

# THE DYNAMICS OF COPING AND ADAPTATING TO THE IMPACT WHEN DIAGNOSED WITH DIABETES

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## ABSTRACT

The coping trajectory of a group of people who were insulin dependent (Type 1 diabetes n=109) was compared with that of a group people who were non-insulin dependent (Type 2 diabetes n=241). The experience of the diagnosis of diabetes mellitus (DM) was different for both groups. Type 1 people were more likely to feel the impact of the diagnosis more severely than Type 2 people and were more likely to use avoidance, denial and fantasy strategies in their attempts to cope with the diagnosis and its implications. The residual effects of not being ill were more likely to be felt by Type 2 group. Those who showed determination not to be beaten by the disease tended to use more positive coping techniques in making the adjustment. Illustrative path diagrams for both the Type 1 and Type 2 groups are presented. Health professionals need to recognise the likely differences in order to provide the most appropriate care.

## INTRODUCTION

The diagnosis of diabetes mellitus is associated with increased distress for the individual. Such distress may include anxiety, fear and depression (eg Beeney et al 1996). The individual may perceive the diagnosis of DM as catastrophic because of the actual and potential changes it imposes. Inevitably there will be demands on the individual to adjust and change as a consequence of being diagnosed with DM. In this paper we explore the dynamics of coping with the diagnosis.

According to Lazarus (1981), coping strategies function in two major ways. First, strategies may be used to change the stressful situation for the better, either by changing one's own behaviour, or by changing the threatening environment. Second, strategies may be used to manage the physiologic and psychological outcomes of stress-related emotions themselves, so that they do not overwhelm the person and damage the ability to function or maintain morale. Lazarus (1981) calls this form of coping 'palliative' because the goal is to relieve the emotional or physiological impact of the stress without actually altering the situation that caused the stress. Through this mechanism, individuals feel better and are able to maintain a sense of wellbeing and hope despite difficult situations (Cohen and Lazarus 1983; Larkin 1987; Moos 1982). Lazarus and Folkman (1984) extended these ideas and argue that any stressor (eg diagnosis and consequences of a chronic disease) is evaluated. This evaluation determines their emotional or behavioural reactions (Maes, Leventhal and de Ridder 1996). There are two evaluative or appraisal processes. Primary appraisal assesses the personal meaning of the event, and secondary appraisal evaluates the resources to meet the demands of coping. Positive emotions arise if the stressor is viewed as a challenge. Negative emotions characterised by anger and/or grief are a consequence of a threat to physical or psychological wellbeing, as is the case in most illnesses.

Maes et al (1996) argue that the Lazarus-Folkman (1984) model with its emphasis on the assessment of the

coping behaviours to the 'virtual exclusion of assessment of disease representation and coping outcomes' is limited because the model, *inter alia*, neglects situational demands, and also personal life goals. The Maes et al model is in itself limited in our view. It fails to take into account factors such as residual socialisation (MacLean 1990; MacLean, Gannon and Gould 1995), where previously learned behaviour may interfere with the acquisition of new roles. It also fails to recognise that there is a difference between taking on 'sick-role' behaviours associated with a chronic illness such as DM, and the acceptance required to acknowledge 'becoming and being' a diabetic.

The impact of a diagnosis like diabetes, cancer or heart disease is such that it will be remembered, as will the circumstances, events and responses of others at that time. Whilst Mechanic (1974) cautions about the accuracy of memory for events, the use of retrospective data need not be invalid provided adequate steps are taken to reduce recall bias. Memory is not static and with the constant reminder of the presence of the disease forgetting the impact of the diagnosis is unlikely. Indeed, where an event is highly significant, like the diagnosis of diabetes may be, it may become a 'life theme' (Guidano 1987). Life themes act as filters for the interpretation of subsequent stimuli, and help to organise and give meaning to the self.

A number of models of response to stressors (Kubler-Ross 1969; Adams, Hayes and Hopson 1976; Spertling 1988) indicate that coping or defensive responses may differ depending upon the stage within the model. Lazarus (1981) and his colleagues (Lazarus and Folkman 1984), for instance, argue that the individual uses primary appraisal followed by secondary appraisal. Schwarzer and Schwarzer (1996), review differing types of coping and argue that coping preferences may occur in a certain time order.

## AIMS

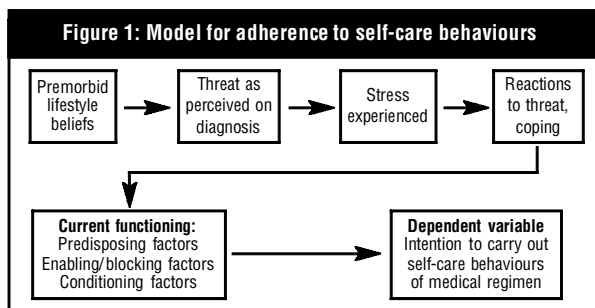
There are two inter-related aims of this paper. The first is to present data that shows there are differences in coping and adaptive behaviours between people with DM who are dependent upon insulin, and those people who are not insulin dependent. The second aim is more speculative in that it attempts to develop models of coping from the impact of the diagnosis to levels of experienced stress.

## METHODOLOGY

The material for this study was obtained as part of a larger cross-sectional study into the psychosocial factors affecting adherence and compliance in people with DM (Lo 1996). The focus of this report is on the respondents' retrospective analysis of the ways in which they coped at

the time of diagnosis. Respondents completed a survey questionnaire seeking responses to Likert-type questions. Well-known, valid and reliable instruments comprised the bulk of the questions included in the questionnaire.

The theoretical model that guided our efforts asked individuals to retrospectively identify their lifestyle beliefs prior to the diagnosis, to indicate the degree of threat this posed and how they coped and lived with this initial diagnosis, and to indicate the ways they currently manage the disease. The following figure shows the model that guided the initial research.



The focus of this paper is on variables in Blocks 1-4. Our concern is not so much with how they are functioning at the moment, but with the dynamics of coping following the initial diagnosis.

## SAMPLE SELECTION

The sample selection procedures have been outlined elsewhere (Lo 1996; MacLean and Lo 1998). Diabetes educators and dietitians randomly distributed 657 questionnaires to individuals who attended community health centres or diabetes education centres throughout New South Wales, Australia. Of the 657 questionnaires that were given out, there was a response rate of 59% (387 useable data). There were eight (1.2%) incomplete responses, and the rest (262) did not reply. Respondents and non-respondents did not differ significantly with regard to age, gender, type of diabetes, or the duration of the illness. Ethics approval was obtained from university and the appropriate hospitals ethics committees throughout New South Wales.

### Instruments used

Pre-morbid beliefs were tapped by the use of 10 Likert-type items. Items for example asked respondents to indicate their agreement on a five point scale to such statements as 'I believed I was in control of my life', 'I was living a healthy lifestyle'; Seven items formed the Premorbid scale ( $\alpha=0.67$ ). The three other items were entered into the equations as single item variables.

The 'impact' on being given the diagnosis of diabetes was regressed against the pre-morbid scale in the first

stage of the model building. The second phase of the model following the pre-morbid items was to measure the impact of the diagnosis. The 'impact' scale ( $\alpha=0.83$ ) comprises three Likert-type items expressing anger, feeling cheated and being depressed at being told of the diagnosis.

The response to the 'impact' of the diagnosis was twofold - by feeling fear and being threatened on the one hand - the 'fear' scale ( $\alpha=0.86$ ) comprising six item (eg I was afraid I could not live a normal life, ... how I would cope at home, ... have complications, ... limit my social relationships and friendships). On the other hand, there was a determination to meet the challenges of the disease (eg I believe that despite my diabetes I can still be a useful person, ... I can still enjoy life, ... a positive attitude will help me cope with diabetes). The 'determine' scale comprised 4 items ( $\alpha=0.83$ ).

Respondents completed four scales (MacLean 1990) derived from the Ways of Coping Checklist devised by Lazarus and his colleagues at University College of Los Angeles (mean internal reliability 0.85). Three of the scales are suggestive of positive ways of coping - obtaining advice, making greater efforts, seeking opportunities for growth. For some of the purposes of this study, they were combined into a scale with its focus on 'newness' - taking advantage of the potential in what might otherwise be a challenging situation. This is the 'newness' scale used in this paper ( $\alpha=0.91$ ). The other scale measures coping by the use of fantasy or avoiding and denying situations. Those who cope well with their diabetes are likely to score well on the positive scale, and those who do badly will tend to use avoidance and denial of the magnitude or severity of their illness as a means of coping.

Two indicators of mental health were included in the study. The first measured depression or 'gloom' ( $\alpha=0.76$ ). The 'gloom' scale was derived from the Dunn et al (1986) ATT39 scale, which purports to measure the emotional component of attitudes to diabetes. Internal consistency was reported for the un-weighted total score as 0.78 and the test-retest reliability coefficient over various periods from a two-week interval to six months ranged from 0.87 to 0.70. The 'gloom' scale comprised five items ( $\alpha=0.78$ ) including 'There is little hope of leading a normal life with diabetes', 'Diabetes is the worst thing that ever happened to me'. The other measure of mental health was the General Health Questionnaire (GHQ) (Goldberg 1972).

## Procedure

The Type 1 and Type 2 groups were compared by the use of Chi Square tests and t-tests wherever appropriate. To build the models, the 'impact' of the diagnosis was regressed against the pre-morbid variables. Then 'fear' and 'determine' variables were regressed against the 'impact' and 'pre-morbid' variables. Thus, all the variables to the

left of a variable were deemed to be predictive of that variable. From the regression equations, the beta weights or path coefficients were extracted and included in the models as an indication of the strength of the direct relationship between variables.

## RESULTS

### Sample characteristics

Table 1 and Table 2 present the biographical data of respondents. Table 3 gives the mean and standard deviations for all variables and scales for both the Type 1 and Type 2 groups. Included in Table 2 is the number of items in the scale and Cronbach's Alpha, as a measure of the internal consistency of the scale. The Table reports the t-test results and probability level for the differences in means between the two groups.

### Differences between people with Type 1 diabetes and those with Type 2

The 241 Type 2 respondents controlled their diabetes and its complications through diet and exercise (95) alone, and by diet, exercise and hypoglycaemic tablets (146). Their mean age (54.1) was significantly higher (Chi Sq. 138.98  $p=0.000$ ) than their Type 1 counterparts (38.3). There were no gender differences between the types of diabetes, but the Body Mass Index was higher for the Type 2 group (28.32) compared with the Type 1 group (26.47:  $t=-3.07$   $p=0.002$ ). The groups also differed significantly in terms of their marital status, largely a function of age. For example, the Type 2 group was over-represented in the widowed category, and under represented in the single category.

**Table 1: Types of diabetes, gender and age of subjects (n=350)**

Age group	Type 1		Type 2		Total
	M	F	M	F	
18-25	8	13	-	-	21
26-35	11	14	-	6	31
36-45	10	13	9	12	44
46-55	18	17	35	48	118
56-65	1	4	64	67	136
Total	48	61	108	133	350

**Table 2: Types of diabetes and marital status of subjects (n=350)**

Marital status	Type 1		Type 2		Total
	M	F	M	F	
married	31	43	93	87	254
divorced	6	3	7	19	35
widowed	2	2	4	22	30
Single	9	13	4	5	31
Total	48	61	108	133	350

**Table 3: Means and standard deviations for major variables: (1) Type 1 (n=109) and (2) Type 2 diabetics (n=241); t for differences between the groups and probability levels**

	Group	Means	S.D.	t	p	Items	α
Premorbid	1	14.68	2.71	-0.95	0.342	7	0.67
	2	14.96	2.46				
Trans 2	1	2.79	1.21	1.55	0.122		
	2	2.57	1.21				
Trans 10	1	4.01	0.98	2.00	0.046		
	2	3.76	1.15				
Impact	1	9.62	3.36	4.29	0.000	3	0.83
	2	7.98	3.24				
Determine	1	16.40	2.98	-2.93	0.004	4	0.83
	2	17.29	2.45				
Fear	1	20.25	5.36	7.28	0.000	6	0.86
	2	15.90	5.10				
Gloom	1	14.18	4.50	4.93	0.000	5	0.76
	2	11.80	4.04				
Newness	1	20.32	4.57	0.86	0.391	6	0.88
	2	19.82	5.29				
Avoid	1	23.75	5.84	5.99	0.000	7	0.88
	2	19.68	5.91				
GHQ	1	25.35	6.29	2.59	0.010	12	0.91
	2	23.65	5.39				

(Number of items in Scale and Cronbach's Alpha for both groups combined)

We found that the ‘impact’ of the diagnosis was greater for people who were insulin dependent (Type 1) than for those people who were diagnosed with Type 2 diabetes (t=4.29 p<0.000). Furthermore, people who were diagnosed with Type 1 diabetes tended to respond more with Fear to the diagnosis (t=7.28 p=0.000); more likely to be depressed (‘gloom’ t=4.93 p<0.000), and experienced greater amounts of stress (GHQ, t=2.59 p<0.010). Type 1’s were more likely to use Avoidance as a defence strategy (t=5.99 p<0.000), whereas, those with Type 2 diabetes were more determined to overcome (t=-2.93 p<0.004) the challenges posed by the diagnosis. There were no differences between the groups in terms of their ‘positive’ coping strategies as measured by the ‘newness’ scale.

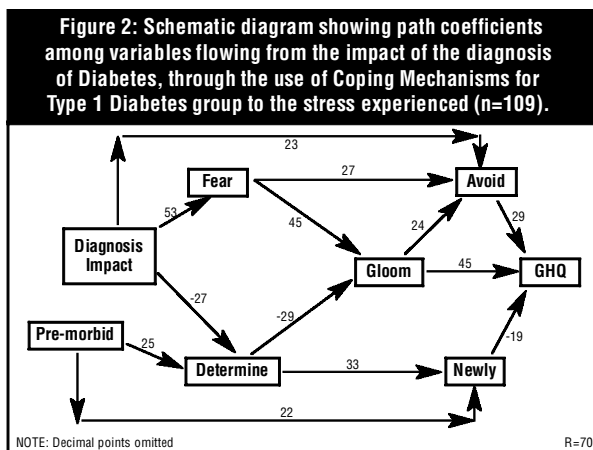
Our data suggested that the diagnosis of early onset diabetes (Type 1) was more traumatic than for those diagnosed with diabetes later in life. The differences between the groups in terms of the dynamics of coping were explored in the path diagrams that follow.

**Analysis of coping - Type 1 group**

For the Type 1 group (see Figure 2) no ‘pre-morbid’ variables had any role in predicting the ‘impact’ of the ‘diagnosis’. There was no association of pre-morbid beliefs with ‘fear’ of the disease, and its consequences. Fear of the consequences of the diagnosis was a function of the strong impact of the diagnosis. Pre-morbid beliefs were, however, related to the ‘determine’ scale. This relationship suggested that having a positive view of one’s health and the virtues of healthy living was positively related to the recognition that the diagnosis posed a challenge to be

overcome. Thus, there were initially two quite separate sets (orthogonal) of responses to the ‘impact’ of the diagnosis - ‘fear’ and ‘determination’.

The higher the path coefficients the greater is the strength of the direct relationship between the variables. In the model above, for example, it can be seen that ‘avoidance’ technique was a function of the ‘impact’ of the diagnosis, the ‘fear’ that this engendered, and the extent of ‘gloom’ experienced. For the Type 1 group, the use of defensive strategies, which implied growth and newness, was a function of an absence of ‘gloom’ or depression, and a determination to ‘beat’ the disease plus a set of positive pre-morbid beliefs.



The model suggested that long-term stress as measured by the GHQ was the outcome of inherent ‘gloom’ mediated by the twin coping processes of ‘avoidance’ and ‘newness’ (taking the opportunity to grow and develop).

Therefore in our model, it is argued that the ‘impact’ of the diagnosis elicits two mutually exclusive responses - Fear and concern for the implications of the disease, and a determination that despite the disease life will be lived to the full. The outcome of the struggle between these opponent processes, and the initial impact of the diagnosis is depression or gloom. Avoidance coping techniques are a function of this ‘gloom’ or depression, the ‘impact’ of the diagnosis and continuing ‘fear’ or concern for the meaning this has for normal living. This ‘fear’ also functions as a motivator for using coping mechanisms, which encourage newness, growth and a continuing determination to not let the disease dominate. Such mechanisms include seeking advice, making an effort and recognising the opportunities for growth within the present framework. Stress is then seen as an outcome of the two broad based opponent coping mechanisms of ‘avoidance’ and ‘newness’, along with ‘gloom’ and ‘depression’. Thus, the greater the depression, the greater the use of avoidance techniques, the greater the chronic stress experienced.

The model above points to two major tracks. The first focuses on the negative aspects of the transition: Impact - Fear - Gloom - Avoid - Stress, as measured by GHQ. The other track is more optimistic and ‘stress’ is negatively associated with ‘newness’, which is predicated on positive prior pre-morbid behaviour and beliefs and the determination not to let the disease get them down. The key ingredient in the first track is ‘fear’ and it is coping with this that leads to depression and gloom, use of avoidance procedures and stress. Fear of the consequences of the diagnosis is also the central feature for the non-insulin dependent group of respondents.

**Analysis of coping - Type 2 group**

The major differences between the models in Figure 2 and Figure 3 was predicated largely on the nature of the difference between the Type 1 and Type 2 groups, in particular the timing of the on-set of the disease. The impact of the diagnosis and quality of pre-morbid beliefs (the Premorbid scale, and two other items (Trans 2 and

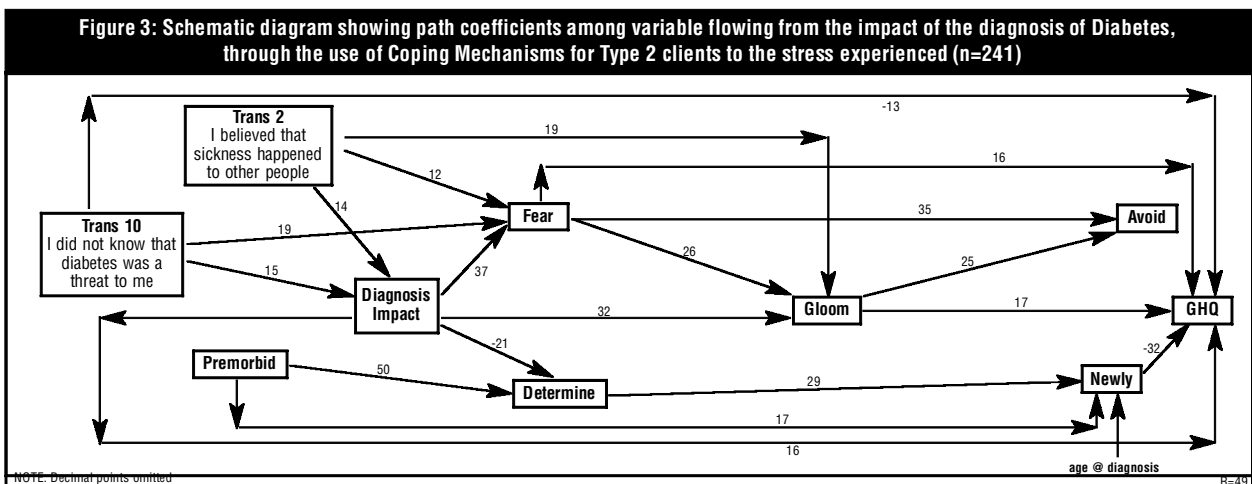
Trans 10) flow right throughout the model. For the Type 2 group, the length of time since being diagnosed was significantly less (4.2 years) than the Type 1 group (7.40 years;  $t=9.10$   $p=0.000$ ).

**DISCUSSION**

There are significant differences between Type 1 and Type 2 groups of diabetic patients to the diagnosis of DM. It would be a mistake to think that the trajectory for both is exactly the same. Coping and adaptation are complex processes, not easily amenable to description or analysis.

Type 1 clients have not only had to live with the disease for a longer time, but were diagnosed at a much earlier age. Thus, part of the reason for the relative failure of pre-morbid functioning to influence the coping process may be because the effects of residual socialisation (MacLean 1990) have been attenuated. Such was not the case with Type 2 clients. Their pre-morbid beliefs permeated the whole coping process. In other words, the Type 2 diabetic group have to make a more difficult if not substantial change in their behaviours.

The shock of the diagnosis generates two processes which may have the characteristics of opponent processes (Guidano 1987), whose expression is seen in vacillation and ambivalence. Thus, it is possible to have the two processes of ‘fear’ or concern for the implications of the diagnosis concurrent with a ‘determination’ that despite this terrible diagnosis, life has to be lived. Both can reside within the individual at the same time. One leads to hope and the other to despair. In our models, this struggle between ‘fear’ and ‘determination’ had its outcomes in the relative presence or absence of ‘gloom’ and ‘depression’. Rather than viewing avoidance techniques and ‘growth’ strategies from the Ways of Coping Checklist as an either/or situation, if they are regarded as complementary opponent processes in the same way as the ‘fear-determined’ system, then the struggle for coherence and balance may be reflected in tension and stress.



It was significant, for example, that this pattern was so much stronger in the Type 1 group. The high multiple correlation ( $R=0.70$ ) in the regression of GHQ on the coping variables, revealed that Type 1 clients as likely to be not only under greater stress ( $t=2.53$   $p=0.01$ ), but to have been under stress for a longer period. The high GHQ multiple correlation is suggestive of the coherence of the patterning of variables that predict GHQ, and the chronicity of the stress. The more diffused patterning of the Type 2 group was reflected in much reduced multiple correlation of the regression of GHQ on the coping variables. The model for the Type 2 group was more elaborate, and complex than that for the group with Type 1 diabetes. Notably, this was in terms of the influence throughout each part of the process of the pre-morbid variables, and the continuing impact of the diagnosis through to the stress perceived as measured by the GHQ. Fear also permeated this model.

Our findings seem contrary to those of Beeney et al (1996). They indicated that 64% of the insulin-dependent group (IDDM) experienced shock compared with 53% of the non-insulin-dependent group (NIDDM). They then stated that there was no significant difference between the proportion of IDDM and NIDDM respondents who recalled experiencing significant distress. Our analysis of their paper suggests that this may be an error. In other words rather than as indicated, it is probable that the proportion of IDDMs experiencing distress is greater than the proportion of NIDDMs. If our analysis is correct, then their data fits in with our data.

The use of fantasy and avoidance techniques seems to be closely related to the strength of the fear and concerns for the future, gloom or depressive outlook and strong beliefs that 'sickness happened to others or disbelief in the possibility that DM could ever be a threat to them. This suggests a non-acceptance of the diagnosis, or more likely an oscillation between accepting it, and a refusal to accept that it applies to them. Perhaps this can be seen in the fact that the BMI for the Type 2 group was significantly higher than that for Type 1 respondents. There is a greater need for the Type 2 group to control their diet, to reduce weight and, probably, to exercise more.

Stage theory models in general tend to posit and focus the distinctiveness of phases. Sperling's (1988) model articulates the processes of adjustment to DM. But, it may be that the very idea of phases or stages may mask the moment to moment, day by day shifting between hope and gloom, between using avoidance coping methods and 'growthful' strategies suggestive in our model. The acceptance of the reality of the disease may be much more difficult for the Type 2 patient. There is, if you like, a double whammy from the re-socialisation and residual socialisation effects. Residual socialisation occurs when previously learned behaviours - the residue of old learning

- continue to assert themselves in situations that are inappropriate.

From a relatively early age, the Type 1 patients have to come to terms with injections - they are socialised into the processes of checking blood sugar levels, managing their diet and so on. Type 2 patients, however, have led a symptom free life for a significantly longer period of time and for a greater proportion of their lives. They have developed lifestyles that, in effect, have to be unlearned, and a new set of behaviours has to be learned. Such learning is much easier if there is an acceptance that they have DM. It is obvious from the study that the positive dynamic structure of 'newness' - growth, advice seeking and acceptance and effort - lead to a healthier lifestyle, and a concomitant increased likelihood of complying and adhering to management regimes.

Indeed, this kind of 'optimism' may lead to an earlier acceptance of what it means to be diabetic and its incorporation into the structure of the self. We believe that this paper is a small step on the way to understanding the dynamics of coping, and suggests to health professionals that a sound knowledge of their client is important. Thus, clients will make some progress, take steps forward and steps backward. This process of adjustment and coping will take time.

## CLINICAL IMPLICATIONS

1. People who are diagnosed insulin dependent are much more likely to have a more intense, and severe reaction, to the diagnosis than those who are diagnosed non-insulin dependent.
2. Those people with a non insulin dependent diagnosis come to the point of diagnosis with a much longer history of 'illness freedom', therefore:
  - a. They may take longer to accept the diagnosis, and to incorporate the disease into their persona - 'being' rather than 'doing'.
  - b. They have residual socialisation effects, which may impede acceptance, adherence and compliance.
  - c. Paradoxically, they are likely to have access to a wider range of adaptive behaviours, family support, age and wisdom, which may facilitate acceptance of the disease with a concomitant reduction in stress and depression.
  - d. It is important to take a social history to identify possible barriers, including residual socialisation effects that impede good health care practices.
3. Recognise that coping strategies are in reality likely to be opponent processes. Clients will oscillate between hope and despair, between determination to cope and

fear of the consequences, between avoidance and growthful strategies. They will manifest ambivalence.

4. Coping is a very complex process, and various coping strategies can 'cut in' at various points within the total process. It must also be recognised that stress and depression are in themselves attempts at adaptation.
5. Depression in clients is likely to be an outcome of a 'battle' between fear and the challenge of the disease. It is probably a normal part of the process of coming to terms with the disease. In itself it is unlikely to be pathological.
6. Stress, in this model is an outcome of a failure to develop 'new-ness' or growthful coping strategies. Relief for stress comes from aiding clients to develop 'positive' attitudes to the disease, to take control and to develop new behaviours and ways of being.

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