when working with a person who regards mania in a positive/ambivalent manner, it is likely to be of most benefit to include practical tests of the skills developed, for instance in the form of planned applications of coping strategies when mood swings are encountered.



#### **4.2.4 Relevance of findings to theoretical issues**

The differences found between participants who are either positive/ambivalent or negative about having manic episodes is not directly addressed in the existing literature but may form the basis for building theoretical or treatment models in future research. Of more direct relevance for the now dominant psychological theories of BPD, Cognitive and Psychodynamic models, is the spontaneous reference to having a “driven” personality made in interviews by 5 participants. This is an “insider” confirmation that at least some individuals with BPD see themselves and their personality in a similar light to that proposed by the major theories on the topic. It was also found that a substantial number of participants subscribe to a developmental or childhood “trauma” factor as having had an important influence on the emergence of the disorder. This would traditionally have been seen as support for the Psychodynamic model of psychopathology but can equally be incorporated into newer, schema-focused cognitive models of the early development of biases in thinking that are now thought to persist over time (McGinn & Young, 1996). As such, the current study confirms that the major theories’ conceptions can ring true for at least some individuals living with the disorder. Similarly for the instability model it was noted that while other treatment components developed on the basis of this model were seen as useful by more participants, the direct targeting of sleep hygiene was spontaneously reported to be useful by 5 participants who therefore added some support to the contention that sleep patterns are disrupted amongst, at least some people with BPD.

But most striking is the overwhelming and unanimous support for the stress-vulnerability conception of the disorder’s aetiology and maintenance amongst the participants who all have an intuitive understanding that stress of various types can trigger the underlying vulnerabilities, be they personality traits, genetic constitution or a combinations of such factors.

#### **4.3 Future research and limitations of the current study**

The current study aimed to explore outcomes and experience of going through a particular intervention. The study employed, amongst other strategies, interviews which were conducted by the same person implementing the treatment with individual participants. This may have introduced a bias toward reporting overly positive

opinions of the intervention and this should be kept in mind when considering the results of the study. However this overlap between therapist and interviewer was a considered choice based on the new status of the intervention which would have made it difficult for another interviewer, without insight and specific knowledge about the particular structure and composition of the treatment, to judge which issues to follow up and which to ignore in interviews. It is noted that special efforts were made to ensure that participants knew that negative or critical views of the treatment were as valid and acceptable as more positive views, and critical points of view were actively sought in all the conducted interviews. Further, the use of quantitative measures, the traditional approach taken to psychological research from within the empiricist paradigm, together with interview data and the extensive use of quotes to illustrate aspects of the research, is indicative of the wish to triangulate and approach the subject matter from different perspectives. As such the study design takes its main inspiration from a constructivist paradigm suggesting that meaning can be created by various means and that it is, in fact, constructed via relationships between people and not merely objectively there to be discovered. From this perspective it is always impossible to divorce a person's actions from his or her interactions with the environment and if a third person had conducted the interviews another "bias" or a different creation of meaning would simply have been introduced. On this basis the question of whether the fact that treatment and interviews were conducted by the same person should be seen as a limitation, because of the possibility of a bias, or as a strength because the interviewer had a well-established relationship with the participant from the outset of the post-intervention interview and further possessed knowledge gained in therapy about which areas of the interview may hold the most important information, is very much a question of which paradigm the question is approached from (Patton, 2002). It is also noted that the results were largely unchanged at 5-weeks follow-up, which was conducted by post and therefore less likely to be influenced by an overlap between the person conducting the treatment and the researcher.

Regarding this follow-up period, its duration was restricted by certain deadlines and future research would benefit from extending this period enough to assess outcomes in the form of changes to relapse patterns, the use of handbook and new coping strategies over time, together with variables such as medicine adherence and doses.



The study has thrown up the possibility that attitude to having manic episodes may determine an individual's response to different types of interventions and this could, with benefit, be explored further in subsequent research. In the area of schizophrenia it has been implied that a client's positive or negative beliefs about the source of voices should determine the choice of intervention (focusing or distraction) (Chadwick & Birchwood. 1994; 1995). Equally, with BPD it is possible that a client's positive or negative beliefs about having mania in future can form the basis for a decision regarding which particular elements should be given priority in treatment, i.e. a hypothesis to be tested further is that clients with a positive attitude to future manic episodes need more practical, behavioural experiments to achieve outcomes in the form of higher perceived control over symptoms and reduced hopelessness compared to clients with negative attitudes to mania who appear to have less of a need for such practical input.

Other areas for future research could be comparisons between the outcomes of the current treatment and other types of treatment, assessment of the treatment when conducted by other practitioners, further assessment of the treatment's ability to facilitate change for clients with moderate or high degrees of confidence in their ability to control symptoms, and the effects of the relatively simple procedure of converting the manual and handbook into an interactive computer program. The latter would give the client more control and make the treatment readily available to a large number of potential users, but would also take away factors of empathy and collaboration.

In summary, time constraints limited the possibility of long-term follow-up and the choice of letting the same person conduct treatment and interviews may be seen as limitations of the study and should be considered when assessing the implications of the findings. Conversely, the research has indicated that clients can benefit from the evaluated intervention which, due to its explicit manual and relatively simple nature, is easily implemented in various clinical services and has in the process thrown up several ideas for future research. This suggested research takes the form of both further evaluations of the TIM and also the form of more basic questions of whether certain client characteristics (attitude to future mania) can predict which types of intervention will be most beneficial. The study can therefore be said, not only to have evaluated a particular intervention, but also to have acted as a facilitator for further

research and has thus lived up to the criteria of *generativity* put forward for assessing research in another context by Henwood and Pidgeon (1994).

#### **4.4 Conclusion**

The scientific literature on BPD illustrates the need for a bio-psycho-social approach to relapse prevention and the current study has shown that the TIM could form a useful part of this overall framework. This follows because the intervention was shown to have a positive impact on important factors such as hopelessness and perceived control over internal states/symptoms. These results were achieved with participants expressing adequate levels of satisfaction, usefulness and without any dropout from treatment. The study also gave an insight into how participants understood or modelled their illness and highlighted that they, together with non-specific or relationship building factors, considered the elements making up the TIM to be useful aspects of treatment. Further the study generated ideas for future research and began a tentative model building process with regards to how clients may respond to elements of treatment based on their attitude to having manic episodes in future.



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## **Appendix A**

Treatment Manual (includes handouts making up the relapse prevention handbook).



## Treatment Manual.

### **Session 1**

This session is designed to familiarize the client with the collaborative therapeutic relationship. Also, an objective description of bi-polar disorder is provided including a presentation of the stress-vulnerability model.

#### **Welcome and short statement about the purpose of the treatment:**

Welcome and thank you for coming. The purpose of what we will be doing is to provide information and coping strategies regarding bipolar disorder, also known by its older name “manic-depressive illness”. During the four sessions we will look at what bipolar disorder is, the signs and symptoms of depression and mania and what can trigger them, and we will be looking at effective ways of coping and living with bipolar disorder.

#### **Guidelines for the intervention:**

- A) While you have the right to stop participation at any time, it is important that you come to all sessions if at all possible, as you, and we, will not be able to assess the benefits of the treatment until all sessions have been completed.
- B) The only situation where I will break confidentiality about what we discuss is if I assess that you, or another person, is at risk of serious harm.
- C) I am here to help you plan a way to cope with problems, so if anything goes wrong or you have concerns please let me know before you leave for the day.

Discussion: How do these guidelines sound to you? Are there other guidelines you want to talk about? Is what I said what you expected?

## **Agenda:**

My goal for today is to cover and discuss:

Causes and influences on the disorder.

The bipolar spectrum, which is everything from so-called normal mood swings to full bipolar disorder.

Stigma, which is related to discrimination because of the diagnosis.

Get to know each other as we go along.

Outline of what we will be doing next time.

**1. Client is educated about the bipolar spectrum and the patterns of the disorder (from normal mood fluctuations over Cyclothymic disorder to bipolar disorder I + II).**

One of the reasons why you are here today is that you, at some point, have been given a diagnosis of bipolar disorder. But the actual expression of this disorder can be quite different from person to person, and it is important for you to understand the different ways that bipolar disorder can look for different people, and also how it relates to similar aspects of so-called normal experiences that have some of the same features.

[Show and explain figure 1 + give figure 1 as handout]

Figure 1 explained: The main features of bipolar disorder are basically exaggerated versions of normal mood swings and appear in all degrees of severity, including what is seen in Cyclothymic disorder, which consists of mood swings as seen in bipolar disorder, but not to the same degree.

In bipolar type 1 the manic period is more extreme than in bipolar type 2, where it is called hypomania, which means mild mania.



Dysthymia is a fairly constant state of lower level depressed mood and functioning, that does not reach the severity of a major depression where the mood and general functioning is reduced to a more severe degree.

Figure 1 also illustrates that bipolar disorder is a disorder which is typically relapsing in nature and which has episodes that can be more or less severe. That means that there are usually long periods with no symptoms, but in the same way as you can live with, say diabetes, without your everyday life being hampered in any serious way, which basically just means that the disorder is under control. In diabetes you might be watching your diet carefully, or you might be taking insulin regularly, or you might be doing both. In bipolar disorder that would correspond to watching out for unhelpful or exaggerated stress, or taking the prescribed medication, or doing both.

If the diabetic drinks a coke with a lot of sugar in, or forgets to take his or her insulin, then there would be a relapse and he or she would experience symptoms of diabetes. Similarly, someone with bipolar disorder who experiences excessive and unhelpful stress or stops his or her medication is unlikely not to get symptoms of the disorder, i.e. to relapse.

Discussion: Do any of the patterns in figure 1 seem familiar to you? Perhaps they have happened to you? Is it your experience that bipolar disorder represents something normal that is being exaggerated? What is it that is being exaggerated?

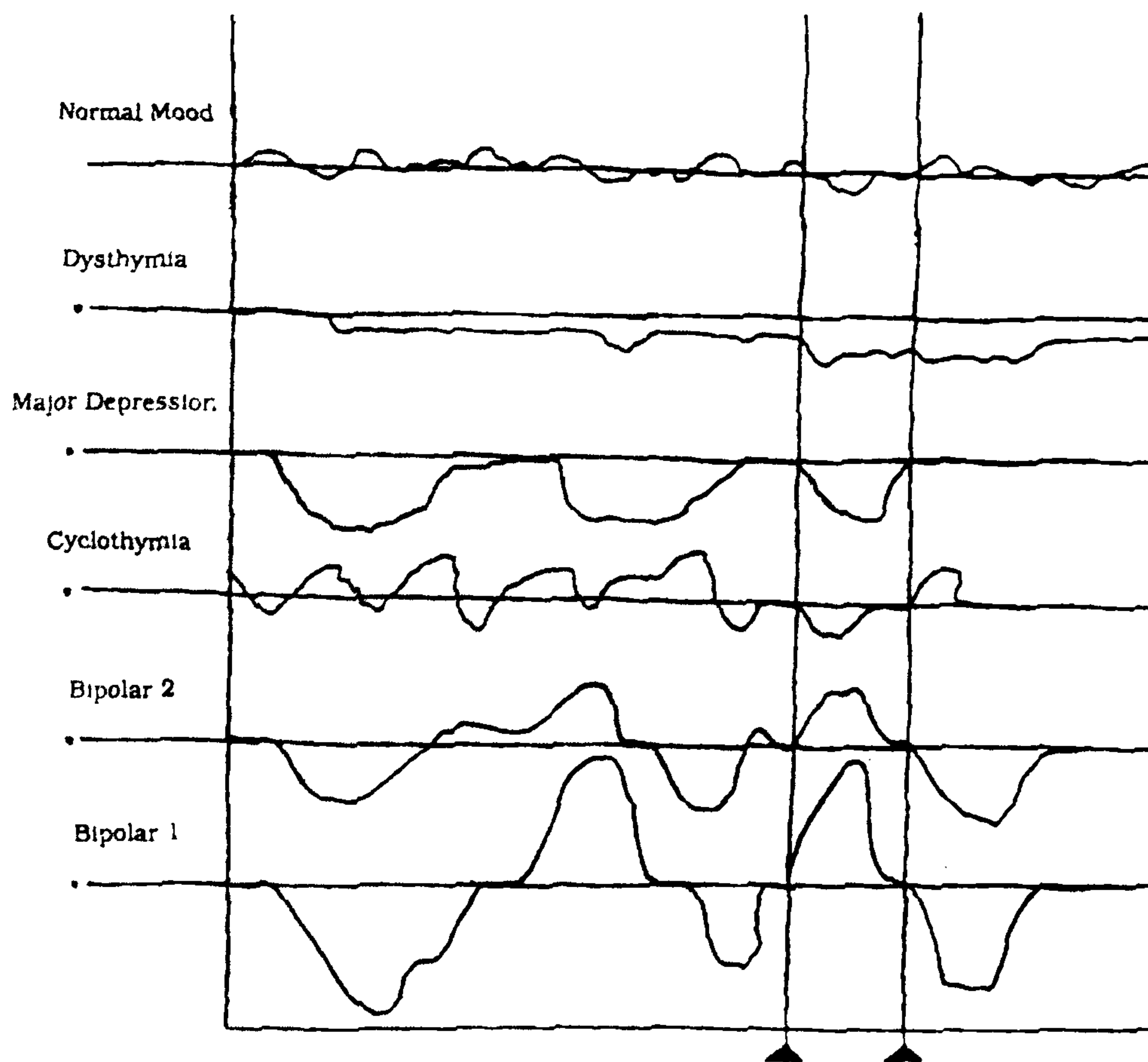


Figure 1. The Bipolar Spectrum. Adapted from Bauer, M. & McBride, L. (1996, p. 138). Structured Group Psychotherapy for Bipolar Disorder. The Life goals Program. New York. Springer Publishing Company.

Often the extremes in mood swings, whether it is up or down, will mean an altered sense of reality. This is sometimes experienced as what professionals call psychosis; others have called the experiences spiritual in nature. There may be hallucinations; that is typically seeing or hearing things that others can not see or hear. Or delusions, which are unusual beliefs, such as believing that special messages are being delivered to you or you can experience extreme suspiciousness or paranoia. These experiences can be both frightening and confusing, but for some people they can, in fact, also be comforting if they have a pleasant content.

Discussion: Can you think of confusing or frightening experiences that you or others have had during ups or downs of the illness?

We have now talked about the main features of manic-depression in broad terms. I have summarized this in a handout, which also includes a few more descriptive words about manic-depression. I suggest that we have a look at this handout now and you



can tell me if there is anything that I have missed, or anything that I should not have included in the descriptions.

[Give handout 2 and go through]

**2. Client is educated about the high prevalence of bipolar disorder and a discussion about stigma facilitates the therapeutic collaboration and relationship.**

Bipolar disorder affects about 1 in every 100 to 125 people; this is about the same number of people as is affected by diabetes. It does not discriminate between genders and it affects people from all walks of life, several famous people have had the disorder. However, despite the fact that it is a relatively common occurrence it is rarely discussed openly in the way that something like diabetes is, which can mean that people who have this type of problem can feel lonely and on their own with the problems that the disorder cause. The reasons why people do not like to talk about having the disorder varies, but it is common to fear the stigma of being labelled, or to fear discrimination because of the diagnosis.

However, it is important to know that lots of people have it, most do not discuss it, and that lots of people live OK with it.

Discussion: Have you met other people with bipolar disorder? How was their life? Have you heard of famous people with the disorder? Do you think people with bipolar disorder share problems similar to people who do not have it? Have you been affected by discrimination because of the disorder?

**3. Causes and influences are presented within the stress-vulnerability model, including genetic, biological, psychosocial and environmental influences. This is used to show the advantage of a multi-modal intervention strategy.**

Important questions to many people with the diagnosis tend to be: “How did I get this?” and “What triggers an episode of mania or depression?”

As we go through the four sessions planned, I will make distinctions between factors that cause the onset of the disorder, and factors that influence the course of the disorder once it is manifest. This is because these factors are not always the same.

The initial cause of the disorder looks to be heavily influenced by genetic factors such as having bipolar disorder or at least depression in the family, but new episodes that develop after the initial one appear to be heavily influenced by other factors such as environmental stress, sleep disruption, alcohol and substance abuse, not taking prescribed medication etc. All are aspects of life that we can make decisions about, work at and change if we so choose, just like someone with diabetes can change what he or she eats.

It is clear that we do not have to think of bipolar disorder as only a chemical imbalance in the brain, or only as a psychological problem in the way we deal with stress. It can be both of those things.

So the model that most people find useful combines these two aspects to explain the ups and downs of the disorder as an interaction between *biological factors*, such as reduction in the effects of chemicals such as Dopamine in the brain, *psychological factors*, such as expectations and predictions about things in your life and *stress factors*, such as change in jobs situation, moving house, financial difficulties etc.

So you have a certain vulnerability to bipolar episodes at the biochemical level, i.e. you might have been born with over- or underproduction of certain chemicals in the brain (Norepinephrine, Dopamine or Serotonin), or the nerve cells in your brain may not be picking up these chemicals in the optimal way.



Much of the time these problems are not having an impact on your day to day life. But when the stressors in you life reach a certain level, then the biological vulnerabilities are expressed as depression or mania. So the biological vulnerability affects your psychological and emotional reactions to stress. If we remove the stress factor that triggered the episode, then it is likely that the biological vulnerability will no longer be expressed and a new episode will therefore be less likely to occur. So we can learn from what has triggered episodes in the past, and thereby start to build up knowledge about the things that stresses you in a way that should be avoided because it makes you ill.

Another way of looking at the same relationship between vulnerability and stress is to say that our psychological and emotional reactions to stress affect our biology and the chemicals produced in the brain.

This is basically what has been called the stress-vulnerability model [Show and discuss figure 2].

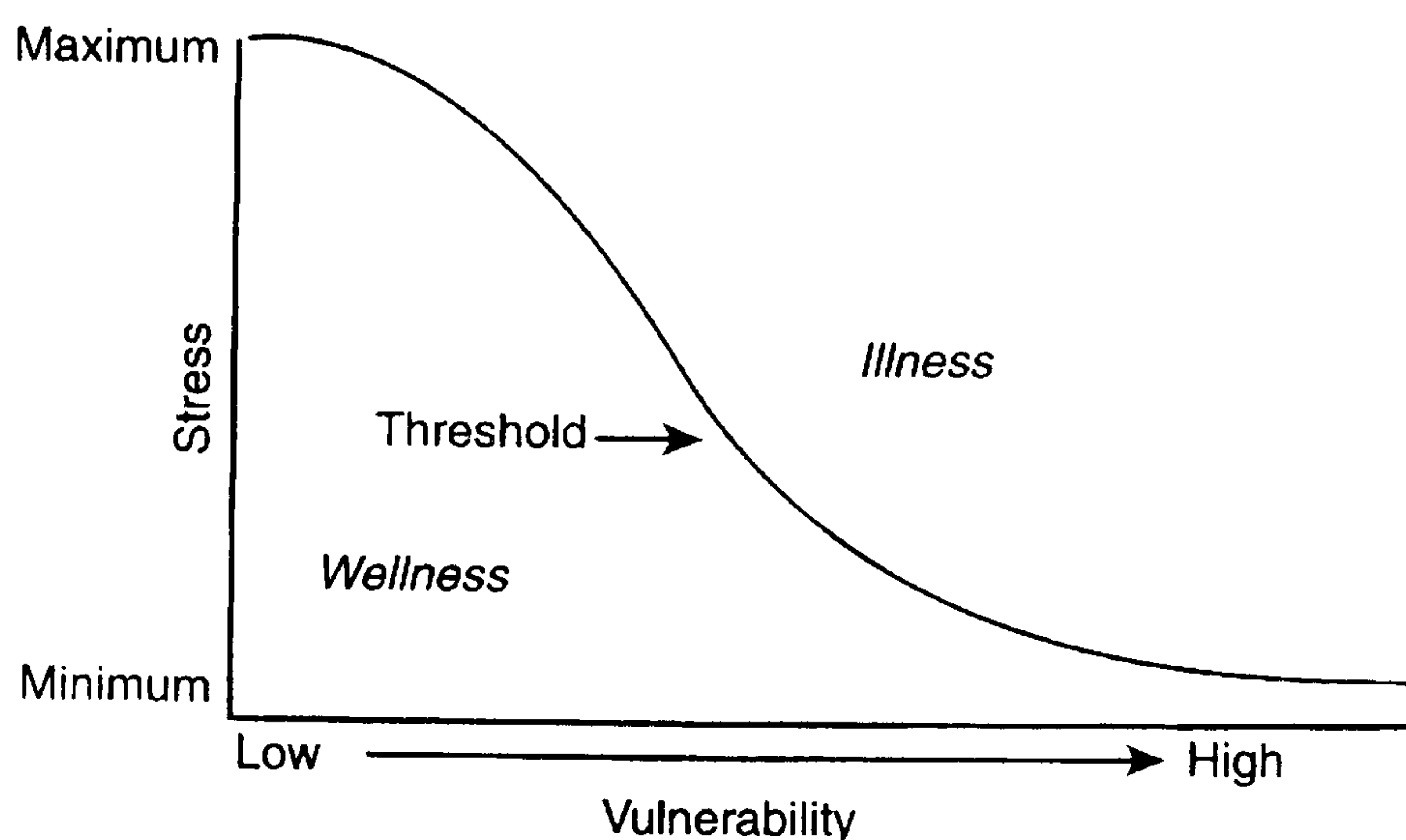


Figure 2. Zubin, J. & Spring, B. (1977). Vulnerability-A New View of Schizophrenia. *Journal of Abnormal Psychology*, Vol. 86, Nr. 2, pp. 103-126.

Figure 2 explained: This model by Zubin and Spring shows how someone who is born with a high degree of genetic vulnerability, for example if bipolar disorder has run through many generations of the family, would need less stress to trigger an episode

and how someone with less genetic vulnerability would need to experience more stress to have an episode.

More important for what we are doing here, the model illustrates that there are things we can do to gain some control over the disorder. If we get to know what particular stress factors to look out for in our own life, then we can reduce these triggers for a bipolar episode and stay on the right side of the line in the figure. In other words there are things we can do from many different perspectives, from the way we live our lives, to the way we approach medication and these are some of the things that we will be looking at during the next sessions.

Discussion: Can you recall an episode being triggered by stress? Have you had the opposite experience, that an episode just came out of the blue?

### **Next Session.**

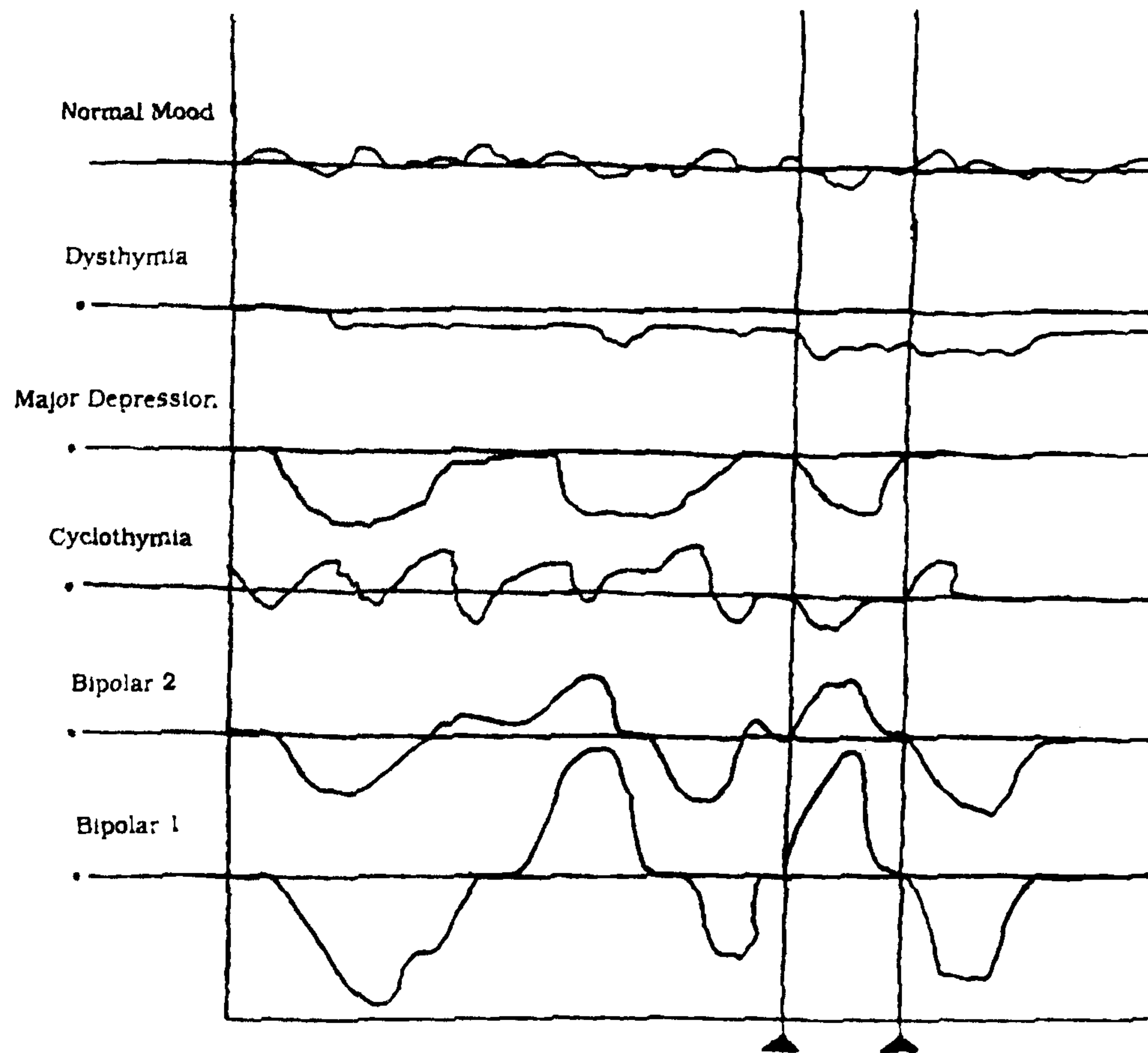
Next time you will develop a list of your own early signs, symptoms and triggers for a depressive episode. This will enhance your ability to manage the problems in a proactive way and therefore increase your ability to control the depressive side of the disorder.

So next time you will:

- 1) Develop a personal list of signs and symptoms of depression.
- 2) Develop a personal list of triggers for depression.
- 3) Develop a personal depression profile (Thoughts, Behaviours and Feelings).
- 4) Determine personal criteria for when to react to changes in the depressive profile and list the actions to take (I.e. “when I feel and think in this way, I contact my GP” etc.).



Session 1 handout 1: The Bipolar spectrum.



The figure is adapted from a book by Bauer, M. & McBride, L. (1996). Structured Group Psychotherapy for Bipolar Disorder. The Life goals Program. New York. Springer Publishing Company. (See page 138).

Session 1 handout 2. The Symptoms of Manic-depressive Illness<sup>16</sup>.

***Mania:***

- Mood: Overly happy to euphoric, possible enhancement of one's senses, may be irritable, moods may shift.
- Thoughts: Easily distracted, difficulty with concentration, accelerated thoughts and speech, enhanced creativity.
- Self-esteem: Decreased inhibitions, increased sense of importance, paranoia.
- Activity: Increased physical activity, decreased need for sleep, spending sprees, increased sexual activity, increased alcohol and drug use, risky behaviour.

***Depression:***

- Mood: Depressed, empty, hopelessness, painful, unable to experience joy or pleasure.
- Thoughts: Impaired thinking, concentration and memory, often preoccupied by death and suicide which can become increasingly attractive.
- Self-esteem: Preoccupied by own shortcomings and faults, feelings of worthlessness, inadequacy and self-hatred.
- Activity: Diminished activity and movement, sleep disturbance and exhaustion.

***Mixed states:***

May include any combination of the above, and may last for varying lengths of time. Agitated depression (depression with restlessness and anxiety) and dysphoric mania (mania with depressed mood and/or thoughts) are examples of mixed states.

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<sup>16</sup> Adapted from Torrey, E. F. & Knable, M. B. (2002, p. 19-20). *Surviving Manic-Depression. A manual on bipolar disorder for patients, families and providers.* New York. Basic Books.



## **Session 2**

This session is designed to aid client's awareness of their own early signs, symptoms and triggers for a depressive episode. This will enhance ability to manage the disorder in a proactive and functional manner.

### **Agenda and aims for session 2:**

- 1) Develop a personal list of signs and symptoms of depression.
- 2) Develop a personal list of triggers for depression.
- 3) Develop a personal depression profile (Thoughts, Behaviours and Feelings).
- 4) Determine personal criteria for when to react to changes in the depressive profile and list the actions to take.

### **Introduction to today's session:**

We saw last time that bipolar disorder is characterized by extremes in mood and related changes in thinking and behaviour. Being able to recognize symptoms is a first step towards developing coping strategies that can prevent, or at least limit an illness episode. This is very important because we can have perfect plans for how to cope and what to do, but if we don't know when to implement them, then it not as useful. Today we will be developing your personal lists of signs, symptoms and triggers of depression. This will allow us to develop a personal depression profile of thoughts, behaviours and feelings that go with your depression. This in turn enables us to develop better personal criteria for when to react to changes in the depressive profile, and we can then also list the actions to take in order to combat the depression. Next week we will be doing something very similar with mania.

## **1. The development of a personal list of signs and symptoms of depression and the development of a personal depression profile.**

Let's talk about the signs and symptoms of depression. Depression is experienced as the way a person thinks, feels and acts. So when talking about depression it can help to think about it in this way: A person's thoughts, feelings and behaviours ARE their signs and symptoms of depression.

Discussion: What are some examples of thoughts, feelings and actions that a person might have, or engage in when they are depressed? Sometimes it helps to recall depressive signs and symptoms by thinking about your most recent episode or perhaps your worst episode of depression.

[Therapist writes down suggestions on board under the headings of: "Thoughts", "Feelings" and "Behaviour". If client does not generate examples *handout 1* is displayed and handed out for inspiration. When a reasonable list has been generated; display and hand out *handout 2 Personal Depression Profile* and ask client to check off symptoms that represents his or her depression and to add personal symptoms not listed in the blank spaces, while checking off early warning signs with an "E"].

It is obvious that some of the symptoms listed are common to all depressions, but it is also important to note that your personal list is a "cluster" of symptoms that is personal to you, and you might have signs or symptoms that someone else with the same diagnosis as you would not have on their list.

Further, depressive signs and symptoms can return in several ways. They can return slowly and gradually, increasing in severity over time or they can return quite quickly. Also, it is possible to have both manic and depressed symptoms intermixed – that is you can be in a depressed or irritable mood with manic energy.

Discussion: I wonder what it has been like for you? How have you experienced the occurrence or return of depression in the past?



## **2. The development of a personal list of triggers for depression.**

Last time I compared bipolar disorder to diabetes where sugar levels can go too high or too low because the body cannot regulate them. In bipolar disorder it is the mood that is not being regulated properly, and so it can go too high or too low. Both illnesses have periods of stability when the person is OK, and times when they are not, in a sense it is part of the disorder to fluctuate in mood, or you could say that instability is a characteristic of the disorder. Stress can increase this instability

Stress can be thought of as either good or bad life events – anything that can stimulate your feelings or upset your pattern of daily life. It is normal to react to good or bad events with good or bad mood, but when you have bipolar disorder you may be more sensitive than others to stress in life. Also, if stress triggers an illness episode, the episode can last long after the stress itself is gone.

Discussion: What types of stresses do you think might bring about, or contribute to, a depressive episode? If you think about your most recent or your worst episode, can you recall if there was a crisis or even a minor stress factor that seemed to occur just before you became depressed? What was it? Have you experienced an episode of depression where you could not see that there were any triggers?

[Therapist lists the examples of triggers on the board and directs the client to *handout* 3 which is then completed].

Now you have a list, or a cluster of depressive signs and symptoms that represents your Personal Depression Profile. You have also developed a personal list of stressors or triggers which you think might bring about, or contribute to a depressive episode.

**3. Determine personal criteria for when to react to changes in the depressive profile and list the actions to take.**

In handout 2 you have marked early warning signs of depression with an “E” and in handout 3 you have a list of potential triggers of depression. So whenever you encounter any of these you know that you should think about taking action, so as not to become depressed. It is important that you read and learn your personal early warning signs and triggers, so that you are aware when they occur, so have a look at them on a regular basis.

In handout 4, I have suggested some things that you can do to cope with depression in such situations.

[Therapist gives out, displays and reads through handout 4 with client. This includes giving out handout 5]

Discussion: If you look at items 8 and 9 on the handout you can see that they mention things to do and things not to do. From your experience what are the things to do and not to do when at risk of becoming depressed?

[Therapist writes own and client suggestions on board and directs the client to write the examples that they see as relevant to them in the space provided in handout].

Now if we look at handout 6,

[Therapist gives out, displays and reads through handout 6 with client]

You can see that there is room for the details of support persons, health care provider and a support group. If you have these detail ready please fill them in now, if not, please fill them in as soon as you get home today so as not to forget. There is also room for writing in the main or most important things to do and not to do. Have a look at the lists we have done and write in what you feel is most important to you.

This little card should be with you at all times, as it can help to have some simple, written information about what to do if you find yourself in a situation that might trigger a depressive episode.



**Next Session.**

Next time you will develop a list of your own early signs, symptoms and triggers for a manic episode. This will enhance your ability to manage the problems in a proactive way and therefore increase your ability to control the manic side of the disorder.

So next time you will:

- 1) Develop a personal list of signs and symptoms of mania.
- 2) Develop a personal list of triggers for mania.
- 3) Develop a personal mania profile (Thoughts, Behaviours and Feelings).
- 4) Determine personal criteria for when to react to changes in the depressive profile and list the actions to take.

**Typical signs of depression<sup>17</sup>**

**Which of these symptoms have you felt or experienced?**

- |   |  |
|---|--|
| <input type="checkbox"/> Hopeless                             | <input type="checkbox"/> Worthless   |
| <input type="checkbox"/> Useless                              | <input type="checkbox"/> Might as well be dead   |
| <input type="checkbox"/> Apathetic                            | <input type="checkbox"/> Emotionless   |
| <input type="checkbox"/> Unresponsive                         | <input type="checkbox"/> Extremely fatigued  |
| <input type="checkbox"/> Desire only to sleep                 | <input type="checkbox"/> No motivation   |
| <input type="checkbox"/> Low energy level                     | <input type="checkbox"/> Slow  |
| <input type="checkbox"/> Sad                                  | <input type="checkbox"/> Down  |
| <input type="checkbox"/> Anxious                              | <input type="checkbox"/> Irritable   |
| <input type="checkbox"/> Short-tempered                       | <input type="checkbox"/> Black attitude  |
| <input type="checkbox"/> Miserable, terrible, horrible, lousy | <input type="checkbox"/> Lonely, alone, abandoned                                      |
| <input type="checkbox"/> Void, empty, hollow                  | <input type="checkbox"/> Self-accusing   |
| <input type="checkbox"/> Guilty of everything                 | <input type="checkbox"/> Cry easily  |
| <input type="checkbox"/> Scared                               | <input type="checkbox"/> Helpless  |
| <input type="checkbox"/> Low self-esteem                      | <input type="checkbox"/> Hoping to die   |
| <input type="checkbox"/> Inability to concentrate             | <input type="checkbox"/> Like a failure  |
| <input type="checkbox"/> Ugly                                 | <input type="checkbox"/> Fat   |
| <input type="checkbox"/> Inability to function                | <input type="checkbox"/> Frozen, dead inside   |
| <input type="checkbox"/> Inability to experience pleasure     | <input type="checkbox"/> Unbearable  |
| <input type="checkbox"/> Angry                                | <input type="checkbox"/> Inability to sleep  |
| <input type="checkbox"/> Want to be alone                     | <input type="checkbox"/> Disorganized  |
| <input type="checkbox"/> Tense                                | <input type="checkbox"/> Silent  |
| <input type="checkbox"/> Quiet                                | <input type="checkbox"/> Paranoid  |
| <input type="checkbox"/> Heavily burdened                     | <input type="checkbox"/> Hateful   |
| <input type="checkbox"/> Sense of futility                    | <input type="checkbox"/> Obsessed with past mistakes                                   |
| <input type="checkbox"/> Wanting to be unconscious            | <input type="checkbox"/> Physically unhealthy  |
| <input type="checkbox"/> Guilty                               | <input type="checkbox"/> Hating my existence   |
| <input type="checkbox"/> Like a grey, dirty window pane       | <input type="checkbox"/> Pain so deep it can't be fixed                                |
| <input type="checkbox"/> As if the world is cloud-covered     | <input type="checkbox"/> Want to curl up and not exist                                 |
| <input type="checkbox"/> Heaviness, and it's a burden to move | <input type="checkbox"/> Deeply buried in anger, and knowing it will never be resolved |
| <input type="checkbox"/> As if I'm in hell                    | <input type="checkbox"/> Aching all over   |
| <input type="checkbox"/> Headache                             | <input type="checkbox"/> Stomach tight   |
| <input type="checkbox"/> Stomach ache                         | <input type="checkbox"/> Nausea  |
| <input type="checkbox"/> Backache                             | <input type="checkbox"/> Chest aches   |
| <input type="checkbox"/> Chest feels constricted              | <input type="checkbox"/> Chest feels empty   |
| <input type="checkbox"/> Chest pain                           | <input type="checkbox"/> Pain deep inside the heart                                    |
| <input type="checkbox"/> Burning, searing pains               | <input type="checkbox"/> Constipation  |
| <input type="checkbox"/> Diarrhoea                            | <input type="checkbox"/> Aching limbs  |
| <input type="checkbox"/> Heaviness in limbs                   | <input type="checkbox"/> Jaws clenched   |
| <input type="checkbox"/> Eyes ache                            | <input type="checkbox"/> Eyes feel heavy   |
| <input type="checkbox"/> Gums ache                            | <input type="checkbox"/> Low blood pressure  |

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<sup>17</sup> Adapted from the book by Copeland, M. E. (2001). *The Depression Workbook. A guide for Living with Depression and Manic Depression* (2<sup>nd</sup> ed.). Oakland, CA. New Harbinger Publications.



## Personal Depression Profile

1. Place a tick next to the symptoms which you experience
2. Add other symptoms if not on the list
3. Mark an "E" next to those which are particular Early Warning Signs

### **Thoughts:**

- Difficulty concentrating
- Memory problems
- Difficulty making decisions
- Thoughts that others do not care when they really might
- Frequent thoughts about dying or suicide
- Paranoia: unreal concerns that you are worthless or evil, or that people are plotting against you
- Hallucinations: unreal voices or visions
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

### **Feelings:**

- Feelings of worthlessness
- Feelings of guilt without cause
- Feeling sad without cause
- Easy irritability
- Not feeling good even when good things happen
- No energy
- No appetite
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

### **Behaviours:**

- Restlessness and pacing
- Trouble sleeping or too much sleep
- Trouble starting or finishing projects
- Keeping away from people
- Stopping work or usual activities
- Easy fighting without good reason
- Frequent crying with little or no reason
- Stop eating or eating too much
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

## **Personal triggers of a depressive episode**

**Tick all those that have triggered depressive episodes for you.  
Add others that you have experienced:**

- Bad life events: \_\_\_\_\_
- \_\_\_\_\_
- Good life events: \_\_\_\_\_
- \_\_\_\_\_
- Change in medication (psychiatric or medical, prescription or over the counter)  
Which medications? \_\_\_\_\_
- Physical illness  
Which illness? \_\_\_\_\_
- Drug or alcohol use
- Changes in smoking habits
- Change in seasons
- Moving house
- Losing your job
- Death of a loved one
- Breakdown of a relationship
- Conflicts with family or others
- Work problems
- Working too hard
- Loneliness
- Childbirth
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_



### Outline of coping strategies for Depression

1. Alert health care provider early.
2. Review medication changes for medical illness.
3. Get early assessment and treatment of physical illness.
4. Do not use alcohol or drugs  
(Note: even increasing tobacco can undo the effects of prescribed medication)
5. Maintain daily activities
6. Minimize sleep loss (see handout 5)
7. Be part of support group
8. Know your personal coping skills: Specific things to do (See below for inspiration).

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9. Know your personal coping skills: Specific things **not** to do (See below for inspiration).

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10. Call a support person and ask them to listen while you talk through the situation.
11. Do some relaxation.
12. Write in your journal for at least one half hour.
13. Ride your exercise bike for forty-five minutes.
14. Play the piano or work on a fun activity for an hour.
15. Reading.
16. Sports.
17. Working with wood, clay or pottery.
18. Drawing, painting.
19. Yoga.
20. Dancing.
21. Shopping.
22. Day trips.
23. Watch a funny movie.
24. Pray.
25. Helping others.
26. Talking to a therapist or counsellor.
27. Arranging not to be alone, but rather spend time with friends.
28. Staying active.
29. Recalling good times and remembering that depression ends.
30. Living one day at a time.
31. Planning activities that involve being outside.
32. Full-spectrum light.
33. Go to work.
34. Force myself to get up in the morning.

### **Good sleep habits**

1. Use your bedroom only for sleeping. Read, watch television and talk elsewhere.
2. Do not go to bed until you are drowsy.
3. Get up at about the same time every day, even on weekends – it's hard to shift your sleep and wake times back and forth.
4. No naps.
5. No alcohol within 2 hours of bedtime.
6. No tobacco within 2 hours of bedtime.
7. No caffeine within 6 hours of bedtime (caffeine is in coffee, tea, chocolate, cola and many other types of soda).
8. Avoid lots of fluids before bed and empty bladder before retiring.
9. Take any bedtime medications 1 hour before retiring (discuss this with your doctor first)
10. Regular exercise, best in the morning or afternoon.

*Notes:*

- Follow the guidelines religiously.
- Don't expect quick changes: 2-3 weeks may be needed to show improvement.
- If you want to wake up earlier because you're oversleeping, move your wake-up time by ½ an hour each day until you're getting up at the time you want.



Session 2 Handout 6. **Action plan for Depression**<sup>18</sup>

| <b>Action Plan for Depression</b>                            |                                      |
|--|--------------------------------------|
| 1. Check Meds  | 6. Coping skills/To do:<br>_____     |
| 2. Check: Alcohol/Drugs/Nicotine?                            | 7. Coping skills/Not to do:<br>_____ |
| 3. Recognize stress triggers?<br>• Physical?<br>• Emotional? | 8. Contact provider?<br>Phone: _____ |
| 4. Maintain daily activities                                 | 9. Support Group?<br>Phone: _____    |
| 5. Activate support persons:<br>Phone: _____                 |                                      |
|  |                                      |
| <b>Action Plan for Depression</b>                            |                                      |
| 1. Check Meds  | 6. Coping skills/To do:<br>_____     |
| 2. Check: Alcohol/Drugs/Nicotine?                            | 7. Coping skills/Not to do:<br>_____ |
| 3. Recognize stress triggers?<br>• Physical?<br>• Emotional? | 8. Contact provider?<br>Phone: _____ |
| 4. Maintain daily activities                                 | 9. Support Group?<br>Phone: _____    |
| 5. Activate support persons:<br>Phone: _____                 |                                      |

<sup>18</sup> Adapted from Bauer & McBride book (see handout 2)

## **Session 3**

This session is designed to aid the client's awareness of his or her own early signs, symptoms and triggers for a manic episode. This will enhance ability to manage the disorder in a proactive and functional manner.

### **Agenda and aims for session 3:**

- 1) Develop a personal list of signs and symptoms of mania.
- 2) Develop a personal list of triggers for mania.
- 3) Develop a personal mania profile (Thoughts, Behaviours and Feelings).
- 4) Determine personal criteria for when to react to changes in the mania profile and list the actions to take.

### **Introduction to today's session:**

We have seen that bipolar disorder is characterized by extremes in mood and we have talked about the related changes in thinking and behaviour, in particular, we looked at the depressive side of the disorder last time. Being able to recognize symptoms is a first step towards developing coping strategies that can prevent, or at least limit a depressive episode. This is also true when looking at the manic side of bipolar disorder.

So today we will be developing personal lists of signs, symptoms and triggers of manic episodes. This will allow us to develop a personal profile of thoughts, behaviours and feelings that go with your particular manic episodes. This in turn enables us to develop better personal criteria for when to react to changes in the profile, and we can then also list the actions to take in order to try to stop or reduce the impact of the manic episode.

There is a lot of variation in the way people experience mania, so it is important to get to grips with your particular profile of signs and symptoms, which is what we will be looking at today.



## **1. The development of a personal list of signs and symptoms of mania and the development of a personal profile of mania.**

Mania is experienced as the way a person thinks, feels and acts. So when talking about mania, as was the case with depression, it can help to think about it in this way: A person's thoughts, feelings and behaviours ARE their signs and symptoms of mania.

Discussion: What are some examples of thoughts, feelings and actions that a person might have, or engage in when they are manic? Sometimes it helps to recall manic signs and symptoms by thinking about your most recent episode or perhaps your worst episode. Some people feel good during these times, others feel irritable, restless and not good at all, what is it like for you? Sometimes it is hard for people to remember the manic phase, so if that is the case for you, what have other people told you about it?

[Therapist writes down client suggestions on board under the headings of: "Thoughts", "Feelings" and "Behaviour". If client does not generate examples; *handout 1* is displayed and handed out for inspiration. When a reasonable list has been generated, display and hand out *handout 2 Personal Mania Profile* and ask client to check off symptoms that represents his or her manic phase and to add personal symptoms not listed in the blank spaces, while checking off early warning signs with an "E"].

What you have now is a list of symptoms and early signs of mania that is personal and possibly unique to you. It is important to get to know the list well, so you can spot the signs when they occur.

Further, manic signs and symptoms can return in several ways. They can return slowly and gradually, increasing in severity over time or they can return quite quickly. Also it is possible to have both manic and depressed symptoms intermixed – so a

person can have both manic and depressive symptoms at the same time. Have a think about what the pattern has been for you.

Discussion: Have you had mania come on very quickly and seemingly without warning? Have you had mania come on gradually and increase in severity over time?

## **2. The development of a personal list of triggers for mania.**

I have compared bipolar disorder to diabetes where sugar levels can go too high or too low because the body cannot regulate them. In bipolar disorder it is the mood that is not being regulated properly and so it can go too high or too low. Both illnesses have periods of stability when the person is OK, and times when they are not, in a sense it is part of the disorder to fluctuate in mood, or you could say that instability is a characteristic of the disorder. Stress can increase this instability.

As we saw in the previous session, stress can be thought of as either good or bad life events. We discussed how someone with bipolar disorder may be more sensitive than others to stress in life. Also, if stress triggers an illness episode, the episode can last long after the stress itself is gone.

Discussion: What types of stresses do you think might bring about, or contribute to, a manic episode? If you think about your most recent or your worst episode, can you recall if there was a crisis or even a minor stress factor that seemed to occur just before you became manic? What was it? Have you experienced an episode of mania where you could not see that there were any triggers?

[Therapist lists the examples of triggers on the board and directs the client to *handout 3* which is then completed].

Now you have a list, or a cluster of manic signs and symptoms that represents your Personal Mania Profile. You have also developed a personal list of stressors or triggers which you think might bring about, or contribute to a manic episode.



**3. Determine personal criteria for when to react to changes in the depressive profile and list the actions to take.**

In handout 2 you have ticked early warning signs of mania with an “E” and in handout 3 you have a list of potential triggers of manic episodes. So whenever you encounter any of these, you know that you should think about taking action, so as not to become manic.

It is important that you read and learn your personal, early warning signs and triggers, so that you are aware when they occur. Have a look at them on a regular basis.

In handout 4, I have suggested some things that you can do to cope with mania.

[Therapist gives out, displays and reads through handout 4 with client]

Discussion: If you look at items 8 and 9 on the handout you can see that they mention things to do and things not to do. From your experience what are the things to do and not to do when at risk of becoming manic?

[Therapist writes client’s suggestions on board and directs him or her to write the examples that he or she sees as personally relevant in the space provided in handout].

As we saw last time, part of good coping is good sleep hygiene, so just to make sure that it is clear how important this is, I’ve included handout 5 about good sleep habits again, this is equally important for depression and mania. [Handout 5 is given out]

Now if we look at handout 6.

[Therapist gives out, displays and reads through handout 6 with client]

You can see that there is room for details of support persons, health care provider and a support group. If you have these detail ready please fill them in now, if not please fill them in as soon as you get home today, so as not to forget. There is also room for writing in the main or most important things to do and not to do. Have a look at the lists we have done and write in what you feel is most important to you.

This little card now contains the most important things to do when you first notice early signs or face triggers of mania, or with the information from the previous session, depression. The card should be with you at all times, providing guidance whenever needed.

### **Next Session.**

Next time we look at how the strategies can fit into your everyday- and social- life. This is very important for successful coping, and is often important for the people you care about. So we will look at how bipolar disorder might be experienced by the people you care about, what you should tell them about it, and also how you might get to grips with employers and employment.

So next time you will:

- 1) Get information about the need to inform family members about bipolar disorder. Discuss and address difficulties arising from family life, such as overprotective partners, reestablishment of reasonable role in family after illness episode etc. This discussion includes information on communication skills that I will be giving you.
- 2) You will determine how your social network can be integrated into the coping strategy developed. (i.e. who has the right to say that it is time to implement an action plan for coping? And for example, determine that it is time to go and see the psychiatrist).
- 3) The personal action plan for coping is finalized and any difficulties addressed
- 4) Say goodbye and set up appointment for interview.



### Typical signs of Mania<sup>19</sup>

Which of these symptoms have you experienced?

- |                          |                                   |                          |                                     |
|--------------------------|-----------------------------------|--------------------------|-------------------------------------|
| <input type="checkbox"/> | Insomnia                          | <input type="checkbox"/> | Increased community involvement     |
| <input type="checkbox"/> | Surges of energy                  | <input type="checkbox"/> | Tingly feeling                      |
| <input type="checkbox"/> | Flight of ideas                   | <input type="checkbox"/> | Friends notice behaviour change     |
| <input type="checkbox"/> | Writing pressure                  | <input type="checkbox"/> | Compulsive eating                   |
| <input type="checkbox"/> | Irritability                      | <input type="checkbox"/> | Feeling great                       |
| <input type="checkbox"/> | Spending too much money           | <input type="checkbox"/> | Feeling very important              |
| <input type="checkbox"/> | Unnecessary phone calls           | <input type="checkbox"/> | Obsessions                          |
| <input type="checkbox"/> | Wanting to keep moving            | <input type="checkbox"/> | Unusual bursts of enthusiasm        |
| <input type="checkbox"/> | Sleeping much less                | <input type="checkbox"/> | Very productive                     |
| <input type="checkbox"/> | Others seem slow                  | <input type="checkbox"/> | Doing several things at once        |
| <input type="checkbox"/> | Speech pressure                   | <input type="checkbox"/> | Inability to concentrate            |
| <input type="checkbox"/> | Making lots of plans              | <input type="checkbox"/> | Short temper                        |
| <input type="checkbox"/> | Inappropriate anger               | <input type="checkbox"/> | Disorganization                     |
| <input type="checkbox"/> | Difficulty staying still          | <input type="checkbox"/> | Ability to foresee things happening |
| <input type="checkbox"/> | Restlessness                      | <input type="checkbox"/> | Noises louder than usual            |
| <input type="checkbox"/> | Increased appetite                | <input type="checkbox"/> | Bizarre ideas, thoughts             |
| <input type="checkbox"/> | Euphoria                          | <input type="checkbox"/> | Laugh to self uncontrollably        |
| <input type="checkbox"/> | Feeling superior                  | <input type="checkbox"/> | Thrill seeking                      |
| <input type="checkbox"/> | Increased creativity              | <input type="checkbox"/> | More sexually active                |
| <input type="checkbox"/> | Overambitious                     | <input type="checkbox"/> | Danger to self and others           |
| <input type="checkbox"/> | Taking on too much responsibility | <input type="checkbox"/> | Spotless, energetic housekeeping    |
| <input type="checkbox"/> | Nervous and wound up              | <input type="checkbox"/> | Itching                             |
| <input type="checkbox"/> | Anxious                           | <input type="checkbox"/> | Flushed and hot                     |
| <input type="checkbox"/> | Overly self-involved              | <input type="checkbox"/> | Increased sociability               |
| <input type="checkbox"/> | Negative                          | <input type="checkbox"/> | Dangerous driving                   |
| <input type="checkbox"/> | Feeling unreal                    | <input type="checkbox"/> | Increased alcohol intake            |
| <input type="checkbox"/> | More sensitive than usual         | <input type="checkbox"/> | Oblivious                           |
| <input type="checkbox"/> | Out of touch with reality         | <input type="checkbox"/> | Poor judgement                      |
| <input type="checkbox"/> | Inappropriate behaviour           | <input type="checkbox"/> |                                     |
| <input type="checkbox"/> |                                   | <input type="checkbox"/> |                                     |
| <input type="checkbox"/> |                                   | <input type="checkbox"/> |                                     |
| <input type="checkbox"/> |                                   | <input type="checkbox"/> |                                     |
| <input type="checkbox"/> |                                   | <input type="checkbox"/> |                                     |
| <input type="checkbox"/> |                                   | <input type="checkbox"/> |                                     |
| <input type="checkbox"/> |                                   | <input type="checkbox"/> |                                     |
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| <input type="checkbox"/> |                                   | <input type="checkbox"/> |                                     |
| <input type="checkbox"/> |                                   | <input type="checkbox"/> |                                     |
| <input type="checkbox"/> |                                   | <input type="checkbox"/> |                                     |

<sup>19</sup> Adapted from the book by Copeland, M. E. (2001). *The Depression Workbook. A guide for Living with Depression and Manic Depression* (2<sup>nd</sup> ed.). Oakland, CA. New Harbinger Publications.

### Personal Mania Profile

1. Place a tick next to the symptoms which you experience
2. Add other symptoms if not on the list
3. Mark an "E" next to those which are particular Early Warning Signs

#### **Thoughts:**

- Difficulty concentrating.
- Thoughts about having special power.
- Racing thoughts, as though the rest of the world is in slow motion.
- Thoughts jump from one idea to another quickly.
- Concerns that people are plotting against you or other such unusual thoughts.
- Thoughts preoccupied with self.
- Hallucinations: unreal voices or visions.
- Thoughts are unusually clear.
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

#### **Feelings:**

- Feeling "high", very optimistic, euphoric.
- More energy.
- Feeling impatient, irritable.
- Unusually cheerful and happy.
- Feeling unusually self-confident or invulnerable.
- Know-it-all attitude.
- Rapid, unpredictable emotional changes.
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

#### **Behaviours:**

- Speech loud and/or rapid.
- Less sleep.
- Overly sociable.
- Stronger sex drive.
- Doing more projects, at times more than are practical.
- Spending more money impulsively, shopping sprees.
- Involvement in dangerous activities.
- Bizarre behaviour.
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_



Session 3 handout 3 (Adapted from Bauer & McBride + Copeland books. See handout 1 + 2 from session 2).

## Personal triggers of a manic episode

**Tick all those that have triggered manic episodes for you.  
Add others that you have experienced:**

- Bad life events: \_\_\_\_\_
- Good life events: \_\_\_\_\_
- Change in medication (psychiatric or medical, prescription or over the counter)  
Which medications? \_\_\_\_\_
- Physical illness  
Which illness? \_\_\_\_\_
- Drug or alcohol use.
- Changes in smoking habits.
- Change in seasons.
- Moving house.
- Losing your job.
- Death of a loved one.
- Breakdown of a relationship.
- Conflicts with family or others.
- Going on holiday or other drastic change in daily routine.
- Working too hard.
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

**Outline of coping strategies for Mania.**

1. Alert health care provider early.
2. Review medication changes for medical illness.
3. Get early assessment and treatment of physical illness.
4. Do not use alcohol or drugs.  
(Note: even increasing tobacco can undo the effects of prescribed medication)
5. Maintain daily activities but do not increase them.
6. Minimize sleep loss (See handout 5).
7. Activate support persons and talk through the situation.
8. Know your personal coping skills: Specific things to do (See below for inspiration).  

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9. Know your personal coping skills: Specific things **not** to do (See below, for inspiration).  

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10. Reading.
11. Do some relaxation.
12. Write in your journal.
13. Yoga.
14. Playing a musical instrument.
15. Exercise.
16. Long walks.
17. Long hot baths.
18. Listening to music.
19. Gardening.
20. Working with wood.
21. Working with clay, pottery.
22. Drawing, painting.
23. Writing poetry.
24. Writing letters.
25. Cleaning.
26. Talking to therapist.
27. Arranging not to be alone.
28. Spending time with good friends.
29. Focusing on living one day at a time.
30. Alcohol and drugs.
31. Write down a list of things to do and stick to it.
32. Stay away from crowds of people and other high stimuli situations.
33. Talk to staff at a crisis clinic or hotline.
34. Handing over all credit cards, checks, etc. to a responsible and trusted person.



## **Good sleep habits**

1. Use your bedroom only for sleeping. Read, watch television and talk elsewhere.
2. Do not go to bed until you are drowsy.
3. Get up at about the same time every day, even on weekends – it's hard to shift your sleep and wake times back and forth.
4. No naps.
5. No alcohol within 2 hours of bedtime.
6. No tobacco within 2 hours of bedtime.
7. No caffeine within 6 hours of bedtime (caffeine is in coffee, tea, chocolate, cola and many other types of soda).
8. Avoid lots of fluids before bed and empty bladder before retiring.
9. Take any bedtime medications 1 hour before retiring (discuss this with your doctor first)
10. Regular exercise, best in the morning or afternoon.

### *Notes:*

- Follow the guidelines religiously.
- Don't expect quick changes: 2-3 weeks may be needed to show improvement.
- If you want to wake up earlier because you're oversleeping, move your wake-up time by ½ an hour each day until you're getting up at the time you want.

Session 3 handout 6. **Action plan for Mania/Depression**<sup>20</sup>

| <b>Action Plan for Depression</b>                            |                                      |
|--|--------------------------------------|
| 1. Check Meds  | 6. Coping skills/To do:<br>_____     |
| 2. Check: Alcohol/Drugs/Nicotine?                            | 7. Coping skills/Not to do:<br>_____ |
| 3. Recognize stress triggers?<br>• Physical?<br>• Emotional? | 8. Contact provider?<br>Phone: _____ |
| 4. Maintain daily activities                                 | 9. Support Group?<br>Phone: _____    |
| 5. Activate support persons:<br>Phone: _____                 |                                      |
| <b>Action Plan for Mania</b>                                 |                                      |
| 1. Check Meds  | 6. Coping skills/To do:<br>_____     |
| 2. Check: Alcohol/Drugs/Nicotine?                            | 7. Coping skills/Not to do:<br>_____ |
| 3. Recognize stress triggers?<br>• Physical?<br>• Emotional? | 8. Contact provider?<br>Phone: _____ |
| 4. Maintain daily activities                                 | 9. Support Group?<br>Phone: _____    |
| 5. Activate support persons:<br>Phone: _____                 |                                      |

<sup>20</sup> Adapted from Bauer & McBride book (see handout 1 session 1)



## **Session 4**

This session is designed to aid the integration of adaptive coping strategies as developed in session 2 and 3 with the client's social and work related network. This includes education about family experience of bipolar disorder and adaptive ways of approaching employers.

### **Agenda and aims for session 4:**

- 1) Gain insight into the importance of involving family in coping.
- 2) Gain insight into adaptive communication skill regarding bipolar disorder.
- 3) Develop plan for how to manage work situations, including communication with employer.

### **Introduction to today's session:**

When you recover from an illness episode, be it a depressive, manic or mixed one, you will in all likelihood want to reintegrate and take your usual position with friends, in the family and at work. But you will possibly have experienced that those you live or work with, don't treat you the same as before. Your loved ones may be angry and critical or they may be overprotective. At work you may feel that you are back to your old self, but your colleagues may not see it that way. And if you do need to make adjustments to the way you work to help your mood to stay stable, how much can you tell your colleagues about bipolar disorder and still get them to treat you as the competent person they knew before the illness episode?

These are the kind of questions we will be looking at today, as you may have experienced, it can be a difficult task to handle, but it is important to know that it can be done, and that it is absolutely possible to have a successful family and work life. If you are not currently working the section of today's session regarding work is still relevant to you, as you might consider employment in the future, or you can relate the discussion to other aspects of your life that may be stressful in the same way as employment can be stressful.

**1) Educate family members about bipolar disorder. And information on communication skills is discussed.**

During your recovery period your close relatives and friends are going to have confused and mixed feelings about the illness and about how they can best help you. One of the most common reactions is anger. People get angry even if they are the most well intended people in the world, partly out of frustration about not knowing how to help. Two typical patterns are what have been called: under-identifying and over-identifying with the illness

Under-identifying with the disorder is when someone attributes your behaviour changes to your personality or your habits, so they criticize you for not trying hard enough, having flawed moral values, your unconscious motives i.e. “if you did something then you must have wanted to do it somehow even if you did not know it yourself” etc.

Discussion: Have you had this type of experience? Have you ever felt blamed for being ill?

Over-identifying with the disorder is when someone attributes most of what you do to the illness, which often leads them to act in an overprotective manner and to label your everyday reactions as signs of your illness. So you may find that your relatives want to watch you very carefully and want to manage your disorder to a degree that makes you feel that you are being treated as if you were a child.

For instance, someone might say that they see the disorder in your anger about something, when in fact you might very well have become angry about this exact same thing before you had your first episode of the disorder.

Discussion: Have you experienced over-identification with the disorder from people close to you? What happened?



One of the problems is that if relatives or friends are confronted with being overprotective or even intrusive, they may refer to the diagnosis as a justification. So for example if you have expressed annoyance with a relative for asking a lot of questions about medication, he or she might tell you that your annoyance is a sign of the disorder. This can get you into a vicious circle in which you complain about their intrusiveness, your relatives react as if you are heading into an episode of the disorder, you become even more annoyed with their labelling of your behaviour as disordered or ill, their beliefs about you moving towards an episode are confirmed even more and they become more overprotective and ask even more questions about whether you are taking your medication etc.

Discussion: Can you recognize this pattern? The worst possible outcome is that this type of pressure actually triggers an episode. Do you think that that has happened to you?

Another common problem after a depressive or a manic episode is to do with physical intimacy. Your partner's discomfort may not be related to things we discussed earlier such as over-protectiveness or criticism, instead he or she may have become emotionally withdrawn. Sexual and other physical intimacy may have stopped during or shortly after your last illness episode. This can be because partners feel angry about events that occurred during the episode, which in turn can make them uncomfortable with closeness. Or if they think that you are a little hypomanic, they may conclude that not only is your sex drive increased, but the same can be said for your irritability, which makes them uncomfortable with closeness.

The opposite can also occur, if you feel depressed and your partner attempts to re-establish physical contact, you may feel that your body is ugly, that you are under too much pressure to perform or you can simply lack energy.

Discussion: Are there any of these difficulties that you can relate to your experiences in the past or present?

If you are experiencing one or more of the problems we have discussed so far today, the good news is that we now go on to look at how they can be addressed.

### **Tools for educating the family after an episode.**

The first step is to realize that even if friends or relatives have listened to your explanations, listened to your doctors and read about bipolar disorder, they can still have misconceptions about the disorder and about your prospects for the future. So educating your close friends and relatives is very important. It is a good idea to do this even if your family and social network is functioning well, but even more important to do so during your recovery periods where negative emotions are at their peak.

[Handout 1 is handed out and explained. It is suggested that participants photocopy and give handout 1 to relatives and other significant people in their lives, and that they make themselves available to answer any questions from significant others arising from the handout].

It is important to develop a common language for talking about the disorder with your family and other people who are close to you. Different terms about the behaviour that relatives see you engage in when ill expresses subtle differences in beliefs about what causes you to act in a certain way. For example, your family members will be more supportive of you if they understand that increased irritability is a sign of the disorder's cycling and does not indicate that you have become a "mean" or "hostile" person. Similarly they should come to understand that you can be in a depressed mood or have problems with concentration, rather than show a "stable pessimistic outlook on life" or "mental laziness".

If you have school aged children around you it is important to use a language that they can understand, and it is usually better to use terms such as "overly happy", "excited", "wired", and "sad", rather than use the more technically sounding terms of "manic" and "depressed".



Discussion: Do you feel that your relatives have an adequate understanding of bipolar disorder or do you need to educate them about it?

### **Communication skills.**

Ability to communicate in an effective way with the people you are close to is closely linked to good coping with bipolar disorder. The skills we will look at here are therefore very important and you need to practice them on a regular basis, preferably when you are well, as this makes them easier to use when you are ill and need them most.

#### Skill no. 1. Active Listening.

When you are under a lot of stress or pressure, such as that coming from episodes of illness, you will most likely find it difficult to listen to the negative feelings, objections or concerns of the people close to you. But if you are not able to do this to their satisfaction, then it becomes more likely that they will find it hard to do some of the things that interfere with their life, but which aid your recovery. For example they might not refrain from putting you under pressure to go to a concert or a movie that they have been looking forward to, but which could be over-stimulating for you if you are in a hypomanic state. In other words they might “force” their needs through if you are not seen to be listening and responding to the needs that they are expressing. Similarly, they are more likely to criticize you if they do not feel that you are listening to their concerns.

This illustrates why it is important for you illness management to help your relatives handle their anger or frustration by listening and explicitly expressing an understanding of their point of view. A good way to do this is called active listening.

[Give out Handout 2 and go through with client].

Discussion: Any questions or comments about active listening?

Skill No. 2: Positive requests for change.

Another way to defuse tension and avoid antagonistic communication is to engage with family members through positive requests for change. This involves stating clearly and without criticizing what you would like to see changed.

Criticizing makes it more difficult for your relatives and friends to adapt their behaviour, simply because we all have a tendency to become defensive if we feel under attack or criticized.

It is therefore more likely to be a successful conversation if you say:

“It is very important to me that I am free to talk and dream about my plans for the future, even if my future will contain elements of bipolar episodes”

rather than:

“It is out of order that you cannot engage in a conversation about what I will do in the future, without dragging questions of my illness into it all the time”.

Stating something in a positive manner makes it much easier to accept and relate to.

[Handout 3 is handed out and explained].

This type of positive communication is a skill that needs to be practised, but you will find that the more you practise the more natural it becomes, and that is really what you should be aiming for, because if it is not part of your normal way of speaking, then it is unlikely to happen when you are under pressure and need it the most. So again, the lesson is to practice when you are feeling good and when there is no tension in the air. It might feel a bit artificial at first, but that will soon pass, once you feel the benefits of this type of communication.

Discussion: Can you recognize from relationships with family members or friends that negative requests are often met with defensiveness? What would be the barriers to you



using this type of phrases and style of communication? Would it be a good idea to involve your family or friends in practising positive request communication?

### **Bipolar disorder and the work place.**

It is essential for your ability to function effectively in employment that you work at maintaining a stable mood. This is another good reason to take medication on a regular basis. However it is also essential to realise that working within a supportive environment is very important to your mood stability. So it becomes important to find the right balance of stability between having an interesting job that challenges you in the way you want it to, and keeping work hours, general stimulation and stress levels at a level that does not, directly or indirectly, as in the case of stress at home because of arguments over long hours, cause an illness episode to happen or become worse.

Discussion: Have you found that having bipolar disorder influences your employment? In what way did that happen? Some people report that their bipolar disorder can enhance their job performance and creativity on the job, partly because they are so full of energy when hypomanic, do you recognize this from your own life? If so, are there any dangers in “using” mania in this way?

A situation where you might be vulnerable to a relapse is when you start a new job or return to your job after an illness episode. The reason for this is that it is not uncommon to want to impress our employer in that situation. This can result in a feeling of needing to overachieve at work sometimes, even to a degree where you might feel “driven” or compulsive about your work. This in turn results in being spent, down and tired when coming home at the end of the day, and it can also result in erratic sleep patterns, with little sleep during the week and then many hours of sleep on the weekend. It is as if the pattern of bipolar disorder moves into the way you structure your work and home life, with hypomania being present at work and depression being present at home.

One of the things that is worth thinking about with regards to work, is that research has shown that situations involving reward that promises more, such as a promotion that can motivate and increase your drive towards other goals, (Lam et al. 2003; Johnson et al.

2000 [give specific references if interested]), can trigger mania. So the logical conclusion is that you can have a fulfilling work life, but it needs to be managed.

[Handout 4 is considered with client].

We have now discussed some of the things that you can do in the workplace. But the actual job, the work setting and your employer can also have an impact on how things go.

With regards to the actual job that you do, some things follow from the stress and trigger factors that we have discussed during the last few sessions. So it is unlikely that jobs with shifting patterns (day/night shifts), lots of sudden social stimulation, no time to “recharge” energy between bursts of work, frequent travel across time zones or a lot of interpersonal stress, would be helpful to you. That does not mean that you cannot work in an environment where these stress factors exist, just that they need to be managed carefully and some arrangement may need to be negotiated with your employer.

In order to come to an agreement with your employer, you first need to make sure that he or she knows that you have bipolar disorder.

Discussion: Can you give me some reasons why not to tell your employer about your condition? Can you give me some reasons why it would be a good idea to tell your employer? Could you use handout 1 to tell your employer about bipolar disorder?

[Handout 5 is worked through and the client is asked if and when they are going to approach their employer].



## **End of treatment.**

Over the last few weeks you have developed a personal plan for coping with the bipolar disorder that you live with. This all adds up to an individual handbook for how to deal with difficult issues such as situations where you notice triggers or early signs of depression or mania. You have a super concise version of what to do in such situations on a card that you can carry with you everywhere. You have also looked at some of the difficulties that may arise in family and work aspects of life, and have material to share with family members in order to educate them about the disorder and about the things that you might find challenging. This included some strategies to improve the way you talk to the people close to you about the disorder. Further you have now developed a plan for the things you would like to see improved at work or alternatively a list of things that you will think about if you were to take up employment in the future.

Remember that many of the skills we have talked about are things that benefit from practise, so read your handbook often and try to the best of your ability to implement the things that you have decided would benefit you. Practise makes perfect so do not despair if you do not get everything right the first time. No one does.

Are there any questions before we set up appointments for the interviews?

**Brief fact sheet on bipolar Disorder for family members<sup>21</sup>.**

**What does it mean to have Bipolar disorder?**

Having bipolar disorder means that I am prone to have drastic mood swings, from the very high and energetic (Manic) to the very low, unmotivated (Depressed). My high periods can last from a few days to several weeks or more. My low periods will typically last from several weeks to several months. About 1 in every 100 people has bipolar disorder, which is about the same number of people with diabetes. So it is a fairly common illness. It most often affects a person for the first time in his or her late teens or young adult life.

**What are the symptoms?**

The main symptoms during a high period may include feeling an exaggerated sense of happiness and excitement or I may feel overly angry and irritable. I can also feel as if I can do things that no one else can do (grandiose ideas), have more energy than usual and not sleep very much. My thoughts can be very fast and running out of control, so I can be rather impulsive in matters of money and other aspects of life and also be easy to distract. I am likely to talk faster and to express many ideas some of which might not be realistic.

During periods where I feel low, I can have symptoms mentioned before under symptoms of mania, such as feeling irritable and having difficulty concentrating. But the main features of the low periods are typically feeling down, sad, bad, guilty, fatigued, sometimes anxious, moving and talking slowly. Also, I may lose interest in people or things that I otherwise care for, sleep too much or find it difficult to fall asleep. I may lose interest in food or eat too much.

Further I may contemplate suicide or actually attempt to take my own life.

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<sup>21</sup> Adapted from Miklowitz, D. J. (2002). The Bipolar Survival Guide. What you and your family needs to know. London. The Guilford Press.



### **How does Bipolar Disorder Affect Family and Social life?**

Bipolar disorder is a challenge to relationships that can be met with good communication and emotional support. The illness may affect my ability to relate to others in the family or workplace, in particular when I'm experiencing an episode of mania or depression. Any relationship problems will be most prominent during these periods, but then will probably improve as I recover. It is important to know that relationship problems can be resolved through good communication, support and problem solving between us. At times it can be helpful to see a family/couples therapist or to join a family support group.

### **What Causes Bipolar disorder?**

Bipolar disorder is related to having an imbalance of chemicals in the brain and the way that brain cells communicate with each other. Having this disorder is not a choice and it is possible that I inherited the tendency for the disorder from my blood relatives. My mood swings are also affected by the things that I experience in life, such as sudden changes or other forms of stress.

### **Treatment?**

I am probably being treated with one of a range of mood stabilizing drugs such as Tegretol, Lamictal or Lithium and I may also be given antidepressants to control both depression and any anxiety symptoms that might be part of my illness. These drugs require that I consult a psychiatrist on a regular basis to make sure that side effects do not get above reasonable levels and to get my blood levels checked.

It can also be useful for me to go to individual psychotherapy, family counselling or to use a support group of people who understand the problems that I/we can encounter. Therapy can help me understand the disorder better, monitor the ups and downs of symptoms and ultimately teach me to prevent relapses and function better in the family and workplace.

If I am one of the many people with bipolar disorder having problems with drugs or alcohol, I may also benefit from support programs such as Alcoholics Anonymous.

**Future prospects.**

The nature of bipolar disorder is such that I am likely to have ups and downs in the future, but that does not mean that there is any reason to lose hope for the future.

With the help of medication, therapy and general supportive surroundings, my mood fluctuations can occur less often and become less extreme. With help and support I can achieve major goals for the family, function well in my social life and also be accomplished in the way I conduct my work and function in the workplace.



Handout 2 session 4

**Active listening step by step**<sup>22</sup>

- 1) Look at the person you are speaking to.
- 2) Pay attention to what is said at all times.
- 3) Nod your head and confirm that you are listening by inserting small confirmative words, such as “yes”, “no” and “uh-huhh”.
- 4) Ask questions to clear up any ambiguity and to show that you are interested.
- 5) Check that you understand what has been said. Use paraphrase but do not overdo this, as it then becomes artificial and patronising.

**Example of Active Listening:**

Person A: “You appeared to be rather annoyed with me last night, what is happening?”

[Clarifying question]

Person B: “I wanted to talk to you about my mother’s birthday next week, but you just did not want to know, and I just keep thinking: what is the point in even trying?”

Person A: “Fair enough, you were annoyed with me and felt that it was pointless even to try to get me to plan your mum’s birthday” [Paraphrasing].

Person B: “YES, and I can feel myself becoming annoyed with you again now, because I had already asked you a million times about the birthday”.

Person A: [Nods] “Yes, I can understand that it must be annoying, but partly it’s because I am going through a rough patch and feel quite low. Did you think that we would not get around to it before next week?” [Clarifying question].

Person B: “I might have been a bit hard on you, I just get so frustrated, and the question remains, when are we going to plan the birthday?”

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<sup>22</sup> Adapted from Miklowitz, D. J. & Goldstein, M. J (1997). Bipolar disorder: A family-focused treatment approach. The Guildford Press.

Handout 3 session 4 (From book by Miklowitz & Goldstein (1997) see handout 2).

### **Positive requests for change.**

In general it works better to ask someone to do something new and positive (Positive request). On the contrary, a criticism usually asks someone to stop what they are currently doing and this is, as a general rule, less effective.

Steps involved in making a positive request:

- 1) Look at the person you are speaking to.
- 2) Say exactly what you would like him or her to do.
- 3) Express clearly how this would make you feel.
- 4) Use phrases that has references to yourself:

“It would mean a lot to **me** if you...”

“I would really appreciate if you help me with...”

“It would really change things for the better for **me** if you would...”

### **Examples of positive request communication:**

Ex. 1: “Mum, it would really change things for the better for me, if you let me know a week in advance when you are going away and expect me to look after your cats”.

Ex. 2: “Dad, it would mean a lot to me if you consulted me before making plans that involve me”.

Ex. 3: “It is very important to me that I am free to talk about my plans for the future even if my future will contain elements of bipolar episodes”

**An example of negative request communication** (Not recommended and only given here as a contrast to the positive examples above):

Ex.: “It is out of order that **you** cannot engage in a conversation about what I will do in the future, without dragging questions of my illness into it all the time”.



Handout 4 session 4

**Key phrases when starting or returning to a job**<sup>23</sup>

Do not try to do everything on the first day.

Take a cautious, measured approach to working.

It is better to be a consistent employee, than a highly productive employee one day who is not present the next.

When not at work; relax but do not stop all activity.

At home, do tasks and activities that are mainly low on stimulus intensity.

Do not schedule a lot of demanding social events during the week.

Do not “oversleep” on weekends, i.e. keep a sleep pattern similar to that in place during the week.

Plan weekend activities so they fit your pattern of getting out of bed at a regular time in the morning. This helps you have a smooth transition between weekend and work days.

***The above is particularly important when starting or returning to a job, but constitutes valuable strategies also when your job routine is more established.***

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<sup>23</sup> Adapted from Miklowitz, D. J. (2002). The bipolar Survival Guide. What you and your family needs to know. London. The Guilford Press. And from Copeland, M. E. (2001). The Depression Workbook. A guide for Living with Depression and Manic Depression (2<sup>nd</sup> ed.). Oakland, CA. New Harbinger Publications.

### **Reasonable Workplace Accommodations**

- Tick box if you think this would benefit you in your current job.
- Put an “E” next to the box if you believe your employer would agree to it.
- Put an “A” next to the box if you intend to approach your employer about this.

#### **Work Hours**

- Working regular daily or nightly hours rather than variable night/day work shifts
- Avoiding work early in the morning if you suffer from “Medication hangovers”
- Reducing work hours or changing from full-time to part-time
- Being excused from, or getting reduction in, overtime work
- Completing some of your tasks at home versus work

#### **Stress Management**

- Being allowed to share responsibilities for projects with others
- Being placed in an office or cubicle that has a degree of distance from noise and stimulation
- Working in well-lit, un-crowded rooms
- Being excused from certain work assignments that historically have been triggers for your mood swings
- Obtaining support or counselling from an employee assistance program
- Leaving work for breaks or lunch to relax, exercise or walk
- Taking a greater number of short breaks rather than two long breaks during an eight-hour work shift

#### **Absences from Work**

- Being granted brief absences for medical appointments, with chances to make up the hours
- Being granted extended leaves of absence with a doctor’s note
- Being allowed to leave work early when having difficult mood swings or anxiety/stress reactions



**Communication with your Employer about Performance Evaluations**

- Having a regular and open communication with your employer about your job performance
- Hearing what you're doing right as well as what you're doing wrong
- Being judged by overall productivity and task completion as well as number of hours worked
- Revisiting these accommodations from time to time to determine if they are enabling you to be productive and remain stable.

| "A"s | Date when I will approach my employer |
|------|---------------------------------------|
|      |                                       |
|      |                                       |
|      |                                       |
|      |                                       |
|      |                                       |
|      |                                       |
|      |                                       |
|      |                                       |

## **Appendix B**

Confirmations of ethical approvals.

Consent form for participants.

Participant recruitment letter.

Information sheet for participants.

Recruitment letter to medical practitioners.

Information letter to medical practitioners.

Questionnaires (Pre- and Post- treatment).

Diary 1.

Covering letter for 5-week follow-up measurement.

Diary 2.

Interview Schedules (Pre- and Post- treatment).

Overview of meaning categories.





**East & North Hertfordshire Hospitals  
Local Research Ethics Committee**

Chairman: Dr Steve Eckersall  
Administrator: Mrs Jenny Austin

Q7, The Mezzanine  
QEII Hospital  
Howlands  
Welwyn Garden City  
Herts  
AL7 4HQ

Our ref: JCA/11.03

John Sorensen  
74 Wadhall Way  
Knebworth  
Herts  
SG3 6DX

Tel: 01707 365397 or 328111 ext 5035  
Fax: 01707 369010 or ext 5078  
Email: jenny.austin@nhs.net

8 December, 2003

Dear John

**Re: ENHLREC/03-11-50/M163 : A multiple case study of bipolar disordered clients going through an intensive psycho-educational intervention program**

The Chairman on behalf of the Committee has considered your response to the issues raised by the Committee at the first review of your application on 26<sup>th</sup> November 2003 as set out in our letter dated 2<sup>nd</sup> December 2003. The documents considered were as follows:

- Client Information Sheet, Version 2, December 2003

The Chairman, acting under delegated authority, is satisfied that your response has fulfilled the requirements of the Committee. You are therefore given approval for your research on ethical grounds provided that you comply with the conditions of approval set out below:

**Conditions**

- You do not undertake this research in a NHS organisation until the relevant NHS management approval has been received.
- You do not deviate from, or make changes to, the protocol without prior written approval of this Committee, except where this is necessary to eliminate immediate hazards to research participants or when the change involves only logistical or administrative aspects of the research. In such cases the Committee should be informed within seven days of the implementation of the change.
- You send a progress report to this Committee one year from the date on this letter and thereafter on an annual basis.
- You send a final report to this Committee when your research is completed which must be sent within 3 months of completion.
- If you decide to terminate this research prematurely you must send a report to this Committee within 15 days, indicating the reason for the early termination.
- You must advise this Committee of any unusual or unexpected results that raise questions about the safety of the research.
- The project must be started within 3 years of the date on this letter.

**Please ensure that you have received approval from the Research & Development Department before commencing your research.**

An advisory committee to Bedfordshire and Hertfordshire Strategic Health Authority

All correspondence should be sent to the administrator. Please ensure that you quote our study reference numbers on **all** future correspondence.

Yours sincerely



**Jenny Austin**  
**Administrator**  
**East & North Hertfordshire Hospitals LREC**

Copy Dr Tim Gale, Q18, R&D Manager, Hertfordshire Partnership NHS Trust, QEII Hospital

Enc List of Members





**Barnet, Enfield & Haringey Local Research Ethics Committee**

Holbrook House,  
Cockfosters Road,  
Barnet EN4 0DR,  
Herts.

Tel: 020 8272 5699

Fax: 020 8272 5691

Email: [alison.okane@enfield.nhs.uk](mailto:alison.okane@enfield.nhs.uk)

17<sup>th</sup> October, 2003.

John Sorensen,  
74 Wadnall Way,  
Knebworth,  
Herts SG3 6DX.

Dear Mr. Sorensen,

**03/83: An intensive Intervention with Bipolar Disorder**

Acting under delegated authority I write to acknowledge receipt of your letter dated 11<sup>th</sup> October 2003 and the enclosed clarification requested by the LREC in our letter to you dated 26<sup>th</sup> September 2003. There is now no objection on ethical grounds to the proposed study. I am therefore happy to give you the favourable opinion of the LREC:

**Paperwork reviewed**

LREC application form  
Protocol  
Patient Consent form  
Patient Information sheet  
CV of lead researcher  
Finalised questionnaire

**Please note that this opinion alone does not entitle you to begin research**

The Barnet, Enfield & Haringey LREC considers the ethics of proposed research projects and provides advice to NHS bodies under the auspices of which the research is intended to take place. **It is the NHS body, which has the responsibility to decide whether or not the project should go ahead**, taking into account the ethical advice of the LREC. Where these procedures take place on NHS premises or using NHS patients, the researcher must obtain the agreement of local NHS management who will need to be assured that the researcher holds an appropriate NHS contract and that indemnity issues have been adequately addressed.

**The following conditions apply to this project**

- The LREC will require a copy of the final report on completion of the project and require

An advisory committee to North Central London Strategic Health Authority

- details of the progress of the project periodically (i.e. annually for longer projects)
- The committee must receive immediate notification of any adverse or unforeseen circumstances arising out of the project.
  - If data is to be stored on a computer in such a way as to make it possible to identify individuals, then the project must be registered under the Data Act 1998. Please consult your department data protection officer for advice.
  - Failure to adhere to these conditions set out above will result in the invalidation of this letter of no objection.

I confirm that LRECs are fully compliant with the International Committee on Harmonisation/Good Clinical Practice (ICH) guidelines as they relate to the responsibilities, composition, function operations and records of an Independent Ethics Committee/Independent Review Board.

Please forward any additional information/amendments regarding your study to the LREC Co-ordinator at the above address.

Your application has been given a unique reference number 03/47 please use it on all correspondence with the LREC.

Yours sincerely



**Alison O'Kane**  
**LREC Co-ordinator**  
**Barnet, Enfield & Haringey**



**CONSENT FORM**

**Title of Project: An Intensive Intervention with Bipolar Disorder.**

**Name of Researcher: John Sorensen**

**Please initial box**

|  |                          |
|--|--------------------------|
| 1. I confirm that I have read and understood the information sheet dated.....(version.....) for the above study and have had the opportunity to ask questions.   | <input type="checkbox"/> |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being effected.  | <input type="checkbox"/> |
| 3. I understand that sections of my medical notes may be looked at by responsible individuals from the research team where it is relevant to my taking part in the research. I give permission for these individuals to have access to my records. | <input type="checkbox"/> |
| 4. I understand that tape recordings will be made of interviews and treatment sessions. I have been informed that these will only be accessible to the researchers and give my permission for these recordings to be used in the research.         | <input type="checkbox"/> |
| 5. I agree to take part in the above study   | <input type="checkbox"/> |
| 6. I further give my permission to inform my GP of my involvement in the study   | <input type="checkbox"/> |
| 7. I further give my permission to inform other doctors in charge of my care of my involvement in the study  | <input type="checkbox"/> |

|   |       |           |
|---|-------|-----------|
| _____   | _____ | _____     |
| Name of patient   | Date  | Signature |
| _____   | _____ | _____     |
| Name of Person taking consent<br>(if different from researcher) | Date  | Signature |
| _____   | _____ | _____     |
| Researcher  | Date  | Signature |

## Participant recruitment letter

*[Date]*

Dear

You have recently been referred to the Psychology Department and as a result of a current study of a treatment for the particular difficulties mentioned in your referral we can offer you an appointment at [*Give address here*] on [*Date and Time*].

At this appointment you will be given further information about the study and the treatment being offered. You will also have the opportunity to ask any questions you may have. I look forward to seeing you.

Yours Sincerely

John Sorensen  
Trainee Clinical Psychologist



## **Client Information Sheet**

### **Study Title.**

A case study of bipolar diagnosed clients going through an intensive treatment program.

### **Invitation.**

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

### **What is the purpose of this study?**

Research has in recent years given increasing support to the idea that psychological and educational elements of care can increase the quality of life for people with bipolar disorder, even when on medication. This study will look at some of the elements of treatment which have been deemed important in this regard. The study will also explore whether these elements of treatment are important from the clients' point of view.

The purpose of the study is to get a better understanding of what life is like with bipolar disorder and to explore how an intensive treatment program for people with this diagnosis is experienced by the participants. The treatment contains weekly sessions over a four week period, and there is an interview before treatment and also an interview after the treatment has finished. The total time involved is 5-6 weeks.

### **Why have I been chosen?**

The Health Care Professional working with you has suggested to us that it may help the research study if you take part. The study will include a total of ten people, all of whom will be seen separately.

### **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard care you receive.

**What will happen to me if I take part?**

You will first be interviewed about your experience of bipolar disorder and about your expectations for treatment. Then you will have weekly, 60 minute sessions for four weeks with a person from the research team. In these sessions you will be given information about bipolar disorder and you will be helped to develop a personal handbook designed to help you cope and live with bipolar disorder. After treatment you will be interviewed about your experiences with the treatment and about what you have found helpful and less so in the sessions. You will also be asked to fill in questionnaires before, during and after the sessions. This will take less than 20 minutes in most cases.

**What are possible disadvantages and risks of taking part?**

There are no obvious disadvantages and risks involved in the study. However if you wish to complain about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you.

**What are the possible benefits of taking part?**

While this cannot be guaranteed, it is hoped that the treatment will help you manage and control the symptoms of bipolar disorder better, and that you will gain a better understanding of the influences on your life that are related to the illness. As part of the research program you will also develop a personal handbook, which could help to support you in your attempt to cope with the negative aspects of bipolar disorder in the future.

The information we get from the study may also help in the understanding and treatment of future clients with bipolar disorder.

**What happens after the research?**

You will continue the treatment regime that has been in place before the research project. Your medication will not be affected by taking part in the research and is strictly a matter for you and your psychiatrist or GP.

**Will my taking part in this study be kept confidential?**

Yes. All information which is collected about you during the course of the research will be kept strictly confidential and only be available to the Researcher (John Sorensen) and his Clinical Supervisor. This confidentiality will only be broken if the Researcher or his Clinical Supervisor assesses that you or another person is at risk of significant harm. If this should happen, the Researcher will inform the Health Care Professional responsible for your care.

Any information about you that leaves the clinic will have your name and address removed so that you cannot be recognized from it.

If you give your permission, your GP and any other medical practitioner treating you, will be informed of your participation in the study.



**What will happen to the results of the study?**

The results of the research will be included in a report forming part of the Doctor of Clinical Psychology course being undertaken by one of the researchers (John Sorensen) and it is further possible that results will be published in recognized scientific journals. All information that could identify a participant in the study will be removed and not included in reports or publications.

**Who is organizing and funding the research?**

The research is organized from the University of Hertfordshire where one of the researchers (John Sorensen) is undertaking a Doctor of Clinical Psychology Degree. None of the persons involved in the research receives extra pay as a result of the study.

**Who has reviewed the study?**

The study is carried out at St. Ann's Hospital, Haringey and has therefore been reviewed by Barnet, Enfield and Haringey local research ethics committee.

**Contact for further information?**

If you require more information about any aspect of the study you can contact John Sorensen (Phone: 07789 080992) who will supply whatever information you need.

Finally I would like to thank you for considering to take part in the study and remind you that if you do decide to take part, you will be given a copy of these information sheets and a signed consent form to keep.

Yours Sincerely

John Sorensen  
MSc. DClInPsy.-student.

## Information letter to medical practitioners

[DATE]

Dear Dr.

RE.: [CLIENT NAME & D.O.B]

I write to inform you that your patient [NAME] has agreed to be included in a research project involving a psycho-educational intervention with bipolar diagnosed patients. The research is supervised from the University of Hertfordshire and is in part completion of my Doctor of Clinical Psychology degree organized from there.

The study will involve active participation from your patient over a six week period starting [Give date relevant for the individual client] and will not interfere with medical treatment.

The aim of the intervention is to provide your patient with greater understanding and practical coping skills with regards to the disorder. While this cannot be guaranteed, it is hoped that the treatment will help [NAME] manage and control the symptoms of bipolar disorder better, and that [HE/SHE] will gain a better understanding of the factors that matter in regards to management of the illness. As part of the research program [NAME] will also develop a personal handbook, designed to support attempts to cope with the negative aspects of bipolar disorder also in the future.

If you have any concerns or require more information about the study please do not hesitate to contact Mr. XXXX XXXXX (Phone: xxxx xxxx xxxxx) who will either answer your questions directly or arrange for me to get in touch with you to supply whatever information you need.



The research has ethical approval from the Barnet, Enfield and Haringey local research ethics committee and from the East & North Hertfordshire Hospitals local research ethics committee.

Thank you for your time.

Yours Sincerely

John Sorensen

MSc. DClinPsy.-student.

**Recruitment letter to medical practitioners**

*[Date]*

Dear Dr.

RE.: Intervention with Bipolar Disorder at the Psychology Dept. *[give location]*,

As part of a research project approved by Barnet, Enfield and Haringey local research ethics committee, we are currently offering bipolar diagnosed patients a psycho-educational intervention.

The study will involve active participation from patients over a six week period and will not interfere with medical treatment.

The aim of the intervention is to provide patients with a greater understanding and practical coping skills with regards to the disorder. While this cannot be guaranteed, it is hoped that the treatment will help in the management and control of symptoms of bipolar disorder and that patients will gain a better understanding of the important factors with regards to relapse prevention. As part of the treatment participants will also develop a personal handbook, designed to support attempts to cope with the negative aspects of bipolar disorder in the future.

If you have patients who you believe are suitable for the research project, or if you require more information about the study, please do not hesitate to contact Clinical Psychologist XXXX XXXX (Phone: xxxx xxx xxxxx) at the Psychology Department, who will either answer your questions directly or arrange for me to get in touch with you to supply whatever information you need.

Thank you for your time.

Yours Sincerely

John Sorensen  
MSc. DClInPsy.-student.



## Pre- intervention questionnaire

This questionnaire asks general questions about your current situation and questions about your experiences in relation to bipolar disorder. All information will be kept in confidence.

Q1. Gender (*please circle your answer*)

**Male**

**Female**

Q2. What is your age? \_\_\_\_\_.

Q3. Ethnicity

Please tick the category that you feel best describes your ethnic origin:

|  |  |
|--|--|
| <p>White</p> <p><input type="checkbox"/> British</p> <p><input type="checkbox"/> Irish</p> <p><input type="checkbox"/> Any other White Background (please write in)</p> <p>_____</p>   | <p>Black or Black British</p> <p><input type="checkbox"/> Caribbean</p> <p><input type="checkbox"/> African</p> <p><input type="checkbox"/> Any other Black Background (please write in)</p> <p>_____</p>  |
| <p>Asian or Asian British</p> <p><input type="checkbox"/> Indian</p> <p><input type="checkbox"/> Pakistani</p> <p><input type="checkbox"/> Bangladeshi</p> <p><input type="checkbox"/> Any other Asian Background (please write in)</p> <p>_____</p> | <p>Mixed</p> <p><input type="checkbox"/> White and Black Caribbean</p> <p><input type="checkbox"/> White and Black African</p> <p><input type="checkbox"/> White and Asian</p> <p><input type="checkbox"/> Any other Mixed Background (please write in)</p> <p>_____</p> |
| <p>Chinese or Other Ethnic Background</p> <p><input type="checkbox"/> Chinese</p> <p><input type="checkbox"/> Any other (please write in)</p> <p>_____</p>   | <p><input type="checkbox"/> Information refused</p>  |

Q4. Please tick your highest level of educational qualifications:

- None
- GCSE / 'O' level
- 'A' level or equivalent

- First degree
- Master's degree
- Doctorate

Q5. Please tick the description that best fits your accommodation status:

- |   |  |
|---|--|
| <input type="checkbox"/> Homeless                     | <input type="checkbox"/> Home owned by me              |
| <input type="checkbox"/> Hostel                       | <input type="checkbox"/> Living with parents           |
| <input type="checkbox"/> Inpatient ward/accommodation | <input type="checkbox"/> Living with friends/relatives |
| <input type="checkbox"/> Rented accommodation         |  |

Q6. Are you currently in employment?  
(Please write Yes or No) \_\_\_\_\_

Q7. Are you in a stable relationship?  
(married or with a partner, please write Yes or No) \_\_\_\_\_

Q8. Approximately how old were you when you first noticed signs of bipolar disorder? \_\_\_\_\_

Q9. Approximately how old were you when you first received a diagnosis of bipolar disorder? \_\_\_\_\_

Q10. Approximately how old were you when you first received medication for bipolar disorder? \_\_\_\_\_

Q11. Approximately how many times have you stopped taking medication? \_\_\_\_\_

Q12. Approximately how many of these medication stops happened after consultation and in agreement with a Doctor? \_\_\_\_\_

Q13. On a scale from 0 to 10, with 0 = very negative and 10 = very positive, how would you rate your general attitude towards taking medication for bipolar disorder? \_\_\_\_\_

Q14. Do you intend to stop taking medication in the future? (Please write Yes or No) \_\_\_\_\_



Q15. Approximately how many episodes of depression have you had?

\_\_\_\_\_

Q16. Approximately how many episodes of mania have you had?

\_\_\_\_\_

Q17. Approximately how many episodes of mixed depression and mania have you had?

\_\_\_\_\_

Q18. On a scale from 0 to 10, with 0 = extremely unpleasant and 10 = extremely pleasant, how would you rate your typical experience of mania? (if no typical experience please rate last episode and put an "L" after your answer ex.: 5L)

\_\_\_\_\_

Q19. On a scale from 0 to 10, with 0 = know very little and 10 = know all main aspects, how would you rate your knowledge about bipolar disorder?

\_\_\_\_\_

Q20. If you have had previous experience of psychological/"talking" treatment please rate the usefulness of this on a scale from 0 to 10, with 0 = not useful and 10 = very useful (if no such experience please write N/A)

\_\_\_\_\_

Q21. If possible, would you choose not to have any experience of bipolar disorder in you life? (Yes or No)

\_\_\_\_\_

**Thank you for completing the questionnaire, all information will be kept in confidence.**

**Please print your name: \_\_\_\_\_.**

**Post- intervention questionnaire**

**This questionnaire asks general questions about your current situation and questions about your experiences and opinions about treatment for bipolar disorder. All information will be kept in confidence.**

Q1. Please tick the description that best fits your accommodation status:

- |   |  |
|---|--|
| <input type="checkbox"/> Homeless                     | <input type="checkbox"/> Home owned by me              |
| <input type="checkbox"/> Hostel                       | <input type="checkbox"/> Living with parents           |
| <input type="checkbox"/> Inpatient ward/accommodation | <input type="checkbox"/> Living with friends/relatives |
| <input type="checkbox"/> Rented accommodation         |  |

Q2. Are you currently in employment?  
(Please write Yes or No): \_\_\_\_\_

Q3. Are you in a stable relationship?  
(married or with a partner, please write Yes or No) \_\_\_\_\_

Q4. On a scale from 0 to 10, with 0 = know very little and 10 = know all main aspects, how would you rate your knowledge about bipolar disorder? \_\_\_\_\_

Q5. On a scale from 0 to 10, with 0 = very negative and 10 = very positive, how would you rate your general attitude towards taking medication for bipolar disorder? \_\_\_\_\_

Q6. Do you intend to stop taking medication in the future? (Please write Yes or No) \_\_\_\_\_



Q7. Regarding the psychological treatment you have received over the past weeks, please rate the usefulness of this on a scale from 0 to 10, with 0 = not useful and 10 = very useful

\_\_\_\_\_

Q8. If possible, would you choose not to have any experience of bipolar disorder in you life? *(Yes or No)*

\_\_\_\_\_

**Thank you for completing the questionnaire, all information will be kept in confidence.**

**Please print your name: \_\_\_\_\_.**

## Diary 1

A. Please put a mark on the line below; marking how easy or difficult the information received in treatment so far has been to understand.

|-----|

Very easy to understand very hard to understand

B. Please put a mark on the line below, marking how useful the information received in treatment has been for your life over the last 24 hours

|-----|

Very useful Not very useful

C. When looking back over the past week, please answer the following questions:

- Have your general life circumstances changed? (i.e. job situation, family situation, moving house or has any other important event happened)  
YES  NO  If yes please give details

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

- Has your medication changed?  
YES  NO  If yes please give details


\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

- Has your intake of alcohol or other substances changed over the last week?  
YES  NO  If yes please give details

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_




D. Please put a mark on the line below, marking how hopeful or hopeless you feel regarding the future. I.e. how do you rate the possibility that things generally will turn out OK for you in the future?



Very  
hopeless

Very  
hopeful


E. Please put a mark on the line below, marking how confident you feel in your ability to control the symptoms of Bipolar Disorder.



No  
confidence  
that I can  
control any  
symptoms.

I am very  
confident  
that I can  
control all  
symptoms.

F. Please put a mark on the line below, marking how satisfied you are with the treatment you have received from Mental Health Services in the past.



Entirely  
dissatisfied.

Entirely  
satisfied.

## Covering letter for five week follow-up measurement

[Date]

Dear

You recently completed a treatment program with me at [*Give locations*] and I am writing to you now to ask if you would please complete the enclosed forms and return them to me in the provided envelope.

You are naturally free to refuse, but it would be very helpful if you would complete and return the forms, as this will allow me to get a better idea of how effective the treatment is now the therapy sessions have ended

Many thanks for your participation.

Yours Sincerely

John Sorensen  
Trainee Clinical Psychologist



**Diary 2** (five week follow-up questionnaire)

A. Please put a mark on the line below, marking how easy or difficult the information received in treatment was to understand.

|-----|

Very easy to understand very hard to understand

B. Please put a mark on the line below, marking how useful the information received in treatment has been for your life over the last 24 hours.

|-----|

Very useful Not very useful

C. Please put a mark on the line below, marking how useful the information received in treatment has been for your life since treatment ended.

|-----|

Very useful Not very useful

D. When looking back over the time since therapy ended, please answer the following questions:


- Have your general life circumstances changed? (i.e. job situation, family situation, moving house or has any other important event happened)  
YES  NO  If yes please give details

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_






F. Please put a mark on the line below, marking how confident you feel in your ability to control the symptoms of Bipolar Disorder.



No confidence that I can control any symptoms.

I am very confident that I can control all symptoms.

G. Please put a mark on the line below, marking how satisfied you are with the treatment you received.



Entirely dissatisfied.

Entirely satisfied.

Thank you for completing this questionnaire and for taking part in the study.

## **Pre- intervention interview schedule**

The main purpose of this interview is to allow you to tell me about your experiences with bipolar disorder and its treatment. I will be asking you some questions of a general nature and also some more specific questions about your experiences. I will keep all personal information in confidence, and you are free to refuse to answer any question that you do not wish to answer. The interview is tape-recorded for later transcription. Please provide as much detail as possible in your answers.

### **A) What do clients believe to be important components of good psychosocial treatment for bipolar disorder?**

Say: Now that you are about to start a psychologically based treatment, what are the things that you would expect and hope the treatment would contain?

Possible Probes if client does not provide information:

- 1) What, in your opinion, are the main elements of a good psychological treatment for bipolar disorder?
- 2) You have chosen to take part in the treatment and research project that I offer, what made you decide to join?
- 3) What are you expecting to happen in treatment?
- 4) What do you hope to get from the treatment?
- 5) Is there anything in particular that you are hoping will be included in the treatment?
- 6) Would it be important for you to have information about bipolar disorder?
- 7) How would you like the relationship with the psychologist to be?
- 8) Would it be important for you to learn how to deal better with issues relating to communication with family, employers and others about bipolar disorder?



**B) Personal model and understanding of bipolar disorder (i.e. causes and influences on disorder, ability to control symptoms etc.).**

Say: How do you explain to yourself that you got bipolar disorder? What do you think are the causes?

Possible Probes if client does not provide information:

- 1) Do biological or genetic influences play a role?
- 2) Does stress or demands on you have anything to do with it?
- 3) How confident are you, that you will be able to keep the symptoms of bipolar disorder under control in the future?
- 4) What can cause a relapse?
- 5) What can you do to control the symptoms?
- 6) How do you feel about medication? (positive and negative aspects).
- 7) Do you expect to stop taking medication in the future, (why/why not?).

**C) The clients' experience of mania.**

Say: Can you describe to me what mania is like?

Possible Probes if client does not provide information:

- 1) What, if any, are the pleasurable aspects of mania? (What are the pleasurable aspects regarding: mood, specific performance/activity such as work and creativity in thought, physical performance, self-esteem, relationships/family life).
- 2) What is the down-side to the experience of mania? (What are the negative aspects regarding mood (do you feel agitation, irritability?), compulsion for speech and physical/mental activity, specific performance/activity such as *flight of ideas*, work, relationships/family life).
- 3) How do you see yourself, others, mental health services, your future during a manic episode?

**D) Role played by bipolar disorder in the client's life (good, bad, minor, major etc.).**

Say: Can you describe the impact on your life that bipolar disorder has had?

Possible Probes if client does not provide information:

- 1) Do you think that your life would have been very different if you did not have the illness? What would be different?
- 2) What has been bad about having bipolar disorder?
- 3) What, if anything, has been good about having bipolar disorder?
- 4) If you could live your life without any manic experiences would you choose to do so? Why/why not?
- 5) What would you miss, if anything, if you never again had a manic episode?



## **Post- intervention interview schedule**

The topics of this interview are your experiences with the treatment you have just completed and also any changes you have noticed since therapy began. I hope that you will tell me about the therapy in your own words. This information will help us to understand better how the therapy works; it will also help to improve the therapy. I will keep all personal information in confidence, and you are free to refuse to answer any question that you do not wish to answer. The interview is tape-recorded for later transcription. Please provide as much detail as possible in your answers.

### **A) What do clients believe to be important components of good psychosocial treatment for bipolar disorder?**

Say: Now that you have been through a certain type of therapy, what are the things that you feel should be included in a good psychological treatment for bipolar disorder?

Possible Probes if client does not provide information:

- 1) What, in your opinion, are the main elements of a good psychological treatment for bipolar disorder?
- 2) What would you expect to happen in a good treatment?
- 3) What would you hope to get from a good treatment?
- 4) Is it be important for you to have information about bipolar disorder included in treatment?
- 5) How would you like the relationship with the psychologist to be?
- 6) Would it be important for you to learn how to deal better with issues relating to communication with family, employers and others about bipolar disorder?

**B) Personal model and understanding of bipolar disorder (i.e. causes and influences on disorder etc.).**

Say: How do you explain to yourself that you got bipolar disorder? What are the causes to your mind?

Possible Probes if client does not provide information:

- 1) Do biological or genetic influences play a role?
- 2) Does stress or demands on you have anything to do with it?
- 3) What can cause a relapse?
- 4) When you think of situations in the past where you have become depressed or manic, how would you explain these relapses now?
- 5) What can you do to control the symptoms?
- 6) How do you feel about medication? (positive and negative aspects. Do you expect to stop taking medication in the future, why/why not?).

**C) Change in beliefs about the disorder and in beliefs about ability to control symptoms.**

Say: If you look back over the last five to six weeks, have you changed anything in your thinking about bipolar disorder, about mental health services, about medication, about yourself, about others or anything else?

Possible Probes if client does not provide information:

- 1) What changes, if any, have you noticed in yourself since therapy started? For example, are you doing, feeling or thinking differently from the way you did before?
- 2) How do you explain the changes?
- 3) Was there anything in particular in therapy that you think resulted in change?
- 4) Is there anything outside of therapy that has influenced your thinking or understanding of bipolar disorder in the last five to six weeks? (Experiences. Family, friends' opinions etc.).



- 5) What specific ideas, if any, have you got from therapy, including ideas about yourself, others, bipolar disorder, medication and mental health services?.
- 6) Have you experienced a change in confidence regarding your ability to control the symptoms? If yes, how do you explain this change?

**D) The experience of therapy, including the development, use and usefulness of the relapse prevention handbook.**

Say: In therapy you did several things including make a handbook for your illness, how did you experience therapy generally and what do you think about making and using the handbook?

Possible Probes if client does not provide information:

- 1) What has been helpful about your therapy?
- 2) What has been less helpful or unhelpful?
- 3) Did treatment meet your expectations? (If not: what was lacking or problematic?).
- 4) How did you experience the relationship between yourself and the therapist?
- 5) How did you experience the information given about bipolar disorder (good/bad, too much/too little?).
- 6) How did you experience the inclusion of information about family and work? (good/bad, too much/too little?).
- 7) Has the handbook been important for your confidence about your ability to control symptoms in the future?
- 8) How do you expect to use the handbook in future? Have you used it so far? If yes, how?
- 9) How do you think the handbook could be improved? Is it easy or difficult to use?
- 10) Do you like the structure or layout of the handbook?
- 11) What was difficult to do or understand when putting the handbook together?
- 12) What was clear or easy to understand when putting the handbook together?
- 13) In general, has anything been missing from your treatment? (What would have made your therapy more effective or helpful?).

## Overview of meaning categories

| Main Dimension 1  | Subcategories (+ , - , 0 )  |
|---|---|
| <p><b><u>Usefulness of treatment.</u></b> This includes any improvements perceived to result from treatment and any factor that is perceived to have made the treatment better or more effective.</p> | <p><u>Early warning signs + triggers profile.</u><br/>Expressions that the development of the personal relapse profile with early warning signs and triggers for relapse is considered important for the usefulness of treatment.</p>   |
|   | <p><u>Development of new coping strategies</u><br/>Expressions that finding new coping strategies that are personally meaningful and tied to particular triggers or signs of relapse is a useful aspect of treatment.</p>   |
|   | <p><u>Development of action-plan</u><br/>Expressions that developing or having the action plan (which is a brief summary of complete coping strategy at time of relapse risk to be carried on a small card) is useful.</p>  |
|   | <p><u>Psycho-education about BPD</u><br/>Expressions that general information about BPD, theoretical models, and research knowledge has been a useful component of treatment.</p>   |
|   | <p><u>Skills to do with network involvement</u><br/>Expressions that inclusion in treatment of practice and development of skills in the inclusion of family, friends and employer in the coping strategy is considered useful. This includes the development in listening and communication skills conducted in treatment.</p> |



|  |   |
|--|---|
|  | <p><u>Sleep problems</u><br/>Expressions that the targeting of sleep problems and the development of strategies to improve sleep within treatment was useful.</p>   |
|  | <p><u>Handbook</u><br/>Expressions that the handbook <i>per se</i> and/or its permanent nature is useful, i.e. that it will be a useful document for coping in the future that can be improved, updated and be in continued use in the future.</p>                  |
|  | <p><u>Collaborative therapeutic relationship</u><br/>The working relationship's "CBT" – nature, including the extensive questioning/challenging of assumptions held by client.</p>  |
|  | <p><u>Empathy and emotional atmosphere of therapy</u><br/>The working relationship's emphatic nature, including the emphasis on listening, and understanding the client's perspective and on creating a supportive, relaxed and equal therapeutic relationship.</p> |
|  | <p><u>Duration and structure of treatment</u><br/>This includes number of sessions, time between sessions and the order of the content (first education, then depression etc.).</p>   |

|  |   |
|--|---|
|  | NEXT TWO CATEGORIES BELOW ARE FOR FURTHER ANALYSIS  |
|  | <u>Not included elements</u><br>Mention of treatment elements that the client would consider to have been useful in treatment but that did not form part of the current treatment.  |
|  | <u>General expression of usefulness</u><br>Client expresses general opinion on usefulness of treatment but does not link this to particular aspect of treatment. This includes expressions that treatment lived up to or exceeded expectations. |

| Main Dimension 2   | Subcategories (+ , - , 0 )   |
|--|--|
| <u>Reasons for change in confidence about ability to control symptoms.</u> This also included a registration of expressions of no such change. | <u>Early warning signs + triggers profile.</u><br>Expressions that the development of the personal relapse profile with early warning signs and triggers for relapse has improved confidence with regards to ability to control symptoms.                                    |
|  | <u>Development of new coping strategies</u><br>Expressions that finding new coping strategies that are personally meaningful and tied to particular triggers or signs of relapse has improved confidence with regards to ability to control symptoms.                        |
|  | <u>Development of action-plan</u><br>Expressions that developing or having the action plan (which is a brief summary of complete coping strategy at time of relapse risk to be carried on a small card) has improved confidence with regards to ability to control symptoms. |



Psycho-education about BPD

Expressions that general information about BPD, theoretical models, and research knowledge has resulted in improved confidence with regards to ability to control symptoms.

Skills to do with network involvement

Expressions that inclusion in treatment of practice and development of skills in the inclusion of family, friends and employer in the coping strategy has improved confidence with regards to ability to control symptoms. This includes the development in listening and communication skills conducted in treatment.

Sleep problems

Expressions that the targeting of sleep problems and the development of strategies to improve sleep within treatment has improved confidence with regards to ability to control symptoms.

Handbook

Expressions that the handbook *per se* and its permanent nature (i.e. that it will improve chances of symptom control in the future) has improved confidence with regards to ability to control symptoms.

Collaborative therapeutic relationship

The working relationship's "CBT" – nature, including the extensive questioning/challenging of assumptions held by client has improved confidence with regards to ability to control symptoms

Empathy and emotional atmosphere of therapy

The working relationship's emphatic nature, including the emphasis on listening, and understanding the client's perspective and on creating a supportive, relaxed and equal therapeutic relationship has improved confidence with regards to ability to control symptoms.

Skills developed in treatment has been seen to work at post treatment interview

Client reports that skills learned in treatment have already proved to be useful/to have "worked" in attempts to control symptoms developing or getting worse and that this has increased confidence for the future with regards to ability to control symptoms.

Expression of no change

Client expressed that no change in confidence with regards to symptom control has happened.

Extra-therapeutic factor that has caused change in confidence

Mention of extra-therapeutic factor that has caused change in the client's confidence with regards to ability to control symptoms.

General expression of change in confidence

Client expresses general experience of change in confidence but does not link this to any particular aspect of treatment.



| Main Dimension 3   | Subcategories (+, -, 0 ratings)  |
|--|--|
| <p><b><u>Client's subjective understanding/model and experience of BPD.</u></b> This includes evaluation (positive/negative) of having BPD and the explanations and beliefs that clients use to understand why they have developed the disorder.</p> | <p><u>Genetics</u><br/>Client mentions that genetic factors are important for the development of his/her BPD.</p>  |
|  | <p><u>Childhood experiences</u><br/>Client mentions that negative childhood factors have been important for the development of his/her BPD.</p>  |
|  | <p><u>Substance misuse</u><br/>Client mentions that substance misuse has been an important factor in the development of his/her BPD.</p>   |
|  | <p><u>Stress</u><br/>Client mentions that stress has been an important factor in the development of his/her BPD (stress can here be: being too busy or "over-doing" things at work or privately, traumatic events, interpersonal conflict etc. i.e. whatever the client perceives to increase the stress levels).</p>                    |
|  | <p><u>Ambitious, "Driven" cognitive style or personality</u><br/>Client mentions that his/her cognitive style or personality is characterised by being strongly "driven" towards getting rewards of any type, and that this has led to, or been an important factor in, the development of BPD. This can be in work or private life.</p> |

|  |  |
|--|--|
|  | <p><u>Other personality traits</u><br/>Individual characteristics such as being particularly sensitive, excitable etc. without any reference to genetics or other underlying reasons for this being given by the client.</p> |
|  | <p><u>Positive experiences with mania</u><br/>Client describes positive aspects to having BPD mania episodes</p>   |
|  | <p><u>Negative experiences with mania</u><br/>Client describes negative aspects to having BPD mania episodes</p>   |
|  | <p><u>Prefer not to have BPD in life</u><br/>Client indicates that he/she would prefer not to have BPD (+, -, 0).</p>  |



| <b>Main dimension 4</b>  | <b>Intermediate categories for the subcategories (“utility” categories for further analysis).</b>   | <b>Subcategories (+, -, 0)</b>   |
|--|---|--|
| <p><b><u>General changes.</u></b><br/>Changes experienced in treatment other than the changes observed in the clients’ confidence with regards to ability to control symptoms of BPD (main category 2).<br/>The changes coded in this category are obtained both from direct client quotes on the topic at post-treatment interview and from comparing pre- and post-treatment interviews.</p> | <p><u>Change linked to treatment.</u><br/>The change registered in a subcategory is linked to/ perceived by client to be the result of element of treatment.</p>                          | <p><u>Change in knowledge about BPD</u><br/>Client expresses having an improved knowledge base regarding BPD.</p>  |
|  |   | <p><u>Change in hopelessness</u><br/>Client expresses an experience of being more hopeful (or less hopeless) about the future for him- or her- self.</p>   |
|  |   | <p><u>Change in feelings</u><br/>Client expresses that his or her feelings have changed in some way.</p>   |
|  |   | <p><u>Change in thoughts</u><br/>Client expresses that his or her thoughts have changed in some way.</p>   |
|  | <p><u>Change linked to extra-therapeutic factors.</u><br/>The change registered in a subcategory is linked to/ perceived by client to be the result of factors external to treatment.</p> | <p><u>Change in behaviours</u><br/>Client expresses that his or her behaviour has changed in some way.</p>   |
|  |   | <p><u>Change in self-knowledge</u><br/>Client expresses that his or her understanding of him- or herself, be it past experiences, thoughts, feelings or behaviour patterns etc. have changed in some way (+, -).</p> |

|  |  |   |
|--|--|---|
|  | <p><u>Change not linked to any factor.</u></p> <p>Client notes a change has happened by does not give reason or explanation for this change.</p> | <p><u>Change in attitude to self</u><br/>Client expresses that his or her acceptance or like/dislike of self has changed in treatment.</p>  |
|  |  | <p><u>Change in attitude to medication</u></p> <p>Client expresses that his or her attitude to medication has changed.</p>  |
|  |  | <p><u>Changes to beliefs about BPD</u></p> <p>Client expresses changed beliefs / personal model of BPD. This includes changes in beliefs about factors of importance for the development of BPD and for relapse to illness.</p> |
|  |  | <p><u>Change in interpersonal relationships</u></p> <p>This includes other peoples' attitudes and support of the client and more generally any change observed in relationships post treatment.</p>                             |



# **Critical Review Paper**

**A Longitudinal Study of Bipolar Disordered Clients Going Through an Intensive  
Psycho-educational Intervention Programme.**

**John Sørensen  
November 2004  
Year 3 DClinPsy. University of Hertfordshire  
4048 words excluding references**

## 1.1 Summary of research study

The reviewed study aimed to evaluate a newly developed psychological intervention with bipolar disorder and in the process investigate what clients perceived to be useful in treatment.

### 1.1.1 Design

The study employed a longitudinal design with replication across 13 participants, combined with the use of multiple case study methodology and qualitative data collection strategies, which allowed for triangulation between the multiple data sources. Semi-structured interviews were conducted before and after the four treatment sessions and data was collected using standardised measures in the form of the Beck Hopelessness Scale (BHS) (Beck, Weissman, Lester, & Trexler, 1974), the Perceived Control of Internal States Scale (PCOISS) (Pallant, 2000) and the Client Satisfaction Questionnaire (CSQ-8) (Larsen, Attkisson, Hargreaves & Nguyen, 1979). Furthermore, questionnaires and pre-structured “diaries” developed specifically for the current study were administered and analysis included both qualitative and quantitative research methodologies.

An outline of the study with data collection points is given in figure 1 below.

| Baseline,<br>2 weeks<br>pre<br>session 1 | Baseline,<br>1 week<br>pre<br>session 1 | Post<br>session<br>1 | Post<br>session<br>2 | Post<br>session<br>3 | Post<br>session<br>4 | Follow-up,<br>1 week<br>post<br>session 4    | Follow-up,<br>5 weeks<br>post<br>session 4 |
|--|---|----------------------|----------------------|----------------------|----------------------|--|--|
| BHS                                      | BHS                                     | Diary 1              | BHS                  | Diary 1              | BHS                  | BHS  | BHS  |
| CSQ-8                                    | CSQ-8                                   |                      | CSQ-8                |                      | CSQ-8                | CSQ-8  | CSQ-8                                      |
| PCOISS                                   | PCOISS                                  |                      | PCOISS               |                      | PCOISS               | PCOISS                                       | PCOISS                                     |
|  | Interview<br>Question-<br>naire 1       |                      | Diary 1              |                      | Diary 1              | Interview<br>Diary 1<br>Question-<br>naire 2 | Diary 2                                    |

Figure 1. The structure of the study with data collection points.



### **1.1.2 Main findings**

The evaluated *Therapeutic Instability Model* was generally shown across the measures to have had a significant and positive impact on hopelessness and perceived control over internal states/symptoms. It was further noted that these results were achieved without dropout from treatment and with high levels of satisfaction with the treatment amongst participants.

As part of the evaluation, insights into which factors are important for client satisfaction and perceived usefulness of a treatment were also gained and it was argued that these should be borne in mind when attempting to develop interventions with high effectiveness and low dropout from treatment. The factors of importance for satisfaction and perceived usefulness of treatment, as identified by participants, corresponded well with the components of the *Therapeutic Instability Model*.

In addition the study found positive changes occurring as a result of the intervention in thoughts, feelings, behaviours and illness related knowledge, and began a mapping of the participants' understanding or subjective models of their disorder's aetiology and maintenance. This led to the conclusion that participants' beliefs about their disorder were largely in line with what has been proposed via the stress-vulnerability model of severe mental illness (Zubin & Spring, 1977).

### **1.2 Specific findings with implications for clinical practice**

Until recently, psychological therapy has not routinely been offered to individuals with bipolar disorder as they were not considered able to benefit from such interventions (Scott, 1995). However, together with other studies set out in Sørensen (2004), the current study showed that brief, intensive interventions can have important effects as assessed from both a client's subjective perspective and as assessed by various other strategies of measurement, including standardised scales and scales developed specifically for the present study.

When looking in detail at the views of clients, it appears that elements of the *Therapeutic Instability Model* are of particular importance for satisfaction with treatment and that these treatment elements are further perceived to be causal for the positive changes experienced by clients during and after treatment. Based on this it is

argued that consideration of the following elements contained in the Therapeutic Instability Model should be made when implementing treatment with a bipolar disordered client:

- 1) Psycho-education about the disorder.
- 2) Development of an individualised relapse prevention 'handbook' or other permanent record of the insights and skills developed in treatment.
- 3) Education about communication skills leading to inclusion of the client's social environment in the overall coping strategy.
- 4) Development of an individualized relapse prevention plan focussing on the identification of early warning signs and related strategies for reducing the risk of relapse. This entails the development of a personal early warning sign/trigger profile for illness episodes and identification of specific and personally meaningful coping strategies.
- 5) Collaborative, 'Cognitive Behavioural Therapy (CBT)-style' working relationship in therapy.

The study also found that differences may exist between clients who have a negative versus a positive/ambivalent attitude to the prospect of having manic episodes in future. It appears that improvements come about later in treatment for the clients who are positive/ambivalent about mania and that these clients may have a greater need to see the coping skills developed in therapy to be working in practice, before they experience reduced hopelessness and perceive their control over symptoms to have improved. These are potentially important insights for treatment planning, whether within, or outside of, the framework of the Therapeutic Instability Model, and should inform the expectations that a practitioner holds for a particular client's rate of improvement. Thus, it may be reasonable to wait longer for improvements with clients who are positive/ambivalent about mania before a change in treatment strategy is considered, compared to clients who are clearly negative about having manic experiences as they would be expected to show improvements later in the treatment process. Also, when working with a person who regards mania in a positive/ambivalent manner, it is likely to be of most benefit to include practical tests

of the skills developed, for instance in the form of planned applications of coping strategies when mood swings are encountered, because the study showed a greater need for such 'experiential' or practical interventions amongst these clients than with individuals who were clearly negatively disposed to having manic episodes in future.

### **1.3 Service implications**

Estimates of lifetime prevalence of bipolar disorder vary but is conservatively estimated at around 8 cases per 1,000 adults in western societies (Johnson, 2004; Kessler, Rubinow, Holmes, Abelson, & Zhao, 1997; Weissman et al., 1996). This prevalence rises when bipolar spectrum disorders are included and, as sufferers are up to three times more likely to seek treatment for depression compared with (hypo)mania (Judd et al., 2002), the finding that 20-33% of people with diagnosed bipolar disorder do not report any lifetime episodes of depression, illustrates how the above given prevalence rates must be considered a relatively loose and conservative estimate of actual rates in the population. This follows because people on the bipolar spectrum who do not experience depression are less likely to become known to services (Depue & Monroe, 1978; Johnson, 2004; Karkowski & Kendler, 1997; Kessler et al., 1997).

As such there is a substantial number of presently unknown, potential users of services, and with the emerging evidence, from the current and other studies, that psychological interventions can have a positive impact on life with the disorder, it is increasing likely that services will be met with raising demands for an adequate ability to provide psychosocial treatment for this client group.

Such demands are likely to come from patients, relatives and politicians as bipolar disorder is also problematic from a budgetary perspective. This latter fact can be illustrated by Johnson's (2004) finding that in a population of mental health in-patients, 45% of the total care costs were spent on patients with a bipolar diagnosis who made up only 8% of the overall patient numbers (*ibid.*).

The fiscal implications of severe mental illness were also noted in the National Service Framework (NSF) (Department of Health, 1999), which stresses that provision of quality services wanted by clients is in the interest of both the service



user and society as a whole. The NSF argument that the involved social and economic costs are significant, is supported by the fact that almost one-third of bipolar clients are unable to return to work for six months following an episode of the illness and by the fact that only one-fifth return to work at their former skill level (Coryell et al. 1993; Dion, Tohen, Anthony & Waternaux, 1988).

It transpires from the studies referred to immediately above that even when symptom relief has been achieved for a given client, functional impairment often persists (Tohen et al., 2003). This lack of functional recovery amongst the bipolar population explains why the World Health Organisation (Murrey & Lopez, 1996, pp. 537-540) ranks bipolar disorder as the seventh most disabling condition globally, when considering disability-adjusted life years and society's loss of productivity due to illness, with only unipolar major depression and alcohol use being ranked higher within the World Health Organisation's category of neuro-psychiatric conditions.

It is clear that bipolar disorder can be a disabling condition and a demand for service provision for these clients is clearly justified on various grounds as set out above. With regards to the particular type of treatment likely to be demanded from various sources in future, it is noted that developments in the provision of mental health services have, in recent years, been moving towards more user input and assessment of the services provided. *Outcome measurement* has become a central pillar of Department of Health (DoH) policy (Department of Health, 2000. p. 110), in which outcome measurement is defined in terms of:

- A) Mortality (suicide rate reduction).
- B) Morbidity (reduction in mental illness).
- C) Quality of life for service users and carers.
- D) Service user and carer satisfaction.

Further, the NSF (Department of Health, 1999) sets out as a guiding value and principle that, "people with mental health problems can expect that services will: involve service users and their carers in planning and delivery of care" (ibid. p. 4) and

that “specific arrangements should be in place to ensure: service user and carer involvement” (ibid. p. 10).

When looking specifically at the services provided to the group of severely mentally ill people to which clients with bipolar disorder belong, the NSF (ibid. p. 66) indicates that performance assessment should take account of the “experience of service users” and also measure “service user satisfaction with respect to a specific mental health service” (ibid. p. 125).

In sum, various demands on services can be expected in the area of provision for clients with bipolar disorder over the coming years and the implications of the present study in relations to these individual demands and requirement will be outlined below.

### **1.3.1 Raising Demands on Services and the Therapeutic Instability Model**

Bipolar disorder has reliably been linked, not only to behaviours that are directly linked to mania such as spending sprees and financial ruin, but also to significant increases in problematic behaviours such as markedly increased rates of substance abuse (Brown, Suppes, Adinoff & Thomas, 2001; Kessler, et al., 1997; Regier et al., 1990), violence (Jamison, 1999) and suicide (see below). As such it can be a daunting prospect for often under-resourced services to think that demands from bipolar disordered patients will rise significantly in the coming years. However the current study has illustrated that interventions such as the Therapeutic Instability Model, can produce significant improvements in clients who were mainly recruited from existing waiting lists and some of whom had a history of the problems mentioned above (drug misuse, para-suicide and violence). As such it has been shown that a short-term and therefore cheap intervention can have important and adequate benefits for a category of bipolar clients similar to those usually encountered in daily clinical practice. This is likely to appeal to hard-pressed psychology departments in many areas and the Therapeutic Instability Model’s low demands on resources and short-term nature, is arguably uncontroversial because the results achieved in the present study showed participants generally reporting high levels of satisfaction and because no dropout from treatment took place. It is also noted that the treatment is conducted following a

highly explicit manual<sup>24</sup> that would allow staff, with very little or no training, to apply the treatment with clients. This aspect is an appealing feature for psychology departments with various demands levelled at them.

### **1.3.2 Department of Health Outcome Measure A: Mortality**

With regards to DoH Outcome Measure A (Department of Health, 2000), it is noted that suicide rates are estimated to be between 15% (Simpson & Jamison, 1999) and 19% (Goodwin & Jamison, 1990) of the bipolar population, with para-suicide rates approaching 50% (ibid; Angst, 1990; Harris & Barraclough, 1997; Inskip, Harris, & Barraclough, 1998; Lam, Jones, Hayward & Bright, 1999). It is therefore obvious that service provision for this client group must involve consideration of suicide risk reduction and that treatments offered should be able to effect the likelihood of suicidal behaviour amongst its users.

An established way to predict suicide is via the Beck Hopelessness Scale (BHS) (Beck, Weissman, Lester, & Trexler, 1974) which has been shown to be a reliable measure of suicidal ideation amongst 294 hospitalized patients who had attempted suicide (Beck, Rial & Rickels, 1974) and to be a reliable predictor of later suicide amongst psychiatric outpatients (Steer & Beck, 1997).

Data obtained in the current study showed that the participants, from the outset, were representative of the bipolar population, as set out above, with regards to suicide risk. The mean baseline BHS score for the participants before treatment fell in the range defined as indicating *high risk of suicide* (Beck, Brown, Berchick, Stewart, & Steer, 1990), a range which has further been described as indicating a state of mind that “requires frequent, regular monitoring” (Williams, 1992, p. 105) because of suicide risk. After treatment and at five week follow-up, only one of the 11 participants, who could be contacted, were above normal levels on the BHS, and the overall mean was comparable to, and somewhat lower than, the mean score found in a normal population of 396 randomly selected adults (Greene, 1981).

From these results, which were confirmed by the other measures obtained as part of the overall triangulation approach, it appears that the Therapeutic Instability Model can reduce suicide risk significantly and as such could be part of the answer to this

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<sup>24</sup> Can be obtained from the author.



central aspect of government targets as expressed by the mortality category of outcome measurement (Department of Health, 2000).

### **1.3.3 Department of Health Outcome Measure B: Morbidity**

When considering morbidity it should first be noted that the central feature of bipolar disorder is unstable internal states, and while the current study did not include a follow-up period long enough to determine actual degrees of stability of mood and other internal states over extended periods, it is noted that the participants' subjective assessment of this aspect of their daily experience was that control over internal states/symptoms had been improved significantly in treatment. This was seen across the measures used in the triangulation approach but can be exemplified here by data from the PCOISS which went from a mean defined by Pallant (2000) to be in the low perceived control range before treatment, to a mean after treatment in the medium range, just below what has been defined as high perceived control for a normal population sample of 439 adults (ibid.).

As such, and while research with longer follow-up measures is awaited, it appears that the Therapeutic Instability Model can have a significant impact on the central feature of the disorder and that morbidity can be reduced by applying this intervention.

### **1.3.4 Department of Health Outcome Measure C: Quality of life**

Quality of life was not specifically considered in the current study and is a question to be explored in future research. It is however noted that eight of the thirteen participants, spontaneous and unprompted, during their post intervention interview, noted that they had experienced a greater acceptance of themselves and their limitations as a result of the intervention and it can be speculated that this also relates to a more general sense of improved quality of life. In a similar fashion it can be argued that the improvements in interpersonal relationships which were reported by eight participants are unlikely to have taken place without a more general improvement in quality of life, but more research is needed for firm conclusions to be made in this regard.

### **1.3.5 Department of Health Outcome Measure D: Satisfaction with treatment.**

Data gained from the CSQ-8 and other measures used to gauge the satisfaction and perceived usefulness of the Therapeutic Instability Model show that these are generally high and stable to follow-up when participants would have had time to use the skills developed in treatment.

More specifically it was noted that participants generally perceived components of the Therapeutic Instability Model to be the reasons for the positive assessments of usefulness and satisfaction. As such this particular treatment has properties that lead to client satisfaction and the treatment comes out positively on this DoH outcome measure.

### **1.3.6 Taking Account of Service User Experiences.**

As set out above, the NSF (Department of Health, 1999) advises that not only should performance assessment take account of the experiences of clients, but also that service users should be involved in the planning and delivery of care. The current study has shown that the Therapeutic Instability Model contains elements referred to explicitly by the participants as the reason for their high degree of satisfaction and as the reason for their perception that the intervention was useful. Implementation of the Therapeutic Instability Model is therefore a good starting point for a service attempting to involve users in decision making about which interventions should be offered. This must naturally be part of a wider, continuous strategy for the involvement of users and more research is needed with regards to the service user perspective on treatment.

Nonetheless the current study has begun to address the conclusion drawn by Gordon (2000) after an extensive review of the research literature on the client's perspective on psychological interventions generally. Gordon (ibid. p. 10) notes that "research which attempts to examine the client's perspective tends, in fact, to examine client variables or the client *as a variable* rather than actually pay attention to the client's view" This has not been the case in the present study and it can therefore be seen as an adequate starting point for discussions with bipolar service users, many of whom, during the study, expressed a need to be listened to, and firm opinions with regards to

the treatment they require, or as expressed by one participants who had used services for several years:

“I mean it would be quite good to develop this service within the NHS and this approach remains better anyway, that’s definitely a thing I want to get down on this recording”.

#### **1.4 Reflections on the Research Process.**

The study took as its starting point the view that a purely quantitative research strategy would be high risk due to the challenging task of both recruiting and treating participants in the relative short time available for the research. In discussion with research supervisors it was therefore decided to base the research around a multiple case study design but to ensure that the design retained the possibility of being adapted and expanded with a quantitative element if recruitment allowed this strategy to progress (See Barlow, Hayes & Nelson, 1984).

The recruitment, while initially slow, quickly picked up when clinicians in the relevant services heard about the study. In fact, at the time the study had to end due to time pressure, phone calls from District Nurses, a GP, in-house Psychiatrists and Psychologists were still being received and all had clients they believed would be suitable for the treatment on offer. It was clear throughout that a research project that offered an actual treatment to this particular client group would be popular with potential referrers. However it was also clear that word of such a project spreads relatively slowly and that recruitment is heavily dependent on starting early and on having active and positive support from supervisors or other in-house people who are trusted and respected in their departments. Both these conditions were fulfilled in the current study and even after the study’s conclusion involvement continues in the form of discussions regarding the possibility of doing further follow-up measurements and the submission of papers, derived from the study, for publication.

During and after the study several clinicians have asked for a copy of the treatment manual and the author has recently been asked by a Consultant Psychiatrist to conduct a yet unspecified number of workshops relating to the Therapeutic Instability Model,



in the relevant department. This request was made because the service in question is currently evaluating its treatment capability with regards to severe mental illness and the Consultant Psychiatrist noted that the workshops would be conducted with a view to implement the Therapeutic Instability Model as a standard, first psychosocial treatment offered to all, newly diagnosed bipolar disordered clients presenting to the service. At the current time the relevant service does not routinely offer psychological input to clients with bipolar disorder and the Therapeutic Instability Model's low cost and explicit manual was seen as attractive to the service which proposes that the implementation will be researched by the author or another suitably qualified person.

### **1.5 Future Research.**

The discussion of the Therapeutic Instability Model's implementation being offered to all newly diagnosed clients in a particular service outlined immediately above opens up the possibility of doing a Randomised Controlled Trial (RCT) which is the next logical step in the treatment's evaluation. This would enable a larger scale evaluation of the treatment and could remove what can be seen as the major limitation of the current study; the possible bias, or "*please the scientist attitude*", which may have been introduced amongst participants by letting treatment and data collection be conducted by the same person.

Other suggested areas of research include further exploration of the Therapeutic Instability Model's effectiveness when using longer follow-up periods and when measuring actual relapse patterns and frequencies. It would also be beneficial to obtain information about participants' use of the handbook and their new coping strategies over time, together with assessments of such variables as medicine adherence and doses.

Further the study has thrown up the possibility that attitude to having manic episodes may determine an individual's response to different types of interventions and this could also be a relevant topic for further research as it may turn out to have important implications for the content and structure of psychological treatment for individual clients with bipolar disorder.

Additional research areas could be an assessment of the treatment's ability to facilitate change for clients with moderate or high degrees of confidence in their ability to control symptoms, and the effects of the relatively simple procedure of converting the manual and handbook into an interactive computer program. The former question was answered with uncertainty in the current study and the latter question would give the clients more control and make the treatment readily available to a large number of potential users, but would also take away factors of empathy and collaboration.

### **1.6 Conclusion.**

This study evaluated a newly developed intervention with bipolar disordered clients and while there were methodological limitations which called for caution in drawing firm conclusions, it was argued that the intervention can offer important benefits for clients and clinical psychology services alike. This follows from the study's main findings that improvements in hopelessness and perceived control over internal states were achieved with participants expressing adequate satisfaction and perceived usefulness of treatment levels. Further the intervention is a short-term, low-cost treatment option that is easy to implement, and as it appears to be able to live up to Department of Health guidelines and adequately address the main targets for outcome measurement set out in the NSF (Department of Health, 1999) it is also likely to appeal to services.

As the treatment is newly developed, it has not previously been researched and it is clear that further evaluation research should be conducted, possibly in the form of a RCT. Nevertheless, it is the author's intention to submit a paper of the study's main findings to a peer-reviewed journal for consideration for publication. It is also the author's intention to pursue the training of relevant staff through already planned workshops with a view to implement the treatment across a whole service. This will allow further evaluation of the treatment while this is disseminated and used by clinicians in their daily practice.

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