

# Chapter 4

Theoretical foundations obtained from health psychology

*"[...] the complex interplay of cognitive, emotional and social elements that must be considered with regard to the burden of making decisions in the presence of genetic risks [...]"*

*(Shiloh, 2000)*

*"Yet people rarely follow formal statistical rules in making decisions outside the laboratory."*

*(Michie and Marteau, 2000)*

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- Sanden, M.C.A. Van Der and Meijman, F.J. (2008). Dialogue guides awareness and understanding of science: An essay on different goals of dialogue leading to different science communication approaches. *Public Understanding of Science*, 17(1): 89-103
- Sanden, M.C.A. Van Der and Meijman, F.J. (2007). Medische publiekscommunicatie een systeembenadering. In *Basisboek Wetenschapscommunicatie*, Willems, J. and Seydel, E. (eds.). Amsterdam: Boom.
- Sanden, M.C.A. Van Der and Meijman, F.J. (2005). The multidimensional dialogue on predictive DNA diagnostics. In *Proceedings of the International Conference on Tailoring Health Messages. Bridging the gap between social and humanistic perspectives on health communication*. Monte Verità, Switzerland, July 6 – 10: 171-176.

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## Preface

This chapter focuses on the comparison of theories governing health psychology (however, we use the domain of medical psychology as our starting point) and biomedical science communication. The rationale for taking medical psychology into account is given in the introduction to this thesis. As in chapter 3, a restricted overview of relevant theories in medical psychology is generated, one that is based on the consolidated and unconsolidated literature we read and one that fits the scope of this thesis. The main research question was: what are the most-recognized variables in medical psychology which are relevant to the development of a profound theoretical framework of effective biomedical science communication on predictive DNA diagnostics?

The sections on the consolidated literature end with a description of the major theories and attached variables. Health psychology appears to be more suitable than medical psychology for comparison with biomedical science communication. We conclude with a metric equation to gain insight into the different variables of health psychology and their relative importance.

The unconsolidated literature shows that in the domain of health psychology information is something that must be treated with caution most of the time. The consolidated and unconsolidated findings are added to the theoretical framework of chapter 3 which eventually leads to the theoretical framework step 2, which is a metric equation.

## 4.1 Introduction

As stated in chapter 1, the volume of the developments in genetics and genetic research is huge, and they have an important impact on individuals and society. With the development of the new field of genetic medicine the position of the individual has changed. In chapter 1 we learned about research by Hendriks (2005) that shows the far-reaching consequences of predictive testing for the individual. It is difficult to get an overview of these consequences, whether for patients or for the lay audience. Marks et al. (2000) write:

*Genetic research premises a host of social, psychological and ethical issues. There is a need for an expanded programme of research to investigate both professional and public perceptions of genetic screening and the impact on different populations.*

And at the same time the relationship between doctor and patient has also changed a lot during the years. Dunning (1999) writes:

*The patient's rights have become the doctor's obligations. The information must be given and privacy protected [...] On the one side there is uneasiness about new genetic developments from the lay audience perspective. On the other side when an individual gets ill all new technology is celebrated and must be available instantly, till that moment this new technology does not work.*

So an important point to begin discussing new technology and genetic topics is in the context of doctor-patient interaction. Research on the doctor-patient relationship and the principles, theories and concepts accorded to it can be of great use for biomedical science communication on predictive DNA diagnostics, for example at a mass communication level. The difference in level, interpersonal versus mass media - as described in chapter 1 - makes medical psychology an interesting domain to investigate in order to develop a profound theoretical framework for biomedical science communication.

In the context of this thesis the main question in this chapter is: which variables in medical psychology as they pertain to the field of predictive DNA diagnostics lead to success or failure with regard to structure, process, outcome and context? The difference in level of medical psychology's interpersonal communication of and biomedical science communication's mass communication means that we must be careful with translation from the individual level to the mass level.

Since the 1980s the number of people working in the medical psychology domain has increased (Marks et al., 2000). According to these authors, this is mainly based on:

- 1 the idea that, most of the time, diseases are caused by certain behaviours;
- 2 the idea that individuals have a responsibility to stay healthy;
- 3 the notion that communication between doctor and patient is not effective and should be improved.

More specific to the field of predictive DNA diagnostics, due to the general increase in knowledge about the human genome, the scope of (predictive) diagnostics has also increased (Wood-Harper and Harris, 2000).

Marks et al. (2000) distinguish three different tests:

- 1 carrier testing;
- 2 presymptomatic testing;
- 3 susceptibility testing. All tests call for a different approach to the patient or not-yet patient and their partners.

How does the domain of medical psychology cope with this issue of testing? After the diagnosis patients and not-yet patients may show a number of successive emotions: astonishment followed by fear and anxiety. Eventually they develop a way to cope with the shock (Marks et al., 2000; Tibben et al., 1993; Wiggins et al., 1992; Tibben, 2006a/b).

The authors state that patients should be well informed when they decide to have a test or to forgo it. Individuals should know about the pros and cons of a test. Medical psychology, like most medical communication with a lay audience is concerned with issues of compliance, trust and credibility. These are variables that are important in the process of biomedical science communication as we have seen in the previous chapters. These variables are well studied in medical psychology and the outcome of this research supports our findings in chapter 3 more precisely.

## 4.2 Literature search

The consolidated and unconsolidated literature has been searched and validated according to the method described in chapter 2. We have spoken with two specialists in the field: Prof. J. Passchier (Professor of Medical Psychology, Erasmus University Medical Center) and Prof. A. Tibben (Professor of Psychology of Clinical Genetics, Leiden University Medical Center). Their expertise guided us as we began to explore the field of medical psychology. One of the most important books on the subject (part of the consolidated literature) is *The troubled helix: social and psychological implications of the new human genetics*, edited by Marteau and Richards (2000). We also searched for textbooks in the same university libraries that were used for the literature search described in chapter 2. In the search for unconsolidated literature, we replaced the Current Contents database with the PsycINFO database, which is more specific to the domain of medical psychology. Of course, (as we said in chapter 3), for practical reasons we were not able to perform an exhaustive search of the literature in the field of medical psychology. Researchers in the field of medical psychology will most certainly be able to cite theories and concepts that are different from the ones we found and used. Therefore, the choice of theories and their application is our responsibility. The explication of the systematic literature search makes the choices we have made clear. Table 4.1 depicts the search results from the consolidated literature search.

Table 4.1: Results of the consolidated literature search. The terms used are in Dutch and English, since we used Dutch libraries. We began with the Erasmus University Library and looked at the search strings with high-level hits in the other university libraries as well.

Relevance	Key words <sup>1</sup>	EUR <sup>2</sup>	VUA	UU
(+++)	Medische psychologie AND voorspellende DNA diagnostiek AND effectiviteit	0	0 <sup>3</sup> (ml) <sup>4</sup>	
(+++)	Medische psychologie AND voorspellende DNA diagnostiek	0	0	
(++)	Medische psychologie AND genetica AND effectiviteit	0	0	
(++)	Medische psychologie AND genetica	0	0	
(++)	Medische psychologie AND effectiviteit	0	0	
(+)	Medische psychologie <sup>5</sup>	12	23	492 <sup>6</sup> 305

<sup>1</sup> Only a few terms are taken into account. It is likely that there are better keywords to be found; however, for practical reasons we conducted only one search action.

<sup>2</sup> We searched in the general catalogue of the university library of Erasmus University Rotterdam (EUR); we searched for 'all words'. With more specialized search strings, like 'medical psychology AND DNA-diagnostics AND effectiveness' we searched in medical libraries as well.

<sup>3</sup> Medical Library.

<sup>4</sup> ML is medical library.

(+++)	Medical psychology AND predictive DNA diagnostics AND effectiveness	0	0		
(+++)	Medical psychology AND predictive diagnostics	0	0		
(++)	Medical psychology AND genetics AND effectiveness	0	0		
(++)	Medical psychology AND genetics	0	0		
(++)	Medical psychology AND effectiveness	0	0		
(+)	Medical psychology	7	14	211 <sup>7</sup>	155
(+++)	Gezondheidspsychologie AND voorspellende DNA diagnostiek AND effectiviteit	0	0		
(+++)	Gezondheidspsychologie AND voorspellende DNA diagnostiek	0	0		
(++)	Gezondheidspsychologie AND genetica AND effectiviteit		0		
(++)	Gezondheidspsychologie AND genetica	0	0		
(+)	Gezondheidspsychologie AND effectiviteit	0	0		
(+)	Gezondheidspsychologie	79	2	10	76
(+++)	Health psychology AND predictive DNA diagnosis AND effectiveness	0	0		
(+++)	Health psychology AND predictive DNA diagnostics	0	0		
(++)	Health psychology AND genetics AND effectiveness	0	0		
(++)	Health psychology AND genetics	0	0		
(+)	Health psychology AND effectiveness	0	0		
(+)	Health psychology <sup>8</sup>	43	38	326 <sup>9</sup>	429
(+++)	Gezondheidspsychologie AND voorspellende DNA diagnostiek AND effectiviteit	0	0		
(+++)	Gezondheidspsychologie AND voorspellende DNA diagnostiek	0	0		
(++)	Gezondheidspsychologie AND genetica AND effectiviteit	0	0		
(++)	Gezondheidspsychologie AND genetica	0	0		
(+)	Gezondheidspsychologie AND effectiviteit	0	0		
(+)	Gezondheidspsychologie	31	2	50	<sup>10</sup>
(+++)	Behavioral psychology AND predictive DNA diagnostics AND effectiveness	0	0		
(+++)	Behavioral psychology AND predictive DNA diagnostics	0	0		
(++)	Behavioral psychology AND genetics AND effectiveness	0	0		
(++)	Behavioral psychology AND genetics	0	0		
(+)	Behavioral psychology AND effectiveness	0	0		
(+)	Behavioral psychology	7	37	834 <sup>11</sup>	321

<sup>5</sup> It appears that there are only single issued hits possible at the EUR library.

<sup>6</sup> Electronic journals are listed as well.

<sup>7</sup> Electronic journals are listed as well.

<sup>8</sup> More specific than behavioural psychology.

<sup>9</sup> Electronic journals are listed as well.

<sup>10</sup> The library database divides the term into gedragspatroon, gedragsprobleem, etc.

<sup>11</sup> Electronic journals are listed as well.

In the university library of the Erasmus University Medical Center we found more than 10 relevant books on medical psychology. We used these to analyse the consolidated literature. From the search we can conclude that there is no consolidated literature to be found that is highly relevant (+++). Also, there was not much highly relevant literature on effectiveness to be found.

We did not abstract new key words from the consolidated literature search to be used in the search for unconsolidated literature. In order to have a best fit with respect to the domain searched we replaced the Current Content database we used for chapter 3 with the PsycINFO database. In Table 4.2 the results from this research are depicted.

Table 4.2: Results of the unconsolidated literature search

Relevance	Key words	Web of Science	PubMed <sup>12</sup>	PsycINFO	Cochrane
+++	Medical psychology AND predictive DNA diagnostics AND effectiveness	0	0	0	0
+++	Medical psychology AND predictive DNA diagnostics	0	0	0	0
+++	Behavioral psychology AND predictive DNA diagnostics AND effectiveness	0	0	0	0
+++	Behavioral psychology AND predictive DNA diagnostics	0	0	0	0
+++	Health psychology AND predictive DNA diagnostics AND effectiveness	0	0	0	0
+++	Health psychology AND predictive DNA diagnostics	0	0	0	0
+++	Clinical psychology AND predictive DNA diagnostics AND effectiveness	0	0	0	0
+++	Clinical psychology AND predictive DNA diagnostics	0	0	0	0
+++	Genetic counselling AND predictive DNA diagnostics AND effectiveness	0 / 0 <sup>13</sup>	0 / 0	0 / 0	0 / 0
+++	Genetic counselling AND predictive DNA diagnostics	0 / 0	4 / 4	0 / 0	0 / 0
+++	Cognitive psychology AND predictive DNA diagnostics AND effectiveness	0	0	0	0
+++	Cognitive psychology AND predictive DNA diagnostics	0	0	0	0
++	Medical psychology AND genetics AND effectiveness	0	0	0	0
++	Medical psychology AND genetics	2 <sup>14</sup>	4 <sup>15</sup>	37 <sup>16</sup>	2 <sup>17</sup>

<sup>12</sup> Although medical psychology, health psychology and clinical psychology are MeSH terms, they all need to be digitally entered because they do not represent subheadings.

<sup>13</sup> Different literature databases use different spelling, e.g. 'genetic counseling' and 'genetic counselling'. These spelling variations lead to different hits in the databases. In the PubMed database this difference does not occur due to the MeSH term genetic counseling which also refers to genetic counselling. In the Web of Science database there is a difference; however, when searching on Genetic counseling AND predictive DNA diagnostics there is no difference, 0 hits.

<sup>14</sup> One of the two publications is relevant. We obtained more articles from the same authors from the references in Web of Science.

<sup>15</sup> Relevant, but one article is in French and for practical reasons it cannot be taken into account.

<sup>16</sup> Generates 6 relevant references.

<sup>17</sup> In the Cochrane database 2 articles were found: 1 in the Cochrane Central Register of Controlled Trials (2 out of 400,976 articles). One of these hits is relevant: Tailoring communication in consultations with women from high risk breast cancer families, Lobb et al. [2002].

++	Behavioral psychology AND genetics AND effectiveness	0	0	0	0
++	Behavioral psychology AND genetics	0	3 <sup>18</sup>	20	0
++	Health psychology AND genetics AND effectiveness	0	0	1	6 <sup>19</sup>
++	Health psychology AND genetics	0	9	104 <sup>20</sup>	10 <sup>21</sup>
++	Clinical psychology AND genetics AND effectiveness	1 <sup>22</sup> / 8 <sup>23</sup>	0	1	10 <sup>24</sup>
++	Clinical psychology AND genetics	2 <sup>25</sup>	15 <sup>26</sup>	120 <sup>27</sup>	13 <sup>28</sup>
++	Genetic counselling AND genetics AND effectiveness	129 / 8 <sup>30</sup>	88 <sup>31</sup> / 88	7 / 5	19 <sup>32</sup> / 15 <sup>33</sup>
++	Genetic counselling AND genetics	197 / 337	9929 <sup>34</sup> / 9929	30 / 366 (10)	31 <sup>35</sup> / 54 <sup>36</sup>

<sup>18</sup> Relevant and checked the 'related articles'.

<sup>19</sup> Six hits in The Cochrane Database of Systematic Reviews in the sub-databases of: 1) Complete reviews : 4 hits, 1 relevant: Decision aids for people facing health treatment or screening decisions, O'Conner et al. [2003]; 2) Protocols: 2 hits, both relevant: a) Influence of comprehensive versus partial information on consumers' screening choices, Broclair et al. [2003]; b) Interventions for improving understanding and minimising the psychological impact of screening, Doust et al. [2003].

<sup>20</sup> Taking the first 10 relevant hits into account.

<sup>21</sup> Five hits from which the first three are comparable with the search results from Health psychology AND genetics AND effectiveness. From the Database of Abstracts: 1 relevant: Psychological consequences of predictive genetic testing: a systematic review (structured abstract), Broadstock et al. [2000]. Original article in European Journal of Human Genetics, 2000, 8:(10): 731-738. From the The Cochrane Central Register of Controlled Trials: 1 relevant hit: A randomized trial of breast cancer risk counseling: interacting effects of counseling, educational level, and coping style, Lerman et al. [1996]. Original article in Health Psychology, 1996, 15(2): 75-83.

<sup>22</sup> Relevant and searched-for articles in which this article is cited.

<sup>23</sup> There is a clear difference between genetic counselling and genetic counseling.

<sup>24</sup> One relevant article which is the same one found by Health psychology AND genetics AND effectiveness.

<sup>25</sup> Both are relevant. One is the same as mentioned in note 6.

<sup>26</sup> Not relevant.

<sup>27</sup> There are only 5 relevant hits. Many articles are about schizophrenia and genetics and eating disorders and genetics.

<sup>28</sup> One relevant article. The same as in Health psychology AND genetics AND effectiveness. A search using these keywords in the Cochrane Central Register of Controlled Trials brought up mostly articles on weight loss and schizophrenia.

<sup>29</sup> Looked for articles in which this article was cited.

<sup>30</sup> Read these 8 hits in case all ++ articles were of interest.

<sup>31</sup> Looked for most relevant and read these articles..

<sup>32</sup> One relevant article in the Cochrane Database of Systematic Reviews, in Protocols: Methods of providing information to women making a decision about genetic screening and prophylactic surgery, Oates-Whitehead et al. [2002]. In the Cochrane sub-database of NHS Economic Evaluation Database, articles on Critically appraised economic evaluation can be found, but most of the time they are about cost effectiveness: Relevant to the field of biomedical science communication but not to the aim of this thesis. In this thesis we are looking for a theoretical foundation for biomedical science communication. Changing this theoretical foundation to one based on cost effectiveness might be possible, but it is beyond the scope of this thesis.

<sup>33</sup> In the Cochrane Database of Systematic Reviews, in Protocols , 1 relevant article that we also found with Health psychology AND genetics AND effectiveness. In the Health Technology Assessment Database 3 relevant hits: 1) Genetic carrier testing for cystic fibrosis original article is titled: Genetic carrier testing for cystic fibrosis. Bloomington, MN: Institute for Clinical Systems Improvement (ICS), 2003; 2) Genetic testing for hereditary nonpolyposis colorectal cancer (HNPCC). Original article together as hit 1; 3) Predictive genetic testing for breast and prostate cancer. Original article cited as: Noorani HZ, McGahan I. Predictive genetic testing for breast and prostate cancer. Ottawa: Canadian Coordinating Office for Health Technology Assessment, 1999, 85.

<sup>34</sup> We chose most recent and relevant articles

<sup>35</sup> In the Cochrane Database of Systematic Reviews, in Protocols, 2 relevant articles: 1) same as with Genetic counselling AND genetics AND effectiveness: 2) Genetic service delivery for individuals at risk of familial breast cancer. Iredale R et al. (2002). In Database of Abstracts of Reviews of Effects, 1 relevant article: What is the impact of genetic counselling in women at increased risk of developing hereditary breast cancer? A meta-analytic review (provisional record), Meiser B and Halliday J.L. Original article in Social Studies and Medicine, 2002, 54(10):1463-1470. In The Cochrane Central Register of Controlled Trials, 8 hits from which 2 are relevant: 1) A randomized trial of specialist genetic assessment: psychological impact on women at different levels of familial breast cancer risk, Brain K et al. (2002). Original article in British Journal of Cancer, 2002, 86(2):233-238; 2) A model protocol evaluating the introduction of genetic assessment for women with a family history of breast cancer. Gray et al. (2000). Original article in Journal of Medical Genetics, 2000, 37(3):192-196.

<sup>36</sup> Articles are in strong accordance with articles found with the key term genetic counselling. In The Cochrane Central Register of Controlled Trials, 28 hits from which 5 were relevant: 1) Education about genetic testing for breast cancer susceptibility: patient preferences for a computer program or genetic counselor. Green et al. 2001. Original article in American Journal of Medical Genetics, 2001, 103(1):24-31. 2) An interactive computer program can effectively educate patients about genetic testing for breast cancer susceptibility. Green et al. (2001). Original article in American Journal of Medical Genetics, 2001, 103 (1):16-23. 3) An experimental study of influences on the perceived likelihood of seeking genetic testing: "nondirectiveness" may be misleading. Salkovskis PM et al. (1999). Original article in Journal of Psychosomatic Research, 1999, 47(5):439-447. 4) Family history of breast cancer: what do women understand and recall about their genetic risk? [comment]. Watson M et al. (1998). Original article in Journal of Medical Genetics, 1998, 35(9):731-738. 5) Efficacy of and patient preference for three counselling formats. Young et al. (1986). Original article in Journal of Craniofacial Genetics & Developmental Biology, 1986, 6(1):3-14. In the Cochrane Database of Systematic Reviews, in Complete Reviews 4 hits from which 1 relevant: Personalised risk communication for informed decision making about entering screening programs. Edwards et al. (2002). In Controlled Trials, 42 hits from which 1 relevant: Psychosocial and educational outcomes associated with home- and clinic-based pretest education and cystic fibrosis carrier testing among a population of at-risk relatives. Chevront B et al. (1998). Original article in: American Journal of Medical Genetics, 1998, 75(5):461-468. In Health Technology Assessment Database, 4 hits from which 1 relevant: same as for the term Genetic counselling AND genetics AND effectiveness.

++	Cognitive psychology AND genetics AND effectiveness	0	0	0	0
++	Cognitive psychology AND genetics	4	0	137 <sup>37</sup>	0
+	Medical psychology	143 <sup>38</sup>	316	4884 <sup>39</sup>	260 <sup>40</sup>
+	Behavioral psychology	71	1592	665	6 <sup>41</sup>
+	Health psychology	657	538	7367	320
+	Clinical psychology	1085	2017	33.058	1896
+	Genetic counselling	1332 / 3066	10.684 / 10.684	60 <sup>42</sup> / 791	49 <sup>43</sup> / 76
+	Cognitive psychology	140	307	7575	40 <sup>44</sup>

From the search we can see that there is not much highly relevant literature (+++) to be found. In the area of less relevant (++) literature, however, there are numerous hits. From the articles found we selected about 150 articles on face value (title) and from this search we analysed 40 (for relevance and validity). The results of this analysis can be found on the thesis' website ([www.bscca.tudelft.nl](http://www.bscca.tudelft.nl)). The next section discusses the consolidated literature we read.

### 4.3 Medical psychology: the consolidated literature

Since 1970 the field of medical psychology has expanded. Gentry (1984) indicates the reasons why: a) failure of the biomedical model to adequately explain health and illness; b) increased concern with quality of life and prevention of illness; c) a shift of focus from infectious disease to chronic disease as the major challenge in medicine, with a concomitant recognition of the influence of lifestyle factors; d) increased maturity of research in the behavioural sciences, including the application of learning theories to disease aetiology and illness behaviour; and e) increased cost of health care and the search for alternatives to the traditional health care system. The first two are likely to be the two main drivers for a lay audience within the field of medical psychology.

In medical psychology the difference between 'healthy' and 'unhealthy' is constructed on three levels: the patient, the audience, the doctor and the society (Kaptein and Smit, 1995). This could be depicted as shown in Rothschild's triangle (see Fig. 4.1). In the earlier literature it is usually the doctor who analyses the patient. Nowadays the patient is central to the medical psychological problem and in the media, the health story is told from the perspective of the patient. Society is represented in the literature as socio-cultural meanings of

37 Many of the articles are on intelligence and genetics.

38 Only the most recent and most relevant articles were selected.

39 In the articles a broad scope of diseases are discussed: specificity is too low.

40 Not specific. Because of the time it would take to check, not all of the articles are checked on face value.

41 In The Cochrane Central Register of Controlled Trials, 6 hits from which 1 relevant. Psychological intervention in patients with poor compliance. Weinstein R et al. [1996]. Original article in *Journal of Clinical Periodontology*, 1996, 23;(3Pt 2):283-288.

42 The relevant articles were also found with the key terms counselling and genetics.

43 In strong accordance with Genetic counselling AND genetics.

44 Not relevant.

being healthy or being unhealthy (Kaptein and Smit, 1995). As we have seen in chapters 1 and 3, the move in science and health communication from a science and scientist orientation toward a more public orientation resembles this development in medical psychology.

The same idea of the triangle, used in medical psychology, can also be used in the domain of biomedical science communication. The angles of the triangle are then occupied by the public, by society and by the biomedical scientist (see Fig. 4.1). By using the term 'biomedical scientist' (or even 'biomedical science communication professional') the triangle cannot remain regular, as in the domain of medical psychology. As a result of the differences in the perceived importance of the communication between doctor and patient and lay audience and scientist, the triangle for biomedical science communication needs to be enlarged between biomedical scientist and lay audience. In chapter 1 we described biomedical science communication as public communication on developments in biomedical research that is aimed at a target group at a non-personal level. This means that the contact between scientist and lay audience for example, is mediated by the media. The scientist or science communicator does not have the same emotional role that the doctor has or should have. Of course, when it comes to the field of biomedical science communication on predictive DNA diagnostics, and a non-patient becomes a not-yet patient or even an actual patient (Nelis, 1998), the distance becomes smaller. With this shift biomedical science communication will be increasingly placed in a medical psychology context. We must take this distance into account when using concepts, theories, constructs and variables on emotion, cognition and behaviour from medical psychology to biomedical science communication (see Fig. 4.1).

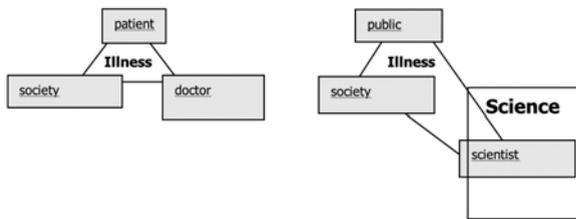


Fig. 4.1: In the left triangle 'Illness' is central and the distance between patient and medical specialist is smaller than in the right triangle, in which 'science' is central. The distance between society and the doctor and society and the scientist is only slightly different.

In the following paragraphs it will become clear how this distance between patient and doctor in biomedical science communication is transformed into a so-called emotional distance. Personal stories from interviews with individuals reveal that health problems are much more important to individuals than not being knowledgeable on a technical or scientific subject (Marteau and Richards, 2000).

Within the field of genetics there is a need for the development of medical psychological knowledge. One of the main reasons for the need is to develop knowledge about human behaviour when, for example, predictive testing is at issue. Little is predictable whereas much is unpredictable, e.g. not known (Marteau and Richards, 2000). Research focuses on the psycho-social consequences of predictive DNA testing as we have already seen in chapter 1. Marteau and Richards write:

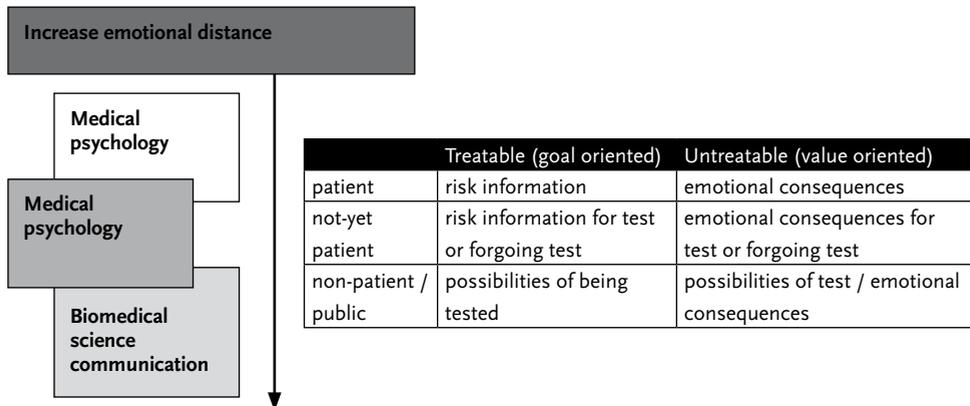
*An example here is the very variable interest that has been shown by families for testing different genetic conditions. For conditions that are incurable, such as Huntington's disease, it would seem that most do not wish to know their future fate. Rather than wanting to know in order to plan their lives, as many suggested would be a usual reaction, it would seem that most decide to preserve uncertainty and so the possibility of hope. But for other conditions, such as hereditary breast cancer, where there are strategies that may well be effective in reducing risk, there seems to be much more interest in testing.*

In the communication process between patient and doctor, the focus of the conversation is situated between cognition, behaviour, emotion and treatment options. Obviously this is not a linear process. Moreover there is a difference in this non-linearity between testing positive for Huntington’s disease and being tested for diabetes, as cited above. For the latter, communication about risk level might be a possibility. Both communication situations require a different strategy.

There may be a difference in the way the doctor and patient encounter the communication process. Physicians mainly use goal-oriented rationality and patients mainly use value-oriented rationality (Van Kleffens, 2005). This difference may result - as Kleffens has found - in patients experiencing that they are not really free to make their own decisions, leading to frustration and miscommunication.

As we have seen in chapters 1 and 3, biomedical science communication has multiple purposes and is multileveled as well. Therefore, the differences between seriousness and reversibility of disease and the differences of being goal oriented and value oriented may be of importance to biomedical science communication on predictive DNA diagnostics. However, due to differences in emotional distance, translation is theoretically difficult. In Table 4.3 the differences are put together.

Table 4.3: Targets and target groups of medical psychology together with biomedical science communication.



We propose the following index for the use of modalities, which instantly shows the relation between the modalities. When increasing emotional distance the sequence should be: 1) medical psychology; 2) health communication; 3) biomedical science communication. Moreover, notions and cultural themes (described in chapter 1 and 3) are all part of the same system. This interdependence gives way to the urgency of the structural planning of a biomedical science communication process.

In summary, there is an emotional distance between communication on biomedical science and communication on one’s health. This emotional distance makes the translation of theories from medical psychology to biomedical science communication more difficult. Moreover, there are big differences in types of disease and their impact on the individual. This factor, together with notions and cultural themes of the lay audience, makes communication even more complex and makes the differences between communication with a patient and non-patient clear. In the following section we describe the aims and levels of medical psychology that we found in the consolidated literature, as relevant to this thesis.

### Theories of medical psychology

One of the first findings described and discussed here is the fact that some theories described in chapter 3 can also be found in the domain of medical psychology. According to Fishbein et al. (2001) and Baum et al. (2001),

there are only three important theories on behaviour and behavioural change concerning medical issues:

- 1 health belief model (an individual needs to feel the urgency of the medical problem. Moreover, there is a balance between an action taken or an action that is not taken, due to barriers);
- 2 social cognitive theory (the start and the completion of action depend on the individual's self-efficacy);
- 3 theory of reasoned action (whether an individual takes action depends on the individual's intention which in turn depends on attitude, perception of social context, and self-efficacy).

The consolidated literature shows that these most important theories are not especially attached to one field of medical psychology. In addition to medical psychology, terms like 'genetic counselling' and 'health psychology' are used.

## Genetic counselling

Sorenson et al. (1981) and Evers Kieboom (1987) state that there are numerous definitions of genetic counselling. These definitions differ in their descriptions of the goals for genetic counselling as well as in their processes. Sorenson et al. describe two elements in these definitions which could be considered as common sense genetic counselling:

*1: virtually all definitions refer to the goal of client education. While there is some variation in professional views as to what clients are to be educated about, there is considerable agreement that counselling is basically an educative undertaking.*

*2: The second frequently cited objective is to provide counsel to clients about their problems and situation. By counseling, these providers mean more than simply client education. They mean helping clients think through their situation, so they are able to use the information they are given in a constructive fashion.*

Michie and Marteau (2000) write that despite the many articles written on the issue of genetic counselling, there are only a few empirical studies from general or controlled trials. Therefore, not much is known about how to improve the process and outcome of genetic counselling. According to Michie and Marteau, one of the main problems with regard to formulating a proper definition lies in the area of ethical constraints.

*Broadly speaking, genetic counselling is a communication process aimed at helping people with problems associated with genetic disorders or the risk of these in their family. Its most uncontroversial goal is to improve the quality of life of the families that seek such help. (Michie and Marteau, 2000)*

Could persuasion, for example, be unethical in the practice of genetic counselling? Antley (1979, in Shiloh, 2000) writes:

*[...] It is more reasonable to expect genetic counsellors to take the role of 'facilitator of counselees' decision-making' [...] This requires that a genetic counsellor acquires expertise in decision-making theories and counselling techniques aimed at helping clients reach a decision wisely, rather than reach a wise decision [...].*

This description implies that knowledge is not the content genetic counsellors need. They help the patient to make a choice and facilitate that choice. This facilitating role could also be an option for biomedical science communication. When we look at health psychology though there are authors who also stress the educational role of health psychology (Sorenson et al., 1981). So both an affectional and a factional way of health psychology are useful. It therefore has multiple levels and is multipurposed. Sorenson et al. write:

*[...] There is virtually universal agreement that one of the essential tasks of genetic counseling is client education. Subsequent to counseling, clients should know more of the medical and genetic facts of their particular problem than they did when they first sought this specialized service. Such information can be useful to clients in a number of ways, but a basic goal of counseling is to enable clients to make informed family and reproductive decisions.*

Emery (1984) writes about genetic counselling:

*Genetic counselling is a process of communication between the genetic counsellor and those who seek genetic counselling. The information to be communicated falls roughly in two main areas. Firstly, information about the nature of the disorder: its severity and prognosis and whether or not there is an effective therapy, what the genetic mechanism is that caused the disease and what are the risks of its occurring in relatives. Secondly, information on the available options open to a couple who are found to be at risk of transmitting a genetic disorder. This latter may include discussions of methods of contraception, adoption, prenatal diagnosis and abortion and artificial insemination by donor (AID). [...] The effective communicator in this field is the one who not only recognizes these problems, but can empathize and help a couple transcend them.*

Regarding to the processes described above, Fraser (1974) describes the different steps in the process of genetic counselling:

*[...] A communication process which deals with the human problems associated with the occurrence, or risk of occurrence, of a genetic disorder in the family. This process involves an attempt by one or more appropriately trained persons to help the individual or the family to:*

- *comprehend the medical facts, including the diagnosis, the probable course of the disorder and the available management;*
- *appreciate the way heredity contributes to the disorder and the risk of recurrence in specified relatives;*
- *understand the options for dealing with the risk of recurrence;*
- *choose the course of action which seems appropriate to them in view of their risk and their family goals and act in accordance with that decision;*
- *make the best possible adjustment to the disorder in an affected family member and/or to the risk of recurrence of that disorder.*

In the mass communication setting of biomedical science communication some of the above-named terms, such as 'comprehend', 'appreciate' and 'understand' are useful. These terms could occur in a different context, which means that on a mass communication level other elements in the field of medical psychology are important. But the same phases still exist and depend on whether communication is with a patient or a non-patient.

### *Medical psychology/health psychology*

Belar and Deardorff (1995) find 'medical psychology' a confusing term. They write:

*[...] Another term, medical psychology, can be confusing in that it has at least three well-accepted definitions and it conveys a narrowness of focus (e.g. it excludes psychologists practicing primarily with dental populations). These definitions include the following: a) the practice of psychology in the medical school establishment; b) the study of psychological factors related to any and all aspects of physical health, illness and its treatment at the individual groups and systems levels (Asken, 1979); c) traditional psychiatry in Great Britain.*

To other authors, health psychology is a more comprehensive domain. Health psychology is a multidisciplinary field, in which theoretical and practical development are central (Matarazzo, 1982; Belar and Deardorff, 1995). This makes health psychology comparable to the domain of medical psychology and, hopefully, to the domain of biomedical science communication. Matarazzo writes:

*Health psychology is the aggregate of the specific educational, scientific and professional contributions of the discipline of psychology to the promotion and maintenance of health, the prevention and treatment of illness, the identification of aetologic and diagnostic correlates of health, illness, and related dysfunction and the analysis and improvement of the health care system and health policy formation. (Matarazzo, 1982)*

*Health psychology is an interdisciplinary field concerned with the application of psychological knowledge and techniques to health, illness and health care.  
(Matarazzo, 1982, in Evers-Kieboom, 1987)*

Marks et al. (2000) looked at health psychology from a more theoretical point of view. The multidisciplinary character of health psychology is attached to the many scientific fields which form the basis of health psychology and most importantly not in the combination of a professionalized practice. They write:

*The study of health psychology is linked to branches of many health and social sciences including medical anthropology, medical sociology, medical ethics, social policy, health economics, epidemiology, medicine, surgery and dentistry. Health psychology overlaps extensively with two highly related fields: behavioural health, concerned with preventing illness and enhancing health, and behavioural medicine, concerned with integrating the behavioural and medical sciences. (Marks et al., 2000)*

As it is in fields of communication, the context of the process is important. (Marks et al, 2000) say that initially psychology and the body are studied and secondarily psychology and social representations are studied.

*The study of health psychology is concerned with developing a better understanding of the psyche and the body and the relationship between the two.*

*The second epistemology in the human science tradition is represented by research concerning discourse, narrative and social representations. People's accounts of health and illness are an interesting and illuminating topic of study in their own right. Much of the research on health and illness narratives has been influenced by social constructionism.*

Even education plays a role within health psychology, as Matarazzo defines it (1982):

*Health psychology is the aggregate of the specific educational, scientific and professional contributions of the discipline of psychology to the promotion and maintenance of health, the prevention and treatment of illness, the identification of aetologic and diagnostic correlates of health, illness, and related dysfunction and the analysis and improvement of the health care system and health policy formation.*

This describes the multidisciplinary character of health psychology. Should biomedical science communication be seen in the same way? A multidisciplinary way of thinking in a biomedical context?

In conclusion, in the following sections the comparison is focused on health psychology. We will discuss the structure, process, outcome and context of processes in health psychology.

## 4.4 Structure

Within the element of structure we focus on the relationship between the genetic counsellor and the patient. According to Harper (2000) people who have a specialist genetic service get better service than they do from less specialized services. This can be measured in:

- 1 the availability of time;
- 2 objective information and the ability to provide information about alternatives;
- 3 an ambiance that is less medical;
- 4 the possibility for patients to return to receive more information or further explanation.

This type of service could also be a success in biomedical science communication. Even the *idea* of the availability of time could enhance the effect of biomedical science communication. Of course one cannot force the target group to ask to take time to read a brochure. But to create an opportunity might work. For example, making a television commercial in which nothing is said and nothing happens, with only a voiceover message: *'take time to think about having cancer....'*

*Objective information* and the ability to provide information about alternatives come close to the ethical context of biomedical science communication. In the case of mass communication, when there is no possibility of direct feedback, one should be careful with a message that is not objective and explicates a particular perspective.

The biomedical science communication professional should carefully choose the ambiance for communicating with his audience. In what type of place can information on predictive DNA testing best be given? In the pub? The pub is not normally a place in which health springs to mind. In the hospital? In what is, for some people, a frightening environment? Thinking about a good ambiance is useful for the practice of biomedical science communication.

*The ability to ask questions:* Is this possible in a mass communication setting of biomedical science communication? A website where people can find answers to their questions is already commonly used, and it is a necessary element in an effective biomedical science communication process.

In conclusion, time, objective information and alternatives, the right ambiance to receive information and the possibility to react, are all important ingredients for the structure of biomedical science communication. This is also stated by Sorenson et al. (1981) and by Harper (2000). Although these elements seem to be widely known, in practice they are seldom taken into account in a coherent way. In the following section the element of process is discussed.

## 4.5 Process

In chapter 3 the section on process is the most elaborate. In health psychology literature process also receives a great deal of attention. The health psychology process consists of four phases (Prochaska and Di Clemente, 1984, in Maes 1995).

- 1 confrontation with the genetic disease. Becoming a patient or a not-yet patient in the case of predictive DNA testing;
- 2 phase of motivation. In this phase a distinction can also be made between a patient and a not-yet patient. Even the possibility of the irreversibility of the disease plays a role in this phase;
- 3 phase of initial behaviour (Maes, 1995). Making a decision;
- 4 phase of consolidation of behaviour.

These phases are strongly related. Maes writes:

*Most of the time campaigns in this domain are mass communication campaigns addressing for example weight loss and the benefits of exercise [...] If nothing happens in phase 2 nothing can be expected from phase 3. (Maes, 1995).*

These phases are comparable with the phases described in chapter 1 and chapter 3. Health psychology differs in its explicit phases of motivation and consolidated behaviour. In the following sections we will elaborate on the health psychology theories and models belonging to the four phases described above.

### 4.5.1 Confrontation

From the moment a person is confronted with a genetic disease he learns about the disorder and his personal risk, and he may be challenged to think about predictive testing and diagnosis. These thoughts, in combination with many other considerations concerning one's own context, lead to types of reactions that can be classed into three major groups:

- 1 *distancers/deniers*: individuals belonging to this group deny that they have a genetic predisposition or they deny that this eventual predisposition will lead to a clinical phase. *'I don't have asthma, just bad lungs'*;
- 2 *accepters*: individuals belonging to this group accept their predisposition or diagnosis, but in a special way. [...] They (patients) emphasised they were not stereotypical asthmatic people but rather more like certain individuals who were able to achieve despite having asthma, e.g. certain athletes [...].
- 3 *pragmatists*: individuals who accept they have a genetic predisposition and accept the diagnosis, but who act with caution when they are amongst others. *'I wouldn't use the inhaler in front of the management.'*

In the mass communication context of biomedical science communication for predictive DNA testing, how do these kinds of reactions fit into the categories of non patient, not-yet patient and patient? See Table 4.4.

Table 4.4: Groups of the public and their reactions to predictive DNA testing.

	distancer	accepter	pragmatist
Non-patient	'This knowledge is not for me.'	'Handy to know.'	'Maybe I will need this information in the future. I will remember then.'
not-yet patient	'We will see.'	'I have to cope with the idea.'	'I will use it when I need it.'
Patient	'My uncle was 100 years old when he died. He never took any medication or stuck to a healthy diet.'	'No I have to cope with it. But even Lance Armstrong has overcome his disease.'	'Yes I know, but I will wait till I know how serious it is.'

According to the table, there are nine different groups of reactions the public can have concerning the categories mentioned above. In chapter 3 we made some remarks in the context of the health belief model on perceived risk and the seriousness of the genetic disease. Vlek (1987, in Evers and Kieboom, 1986) differentiates so-called *operational levels for measuring perceived risk* and describes three levels on which behaviour can be based:

- 1 *Physiological (P)*: 'arousal' or anxiety as expressed in autonomic nervous system activities;
- 2 *Behavioural (B)*: autokinetic patterns interpretable as: adopting a defensive strategy, being frightened, turning or fleeing away from the risky situation; denying the risk and becoming apathetic;
- 3 *Cognitive (C)*: verbalized descriptions of and/or attitudes towards critical event or activity; evaluative comparisons of alternative courses of action; judgmental consequence assessments, etc.

These three levels occur in different ways in all cells of Table 4.4. To know how these operational levels for measuring perceived risk will occur the different drivers for perceived risk are needed.

Vlek (1987) and Marks (2000) differentiate between:

- 1 potential degree of harm or lethality;
- 2 controllability through safety and/or rescue measures (Marks et al., 2000: Controllability: the way the individual can cope with or control the disease);
- 3 number of people simultaneously exposed;
- 4 familiarity of consequences and effects;
- 5 degree of voluntariness of exposure. Marks et al (2000) add: Stability, the way the disease is stable or changeable. Bishop (1987) adds two basic conditions: seriousness and contagiousness. Bishop thinks people need these two conditions to form a personal opinion of the symptoms corresponding to diseases;
- 6 Marks et al. (2000) locus of control (internal/external). We described this driver in chapter 3.
- 7 Marks (2000 from Bishop, 1987): location in the body;
- 8 Marks (2000, from Bishop, 1987): psychological cause;
- 9 Marks (2000, from Bishop, 1987): degree of activity disruption.

The above levels and drivers can be connected to the individual's need for knowledge. From a needs assessment and evaluation study Sorenson et al. (1981) composed a list of the most commonly occurring questions and concerns regarding genetics and predictive testing.

Genetic-Medical Topics:

- 1 aetiology of disorder/disease;
- 2 chance of having an affected child;
- 3 medical treatment of disorder/disease;
- 4 diagnosis of child;
- 5 prenatal diagnosis;
- 6 diagnosis of client;
- 7 prognosis of disorder/disease;
- 8 care for affected child at home;
- 9 diagnosis of other family member;
- 10 medical status of affected child.

Sociomedical topics:

- 1 client's feelings about affected child;
- 2 school or other special programmes;
- 3 financial costs of disorder/disease;
- 4 relationship with other children;
- 5 relationship with spouse.

If we combine the different groups of reactions with the levels of perceived risk and with the drivers described above we are able to construct Fig. 4.2. As one can see there are many variations in the ways an individual might behave.

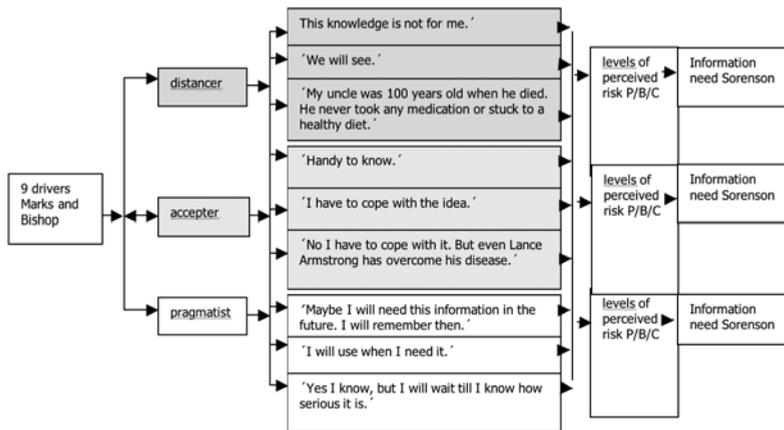


Fig. 4.2: Systematic overview of how disease, seriousness of prognosis and behaviour are connected. The flow chart starts on the left with the nine drivers for behaviour, which lead to being a distancer, an accepter or a pragmatist. Within these different groups there are several levels of perceived risk to detect, which eventually lead to a need for information.

We can conclude from the above that biomedical science communication can expand with different target groups, drivers and levels of perceived risk with respect to the mass communication perspective of non-patient, not-yet patient and patient. But most of all the elements of the confrontation phase lead to a phase of interest in which all the factors (more than 1000!) are combined into an emotion felt by the individual, which in turn may lead to a motivation to either cope or not to cope with the genetic disease. The next section therefore deals with motivation.

### 4.5.2 Motivation

One of the main variables of motivation is the perceived seriousness of the disease. For example if one decides to have children the seriousness of predictive testing becomes more immediate. Kessler (1990, in Michie and Marteau, 2000) writes:

*[...] criticised the health belief model as a model for genetic counselling, because it assumes that risk perception motivates preventive behaviour. For many counsellors, argued, evaluation of a risk is shaped by prior reproductive decisions, not vice versa.*

If we take this observation to the field of biomedical science communication the seriousness of a disease depends on the emotional distance one has to the disease. This distance can occur on the level of the: 1) individual; 2) family and friends; 3) community or society. And in addition, on the level of the non-patient, the not-yet-patient, and the patient. The emotional distance is much smaller for a patient who has to deal with the disease on an individual level than for a non-patient for whom the distance is a subject that concerns society rather than him personally.

To get a grip on the many parameters we have already gathered from the consolidated literature we have tried to put them into the shape of a metric algorithm, as is often used in econometrics. In the case of our subject we could call this *communicametrics* (Van Der Sanden and Meijman, 2007). The level of motivation (M) depends on the emotional distance (E), which depends on being a patient or not ( $P^{1,2,3}$ ) and if the disease is serious (S) or not and irreversible (R) or not.

### (1) $(R^{+/-} + S^{+/-})P^{1,2,3} \Rightarrow E \Rightarrow M$

In the area of biomedical science communication the different target groups can be segmented into different smaller groups which probably need varying approaches, depending on their (possible) level of motivation. The lay audience, for example, which is usually comprised of non-patients, is less motivated to listen or to learn about a disease that is not serious and is reversible due, to its large emotional distance from the disease. So emotional distance and its accompanying variables deepens and broadens biomedical science communication in which the factors described above play a role.

#### 4.5.3 Initial behavioural phase and decision

The next question is how to manage the number of variables in an effective way. According to Maes (1995), in psychology there are many theories to help develop effective biomedical science communication, such as: conditioning, behaviour modification principles, cognitive modelling, stress theories, social learning theories and self-control theories. Owen and Lee (1985), tried to develop an instrument for structuring all of these theories. This instrument also provides insight into psychological interventions, including the following rules of thumb:

- 1 change is not an event but a process;
- 2 individuals normally take the route of least resistance;
- 3 observational behaviour is steered by its underlying mechanisms;
- 4 behaviour is the result of an interaction between an individual and his environment.

In the domain of biomedical science communication these rules or premises are also useful. Change is not an event but a process is an important notion. This is of course already part of the analysis in this thesis, but in practice communication is usually seen as an event: a one-time exposure of a target audience to the subject. The biomedical science communication process on predictive DNA diagnostics, however, should be seen as a process. The target group should be followed in time and communication goals can change in time as well. The notion that individuals take the route of least resistance also plays a part in biomedical science communication. It takes time, energy and attention to read or to listen to information, or to be confronted in another way with predictive DNA diagnostics. Therefore, as said before, motivation is an important parameter which is underdeveloped in its variables and meaning for the biomedical science communication process. Knowledge of the underlying mechanisms and factors of behaviour are important in developing an effective process for biomedical science communication. Maes (1995) says:

*Starting a communication process without knowing how to deal with the behavioural aspects of the respondent is like giving a medicine without diagnosis.*

The behaviour, according to rule of thumb number four, can be analysed on the basis of its four control mechanisms: 1) social control; 2) emotional or stress control; 3) symptom control; 4) cognitive control (Maes and Scholten, 1989). In biomedical science communication therefore it is important to give the target group the instruments or knowledge to deal with these levels of control. For example biomedical science communication on predictive DNA diagnostics should not lead to emotional stress or loss of social control. In an effective biomedical science communication process these four rules are continuously present, in a varying mix. This is what makes the process multileveled and multipurposed. The biomedical science communication professional should keep this in mind at all times. These four rules could be used as a checklist. Moreover, the process should aim at the variables of behaviour that steer the behaviour on a deep level, rather than the variables that cause superficial changes. Therefore the basic notions of chapter 1 and the determinants of behaviour in chapter 3 are important as a background for understanding social control, emotional or stress control, etc. All this deepens and broadens the biomedical science communication process and can be seen in the process of decision making.

Decision making on predictive testing is well documented in the consolidated literature. Individuals try to control themselves and their environment by taking decisions. In health psychology and medical psychology the compliance with therapy as a result of making decisions has been studied. The decision making process can for the same reason be important to the process of biomedical science communication. Do I already need to search for information on predictive DNA diagnostics?

In the case of predictive testing, most of the time this process of making decisions is studied when people are thinking about having children, but now that there are more predictive tests available some attention is also being paid to decision making in non-reproductive situations (Shiloh, 2000). According to Shiloh - and as mentioned in the sections above - the drivers for making a decision are based on: 1) severity; 2) relevance of the genetic disease for the individual, children and friends and family; 3) irreversibility; 4) relation of the genetic disease to one's deepest emotions on the normative values of life.

These four factors in decision making and the four rules of thumb could form an instrument for the biomedical science communication professional to get a grip on the target audience's behaviour. The difficulty is that, as a result, the multiple levels and purposes of the process ensure that the decision making process is not a linear one. *'Yet people rarely follow formal statistical rules in making decisions outside the laboratory'*, as Michie and Marteau (2000) write. According to Michie and Marteau, making decisions is driven much more by *normative decisions* than by rational decisions. These normative decisions are highly adaptive, especially when decisions are made in situations that are changing, uncertain and dynamic.

This process of making normative decisions is also relevant for biomedical science communication. Since the target audience needs to control itself and its social environment, when it fails to oversee the rational information on predictive DNA diagnostics it tends to make a normative choice based on its notions and cultural themes. Non-useful information only makes the process of making decisions more difficult.

In the case of doctor-patient relationships, for example, most patients will leave decisions to the doctor after a diagnosis of cancer (Degner and Sloan, 1992). Only a small number of patients will make these decisions by themselves. Moreover, trust in the doctor will increase when the patient is confronted with making a decision that determines his own future health (Marteau and Anionwu, 1996).

Making a decision consists of 7 different steps, in which the individual has to choose between the occurring options (Michie and Marteau, 2000): 1) recognise; 2) formulate; 3) generate alternatives; 4) seek information; 5) validate and choose; 6) take action; 7) receive feedback. This model can be useful in the domain of biomedical science communication as well. Within the communication process the steps in the model can be used to support the target audience at the right moments when discussing alternatives. The sequence of the different phases in the communication process can be categorised by means of this decision-making model.

In the phase of initial behavioural change there are many phases and steps to take. All these phases and steps need to be seen in light of motivation, as discussed in the previous paragraph. From health psychology we learn that for biomedical science communication there are numerous processes and ways that eventually lead to compliance and consolidated behaviour. The variables of compliance may help to formulate a strategy for biomedical science communication to achieve sustained behavioural change.

#### 4.5.4 Compliance

One of the aspects of the complexity of the doctor-patient relationship is compliance. A great deal of literature about compliance can be found in the health psychology domain. The psychological processes for compliance could be helpful to the process of biomedical science communication as well. From chapter 1 we know that individuals use the information obtained through the communication process in various ways: using information directly, letting information develop or becoming aware of information. For the communication process it is important to decide if compliance with the information search should culminate in one of the three functions of knowledge for the individual, or if there is a need for the sequencing of these three functions. Is the growth of information once in a lifetime or is there a need for a sequencing of phases of information growth over a period of years? If there is compliance of the information-seeking behaviour of the individual the 'chill factor' of making a large effort will probably decrease and this will increase motivation. Should the target audience therefore always be kept informed about predictive testing?

A critical factor in compliance is the severity and visibility of the symptoms of the genetic disease. Severity and visibility steer the way the individual copes with his disease (Marks et al., 2000). However, there is a delicate balance between severity, visibility and compliance. An individual who has to cope with severe symptoms of cancer might be less compliant than a person who has less severe symptoms of cancer (Dogin et al., 1986). On the other hand a disease that is not severe will not lead to compliant behaviour. Obviously there is an optimum of fear arousal, for example, to simulate compliant behaviour. Marks et al. (2000) write that fear of medication could hinder compliance if it is not taken into account in the process of health psychology. They write:

*From the physician's perspective, non-compliance can seem a foolhardy process. However, to the lay person non-compliance can be perceived as a means of reducing a variety of fears.*

There are different fears about medication: 1) fear of side effects; 2) fear of dependency; 3) fear of the medication's reduced effectiveness; 4) fear of a disrupted lifestyle; 5) drugs as a sign of weakness; 6) drugs not fitting with an individual's health beliefs.

For biomedical science communication, fear arousal due to difficulties in, for example, admitting that one needs information could be seen as a lack of self control and a sign of weakness, which in the end leads to a decrease in compliant behaviour. Or perhaps information-seeking behaviour does not fit the lifestyle of the individual. 'I never go to a library. None of my neighbours do.'

To diminish these fears, trust and credibility, as mentioned in chapter 1, are important drivers in the communication process. If trust and credibility could decrease the fear of being considered weak and stupid the emotional distance to the subject might decrease as well. And if, for example, the emotional distance diminishes, compliance information-seeking behaviour will increase. The problem is no longer owned by the sender but is a part of the individual's life.

Marks et al. (2000) bring this idea of compliance back to the health belief model:

Literally dozens of studies have confirmed the association between patients' health beliefs and compliance. In an attempt to bring some order to this plethora of research, some investigators have turned to the popular social cognitive models. Probably the most frequently used such model has been the Health Belief Model.

They mention the following research results:

*[...] the patients perceive their condition to be serious, the more likely they will be to comply with the recommended treatment [...] Glasgow et al. (1997) found that the perceived effectiveness of the treatment was a better predictor of compliance in diabetes than the perceived barriers [...] Social learning theory has also been used with varying degrees of success to explain non-compliance. For example, Tillotson and Smith (1996) found that although internal locus of control predicted compliance with a weight-control programme for patients with diabetes, its importance was small and depended on the degree of social support. In a study of patients with rheumatoid arthritis Beck et al. (1988) found that patients' predictions concerning their compliance (self-efficacy expectations) with treatment predicted actual compliance.*

As we mentioned, fear arousal caused by a lack of knowledge can play a part in the process of biomedical science communication. Which health psychology therapeutic techniques are used to cope with this problem? Marks et al. (2000) state that the following aspects of treatment should be considered when answering this question:

1. too much information endangers compliance. Marks et al. quote Ley (1982): "There have been considerable attempts to improve knowledge by providing the patient with written instructions [...] However, despite this endeavour to increase patients' understanding of treatment, there is limited evidence relating increased knowledge with compliance (Marks et al., 2000);
2. the duration of therapy. Lack of results is a particular threat to compliance;
3. what is the impact of the therapy at the level of social life? An increasing impact means decreasing compliance. Marks et al. Write: [...] patients adjust their medication so as to balance control of symptoms with disruption of their lifestyle [...].

These remarks are important to biomedical science communication on predictive DNA diagnostics. A lot of information has no effect in a best-case scenario, and a negative effect in a worst-case scenario. Such a trend is recognisable in science communication in general and in biomedical science communication in particular. For example, Eurobarometer research has shown that communication about science does not automatically lead to scientific knowledge. During the past decade the level of understanding of scientific knowledge of the European citizen has not improved, even though the number of science communicators has increased.

Another issue we can discern from the list of Marks et al. is the importance of feedback regarding communication on predictive DNA diagnostics. But this feedback is difficult to organise in terms of mass communication. A lay audience's ability to deepen its knowledge, as a follow-up to what they already know, constitutes a different sort of feedback. This form of indirect feedback shows the potential of the audience's knowledge and what one can do once knowledge is obtained. The knowledge then becomes more *tailor-made* to the individual.

Interpersonal aspects are another factor that can be derived from the consolidated literature. Marks et al. differentiate between a patient-centred relationship and the authoritative doctor-patient relationship. Patients prefer the patient-centred relationship. DiNicola and DiMateo (1982, quoted by Marks et al.) write:

*Patients are more compliant if their physician is warm, caring, friendly and interested.* A difference between the two parties is that the doctor normally begins communication from the basis of the medical problem and the possibilities for medical treatment, whereas the patient begins communication from the basis of how to cope with the problem. This difference is likely to lead to miscommunication and misunderstanding. Also for biomedical science communication on predictive DNA diagnostics it is important that the target audience's feelings are well understood. Also, the social and organisational environment of the target group is of importance (Marks et al., 2000).

In summary, this section has described new process elements that are of importance to the process of biomedical science communication on predictive DNA diagnostics. The seriousness of the genetic disease and individual motivation are, for example, important elements that determine the emotional distance between the audience and the medical problem. There is less emotional distance from medical problems than there is from technical, natural and social science issues, such as climate change. The importance of feedback, even in mass communication, has become clear. All of these could be points of reference for the measurement of patient or target group satisfaction, also in biomedical science communication. It is important to know that the target audience is an audience which, on average, does not normally ask questions. A website that stimulates people to ask questions could be helpful in this case.

## 4.6 Outcome

As we know from the process section it is quite possible that doctor and patient do not communicate effectively as a result of miscommunication about a medical problem and its social-psychological factors. This miscommunication can lead to patient dissatisfaction. The patient's expectations can be studied by the elements of effect satisfaction, empowerment, risk perception, and process satisfaction. These elements are also important to the process of biomedical science communication on predictive DNA diagnostics.

### *Satisfaction*

Patient satisfaction is seen as an important point of reference for successful communication. Also for biomedical science communication satisfaction could be an important means by which to measure the outcome of the communication process.

The level of patient satisfaction depends on the patient's personality (Waitzkin, 1985; Street, 1991, quoted by Marks et al., 2000). The type of patient can be determined by his communicative style, in which asking questions, affective expressions and expressing opinions are important elements. Video recordings of dialogues between patients and medical doctors registered the following elements of verbal behaviour: 1) physician giving information; 2) physician building a partnership; 3) patient expressing an opinion; 4) patient's affective expressions; 5) patient asking questions.

This could also be a criterion for measuring the outcome of the process of biomedical science communication on predictive DNA diagnostics - not by asking questions but by measuring behaviour. Compliance could also be a measure of patient satisfaction (Ley, 1982, quoted by Marks et al., 2000).

In biomedical science communication, beginning the communication process by making it clear to the target audience that questions should be asked is probably effective. Asking questions is a measure of self-efficacy. Once the target audience is accustomed to the idea of asking questions they are likely to search for information by themselves in order to answer their own questions. In an initial phase of the communication process asking questions could be central to sustaining compliant behaviour. This could eventually lead to the empowerment of the target audience.

## Empowerment

Empowerment (see also chapter 1) is more than simply asking questions. Empowerment creates a sustained emotional basis from which an individual can form an opinion, and be proactive (Marks et al., 2000). The term 'empowerment' was first used by health communication professionals. Marks et al. write:

*The focus of this approach is the enhancement of the strengths and potential of the patient. Through dialogue the health professional seeks to understand the needs of the patient. [...] the aim of patient education within this model is to 'blur' the boundaries between professional-as-teacher and patient-as-learner.*

## Risk perception

The level of risk perception can be a measure of the outcome of the biomedical science communication process. According to Michie and Marteau (2000) risk perception consists of two parameters: 1) probability of an outcome; 2) perception of that outcome. These parameters are influenced by the properties of the risk and the presentation of the risk. Michie and Marteau write:

*In genetic counselling, the primary focus of interest has been communication of probabilistic information, to the neglect of information about the actual condition. The risk of occurrence or recurrence is not the most common reason given by clients for attending genetic counseling. This may explain why 54% of clients are not able to report the risk they have just been given in a counselling session (Sorenson et al., 1981).*

In the doctor-patient conversation the subject of risk is a difficult issue. When it comes to public communication on probabilities of outcomes and the perception of those outcomes the difficulty becomes more differentiated. A non-patient, for example, is probably not eager to hear a 'yes' or 'no' answer. This group can probably cope with probability and their perception of the outcome of a predictive test since for them it is not a life-threatening situation. A not-yet patient comes closer to the communication difficulties explained in the quote from Sorenson et al. So emotional distance and comprehensiveness of risk are related positively in public communication on predictive testing.

## Process satisfaction

The difference between goal satisfaction and process satisfaction is important for understanding the difficulties of the process. One could be very satisfied by the process unless the outcome of the process is not the outcome predicted. For example: '*I was pleased by the doctor's attention, even if I had a hard time understanding his message, the attention was warm hearted*'. So process satisfaction should not be neglected in the biomedical science communication process on predictive DNA testing.

For goal satisfaction Belar and Deardorff (1995) describe the questions a doctor should try to answer before an intervention is undertaken:

- 1 How efficient is the intervention in terms of time involved and effort made?
- 2 How long are the results expected to last?
- 3 What percentage of patients with similar problems can be expected to respond using the intervention?
- 4 How convenient or inconvenient is the treatment to the patient and to his or her environment (including the therapist)?
- 5 What is the cost of the intervention?
- 6 What are the side effects of the particular strategies or the programme used?
- 7 How competent am I to use a particular intervention strategy?

The questions could also be asked in the case of biomedical science communication. But in addition to these questions a doctor should also listen to the important questions the patient has (Sorensen et al., 1981). The doctor could try to couple the patient's questions to the goals as described by Belar and Deardorff. By matching goals and questions miscommunication can be avoided. But when these goals and questions are intertwined the risk of miscommunication increases. Sorensen (1981) and Michie and Marteau (2000) write:

[...] Difficulty in grasping key concepts, intense emotion interfering with information processing, and counsellors' poor communication skills, including failure to use educational skills (Michie and Marteau, 2000).

In short, genetic counseling, at least from the perspective of informing clients about their diagnosis, appears to educate a substantial proportion of those clients who are ignorant about a diagnosis. However a full 40% of such clients (by our scoring method) appear to be ignorant diagnostically after counseling. At the same time, there does not appear to be any significant drop in the accuracy of diagnostically knowledgeable clients during counseling, although a few do appear to have less accurate knowledge after counseling than before. (Sorensen et al., 1981).

Recognition that there is an educational problem in genetic counseling is important, but more useful is some understanding of what contributes to the problem. (Sorensen et al., 1981).

In summary, this section enumerates and explains parameters for health psychology that are useful for biomedical science communication for predictive DNA diagnostics, such as: process satisfaction, goal satisfaction, empowerment and risk perception.

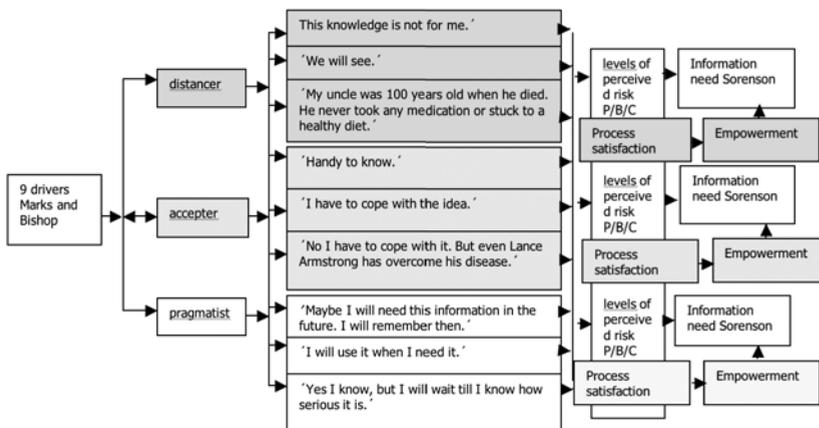


Fig. 4-3: The relationship between multileveled, multipurposed, empowerment and the target group. The figure is the same as Fig. 4-3, though slightly expanded, with process satisfaction and empowerment which are coloured by the different target groups. A need for information arise from the levels of risk perception. This need for information depends on the satisfaction with the process and the empowerment of the target audience. If satisfaction with the process is strong enough, this will lead to an increase in empowerment, which changes the information need, as described by Sorensen et al. (1981).

Figure 4.3 shows how empowerment could be described by aspects from which the communication process could be steered. For example:

A non-patient hears from the doctor that because high cholesterol levels are frequent in his family, it would be safest to test them. The non-patient wants to test (acceptor). But which information will be most suitable for the acceptor? Does the non-patient ask for information on his own? He wants to know, for example, what the costs of treatment are. Now satisfaction with the process becomes important. The non-patient might learn to ask questions. From this moment the non-patient can ask more difficult questions and probably feels in charge of finding the solution to his problems.

## 4.7 Context

The consolidated literature contains terms that refer to the context of the communication process, such as: socio-economic status (SES) of the target audience, lay notions, kinship and ethical dimensions. These facets of context will be explained and discussed according to their relevance to biomedical science communication on predictive DNA diagnostics.

### SES

*It is more important to know what kind of man has a disease than to know what kind of disease a man has. (in Belar and Deardorff, 1995).*

One of the main aspects influencing health is an individual's socio-economic status (SES). Miller and Kimmel (2001) discussed several surveys on the subject of SES. They have calculated the relative contribution of SES aspects to biomedical communication. Other authors have made the following comments on this subject:

*The SES construct has traditionally been analysed from a sociological perspective and has been found to control large amounts of the variance in health outcomes (Carroll et al., 1996; Carroll et al., 1997).*

*Meaning of health shows class related differences. Working class men and women see health in a more utilitarian way, concerned with an absence of disease, being able to work and get through the day without feeling ill. Middle class people see health as a value concerned with feeling good and having energy to indulge in leisure activities.*

*Chamberlain (1997), however, suggests a more complex picture, with four differing views of health.*

- 1 *the solitary view: presented by participants with lower SES, they see health as involving only the physical components of energy, lack of symptoms and a good diet;*
- 2 *the dualistic view: held by participants with lower SES, and some with a higher SES, they see health as having both physical and mental aspects, which act in parallel and independently of each other;*
- 3 *the complementary view: presented mainly by people with a higher SES, sees physical and mental elements as integrated together in an alliance;*
- 4 *the multiple view: held by people with a higher SES, sees multiple aspects to health: physical, mental, emotional, social, spiritual, as interdependent, interconnected, in balance in health and out of balance in illness.*

In terms of biomedical communication on predictive DNA diagnostics, these different SES groups require different communication approaches. For example, for people with a solitary view, predictive testing is seen as an instrument to maintain health in a physical way. Communication to this target group should start on this level of maintenance. People with a complementary view are probably interested in a message in which emotions and physical well being are integrated. They are not satisfied by facts alone. Certainly, all these factors could be 'on air' during effective biomedical science communication. This makes the communication process on biomedical science more complex to develop. In studies the complexity of the factors is difficult to investigate. Most studies to date have been descriptive investigations of the attitudes and reactions of counsellors to genetic counselling and prenatal diagnosis, and are weak theoretically and methodologically. Very few have used psychological models to guide question framing, data collection or the interpretation of results (Michie and Marteau, 2000).

### Lay notions

The lay audience's ideas about and prejudice towards genetics and predictive DNA testing are deeply embedded in their minds (Snelders and Pieters, 2002). These lay notions - as described in chapter 1 - are important to consider in communication on genetics to a lay audience (Van der Sanden and Meijman, 2008). A touching example of such a lay notion is an anecdote in the NRC Handelsblad in 2004 in which a woman indicated her desire to have rhinoplasty done before getting pregnant in order to be sure her child would not be born with the same nose she had. People often have their own theories about illnesses, leading to discrepancies between the intended and the received messages. New knowledge, especially where science or technology is involved, is assimilated into individuals' existing frameworks of knowledge and understanding by anchoring the unfamiliar to what is already familiar, and rendering abstract concepts into something more concrete (Michie and Marteau, 2000). Knowledge, including knowledge about genetics, is socially constructed. Knowledge acquisition is therefore a dynamic process that takes place within a social context, rather than an individual one. This is illustrated in a study of public representations of the Human Genome Project in Britain (Durant et al., 1992). While there was a relatively low public awareness and knowledge of the Human Genome Project, representations of the project were dominated by its close association with the better-known fields of genetic engineering and genetic fingerprinting, which shaped the concerns that people had (Michie and Marteau, 2000). Mendelian genetics is not commonly known among the lay audience (Richards, 2000):

- 1 lay knowledge does not often seem to include a notion of something that is inherited, aside from the condition itself. It is the condition that is inherited, or a proneness to it, rather than a gene mutation that may be expressed as the condition. This can lead to a number of difficulties in making sense of Mendelian explanations. If you do not have the condition, how can you pass it to your child?;
- 2 Mendelian ratios are easy to understand if you have a concept of chromosomes as paired structures, with gametes being produced by reduction division [...] most people are unable to fully understand these ratios;
- 3 geneticists talk in terms of risks and probability. As much research has demonstrated, some of the geneticists' clients have a good deal of difficulty in making human sense of what they are talking about.

Discussion could lead to miscommunication because of different ideas and notions. This has happened in the Dutch debate on transgenic food, which culminated in a report known as *Eten en Genen*. The debate's organisers presented the scientific details of transgenic food, whereas the audience wanted to talk about their fears and emotions. This asymmetry in terms of facts and emotions has led to miscommunication and anger on the part of the different actors participating in the process.

In the case of genetic counselling the communication differences between lay knowledge and professional knowledge are 'solved' by being *non-directive*. For example, asking questions instead of giving information. This could also be useful within biomedical science communication on predictive DNA testing.

## 4.8 In summary: communicametrics

From the consolidated literature we learned that lay notions, predispositions and emotional distance are important variables in the biomedical science communication process on predictive DNA diagnostics. These facets are summarised in Table 4.3. Insight into knowledge about how these facets influence self-efficacy, empowerment, risk perception and satisfaction with the process is needed to develop an effective science communication process. From the consolidated literature we have also learned that a non-directive communication strategy is needed to communicate about lay notions in order to bridge the differences between the lay audience and genetic specialists. In the following we will summarise all of the aspects in a metric formula, as we already described in section 4.5.2. In this depiction not only static mutual dependence but also dynamic mutual dependence becomes clear.

### STEP 1: *emotional distance (E) to subject*

The emotional distance depends on an individual's status as a patient, a not-yet patient or a non-patient ( $P^{1,2,3}$ ).

### STEP 2: *biomedical science communication or health communication*

When the emotional distance is great, then biomedical science communication could be a more effective communication modality than health communication. When the emotional distance decreases, health communication as a modality becomes more suitable.

biomedical science communication < E < health communication

### STEP 3: *motivation (M)*

Motivation of the audience depends on the reversibility or the irreversibility ( $R^{+/}$ ) and seriousness ( $S^{+/}$ ) of the genetic disease. But motivation depends also on self-efficacy ( $SE^{+/}$ ) and the knowledge locus of control ( $KLC^{+/}$ ). These elements form the basis for motivation, as we learned from the health belief model described in chapter 3.

$$(2) M \Rightarrow E = > ((R^{+/} + S^{+/})P^{1,2,3}) \times SE^{+/} \times KLC^{+/}$$

### STEP 4: *acceptor, distancer and pragmatist*

The motivation depicted in the second rule of the communicametric equation forms the basis for the difference in motivation, which in turn makes a difference between acceptors (A), distancers (D) and pragmatists (P). As we have seen in Table 4.2, this makes a difference in perceived risk (PR).

$$(3) PR[A/D/P] M \Rightarrow E = > ((R^{+/} + S^{+/})P^{1,2,3}) \times SE^{+/} \times KLC^{+/}$$

### STEP 5: *message*

Now that the level of perceived risk has been evaluated and the acceptance mode and motivation have been described, the message can be described in terms of content (MC) and level (ML). The level of knowledge depends on perceived risk. The content of knowledge, for biomedical science communication, depends on what we described in chapter 3 (Fig. 3.5) as the different use of biomedical knowledge: 1) notions of knowledge (N); 2) growth of knowledge (G); 3) use of knowledge (U). This ultimately forms the use and level content of the message.

$$(4) [(((R^{+/} + S^{+/})P^{1,2,3}) \times SE^{+/} \times KLC^{+/}) \Rightarrow E \Rightarrow M] A/D/P] PR \Rightarrow ML \times MC^{N,G,U} \Rightarrow \text{message}$$

In summary, beginning between the brackets one sees the different steps and dependencies in formulating a message. If one does not have information on any one of these facets the message will carry more risk of miscommunication.

STEP 6: *biomedical science communication modality*

The modalities biomedical science promotion, biomedical science education and prevention of biomedical knowledge deprivation were described in chapter 3.

< MC<sup>C</sup> (low knowledge need; low motivation; an external need for information) => prevention of knowledge deprivation

> MC<sup>C</sup> (high knowledge need; high motivation; an internal need for information) => biomedical science education

< MC<sup>U</sup> (low knowledge need; low motivation; need for knowledge use) => prevention of knowledge deprivation

> MC<sup>U</sup> (high knowledge need; high motivation; an internal need for information) => biomedical science education

< MC<sup>N</sup> (low knowledge need; low motivation; need for knowledge use) => biomedical science education

> MC<sup>N</sup> (high knowledge need; high motivation; an internal need for information) => biomedical science promotion.

(5) [(((R<sup>+/</sup> + S<sup>+/</sup>)P<sup>1,2,3</sup>) x SE<sup>+/</sup> x KLC<sup>+/</sup>)=>E =>M] A/D/P] PR =>ML x MC<sup>N,G,U</sup> => message] modality

STEP 7: *communication strategy: transmission, transaction*

Following the 6 steps above we see that an effective strategy for biomedical science communication on predictive DNA test depends on the message, which in turn depends on the level of knowledge needed and the motivation. Motivation depends on many facets, as depicted in the communicametric formula.

Motivation depends on the emotional distance of the target audience to the subject of the communication (predictive DNA testing). An increase in motivation can be reached by decreasing the emotional distance. How can this be done? According to the metric formula - by changing self-efficacy and/or the knowledge locus of control. In the case of biomedical science communication, research should be conducted to find whether an increase in self-efficacy diminishes or enlarges emotional distance. Does emotional distance decrease when a person feels more confident about a particular subject? What happens if the knowledge locus of control is changed? Does emotional distance diminish when the knowledge locus of control lies at the level of the individual? This could be the case, but it should be investigated further. Moreover, is emotional distance a product of knowledge locus of control and self-efficacy (SE x KLC => E) or SE x E => KLC or KLC x E => SE? This sequence of constructs and variables should be researched and validated.

Empowerment depends on motivation and on satisfaction with the process. Process satisfaction in turn depends on the way the target audience is involved. Involvement of a target audience that has significant emotional distance from the topic in question can be effected by asking questions about their feelings in order to decrease the emotional distance, which leads to an increase in motivation and empowerment. Asking questions about emotions can be comprehensible to a remote audience, and asking questions about facts could be comprehensible to an audience that is less remote (Van der Sanden and Meijman, 2007). Fig. 4.4 presents this in a graph.

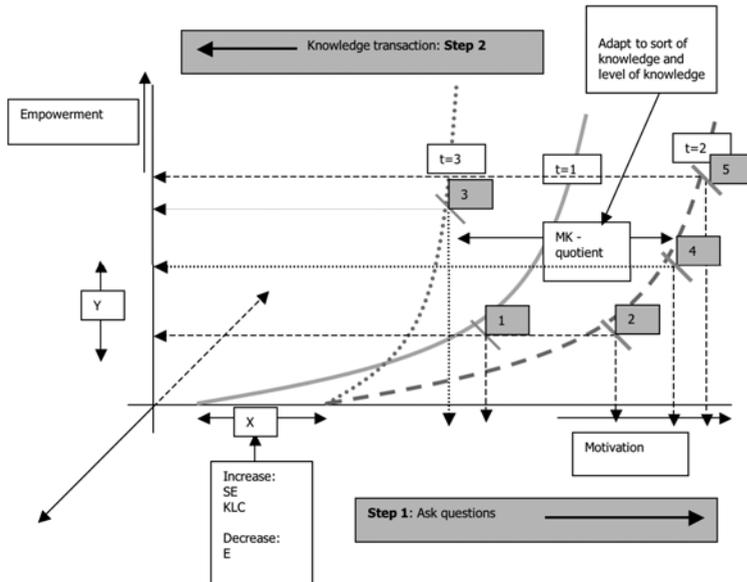


Fig. 4.4: Empowerment diagram. See text below for explanation.

Figure 4.4 depicts the relation between motivation and empowerment. In this figure one sees that the motivation changes when the degree of emotional distance changes. Emotional distance, as we have learned in genetic counselling, can be changed by asking questions (conceptual/factual). An increase in motivation does not help to increase empowerment (compare point 1 and 2 in diagram). Only by changing the content and level of knowledge does process satisfaction become an issue (point 3). One then sees that once the target audience is empowered the level of empowerment either decreases or increases motivation. So the change in motivation/knowledge (MK-quotient) is a measure of empowerment. This MK-quotient should be as small as possible. When a person needs a lot of time to be motivated to gain knowledge it does not constitute empowerment. Empowerment occurs when the need for information becomes a part of the individual's system.

Of course it could be the case that the motivation/knowledge curve for Huntington's disease is much different from the curve for breast cancer. The MK-quotient maybe be different for different levels of empowerment and biomedical communication effort. The curve in Figure 4.4 is drawn as a parabola, but this could also be a hyperbola or a straight line.

In summary, and as an addition to Fig. 3.14, medical psychology provides a lot of insight into the different variables for reaching empowerment. Health psychology broadens and deepens the models, like the health belief model and other models described in chapter 3.

## 4.9 Unconsolidated literature

We have read and validated the unconsolidated literature as depicted in Table 4.2. From this unconsolidated literature we used newly obtained insights from the domain of health psychology to validate the consolidated literature and to add new relevant and validated knowledge.

### 4.9.1 Structure

As we found in chapter 3, for health psychology the communication element 'structure' could be differentiated into sender, means and receiver. In the following section the relevant and valid and less relevant and non-valid new insights from the literature on health psychology are cited. Every paragraph closes with a conclusion on the significance of the findings obtained for the domain of biomedical science communication on predictive DNA diagnostics.

#### Sender

##### Success

##### (+++R/+V)

- Slightly more than half of the respondents (general practitioners, mvds) were in favour of referring (patients) to a genetic centre to seek the information they need (Decrynaere et al., 1993).
- How and what health professionals communicate with patients about genetic testing may explain the differences between type of health professional and country of testing and attitudes toward bowel screening. If this is the case training in communication may change patient's perceptions and, in turn, their behavioural intentions and actions following a negative test result (Michie et al., 2002a).

##### (++R/-V)

- Follow-up visits (patient and doctor, mvds) are increasingly considered to be necessary (Reif and Baitsch, 1985)
- Another facet of the psychological paradigm shift emphasizes the multilevel structure of psychological processes. At least two levels are always present, a deep structure and a superficial one [...] Education can succeed only when learning takes place. In considering learning, one also needs to examine reinforcement contingencies. Reinforcement is a term frequently used in the genetic counselling literature generally in connection with re-emphasizing certain pieces of previously conveyed information. The psychological and behavioural consequences of such tactics are seldom considered, although they are unquestionably there (Kessler, 1980).
- In some countries, family cancer clinics offer professional psychosocial support to asymptomatic women from HBOC [Hereditary Breast and Ovarian Cancer] families. However more data are needed to determine: 1) how much and what type of information and support are required for those offered genetic testing and how this can be most efficiently provided and 2) how to achieve better understanding of genetic testing and its results, and how one can best facilitate risk-reducing behaviour without high levels of emotional distress or false reassurance (Bleiker et al., 2003).
- The International Society of Nurses in Genetics strongly recommends that all nurses study the principles of human genetics, cancer genetics, and the implications of genetic testing (Pasecra et al., 2002).
- I (Kessler, mvds) would strongly encourage the various research groups to publish case reports similar to those in Bloch et al. (1992, in Kessler, 1994), with an eye to providing details so that others with differing theoretical orientations might have a basis upon which to draw their own conclusions [...] Considering everything, an underlying faith continues to exist among many professionals in the field, as well as among many in the at-risk community, that the net benefits of predictive testing for HD will prove to be worthwhile (Kessler, 1994).
- Various institutions and funding agencies are sponsoring the establishment of multidisciplinary teams (consisting of oncologists, geneticists, ethicists and sociologists, among others) to address the spectrum of outcome issues (Cole et al., 1996).
- [...] We (the authors, mvds) propose a framework for categorizing genetic tests according to two characteristics: 1) their clinical validity, that is the accuracy with which a test predicts a particular clinical outcome (Holzman and Watson, 1999) and 2) the availability of effective treatment for the condition or risk status identified by testing. We argue that this framework accounts for a substantial proportion of variation in the ELSI (Ethical, Legal and Social Implications) of different genetic tests [...] The availability of effective treatment is a recognized and powerful mediator of the ELSI. When an effective treatment exists, the ability of a genetic test to identify people who would benefit from that treatment is an important justification for its use [...] Genetic tests can be categorized according to two properties, clinical validity and effectiveness of treatment available to people with positive results. This progress yields four test categories each with characteristic concerns, and thus allows an initial estimate of the medical and broader societal implications of new tests in each category (Burke et al., 2001).

**Sender**

Failure

(++R/-V)

- Genetic counsellors have become aware of large discrepancies between their goals as genetic educators and the realities actually achieved (Kessler, 1980).
- No large-scale, population-based studies have been undertaken to determine the type and degree of psychosocial effects such women experience, and as a result little is known, for example, about their intention to undergo testing. Consequently, women can't be counselled adequately on the risks and benefits associated with testing. Clinicians don't have sufficient detailed evidence about the impact of genetic testing on women's lives – including relationships, childbearing, employment and finances [...] The International Society of Nurses in Genetics strongly recommends that all nurses study the principles of human genetics, cancer genetics, and the implications of genetic testing (Pasecra et al. 2002).
- It is suggested that many, if not most, problems involving the issue of nondirectiveness arise because of inadequacies in applying basic counselling skills [...] The need to raise standards in counselling training should be underscored if the field of genetic counselling is to remain non-directive (Kessler, 1994).
- Most counsellors have not received extensive training in risk communication (Koenig and Silverberg, 1999).
- Among other challenges they described schisms between researchers and practitioners that could potentially fracture our (psychology, mvds) profession (Tovian et al., 2003).

(+R/-V)

- Kessler [1997a] argues compellingly for the importance of both practice models and the counselor's flexibility and skills working within both of them (Biesecker and Peters, 2001).

**Means**

Success

(++R/+V)

- The attending gynaecologist was the most significant source of information about breast cancer and the magnitude of the patient's personal risk (72%). Communications media (books, magazines, radio and television) and family members who developed breast cancer also represented important sources of information (57% and 39%) (Neise et al., 2001).
- Over half the subjects reported hearing about the study either through the mailing or through family and friends of members of the HD voluntary group. The major source of information about HD, developments in HD research, and about the predictive test came from newsletters and other materials issued by the HD voluntary organisations (Kessler, 1987).

(+++R/-V)

- In evaluating the success of a genetic counseling session, the nature of the interpersonal interaction is of primary importance to both counselors and clients [...] Collaboration between researchers in the fields of genetic counseling and psychology could lead to more informed studies evaluating genetic counseling. (Bernhardt et al., 2001).

(++R/-V)

- The name of the specific counsellor, an appointment time, and a map with written instructions on how to find the clinic may facilitate making contact and creating a relationship of confidence (Reif and Baitsch, 1985).

**Means**

Failure

(No relevant or valid unconsolidated literature found)

**Receiver**

Success

(+++R/+V)

- Most at-risk individuals and their partners would like to discuss an increased risk outcome with their general practitioner (71%) [...] About two-thirds of all respondents expect to discuss an increased risk result with their family physician, whose support may be sought as the most knowledgeable professional on personal and family circumstances (Tibben et al., 1993).

(++R/+V)

- A great majority (83%) said the test should be made available as soon as possible, but 17% believed the test should be available unless it was accompanied by a cure. The imminent availability of a predictive test made 12% of the respondents more anxious, 14% less anxious, and 74% reported it made no difference in their level of anxiety (Meissen and Berchek, 1987).

(+++R/-V)

- In evaluating the success of a genetic counselling session, the nature of the interpersonal interaction is of primary importance to both counselors and clients [...] Collaboration between researchers in the fields of genetic counseling and psychology could lead to more informed studies evaluating genetic counselling (Bernhardt et al., 2000).

**Receiver**

Failure

(+++R/+V)

- Low uptake of HNPCC (hereditary non-polyposis colorectal cancer, mvds) testing was mainly due to the long distances between the place of residence of those invited for testing and the study centre where counselling and testing were performed (Collins et al., 2000a).

**Conclusions: structure**

In the unconsolidated literature the most relevant and valid articles (+++R/+V) we found discuss general practitioners who play an important role in genetic testing (Decryenaere et al., 1993). The majority of the public likes to talk to the general practitioner, who may advise them to see a geneticist (Tibben et al., 1993).

The less relevant and valid (++R/+V) literature points to family members, friends and patient societies as the main and most reliable source for new knowledge on genetic testing (Kessler et al., 1987). Therefore, there is a possibility that biomedical science communication with mass media theories and techniques may not be effective where new knowledge is concerned. A complicating factor is that there is a lack of knowledge among genetic counsellors about all of the available options for testing and the variety of outcomes. This means that not all information is available in non mass-communication settings either (Kessler, 1980; Pascreta et al., 2002; Kessler, 1997; Koenig and Silverberg, 1999; Tovian et al., 2003).

With regard to biomedical science communication on predictive DNA diagnostics, this idea of a focal point for communication other than mass communication could be useful. A good option is to offer an interactive website that can generate tailor-made information. The main focus should be on communication, via a reliable person, website, book, or another source. Moreover, a comprehensive education programme for biomedical science communication professionals should also be available. The competencies of biomedical science communication professionals could be enhanced by using different kinds of communication processes that reflect different genetic tests and their implications (Burke et al., 2001) (relevant/not valid).

An important ethical constraint is that communication about tests for diseases for which no treatment is available should be avoided. However, public communication about these tests and their implications, as in a public debate or in the media is in line with the democratic principle on biomedical science communication as described in chapter 1. This is exactly the point where medical treatment, doctor-patient communication and communication in a public sphere contradict each other (Van der Sanden and Meijman, 2007). The unconsolidated literature that is less relevant and valid (++R/+V) shows that most people interviewed in the survey research described believe that genetic testing should be available. A minority (17%) believe that a genetic test is only acceptable when a treatment for the genetic disease is available (Meissen and Berchek, 1987). Future thinking and research on these ethical aspects should be carried out.

**4.9.2 Process**

As we did for structure, we can make the same differentiation in terms of sender, means and receiver for process.

**Sender**

Success

(+++R/+V)

- Unsolicited screening and genetic counselling for thalassemia trait in a health maintenance organization can result in highly satisfactory learning and excellent retention without detected adverse effects on sexual behaviour, marital adjustment, or self-concept (Rowley et al., 1984).

- It is unlikely that a lower perceived risk per se will lead to attending bowel screening, but may reflect other aspects of communication [...] Gaining more understanding about communication processes is necessary to improve training of health professionals (Michie et al., 2002b).
- (++R/+V)
- Their appraisal of the birth defect's recurrence risk, understanding of its aetiology, and perceptions that the counsellor had directed a particular reproductive decision indicate that greater attention to personal frames of reference might enhance counselling effectiveness (Welshimer and Earp, 1989).
  - The role of the counsellor in the pre-test process for both predictive and prenatal testing in our (the authors, mvds) programme is one which includes provision of knowledge, assessment of the psychological and social resources of the candidate, assistance and guidance in developing and utilizing these resources, exploring the motivation and commitment of the candidate to take the test, and supporting him or her (Bloch et al, 1989).
  - This process of perception hinges on the availability of information about breast cancer. Aside from being aware of the risk factors, the patient must appreciate how they apply to her personally [...] The high proportion of women who overestimated their risk of contracting the disease emphasizes how important it is to critically examine the patient's personal views during every new consultation with a physician. This gives the care provider an opportunity to correct excessive misconceptions. This would appear to be particularly important in light of the psychological stresses described by Lerhman et al. (1993) and Kash et al. (1995) that frequently accompany such sessions and also have a negative impact on diagnostic screening compliance (Neise et al., 2001).
- (+++R/-V)
- Both clients and counsellors commented that a positive interpersonal interaction and 'connecting' are primary measures of success. All clients appreciated the large amount of time spent with the counsellor, and the manner (clear, comprehensive, and unhurried) of providing information [...] Another unanticipated finding from this study is the high regard clients have for the expertise of their counsellor. Counsellors were frequently described as extremely knowledgeable, often more well informed than other health care providers. This impression stems not only from the fact that genetic counsellors generally know more about rare genetic disorders and genetic testing than other non-geneticist providers but also from the willingness of counsellors to share their knowledge and to educate clients effectively [...] [There is] a need to educate clients about the process of genetic counselling before the visit and to find ways to help clients identify realistic expectations of genetic counselling. (Bernhardt et al., 2000).
- (++R/-V)
- The description of counselees' use of scenarios reported here suggests that the use of more formal scenarios may be a useful counselling tool in some situations (Arnold and Winsor, 1984).
  - The contributions that health psychologists can make to the study of appraisal can potentially provide broader insights into the psychology of reasoning, emotion and adaptation (Shiloh, 1994).
  - Three elements are involved in the process of human communication: 1) a relationship between two or more persons is implied; 2) there is a shared focus of attention; 3) the message being transmitted has shared meanings [...] information that is assimilated is moulded so as to fit pre-existing mental schemes of the self and the world. Accommodation to new information requires that the person change his or her mental schemas [...] The psychologically oriented paradigm emphasizes the fact that communication in genetic counselling is a two-way street (Kessler, 1980).
  - Directiveness in genetic counselling needs to be thought of as a form of persuasive coercion. Like all such techniques, one or more of the following elements exist: 1) deception; 2) threat; 3) coercion [...] In the genetic counselling literature, ND [non-directiveness] is often formulated as the absence of directiveness as if the two concepts were mutually exclusive. This I (Kessler, mvds) believe is a mistake. There is vast grey area between directiveness, with its techniques of coercion (Milunsky, 1975; quoted by Kessler; Antley, 1979, in Kessler) and ND [...] It is possible to withhold advice and remain nondirective. The secret in the latter is how (cursive, Kessler) the advice is given. [...] What makes the examples (transcription of counselling sessions, mvds) above nondirective are two things. First, the counsellor presents the advice as a suggestion as if it was a possibility of action rather than a certainty in his mind [...] ND is more than withholding advice. It is a way of interacting and working with clients that aims to raise their self-esteem and leave them with greater control over their lives and decisions. Genetic counselling based on the provision of information (Hsia, 1979, in Kessler) is limited in achieving these goals. Information giving may provide facts, but does not necessarily give clients a way of thinking about the information they receive [...] It might be a way of asking for clarification of previously given information [...] Clients also need to be encouraged to talk more in the counselling session since this gives them a sense that they have greater control over the situation (Kessler, 1997).
  - Consistent testing procedures and risk-estimation algorithms are needed, and the limitations and pitfalls inherent in any molecular study should be well understood by the health care professionals involved so that they can explain these uncertainties accurately to their patients (Cole et al., 1996).

- The common use of nondirective counseling reflects the principle that many testing decisions should be determined by personal values [...] the predominant concern is adequate nondirective counseling to ensure an informed autonomous decision [...] Where uncertainty exists concerning both clinical validity and effectiveness of treatment, as in the case of BRCA1/2 mutation testing [for hereditary breast cancer], the value of testing may vary according to different testing contexts. This approach to test categorization allows a rapid determination of the predominant ELSI (Ethical, Legal and Social Implications) concerns for different kinds of genetic tests and identifies the data most urgently needed for test evaluation [...] In non-directive counseling, a cornerstone of medical genetics practice [American Society of Human Genetics, 1975], the counsellor provides information about genetic risk and explains choices regarding testing or management but does not provide recommendations about the appropriate course of action [...] Much has been written about the difficulties of achieving nondirective counseling and its effectiveness in helping patients achieve decisions that are satisfactory to them; whether or not counseling can or should be strictly nondirective is a continuing conversation within medical genetics (Yarborough et al., 1989; Clarke, 1991; Kessler, 1992; Bernhardt, 1997; Michie et al., 1997; Wertz and Gregg, 2000). However, the underlying principles that inform the concept can be easily justified in many genetic counseling situations, as well as in other medical practice settings. These principles include placing a high value on patient preferences and on the educational processes needed to ensure informed consent in complex risk and testing situations. The term 'shared decision making' may better reflect this, more limited meaning of non-directiveness (Frosch and Kaplan, 1999) [...] 1) High clinical validity, no treatment (HD): this category represents the prototype around which traditions of genetic counseling have developed and justifies careful, nondirective, pre-test counseling that allows the person counselled to determine whether or not to proceed with testing. 2) High clinical validity, effective treatment. In this test category, the predominant ELSI concern is to ensure that eligible persons are tested and have access to treatment. 3) Low clinical validity, lack of effective treatment. Testing is difficult to justify on either medical or social grounds. 4) Limited clinical validity, effective intervention. Factors to be weighed include the nature of the condition, its potential for stigma, and the nature and effectiveness of treatment [...] For tests with high clinical validity and effective interventions, health services research is needed to determine the best strategies to ensure access to testing and treatment. When tests have limited predictive value, a careful consideration of both medical and social outcomes is needed to provide clinicians and policy-makers with the information they need to determine appropriate test use (Burke et al., 2001).

(+R/-V)

- The authors stress the importance of education about the limitations of testing and about the need for screening follow-up (Gilbert, 1996).
- Debra Roter from The Johns Hopkins University developed a tool for assessing health care communication between patient and provider, the Roter Interaction Analysis System (RIAS) [...] it digitizes the verbal communication between health care provider and patient for both quantitative and qualitative analyses. Quantitative assessment includes the fraction of time the provider speaks compared to the patient, the balance between emotional and factual based information, the attention paid to the emotional concerns of the patient and the patient's agenda [...] The ABGC (American Board of Genetic Counseling) drafted genetic counsellor competencies: a) eliciting and interpreting individual and family medical, developmental, and reproductive history; b) determining the mode of inheritance and risk of occurrence and recurrence of genetic conditions and birth defects; c) explaining the aetiology, natural history, diagnosis, and management of these conditions; d) interpreting and explaining the results of genetic tests and other diagnostic studies; e) performing a psychosocial assessment to identify emotional, social, educational, and cultural issues; f) evaluating the client's and/or family's responses to the condition or risk of occurrence; g) providing client-centred counseling and anticipatory guidance; h) promoting informed decision-making about testing, management, reproduction, and communication with family members; i) identifying and using community resources that provide medical, educational, financial and psychological support and advocacy; and j) providing written documentation of medical, genetic, and counseling information for families and other health professionals [...] the successful future of the genetic counseling profession depends on the gathering of empirical data that substantiates the competencies needed by genetic counsellors to meet client needs (Biesecker and Peters, 2001).

Sender

Failure

(++R/+V)

- This illustrates that genetic counseling's usual emphasis on risk and other genetics-related factors as the most important considerations in decision-making may be counterproductive if it diverts people from examining other beliefs and values more central to their ability to make satisfactory decisions (Welshimer and Earp, 1989).

(+++R/-V)

- The distinction (between long and short-term effects, mvds) also has implications for practice in that genetic counsellors may underestimate long-term outcomes since counselors may not have much contact with clients over a long period of time (Bernhardt et al., 2000).
- Faced by a professional who expects counselees to play a passive role may lead to misunderstandings and mutual dissatisfactions (Kessler, 1980).
- Directiveness in genetic counselling needs to be thought of as a form of persuasive coercion. Like all such techniques, one or more of the following elements exist: 1) deception; 2) threat; 3) coercion (Kessler, 1997).

(+R/-V)

- The teaching model of genetic counseling assumes a goal of client education while the goals assumed by the counseling model are to understand the client, bolster the client's sense of competence, promote a greater sense of control over their lives, relieve psychological stress, support and raise self-esteem, and help the client find solutions to specific problems [...] Studies suggest genetic counseling may more often reflect a teaching model and less often a counseling model, also in conflict with Kessler's argument that both models are important. Further research is needed to assess how widespread this practice model is (Biesecker and Peters, 2001).

**Means****Success**

(+++R/+V)

- The results of this study suggest that the way the same information is presented can affect the decisions made by both doctor and patient. Options that were framed positively, whether reflecting outcomes or the status quo, were more likely to be chosen than similar options framed negatively [...] Nonetheless the results suggest that the way information is presented to both doctor (adviser) and patient (recipient) can have a significant influence upon subsequent decisions [...] That the presentation of the same information in different ways can influence subsequent decisions raises questions of how information should be presented to patients when eliciting consent or when patients are actively involved in making a health decision to ensure that neither a positive nor a negative frame predominates (Marteau, 1989).
- Outreach and prevention programmes to compliment the more traditional genetic counselling that will surely accompany the predictive test have been suggested (Meissen and Berchek, 1987).

(++R/+V)

- This process of perception hinges on the availability of information about breast cancer. Aside from being aware of the risk factors, the patient must appreciate how they apply to her personally [...] The high proportion of women who overestimated their risk of contracting the disease emphasizes how important it is to critically examine the patient's personal views during every new consultation with a physician. This gives the care provider an opportunity to correct excessive misconceptions. This would appear to be particularly important in light of the psychological stresses described by Lerhman et al. [1993] and Kash et al. [1995] that frequently accompany such sessions and also have a negative impact on diagnostic screening compliance (Neise et al., 2001).

(++R/-V)

- The description of counselees' use of scenarios reported here suggests that the use of more formal scenarios may be a useful counselling tool in some situations (Arnold and Winsor, 1984).
- In short, the entire process of genetic counselling is at its very core a psychological enterprise whose effectiveness (or ineffectiveness) rests on the extent to which realistic behavioural and psychological principles and methods are understood and applied in the counsellor-counselee relationship (Kessler, 1980).
- The understanding of risk information is a highly personal process and demands individualized counseling to address individual needs. In light of the difficulty inherent in effective communication about disease risk, individuals undergoing genetic testing for AD (Alzheimer's disease) should be provided with risk information designed with full consideration of the complexities of framing and other effects, to the extent possible. Such materials would present information in a variety of ways, presenting complex probabilistic information in many forms, numeric as well as linguistic. The counseling process should assist individuals in developing personal meanings of risk information. However, genetic counseling is clearly not a panacea (Koenig and Silverberg, 1999).
- The common use of nondirective counseling reflects the principle that many testing decisions should be determined by personal values [...] the predominant concern is adequate nondirective counseling to ensure an informed autonomous decision [...] Where uncertainty exists concerning both clinical validity and effectiveness of treatment, as in the case of BRCA1/2 mutation testing, the value of testing may vary according to different testing contexts. This approach to test categorization allows a rapid determination of the predominant ELSI (Ethical, Legal and Social Implications) concerns for different kinds of genetic tests and identifies the data most urgently needed for test evaluation [...] In non-directive counseling, a cornerstone of medical genetics practice (American Society

of Human Genetics, 1975), the counselor provides information about genetic risk and explains choices regarding testing or management but does not provide recommendations about the appropriate course of action [...] Much has been written about the difficulties of achieving nondirective counseling and its effectiveness in helping patients achieve decisions that are satisfactory to them; whether or not counseling can or should be strictly nondirective is a continuing conversation within medical genetics (Yarborough et al., 1989; Clarke, 1991; Kessler, 1992; Bernhardt, 1997; Michie et al., 1997; Wertz and Gregg, 2000). However, the underlying principles that inform the concept can be easily justified in many genetic counseling situations, as well as in other medical practice settings. These principles include placing a high value on patient preferences and on the educational processes needed to ensure informed consent in complex risk and testing situations. The term 'shared decision making' may better reflect this, more limited meaning of nondirectiveness (Frosch and Kaplan, 1999) [...] 1) High clinical validity, no treatment (HD): this category represents the prototype around which traditions of genetic counseling have developed and justifies careful, nondirective, pre-test counseling that allows the person counseled to determine whether or not to proceed with testing. 2) High clinical validity, effective treatment. In this test category, the predominant ELSI concern is to ensure that eligible persons are tested and have access to treatment. 3) Low clinical validity, lack of effective treatment. Testing is difficult to justify on either medical or social grounds. 4) Limited clinical validity, effective intervention. Factors to be weighed include the nature of the condition, its potential for stigma, and the nature and effectiveness of treatment [...] For tests with high clinical validity and effective interventions, health services research is needed to determine the best strategies to ensure access to testing and treatment. When tests have limited predictive value, a careful consideration of both medical and social outcomes is needed to provide clinicians and policy-makers with the information they need to determine appropriate test use (Burke et al., 2001).

(+R/-V)

- [...] genetic testing for FAP (familial adenomatous polyposis) should always include a minimum of two face-to-face education-counseling sessions, one to fully explain the test and discuss its potential implications for the patient (preparatory session) and another to disclose test results to the patient (disclosure session). For all gene-positive patients, we strongly recommend a third session (follow-up session) [...] 1) preparatory session: the goal of this session is to ensure that the patient is adequately equipped to make a fully considered, independent decision to undergo genetic testing and is well prepared to receive the results. The session should focus on providing patient education and achieving an understanding of the perspective that the patient brings to genetic testing. With genetic diseases such as FAP, at-risk patients typically have a preformed, well-entrenched conception of what having the disease entails because of their extensive first-hand, often multigenerational, experience with affected relatives. Discussing the patient's risk perception thus allows the clinician to foresee problems when prior beliefs are considerably at odds with determined genetic status. Obviously, it should be expected that those who are gene positive and feel prior to testing that their risk is minimal require additional support in adjusting to knowledge of their genetic status. Discussion of patient's reasons for seeking genetic testing and anticipated meaning of a gene-negative or gene-positive result can serve to unearth understanding of genetic testing and treatment implications as well as to illuminate some of the less visible, yet profound, effects precipitated by the testing. In our (the authors, mds) experience, simply asking the following three questions has been invaluable in this regard: 1) why did you decide to undergo genetic testing for FAP at this time? 2) What do you think it will mean for you and your family if you have the FAP gene? 3) What do you think it will mean for you and your family if you don't have the FAP gene? (Petersen and Boyd, 1995).

#### Means

Failure

None

#### Receiver

Success

(+++R/++V)

- It is unlikely that a lower perceived risk per se will lead to attending bowel screening, but may reflect other aspects of communication [...] Gaining more understanding about communication processes is necessary to improve training of health professionals (Michie et al., 2002b).

(+++R/+V)

- Unsolicited screening and genetic counselling for thalassemia trait in a health maintenance organization can result in highly satisfactory learning and excellent retention without detected adverse effects on sexual behaviour, marital adjustment, or self-concept (Rowley et al., 1984).

- Self-efficacy had a direct influence on intentions and interacted with two other variables of protection motivation

theory [...] Self-efficacy expectancy proved to be the most powerful predictor of behavioural intentions. In addition, expectations of self-efficacy influenced the effect of two other major components of protection motivation theory: probability of a threat's occurrence and coping response efficacy [...] Thus, a general model of attitude change incorporating protection motivation and self efficacy, would include four basic components: 1) outcome expectancy-current behaviour; 2) outcome expectancy-alternative behaviour; 3) self-efficacy (for the alternative behaviour) and 4) the relative value of the different sets of outcomes (Maddux and Rogers, 1983).

- It appears that an increased focus on breast cancer genetics knowledge would be warranted, as improved knowledge may act as a mediator of reductions in breast cancer anxiety (Lerman et al., 1996) and improvements in risk perception accuracy [...] One of the main motivations for women attending familial cancer clinics is to obtain information on breast cancer screening and preventative strategies (Audrain et al., 1998; Bernhardt et al., 1997; Hallowell et al., 1997; Meiser and Halliday, 2002).

(+R/+V)

- Several subjects pointed out that they or a relative, rather than a physician, had been the first to recognize the presence of HD in the family, generally following a program on television or an article in a magazine or newspaper. These non-professional diagnoses were then later confirmed generally on autopsy of a relative or when the affected person was hospitalised (Kessler et al., 1987).

(++R/-V)

- First of all it is important to find a shared focus of attention and shared meanings [...] what is needed then is continuous reciprocal communication, understanding and feedback (Reif and Baitsch, 1985).
- [...] knowing that one is at substantial risk for a disease may help people avoid or 'prepare' for it. There may be steps one can take to prevent disease onset, and there may be important personal issues that need to be resolved before illness develops [...] unfortunately, with the ability to predict or anticipate health threats comes fear, worry and distress [...] Although many recognize the possibility of bad news and report concerns and worries about how they would react to a bad result (Baum and Zakowski, 1997) they would still seek to gain more certainty about their disease risk (Baum and Zakowski, 1997).
- Among persons who have participated in predictive testing for HD there has been a relatively low rate (at least so far) of psychiatric fallout (Kessler, 1994).
- In the genetic counselling literature, ND is often formulated as the absence of directiveness as if the two concepts were mutually exclusive. This I (Kessler, mvds) believe is a mistake. There is vast grey area between directiveness, with its techniques of coercion (Milunsky, 1975; quoted by Kessler; Antley, 1979; quoted by Kessler) and ND (Kessler, 1997).
- The common use of nondirective counseling reflects the principle that many testing decisions should be determined by personal values (Burke et al., 2001)
- Predictive information provided prior to the development of symptoms enables individuals to make informed choices regarding disease management and the future, removing the anxiety associated with the unknown (Bennett et al., 1998).

(+R/-V)

- In fact, evidence from social cognition research suggests that both accuracy goals and self-enhancement goals play important roles in the pursuit and processing of self-relevant information [...] The comparison information significantly affected threat appraisals. Participants who were told that four members of the group had tested positive rated the disorder as a less serious threat to health [...] As more is learned about how to deal with the threat and behavioural plans are made, self-efficacy increases to a level necessary for the successful completion of effective action (Rogers, 1983) (Croyle, 1992).

**Failure**

Receiver

(+++R/++V)

- A primary source of the stress associated with being at risk for HD is believed to be the lack of control (Meissen et al., 1991).
- Though attitudes and intentions were quite positive toward predictive testing, levels of knowledge were surprisingly low (Meissen and Berchek, 1987).

(++R/-V)

- One of the greatest difficulties is that most clients are not used to thinking about their problems in a quantitative way and to giving numerical probabilities and valuations (Reif and Baitsch, 1985).
- How can the normal, healthy individual perceive reality accurately if his or her perceptions are so evidently biased and self-serving? [...] false optimism may, for example, lead people to ignore important health habits (Taylor and Brown, 1988).

- Most of the women claimed that these problems were exacerbated by a lack of knowledge about oophorectomy and its after effects. Women reported that they would have liked more information about ovarian function and menopause [...] Again, in this UK study, one of the conclusions was that there is an unmet need for information about the physical and emotional after effects of oophorectomy (Bleiker et al., 2003).
  - [...] knowing that one is at substantial risk for a disease may help people avoid or 'prepare' for it. There may be steps one can take to prevent disease onset, and there may be important personal issues that need to be resolved before illness develops [...] unfortunately, with the ability to predict or anticipate health threats comes fear, worry and distress (Baum and Zakowski, 1997).
  - Interpretation of risk information is also affected by how personalized the risk is. Some researchers discovered that population rate information was discounted as impersonal [Lippman-Hand and Fraser, 1979] because it did not provide certain information about what would happen to the individual. Uncertainty was decreased but not eliminated (Koenig and Silverberg, 1999).
- (+R/-V)
- People may minimize the seriousness of their own health problems so that they can perceive themselves as healthy and thereby control anxiety (Croyle, 1992).

### Conclusions on process according to the unconsolidated literature

Taking the unconsolidated literature on health psychology into consideration, one of the main issues appearing in the most valid and most relevant literature (+++R/++V) is the concept of self-efficacy (Maddux and Rogers, 1983). The concept of self-efficacy is also a central concept in health communication and is analysed in chapter 3. The relevant and valid literature shows that self-efficacy - or the lack of it - can lead to feelings of anxiety. It is important to balance the use of self-efficacy to optimise the feeling of anxiety, whereas both too little and too much anxiety will not lead to effective biomedical science communication. Self-efficacy is considered to play an important predictive role in the process of genetic counselling. The question is how to operationalise self-efficacy within the case of predictive DNA testing.

Although the public is generally positive about predictive testing, a large part of the audience has no accurate knowledge about predictive testing itself (relevant/valid) (Meissen and Berchek, 1987). Also, lay knowledge on the impact of predictive testing with respect to distinct target groups is of importance (relevant and valid) (Michie et al., 2003) but hardly available. Therefore the way information is communicated matters. Information presented in a positive way will be taken into account in a positive manner (relevant/valid) (Marteau, 1989). The competence to make an optimal choice may help people to gain self-control (Meissen et al., 1991). Taking the literature with less convincing power into account, it becomes clear that the individual's context is important, because it contributes to the person's self-efficacy (Welshiner and Earp, 1989; Bloch et al., 1989). Therefore, information communicated to the target audience must be nondirective and irrelevant (see also chapter 5). Not all authors share this viewpoint. According to Bennett et al. (1998) (relevant/not valid) having information before symptoms occur diminishes feelings of anxiety.

For biomedical science communication on predictive DNA diagnostics it may be useful to delay giving information by focusing on irrelevant information. Even the less relevant literature starts by formulating a common starting point, which is all about the context, timing and phasing of the biomedical science communication process (Petersen and Boyd, 1995). All these steps, however, need to be evaluated. The RIAS (Roter Interaction Analysis System) could be an option for evaluating the different phases (Biesecker and Peters, 2001) (relevant not valid).

Also the context of the target audience is of prime importance. An effective biomedical science communication process is hard to design without knowledge of the background of the target audience. For example, the idea that individuals are willing to take risks when they know they can cope with the feelings of disappointment (Maddux and Rogers, 1983) (relevant and valid). This, and the idea that different kinds of tests require different means of communication, makes predictive DNA testing complex.

### 4.9.3 Outcome

As described in chapter 3, the element of outcome can be separated into knowledge of change, notions of knowledge and use of knowledge.

#### Knowledge growth

success

(+++R/++V)

- Surprisingly, knowledge about predictive testing was quite low and a majority of those least knowledgeable about predictive testing intended to use the test. These findings emphasized the need for outreach and prevention efforts to prepare the at-risk and specialized programs of genetic counselling and follow up to accompany predictive testing [...] Intended users of the presymptomatic test were significantly more likely to encourage their adult children to test themselves and to test themselves prior to marriage and childbearing [...] Knowledge about the predictive test and the manner in which it is obtained could play an important role in test-related decisions (Meissen and Berchek, 1987).

(+++R/+V)

- Compared with the controls, who do not show any significant change, there is, immediately after counselling, a striking increase in knowledge [...] There is no statistically significant change in these levels at 2 months or at 10 months after counselling; knowledge is well retained [...] At each time after counselling, counselees scored significantly higher than controls (Rowley et al., 1984).
- Almost all participants (95%) said they would rather learn that they have HD gene than remain at 50% risk [...] at-risk participants were asked to rate their likelihood of possessing the HD gene. About 25% thought it unlikely that they possessed the HD gene, but 60% of those participants received unfavourable results. Almost half (42.5%) thought they were at 50% risk; they believe it neither likely nor unlikely that they possessed the gene [...] even with unfavourable results, most participants believed that there would be benefits to knowing that they were probable gene carriers [...] 93% of those at risk [...] thought it likely that taking the test would provide more control over life (Meissen et al., 1991).
- Most clients feel their information needs are adequately met and an increase in knowledge of colorectal cancer genetics after attendance at the clinic has been demonstrated (Collins et al., 2000b).
- These (articles reviewed, mvds) studies show consistently that genetic counseling led to statistically significant increases in knowledge about breast cancer genetics (Meiser and Halliday, 2002).

(++R/+V)

- Candidates are well informed both about HD and the predictive test [...] the state of flux in the technology implies the need for continuous education of families and the re-evaluation of family structures (Bloch et al., 1989).

(+R/+V)

- In response to the question 'what is your understanding of the chances or risk of your having inherited the HD gene?' 87.9% were able to answer correctly (Kessler et al., 1987).

(++R/+V)

- The communication of information refers to: a) the general concerns and specific questions formulated by the client; b) the possibilities of genetic counselling in so far as these differ from the expectations of the client; c) the reasons why certain expectations cannot be met; d) reasons for the procedure in genetic counselling; e) the central contents of genetic counselling (Reif and Baitsch, 1985).

(+R/-V)

- Outcome studies in psychotherapy have assessed the potential benefits that constitute observable changes in clients. These include improved psychological well-being, understanding information, satisfaction, work and social adaptation, reduction of symptoms (such as anxiety or fear) or behavioral change (Biesecker and Peters, 2001).

#### Knowledge growth

failure

(+++R/+V)

- The fact that a rather large proportion did not know whether or not they would make use of a predictive test reflects the unfamiliarity and doubt about the issues (Decruyenaere et al., 1993).
- The majority of participants eligible for DNA testing thought they would go ahead with it. Several studies of breast cancer have shown that more people say they are interested than actually have genetic testing (Collins et al, 2000b).

(++R/+V)

- We found that, despite having been given objectively similar information, the women had different perceptions of many aspects of the counselling session: the recurrence risk, the aetiology, whether the counsellor had suggested a particular course of action, and whether counselling had clarified the decision for them (Welshiner and Earp, 1989).
- The counselling style was content-oriented, implying that his interactions with the counsees tended to significantly favour attention to factual information rather than to affective and expressive material and process issues [...] it is highly likely that virtually every session would show a major focus on the provision of factual information (Kessler and Jacopini, 1982).
- Most (79%) respondents indicated they would participate in genetic counselling related to the predictive test but only 22% said they had seen a genetic counsellor prior to the survey (Meissen and Berchek, 1987).

(R/+V)

- The present data suggest that despite the many articles, pamphlets, and programs explaining the recently developed predictive test, many potential users of the test remain inadequately informed about what the test consists of and its limitations in terms of informativeness and accuracy. This suggests that considerable attention will need to be given to more effective educational methods and to the problem of obtaining informed consent for predictive testing (Kessler, 1987).

(++R/-V)

- [...] data suggest that anywhere from 20 to 75 percent of counsees either do not remember or understand the information they receive [...] These investigators found that among counsees who had an inaccurate precounselling knowledge of the pertinent diagnosis, over 60 percent continued to have an inaccurate or marginally accurate level of knowledge after genetic counselling (Kessler, 1980).
- Female respondents expressed high levels (telephone survey) of interest (93%) in learning about genetic testing for breast cancer, but only 53% of them indicated that they had a good or excellent understanding of genetics (Pasecreta et al., 2002).
- Although the condition was perceived to be genetic, genetic status was seen as transient, so a result today could not predict the future. The condition was also seen as caused by factors other than genes, so information about only one risk factor could not be reassuring [...] These results suggest that some individuals receiving negative test results are not reassured because of their representations of the cause of their condition and the nature of the tests they undergo. It may be that eliciting, and when appropriate, changing people's representations prior to testing may enable those receiving negative results to be more reassured about their residual risk (Michie et al., 2003).
- Because of the fundamental complexity of risk communication, the ethical goal of informed consent for genetic testing, even when such consent is obtained as part of an ideal education and counseling process, may be more illusory than real [...] upon hearing that one in 250 people will develop a certain type of cancer, participants wondered if that is 'a lot or a little'. Participants reacted negatively to language that they could not understand, including terms like 'four fold' and 'lifetime risk' [...] The genetic testing paradigm does not define risk in the way most individuals define risk. Rather than answering the questions 'Will I or won't I get the disease? What will it look like? When will I get it?' testing reveals numbers that align a person with an impersonal category [...] The very process of taking risk numbers and converting them into colourful graphs and charts presented in easy-to-read patient education brochures creates the idea that the information is certain (Koenig and Silverberg, 1999).
- In the end, testing will not provide the kind of certainty they the lay public may expect or desire, but it can substantially improve risk estimates for certain families and individuals (Cole et al., 1996).

**Notion of knowledge**

success

(+++R/+V)

- Although both optimism and self-esteem contribute significantly to the prediction of anxiety, even when all other variables are entered into the regression equation before them (Michie et al., 2001), neither were found to moderate the associations between test result and test or anxiety. These test results suggest that it is not general dispositional factors that influence emotional response to genetic testing, but more specific cognitions related to the illness and the test, and the family context (Michie et al., 2003).
- Thus in this meta-analysis, we demonstrated the efficacy of genetic counselling in meeting two of its objectives: reducing women's anxiety levels and improving the accuracy of their perceived risk (Meiser and Halliday, 2002).

(++R/-V)

- Positive illusions may also facilitate some aspects of intellectual functioning by means of positive mood, although this possibility has not been tested directly [...] Evidence relating beliefs on personal control to motivation,

persistence and performance comes from a variety of sources. Research on motivation has demonstrated repeatedly that beliefs on personal efficacy are associated with higher motivation and more efforts to succeed [...] The individual who responds to negative, ambiguous, or unsupportive feedback with a positive sense of self, a belief in personal efficacy, and an optimistic sense of the future will, we maintain, be happier, more caring, and more productive than the individual who perceives this same information accurately and integrates it into his or her view of the self, the world, and the future (Taylor and Brown, 1988).

- Exploration of genetic counselling sessions indicates that counselees frequently create their own mental scenarios. [...] They may also assist counselees in exploring and clarifying feelings, may lead to a reduction in 'ruminations' over alternatives and lead to increased satisfaction with ultimate decisions (Arnold and Winsor, 1984).

(+R/-V)

- Lazarus and Folkman [1984] distinguish two basic forms of cognitive appraisal, primary and secondary. Primary appraisal refers to an individual's initial evaluation of an encounter with the environment as irrelevant, benign, or stressful. Stress appraisals include harm, threat and challenge [...] Secondary appraisal refers to an individual's evaluation of what might and can be done about the threat. These often include behaviours intended to deal with the threat itself or its possible consequences. Secondary appraisals therefore include judgements and decisions concerning the wide array of coping options faced by the individual (Croyle, 1992).
- Outcome studies in psychotherapy have assessed the potential benefits that constitute observable changes in clients. These include improved psychological well-being, understanding information, satisfaction, work and social adaptation, reduction of symptoms (such as anxiety or fear) or behavioral change (Biesecker and Peters, 2001).

#### Notion of knowledge

failure

(+++R/++V)

- Patients' expectations of future bowel screening after receiving negative predictive genetic test results is associated both with the specialty of the health professional giving the test results and the country in which the test is conducted (Michie et al., 2002b).

(+++R/+V)

- A patient-structured counselling method, designed to minimize negative psychological effects via discussion of feelings, was not superior to conventional and programmed methods, described in our previous reports, in terms of learning or attitude change (Rowley et al., 1984).

(++R/-V)

- A model is proposed that predicts long-term distress when risk analysis suggests a very high risk, when uncertainty is not reduced, when results of testing are at odds with preventive actions already taken, and when people who receive a positive, risk-increasing result lack strong social support, coping skills, other psychosocial resources, or all these [...] Uncertainty about whether one will develop breast cancer cannot completely be assuaged by genetic testing, and worries about when and if one will become ill may not appreciably be altered. This difference between breast cancer and Huntington's disease risk assessment is important because one of the major psychological benefits of genetic testing is reduction of uncertainty. To the extent that genetic testing can reduce uncertainty about the disease, it can help reduce distress and its sequelae (Baum and Zakowski, 1997).
- Indicating that individuals who do not proceed with testing tend to perceive themselves as being less capable of dealing with a positive test outcome (or increased risk), or possibly feel inadequate to deal with the anxieties that the testing protocols may engender. Conversely, test participants perceive themselves as being able to cope with the situation (Kessler, 1994).
- Although the condition was perceived to be genetic, genetic status was seen as transient, so a result today could not predict the future. The condition was also seen as caused by factors other than genes, so information about only one risk factor could not be reassuring [...] These results suggest that some individuals receiving negative test results are not reassured because of their representations of the cause of their condition and the nature of the tests they undergo. It may be that eliciting, and when appropriate, changing people's representations prior to testing may enable those receiving negative results to be more reassured about their residual risk (Michie et al., 2003).

#### Knowledge use

success

(+++R/+V)

- Reasons for taking the test centred on the reduction of anxiety and uncertainty associated with being at risk and enhanced planning and decision making (Meissen et al., 1991).
- The 3 main reasons for applicants to take the test were planning a family and either relieving uncertainty or obtaining certainty (Tibben et al., 1993).

- Thus when people believed they would be exposed to danger [...] their intentions were stronger if they believed either a) they could perform the coping response or b) the coping response could effectively avert the danger [...] When confronted with a threat, people 'satisfied' it by intending to adopt the recommended coping response when, from a strictly logical perspective a) the response is not really necessary (the precaution strategy) and b) the danger cannot be avoided (the hyperdefensiveness strategy) (Maddux and Rogers, 1983).
  - Attendance at this familial colorectal cancer clinic alleviated worry for many individuals, partly due to improved information about the risk of colorectal cancer [...] Most clients feel their information needs are adequately met and an increase in knowledge of colorectal cancer genetics after attendance at the clinic has been demonstrated (Collins et al., 2000).
- (++R/+V)
- Surprisingly, knowledge about predictive testing was quite low and a majority of those least knowledgeable about predictive testing intended to use the test. These findings emphasized the need for outreach and prevention efforts to prepare the risk and specialized programs of genetic counselling and follow up to accompany predictive testing (Meissen and Berchek, 1987).
- (+++R/-V)
- Many clients said that genetic counselling resulted in improved communication with their partners and other family members [...] Genetic counselors agreed that helping clients reach decisions is an important goal of genetic counseling and that a 'good' and autonomous decision should be an outcome [...] In our study (authors, mvs), the majority of genetic counselors said that meeting client expectations was the most important goal of genetic counselling [...] There seems to be an assumption by both clients and counselors that knowledge and understanding can lead to increased control over the situation and a reduction in stress [...] Within the therapeutic relationship, there are short- and long-term goals of genetic counselling. Short-term outcomes relating to the process of genetic counselling that were voiced by participants in this study include a client's sense of being heard, encouraged, valued, supported and attended to. Longer term outcomes cited by study participants include improved communication about genetic issues within the family, anticipation of feelings or experiences stemming from future events, and clarifying values underlying decisions or attitudes (Bernhardt et al., 2000).
- (++R/-V)
- One of the major aims of genetic counselling is to facilitate the decision making of the counselee. This can be done by transforming the genetic data into information that is relevant for the decision under consideration and by providing a framework for utilizing the information in a way that would lead to a decision most compatible with the counselees' values (Shiloh, 1994).
  - Effective genetic counselling eventually leads to accommodation and hence to changes in cognitive, affective and behavioural functioning, which is the same goal as any other counselling (or psychotherapeutic way) process [...] One of the new perspectives offered by a psychological-oriented genetic counselling is more realistic exposition of the goals of genetic counselling (Kessler, 1980).
  - If little (treating or preventing, mvs) can be offered, most people do want information about their risk status (Bleiker et al., 2003).
- (+R/-V)
- The results of the studies presented also suggest that emotional responses to health threats are governed by a different process than the one guiding long-term behavioural planning. In many situations, the two are not highly correlated and are determined by different factors. This pattern of data is best accounted for by Leventhal's self-regulation model of coping. According to the self-regulation model, the processing of a health threat occurs along two parallel and semi-independent pathways. One involves emotional responses to the threat (e.g. fear) and the other involves a cognitive representation of the objective features of the threat itself (e.g. contagious disease). Therefore, an individual who is facing the threat of illness must cope with his or her emotional reaction to the illness and with specific dangers posed by the disease (Croyle, 1992).

#### Knowledge use

##### failure

(++R/+V)

- The majority of those women who exhibited an increased risk perception were also those who overestimated their probability of personally contracting the disease. They underwent recommended screening examinations significantly less often than women with a low risk perception. However, women subjected to intense psychological strain showed above-average participation in screening programs (Neise et al., 2001).

(+++R/-V)

- The goals of genetic counseling are often unclear to both provider and to the client (Bernhardt et al., 2000).

(++R/-V)

- Most individuals with a family history of cancer (including those at low to moderate risk) overestimate their personal cancer risk [...] Awareness and recall of the risk information of genetic testing is limited (Bleiker et al., 2003).
- In theory, genetic testing of presymptomatic patients at risk for late-onset hereditary disease is intended to help them make informed decisions about health care and to influence their self care. But several aspects of genetic testing for breast cancer and ovarian cancer risk render its potential benefits uncertain and make its psychosocial aspects especially compelling (Pasecra et al., 2002).
- It is likely that some of those who receive negative test results will be so relieved by them that they are no longer motivated to participate in screenings and other early detection activity. Even when stress is not enhanced by the testing and test results, adherence with surveillance programs may suffer after testing (Baum and Zakowski, 1997).

( +R/-V)

- At present there are significant limitations in conducting meaningful outcome studies in genetic counseling [Clarke et al., 1996; Bernhardt et al., 2000]. First, there is a lack of consensus on the clinical goals of counseling and therefore, its desired outcomes. Second, client goals can be discrepant from those of providers (Biesecker and Peters, 2001).

#### Conclusions on outcome according to the unconsolidated literature

In the most relevant and valid literature it is stated that on the one hand, being knowledgeable enhances the feeling of having control of one's own situation (Meissen et al., 1991; Tibben et al., 1993), but on the other hand, being knowledgeable can enhance anxiety (Collins et al., 2000).

If we take the less relevant and valid literature into account then the research of Taylor and Brown (1998) is interesting. They found that self-efficacy coincides with motivation, which we have already learned from the consolidated literature.

If we compare the above to biomedical science communication on predictive DNA diagnostics we see that knowledge is something that must be treated with care. When a severe genetic disease is in question, the process of knowledge transfer or transaction must be carefully designed, especially when self-efficacy is close to motivation.

### 4.9.4 Context

In the case of the context of health communication, we differentiate between individual and societal, as we did in chapter 3.

#### Individual success

(+++R/+V)

- We (the authors, mvds) found no association with sociodemographic variables [...] The possibility of having some certainty about the future and the need to know things in advance seem to play an important stimulating role in the attitudes towards predictive tests (Decruyenaere et al., 1993).
- The main reason (60%) for taking the test was for family planning. Other reasons were either to reduce uncertainty (43%) or to obtain certainty (38%) [...] the general impression is that the current group of candidates is self-selected, highly motivated, well educated and mentally resourceful (Tibben et al., 1993).
- Worry about bowel cancer was positively associated with younger age, higher education level and higher perceived risk of developing cancer [...] Of those intending to go ahead with DNA testing, 58% were 'very worried' about bowel cancer compared with 15% of those not intending to proceed with testing, suggesting that worry was a motivation for interest in DNA testing [...] When stratified by a personal history of bowel cancer, about 50% of both those with and those without a previous diagnosis were very worried about bowel cancer. After the clinic, the proportion had dropped to 32% in those without a previous history, but had stayed much the same (47%) for those who had a previous history [...] it is important to consider worry in the context of familial colorectal cancer, not only with respect to the emotional well being of clients, but because anxiety and stress can impede the

comprehension of information and interfere with decision making. Worry may also impact on screening behaviour and decisions regarding genetic testing [...] We were not able to measure how worry will impact on screening behaviour, but our measure of worry appears to be a motivating factor in the intention to undergo genetic testing, as is risk perception [...] It should also be noted that worry and risk perception are only partly predictive of whether an individual will adhere to screening recommendations or undergo genetic testing. Individual psychological factors, such as perceived behavioural control, coping style and self-efficacy, are likely to be important, as well as the influence of normative beliefs, i.e. beliefs about what significant others (such as physicians) think is the right action and the lack of barriers to accessing screening or genetic testing. [...] More younger than older people were very worried about bowel cancer and other cancers (Collins et al., 2000b).

(++R/+V)

- The data suggest how prior reproductive attitudes and expectations for counseling influenced the mothers' understanding of information [...] Our initial test of the model suggests that beliefs about personal and family life, not genetic and medical factors, are the key considerations around which decision-making revolves. We provide additional empirical evidence that pre-existing attitudes and beliefs are of critical importance to a decision-making process (Welshiner and Earp, 1989).
- Of the 36 participants who intended to be tested, 21 (58%) wished to be able to better plan the future in general and 6 (17%), all of childbearing age (35 or less), wished to know specifically for family planning. Another 15 (42%) wanted to eliminate doubt and worry. Surprisingly, 12 (33%) indicated they simply wanted to know as their primary reason and 5 (14%) said they had no reason but definitely intended to be tested, 6 (43%) were afraid of adverse emotional reactions, and 4 (29%) did not have a reason but did not wish to be tested. Only one participant indicated that the incurable nature of HD was the reason he wished not to be tested (Meissen and Berchek, 1987).
- The thinking in health psychology is that patients' willingness to adopt preventive health behavior is contingent on their perceiving an increased risk of disease and is influenced by accompanying psychological stress [...] 21% of women participating in recommended screening programs show minor psychological strain, 27% show medium psychological strain and 31% show intense psychological strain. Low participation rates are more often found in women with minor and medium psychological strain than in women with intense psychological strain (31% and 48% vs. 19%) [...] Previous personal experience and the perceived controllability of an event are important for the development of the optimistic bias (Neise et al., 2001).

(+/R/+V)

- However, at-risk persons who were married for less than 10 years and, presumably, had not yet completed their families, showed significantly greater interest in taking a predictive test than persons married for longer periods of time (Kessler et al., 1987).

(++R/-V)

- Studies have found that the interpretation of risk data is not uniform; rather it is subjective, displaying interpersonal variance based on the attributes of the person receiving information (Lippman-Hand and Fraser, 1979; Wertz et al., 1984; Shiloh and Sagi, 1989). The personal attributes that affect and interact with an individual's perception of risk information include: their ideas about who is vulnerable to a risk, their own experience with the disease, their level of comfort with mathematics, their interpretation of probability statistics as well as verbal statements, their personality and mood and their willingness to engage with potentially threatening information (Kessler and Levine, 1987; Davison et al., 1991; National Council on Aging, 1997) [...] Given the high prevalence of AD and the fact that a positive family history is popularly understood to be a risk factor, some individuals have ideas about how 'at risk' for an illness they are (Koenig and Silverberg, 1999).
- If Bandura is right, the success of cardiac or other rehabilitation programs may depend as much on increasing self-efficacy to perform as on increasing physical ability to perform (Rosenstock et al., 1988).
- According to the anchoring bias, counselees will judge their recurrence risks according to their expectations, but their final appraisals, although closer to the 'real' risk, will still be influenced by their prior conceptions (Shiloh, 1994).
- Research suggests that most people are future oriented [...] an individual's social and cognitive environment may not only fail to undermine positive illusions but may help maintain or even enhance them through a variety of mechanisms (Taylor and Brown, 1988).
- Recent research indicates several factors in common among people who have a great interest in genetic testing for breast and ovarian cancer risk: many female relatives affected with breast cancer, a high school or higher education level, health insurance, being female and white, and the perception that the benefits of testing outweigh the financial and emotional costs [...] Many factors have been identified as predictive of whether women of families with hereditary breast and ovarian cancer will actually undergo genetic testing, including: 1) a known familial mutation; 2) wanting information for the benefit of family members; 3) concerns about insurance or job

discrimination; 4) a lower level of optimism; 5) greater cohesiveness within the family, which may motivate its members to help other members by undergoing genetic testing (Pasecra et al., 2002).

(+R/-V)

- A recent pilot study of couples undergoing preimplantation genetic diagnosis (PGD) indicated that the personal beliefs, attitudes and values of the clients were powerful reinforcers of the importance of pursuing the technology (Leib, 2001) (Biesecker and Peters, 2001).

#### Individual

failure

(+++R/+V)

- Optimism and self-esteem were not found to moderate the associations between the test result and threat, test result and anxiety, or between threat and anxiety (Michie et al., 2002).

(++R/+V)

- Awareness of an increased personal risk of developing the disease and increased psychological strain always correlate with an intensified feeling on breast cancer screening. On the contrary, the awareness of being at significantly greater risk than the average population can trigger a feeling of loss of control and of helplessness among affected women. This in turn can discourage the patient from undergoing recommended early detection procedures based on patient risk. Perception of low risk can have a similar effect as the patient may feel that special precautionary behavior is not necessary in the light of low risk. According to this, participation in recommended screening programs would probably be high among women experiencing medium psychological strain who perceive their risk as average (Neise et al., 2001).

(++R/-V)

- Decision-making about genetic testing is strongly influenced by perceptions of personal cancer risk and less so by actual risk based on genetic testing [...] Perceptions of personal risk of cancer are resistant to standard education and counselling approaches [...] psychological distress and coping processes influence the processing of risk information and subsequent decision-making in genetic testing (Bleiker et al., 2003).
- In theory, genetic testing of presymptomatic patients at risk for late-onset hereditary disease is intended to help them make informed decisions about health care and to influence their self care. But several aspects of genetic testing for breast cancer and ovarian cancer risk render its potential benefits uncertain and make its psychosocial aspects especially compelling [...] Female respondents expressed high levels (telephone survey) of interest (93%) in learning about genetic testing for breast cancer, but only 53% of them indicated that they had a good or excellent understanding of genetics (Pasecra et al., 2002).
- There was not a developed understanding of how the genetic test worked. To know that the test was scientific appeared to be sufficient [...] It is possible that people use similar constructs to evaluate tests as they do to evaluate treatments (Michie et al., 2003).
- Straightforward mathematical ability, or lack thereof, may compound the problem of reaching consensus on the meaning of risk [...] It is well known that individuals and whole communities have demonstrated resistance to the imposition of medical explanations of disease that conflict with their own beliefs and experiences (Koenig and Silverberg, 1999).
- Decisions related to genetic testing are fundamentally social decisions, dictated by personal preference rather than by medical indications (Burke et al., 2001).

(+R/-V)

- [...] many important health decisions are made with incomplete information under conditions of high uncertainty. As such illness-related appraisals are likely to be affected by a wide variety of both personal and social psychological factors [...] The study of illness-related appraisal therefore can contribute to our understanding of both the psychology of illness and the social psychology of appraisal processes in general (Croyle et al., 1992).

#### Societal

success

(++R/-V)

- Some counsellors emphasize facts, others focus on the various meanings that facts have for clients (Reif and Baitsch, 1985).
- These differences in test uptake between countries may reflect cultural differences in attitudes toward genetic testing and risk-reducing surgeries, differences in the clinical facilities available for the management of familial cancer, differences in source of recruitment, differences in the social consequences of genetic testing (Bleiker et al., 2001).
- Two important influences on the development of these representations are the person's direct experiences of their illness and health care, and cultural information that helps them organize such experiences (Michie et al., 2003).

(+R/-V)

- We (the authors, mvds) found that the gene test is imbued with meaning beyond the determination of gene status in families who choose testing. The at-risk patient has preformed, well-entrenched conceptions of what having FAP (familial adenomatous polyposis) or colorectal cancer entails, and family and relationships and identity may be strongly linked with disease or gene status (Petersen and Boyd, 1995).

**Societal**

failure

None

**Conclusions on context according to the unconsolidated literature**

As in the consolidated literature, in the unconsolidated literature the notions and ideas of the audience influence the way communication on predictive DNA diagnostics is developed (Shiloh, 1994; Welshiner and Earp, 1989). Self-efficacy plays a central role (Rosenstock et al., 1988), as we also saw in chapter 3. However, in health psychology self-efficacy is approached through risk and anxiety (Neise et al., 2001; Collins et al., 2000b). In the process of choosing to undergo a genetic test, the individual's context and ideas about life are far more important than information on genetics itself (Welshiner and Earp, 1989). The less relevant literature describes SES factors such as educational level, age and gender, which also have an influence.

**4.10 Conclusion and discussion: theoretical framework step 2**

Looking at the conclusions drawn from the unconsolidated literature, there is nothing new we can add to the conclusions drawn from the consolidated literature (communicametric formula) regarding biomedical science communication on predictive DNA testing. Also, the training of health professionals mentioned by Michie et al. (2002) is already taken into account in chapter 3. However, the unconsolidated health psychology literature makes clear which elements of the formula must be emphasised based on literature with convincing power. Moreover, the opportunity to ask questions should be incorporated into the model. The formula therefore should be expanded with a module on communication strategy and communication means that logically follow from the outcome of the formula.

The opportunity to ask questions and its consequences are described in Fig. 4.4. If we know which part of the formula asking questions has the strongest influence upon, i.e. self-efficacy, then we know for the case of biomedical science communication on predictive DNA diagnostics which elements interactivity should focus upon in order to enhance empowerment. Candidates for enhancement obtained from the unconsolidated literature are:

- self-efficacy;
- asking questions;
- family members seen as the most reliable source;
- means should be tailor-made;
- knowledge/information is something to be treated with care, for it may raise anxiety.

One can conclude that if there is no information on these subjects with regard to a target audience or if there is not yet contact with the target audience from which insight into these subjects can be obtained, biomedical science communication might not be effective.

Regarding the main research questions we can conclude that biomedical science communication can be strengthened by the health psychology domain. Furthermore, it becomes clear that health psychology is indeed

a fundamental domain in the field of biomedical science communication because the results obtained from the consolidated and unconsolidated literature fit into the levels and purposes of the results of chapter 3. The metric formula and the empowerment diagram (Fig. 4.4) should be situated in Fig. 3.14 at the level of needs assessment and at the level of communication strategy. The empowerment diagram deepens and broadens the ideas concerning dialogue, forming, persuasion, informing, transmission and transaction. It becomes obvious that the structure, process, outcome and context of biomedical science communication are highly complex, as a result of the many possibilities of level and purpose. And again, information seems not to be the most important component in biomedical science communication on predictive DNA diagnostics. In the next chapter, on (medical) commercial communication (advertising), a distinction is made between the issue (predictive DNA diagnostics) and issue-relevant and issue-irrelevant information.

