The evaluation of the ‘stages of change’ model for use in counselling client’s undergoing predictive testing for Huntington’s disease

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INTRODUCTION

This paper aims to review the literature of predictive testing for Huntington’s disease and for Prochaska & DiClemente’s (1983) ‘stages of change’ model. The usefulness of this model in counselling people undergoing predictive testing for the condition will then be evaluated.

Huntington’s disease is an autosomal dominantly inherited, progressive, neurodegenerative disorder of adult onset caused by a single defective gene (Harper 1996). People affected with the disease experience a range of psychological and physical problems over a number of years, the person becoming increasingly dependent on others for assistance with all activities of daily living. The clinical features of the condition have been well documented (Gussella et al. 1983, Folstein 1989, Harper 1996). These include abnormal involuntary movements involving all parts of the body, psychological disturbance and cognitive decline. Huntington’s disease is also a cause of pre-senile dementia (Harper 1996, Folstein 1989). Onset of the disease is usually in the third or fourth decade of life, but 10% of people manifest signs of the disorder for the first time below the age of 20 or above 60 years (Walker 1979).

The offspring of an affected individual have a 50% chance of inheriting the Huntington’s disease gene, and because the gene is dominant and fully penetrant, a person who has inherited the gene will always develop the disease if they live long enough.

There is presently no cure for the condition and treatment is palliative and does nothing to halt the 10-20 years progressive course of the disease. Harper (1988 p.2395) goes so far as to say:
The combination of progressive physical disability, mental involvement and its dominant inheritance possibly lay a greater burden on patients and their families than any other neurological disorder.

Huntington’s disease affects not only the individual suffering with the disorder but also the whole family, emotionally, physically and socially.

The condition remains a rare disorder, but the effects it has upon families within which it is expressed are profound. There are estimated to be about 100,000 people worldwide with the disease, 4,000 of whom are in the United Kingdom (Harper 1993).

Huntington’s disease was the first condition in which linked deoxyribonucleic acid (DNA) markers were discovered (Gusella et al. 1983). This discovery allowed some individuals at risk of Huntington’s disease to discover whether they carried the gene for the disorder with varying degrees of certainty (Conneally et al. 1989). More recently, the isolation of the Huntington’s disease gene (The Huntington’s Disease Collaborative Research Group 1993) has provided a definitive test for any person at risk of the disorder. This has resulted in predictive testing for the condition being offered by many of the genetics centres in the United Kingdom. However, because there is no cure or preventive treatment for the disorder, concern for at-risk people taking the test resulted in the development of a UK protocol for counselling people prior to and following a predictive test result (Tyler et al. 1992).

As a consequence of cloning the Huntington’s disease mutation this protocol has been revised to take account of what is now a virtually definitive test (Houlihan & Harper 1993). This was necessary because individuals are now informed of whether they have the mutation or not, as opposed to being given a raised or lowered percentage risk, which was the case with other forms of genetic testing, which became available in the late 1980s (Quaid et al. 1987).

The overall goal of counselling is to ensure that the person has carefully thought through the full implications of both adverse and favourable testing outcomes, and is prepared to make an informed decision about testing. The counselling is designed to raise issues and questions that might not have been considered previously, any one of which may cause a person to re-evaluate the desire to be tested. These considerations are especially important in view of the fact that effective treatment for Huntington’s disease is not currently available.

Several in-depth, structured counselling sessions over approximately 4 months are highly desirable in order to allow a relationship to develop with the at-risk client, as any potential conflicts and problems are more likely to surface in the context of such a relationship. At the same time, the foundation for continued support after testing is established. Clients considering testing are reassured at the outset that they can either discontinue or postpone testing at any point in the programme. The time frame in which counselling is carried out also provides the opportunity for the client to reflect upon whether their decision to go through with testing is the right decision for them at that time. This protocol is used throughout all the genetics centres in the UK.

In reviewing the nursing literature it is apparent that no existing nursing models or theories would be a particularly good fit when counselling people undergoing predictive testing for Huntington’s disease. Fawcett (1989) recognizes the fact that many models and theories used by nurses have been borrowed from other disciplines and states that:

“There is an increasing awareness of the need to test borrowed theories to determine if they are credible in nursing situations (Fawcett 1989 p.23).”
This would appear to be particularly relevant in new and novel nursing situations, such as genetic counselling. Consequently, the author has chosen to evaluate Prochaska & DiClemente’s (1983) stages of change theoretical model which might be useful if used when counselling people undergoing predictive testing for Huntington’s disease.

Counselling clients who are undergoing predictive testing for Huntington’s disease is primarily a communication process. For this communication process to be effective the at-risk client and the nurse should be able to interact with each other in an emotional, personal and professional way. Consequently, the quality of communication between the nurse and client is an essential determinant of the success of the professional relationship (Leddy & Pepper 1993). Therefore, Prochaska and DiClemente’s stages of change model, which has its roots in psychological theory, has been evaluated with the aim of determining whether it would provide a useful framework for effective communication as part of the counselling process.

**Uptake of predictive testing for Huntington’s disease**

Before the possibility of a predictive test was realized most surveys suggested that approximately two-thirds of the at-risk population would undergo predictive testing (Stearn & Eldridge 1975, Schoenfeld et al. 1984). A community-based study by Tyler & Harper (1983) indicated that 56% of the Huntington’s disease population in industrial South Wales would be interested in testing for themselves. However, this predicted high level of demand for predictive testing has not been realized (Quaid et al. 1987, Craufurd et al. 1989).

More recently Houlihan & Harper (1995) reported a continuing low level of uptake for predictive testing in the UK following the isolation of the Huntington’s disease mutation (The Huntington’s Disease Collaborative Research Group 1993). This discovery has made definitive testing possible for any person at risk of the disorder. It is therefore possible for people at risk of the disease to know with a high degree of certainty whether they have inherited the Huntington’s disease mutation. Because the disease does not usually express itself until adult life it could be argued that an adverse predictive test result merely replaces one uncertainty with another; the uncertainty of whether or not the person has inherited the mutation, with the uncertainty of when the disease will onset. The result is given to the individual with the knowledge that neither the nurse or client have any power to change the outcome.

Therefore when evaluating a model that may be useful in counselling people making a decision regarding testing it is important to determine why people choose for or against testing.

**The decision whether or not to have testing**

There have been several studies which have examined the reasons given by applicants for taking the predictive test (Bloch et al. 1989, Evers-Kiebooms et al. 1989, Tyler et al. 1992). Tyler et al. (1992) reported on a series of people requesting testing from South Wales and southern England whose motives mainly related to childbearing, informing existing children and planning for the future. Meissen et al. (1991) conducted structured interviews with 40 at-risk candidates requesting predictive testing, and 31 companions.

They found that the four most frequently cited reasons for requesting testing were: need to know (47.5%), planning and decision-making (40%), clarify risk status of children (22.5%) and family planning (22.5%). Similar findings were reported by Morris et al. (1989), who suggest that the most frequent reasons given for requesting testing were to inform existing children and to relieve the uncertainty. A more recent study by Quaid & Morris (1993) explored why 137 at-risk individuals had chosen not to be tested. They found that the main reasons subjects chose not to
seek testing was because there is no effective cure, possible loss of health insurance and the possibility of increasing their children’s risk. Because the condition is passed on in an autosomal dominant way if a parent is shown to have inherited the mutation, then the risk to their children goes up to 50%.

The literature reports a variety of reasons for why people do and do not seek testing; this suggests that people reach their decision in different ways, implying differences in the decision-making process.

Therefore, when considering a model which may enhance communication when counselling people undergoing testing it is important to understand how a person makes their decision.

The stages of change model
Prochaska & DiClemente’s (1983) stages of change model may be of value not only in exploring how people make decisions concerning predictive testing but also in the general context of genetic counselling of individuals at risk of the disorder. Prochaska & DiClemente’s (1983) stages of change model describes the structure underlying intentional change.

The model was originally developed in the context of changing problem behaviours, but has been used to examine the acquisition of positive health-related behaviours as well. This is potentially one of the problems in applying the stages of change model to predictive testing as one cannot make a value judgement about uptake of testing being good or bad.

The stages of change model describes a process whereby individuals move from being unaware or unwilling to do anything about a behaviour (pre-contemplation), to considering the possibility of change (contemplation), and finally to taking action (action) and sustaining or maintaining that change over time (maintenance). It can be recognized that there are important differences between applying the stages of change model to changing health behaviour vs. making a decision about predictive testing and how the model is operationalized in this context. However, in the context of predictive testing for Huntington’s disease the model is not considered with respect to decision-making concerning testing. As part of the individual’s decision making about whether to have the test there should be no sense on the part of the nurse of wanting to move people through a process, i.e. from pre-contemplation to action.

Results based on this model have been equivocal and what began as a linear model of progression through the sequential stages of pre-contemplation, contemplation, action and maintenance (Miller 1983, Rollnick et al. 1992) has evolved in a number of ways. Observations of self-changers have shown that people rarely negotiate change in an orderly, progressive fashion (Prochaska et al. 1992).

Correlation’s between stages have been inconsistent, with some studies showing positive correlations between non-adjacent stages (Sutton 1996). Prochaska et al. (1992) propose a spiral of change as more accurately describing the change process, with individuals frequently recycling to earlier stages in their pursuit of activating and maintaining a change (Figure 1).

Some authors have identified a number of distinct client profiles on the basis of cluster analysis (McConnaughy et al. 1983). These clusters of high scores have been interpreted in various ways. Prochaska et al. (1992) suggest that an above-average score in both contemplation and action stages is indicative of a fifth ‘preparation for action’ stage which comes between contemplation and action stages.
Sutton (1996) argues that if participants can be thought of as being in two different stages at once, the concept of stages, which implies ordering or sequence, loses its meaning. He suggests that ‘states’ rather than ‘stages’ is conceptually more appropriate to the change process (Figure 1).

![Figure 1](image-url)  
**Figure 1** A timeline showing an individual’s movement between different states of change. PC: pre-contemplation; C: contemplation; P: preparation; A: action. Not ordered or sequential, states rather than stages. Adapted from Sutton (1996 p.197).

**Processes of change**

Prochaska *et al.* (1992) have elaborated their model to examine the processes that bring about change. Based on their analysis of leading systems of therapy, Prochaska *et al.* (1992) have distilled 10 core change processes, overt and covert activities that people use to effect change.

“Each process is a broad category encompassing multiple techniques, methods and interventions traditionally associated with disparate theoretical orientations (Prochaska *et al.* 1992 p.1107).”

They have developed a 40-item questionnaire that measures these processes. The processes of change have been integrated with the stages of change model on the basis of their frequency of occurrence or emphasis in the respective stages (Prochaska & DiClemente 1983). They may be thought of as a set of tasks that need to be accomplished before the person can proceed to the next stage.

**The decisional balance measure**

Another construct that has been incorporated into the stages of change model is the decisional balance measure (Prochaska *et al.* 1994). Based on an earlier decision-making model (Janis & Mann 1977). Verlicer *et al.* (1985) developed a 24-item decisional balance measure that assesses decision making across the stages of change for smoking cessation. Principal component analysis identified two components, the advantages and disadvantages of smoking, that accounted for 40-80% of the variance across samples. These two decisional balance measures have become critical constructs in the transtheoretical model.

The balance between the advantages and disadvantages differs according to the stage at which the person is. For example, at pre-contemplation, individuals across 12 different behaviours judged the advantages of the problem behaviour to outweigh the disadvantages (Prochaska *et al.* 1994).

Conversely, in the action and maintenance stages, the disadvantages of the problem behaviour outweighed the advantages (with the exceptions of smoking cessation and withdrawing from cocaine).
For all 12 behaviours, the advantages of changing the behaviour were higher in the contemplation stage than in the pre-contemplation stage, suggesting that movement from pre-contemplation to contemplation involves an increase in the evaluation of the advantages of changing. Prochaska et al. (1992) propose that the pre-contemplative and contemplative stages involve cognitive, affective and evaluative processes of change, processes that are associated with experiential, cognitive and psychoanalytic therapies.

On the other hand, the latter stages of change are action orientated and the core processes are those traditionally associated with the existential and behavioural traditions. Exploring any perceived barriers to action and the detail of implementing the proposed change are important tasks of the preparations stage (DiClemente 1991).

DISCUSSION
Prochaska & DiClemente’s (1983) stages of change model indicates that it may be too simplistic to consider people at risk of Huntington’s disease as belonging to two discrete categories, those for and against predictive testing. The model indicates that individuals negotiate behaviour change and decision-making on a continuum which incorporates all the stages of change, but the individuals may alternate between stages.

The model also suggests that an individual may vary in where they are on the stages of change continuum and that this may affect how they will perceive information given to them. It is therefore important that nursing interventions are matched to the stage the individual is at. A study of smoking cessation interventions provides persuasive evidence for the importance of stage matched interventions (Prochaska et al. 1993). In stage-matched interventions the task of the nurse is to assess where the client is in terms of the stages of change and then respond with appropriate, stage-matched strategies, the goal of intervention being to help the client in efficient and effective decision-making by the appropriate timing of communications.

The early stages of change (pre-contemplation and contemplation) are, according to the process of change analyses, focused on gaining insight and awareness. Action-orientated nursing interventions may be ineffective or detrimental with individuals in these stages. The contemplation stage is characterized by a great deal of ambivalence towards the considered change.

In Prochaska et al.’s (1992) study, individuals in the contemplation stage were most open to consciousness-raising techniques (observations, confrontations, interpretations) and dramatic relief experiences. As regards the latter, Kessler (1994, p.165) notes that:

“exposure to and mastery of disquieting, anxiety provoking thoughts in a safe, controlled environment is believed to help the person deal with the distressing realities later on.”

DiClemente (1991) observes that people considering changing a behaviour will often concentrate on all the negative aspects of the behaviour.

Therefore, the challenge for the nurse is to assist in creating a more balanced perspective of the advantages and disadvantages of the behaviour or decision.

It is important to consider the appropriateness of a model developed in the context of changing addictive behaviours to the aim of facilitating effective communication and decision-making in genetic counselling.
The main departure of genetic counselling from motivational interviewing is that it is non-directive; the chief similarity between the two approaches is that they are client-centred. The primary contribution of the stages of change model is in the decision making-process and matching intervention strategies accordingly.

In trying to understand and support the individual’s decision regarding predictive testing, the nurse can draw on a number of theories and models which explain the psychological processes involved in the enactment of health related decisions.

However, the change event of receiving a predictive test result differs from other health-related decisions to which the stages of change model has been applied in two obvious ways: (i) it is a one-off change and (ii) a value judgement cannot be attached to it.

As a consequence, the model is not intended to promote one or the other decision, but rather to understand and support the decision-making process through good communication.

Successful genetic counselling requires that the client is psychologically ready to receive, assimilate and comprehend the genetic information (Targum 1981). Therefore the nurse needs to discern and respond to the client’s readiness to consider certain issues and to receive new information. All ill-timed communication may raise the client’s anxiety and have a negative impact on comprehension and retention of genetic information (Sharpe 1994a), e.g. if the individual is unaware or not ready to discuss the possibility of risk alteration to their children.

The experiences of the Canadian Collaborative Study of Huntington’s Disease Predictive Testing indicates that appropriate assessment should be undertaken to determine the client’s readiness for the predictive test (Sharpe 1994b). However, the stages of change model should not be used to assess the client’s ‘eligibility’ to receive a test result.

Potential weaknesses of the stages of change model have been identified. For example, there is no strong evidence that using a particular process in a particular stage promotes movement to a subsequent stage. This observation is, however, not a limitation in the context of ‘non-directive’ genetic counselling.

Most research examining individual factors involved in the uptake of predictive testing classifies individuals as either ‘for’ or ‘against’ testing.

This suggests that the decision to receive a predictive test result is a discrete event rather than a dynamic process and does not take cognizance of those people who intend delaying testing, or who enter testing programmes and then decide against receiving a result.

The author suggests that it is more useful to conceptualize at risk individuals as being on a continuum as regards their ‘readiness to receive a test result’. This will facilitate the effective timing of communications.

The stages of change model might be further researched in practice by analysing data obtained by semistructured interviews from a cohort of test applicants and a random group of at-risk individuals who had not requested testing. Questions included should aim to determine why at-risk individuals do or do not seek testing. It should also include questions concerning which aspects of the predictive testing counselling were perceived by those who underwent testing as helping in their decision-making. Responses of applicants who had undergone testing without the adoption of the model could also be compared to those who had undergone predictive testing where the model had been used as a framework for counselling.
A more qualitative approach may involve comparing the content of retrospective personal interviews from individuals who have been through testing when the model had not been adopted with a cohort of individuals about to undergo predictive testing using the model to facilitate the counselling process. This could explore how and why individuals made their decision to be tested, and whether there are any differences between the two groups with respect to coping strategies used following counselling and the generation of a predictive test result.

**CONCLUSION**

The direct clinical implication of Prochaska & DiClemente’s (1983) stages of change model is in terms of stage matched interventions; that is, assessing a person’s readiness to change, and the tailoring nursing interventions accordingly.

The model may have value as a clinical tool for building effective communication and therefore effective decision-making. It is recognized that not discerning and therefore responding inappropriately to an individual’s psychological state has a negative impact on comprehension and retention of genetic information (Sharpe 1994b). Timing is a crucial element in effective communication and client comprehension, hence the need to provide clients with well-timed, personally relevant information.

This paper has suggested that testing and refining appropriate theories, irrespective of their origin, can provide a useful framework to guide nursing practice, especially in new nursing situations.

Therefore the stages of change model could provide a useful model for improving the quality of communication in counselling people undergoing predictive testing for Huntington’s disease. The model’s non-reliance on the medical model of the concept of illness means that it may also be useful in other nursing situations. There is a need to test the application of this model in practice. This is especially important as the genes for a growing number of physical and psychological conditions are being identified with the possibility of predictive tests for these conditions being offered as a service in the future.

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References


