

# Chapter 3

Theoretical foundations obtained from health communication

*'There is nothing as practical as a good theory.'*

*(Tones and Tilford, 1994)*

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## Preface

This chapter focuses on the comparison between health communication and biomedical science communication at the level of concepts, theories, models, constructs and variables. Health communication differs from biomedical science communication in its domain. After a short introduction in which the rationale for choosing health communication is explained, the results of the consolidated and unconsolidated literature search are described, in section 3. How is the domain of health communication categorized? Which theories are used? This information has been obtained from an analysis of the consolidated literature and has been analysed for structure, process, outcome and context, divided into variables of success and failure. This section concludes with a proposal for a provisional theoretical framework for effective biomedical science communication. In section 4 the unconsolidated literature is analysed and the new insights obtained are added to the 'consolidated model'. In section 5 this model will be discussed and the relation between health communication and biomedical science communication will be explained.

### 3.1 Introduction

In this chapter health communication is compared with biomedical science communication. The central question in this chapter is: which variables of effective health communication processes in the field of predictive DNA diagnostics lead to success or failure with regard to structure, process, outcome and context? And which of these variables could be used in developing an effective biomedical science communication process? For example, are the socio-economic variables that are important to the process of health communication relevant to biomedical science communication as well?

Why health communication? As stated in chapter 1, health communication is a communication domain that is practically and theoretically close to biomedical science communication. However, the domain differs: Health communication is about health and biomedical science communication is about biomedical research. Health communication aims to promote health by influencing human behaviour in a broad sense (Pieterse et al., 2000; Waarlo, 1997; Waarlo, 2005). Moreover, this communication domain has a relatively long tradition (compared to biomedical science communication) of communicating with a lay audience on many health aspects. This tradition can be seen in theoretical developments as well as in practical achievements, which offer much to learn from. Using health communication as a theoretical and effective practical example, it is possible to learn which questions are there to be asked to enhance the effectiveness of biomedical science communication.

Health, the central issue of this chapter, is broadly defined. Many authors refer to the definition used by the World Health Organization (WHO): health is a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity. In this chapter, 'health' is taken to be more than the absence of illness, and the mental and social factors of well-being are taken into account in the analysis as well. As described in chapter 1, genetics and predictive testing need more than just routine attention. The current practice of health communication, analysed in the first sections of this chapter, is usually determined by the need to improve health knowledge in order to influence the health behaviour of individuals. However, as many researchers in the field attest, motivation is a key factor, and motivation is not increased by information only. Motivation is an interplay of affective and cognitive factors (Pieterse et al., 2000).

### 3.2 Literature search

As described in chapter 2, both the consolidated and the unconsolidated literature have been searched. The main focus is on the variables for success and failure within the process of effective health communication with regard to structure, process, outcome and context. We spoke with two Dutch experts in this field, Prof. A.J. Waarlo (Professor of Genetics and Health Communication, Utrecht University)<sup>1</sup> and Dr. M. Pieterse (Senior Researcher at the Netherlands Institute for Health Promotion and Disease Prevention) to get an idea of the main focus in health communication and the most important theories, models and concepts being researched in the field of health communication. We then searched and selected consolidated and unconsolidated literature which is of course our responsibility.

<sup>1</sup> Affiliation at the time the experts were interviewed.

Table 3.1 depicts the results from the consolidated literature search.

Table 3.1: Results of a search of consolidated literature on health communication. The search terms are in Dutch and English. We began our search with the library at Erasmus University Rotterdam and also looked at the search strings with high-level hits in two other university libraries.

Relevance	Key words <sup>2</sup>	EUR <sup>3</sup>	VUA <sup>4</sup>	UU <sup>5</sup>	
+++	Gezondheidsvoorlichting AND voorspellende DNA-diagnostiek AND effectiviteit	0	0 (ml <sup>6</sup> )		
+++	Gezondheidseducatie AND voorspellende DNA-diagnostiek AND effectiviteit	0	0		
+++	Health education AND predictive DNA diagnostics AND effectiveness	0	0		
+++	Health promotion AND predictive DNA diagnostics AND effectiveness	0	0		
+++	Health prevention AND predictive DNA diagnostics AND effectiveness	0	0		
++	Health information AND DNA diagnostics	0	0		
++	Health information AND genetics	0	1		
++	Health communication AND DNA diagnostics	0	0		
++	Health communication AND genetics	0	0		
++	Gezondheidsvoorlichting AND voorspellende DNA diagnostiek	0	0		
++	Gezondheidseducatie AND voorspellende DNA diagnostiek	0	0		
++	Health education AND predictive DNA diagnostics	0	0		
++	Health promotion AND DNA diagnostics	0	0		
++	Ill health prevention AND DNA diagnostics	0	0		
++	Gezondheidsvoorlichting AND effectiviteit <sup>7</sup>	0	0		
++	Gezondheidseducatie AND effectiviteit	0	0		
++	Health education AND effectiveness	2	1		
++	Health promotion AND effectiveness	1	1		
++	Ill health prevention AND effectiveness	0	0		
+	Health information	50	30		
+	Health communication	4	2		
+	Gezondheidsvoorlichting	13	9	45	32
+	Gezondheidseducatie	1	2 <sup>8</sup>	10	10
+	Health education	70	61	855	1062
+	Health promotion	27	30	81	39
+	Ill health prevention	22	30	97	0
+	Voorspellende DNA-diagnostiek	0	0		

<sup>2</sup> We searched by using several different combinations of key words. Key words were obtained from conversations with the experts and were expanded upon by searching the literature. There are probably many more key terms to be selected, but for practical reasons we selected only a few.

<sup>3</sup> We searched the general catalogue and the medical catalogue of Erasmus University Rotterdam. We used the searched command 'all words'.

<sup>4</sup> VU University Amsterdam

<sup>5</sup> Utrecht University

<sup>6</sup> Medical Library, Erasmus University Rotterdam

<sup>7</sup> This is a powerful set of key words, since the search term A AND term B AND term C generates 0 hits and the search term A AND term C = 0 hits; term B does not determine the number of hits so there is no need to search for hits by using: predictive genetic testing; clinical medicine; medical genetics; genetic counseling; health behaviour; illness behaviour; mass screening; cancer screening; health screening; preventive medicine; genetic disorders; genetic linkage; hereditary disease; genotypic prevention; genetic susceptibility; genetic information; or pre symptomatic DNA diagnostics, since the combination with health communication and effectivity does not occur in the library's catalogue.

<sup>8</sup> There are big differences between the different libraries. By adding a search of a domain-specific library and a general library to Fig. 3 in the Science Communication article of chapter 2, most books are likely to be found.

+	Predictive DNA diagnostics	0	0		
+	DNA-diagnostiek	1	1		
+	DNA diagnostics	0	1		
++	Gezondheidsvoorlichting AND voorspellende geneeskunde AND effectiviteit	0	0		
++	Gezondheidseducatie AND voorspellende geneeskunde AND effectiviteit	0	0		
++	Health education AND predictive medicine AND effectiveness	0	0		
++	Health promotion AND predictive medicine AND effectiveness	0	0		
++	Illness prevention AND predictive medicine AND effectiveness	0	0		
++	Gezondheidsvoorlichting AND voorspellende geneeskunde	0	0		
++	Gezondheidseducatie AND voorspellende geneeskunde	0	0		
++	Health education AND predictive medicine	0	0		
++	Health promotion AND predictive medicine	0	0		
++	Illness prevention AND predictive medicine	0	0		
+	Voorspellende geneeskunde	3	0		
+	Predictive medicine	0	0		
++	Effectiviteit AND voorspellende DNA-diagnostiek	0	0		
++	Effectiveness AND predictive medicine	0	0		
+	Public health genetics	0	2		
+	Public health communication	0	0		
+	Presymptomatic DNA diagnostics	0	0		
+	Medical genetics	0	39		
+	Genetic counselling	5	0		
+	Cancer screening	9 <sup>9</sup>	8		
+	Health screening	3	8		
+	Preventive medicine	14	10	154	179

From the search we can conclude that there is no highly relevant (+++) consolidated literature on health communication, predictive DNA diagnostics and effectiveness to be found, neither is there much literature to be found on the topic of effectiveness.

Our search of the consolidated literature led to the formulation of two new strings of key words, health communication and health information. These were then used for searching the consolidated literature and were automatically integrated into the search strings for the unconsolidated literature. For the search in databases we made use of two specialized databases, Cochrane Library and PubMed, and two less specialized databases, Web of Science and Current Contents. See Table 3.2.

<sup>9</sup> Refers to scientific journals.

Table 3.2: Results of the search of the unconsolidated literature.

Relevance	Key words	Web of Science <sup>10</sup>	Current Contents <sup>11</sup>	Cochrane <sup>12</sup>	PubMed <sup>13</sup>
+++	Predictive DNA diagnostics AND health AND promotion AND effectiveness	0	0	0	0
+++	Predictive DNA diagnostics AND health AND promotion	0	0	0	0
+++	Health promotion AND predictive DNA diagnostics	0	0	0	0
++	Health promotion AND DNA diagnostics	0	0	0	0
++	Predictive DNA diagnostics	1	0	0	37
++	Predictive DNA diagnostics AND health	0	0	0	3 <sup>8</sup>
++	Health AND genetics AND promotion AND Dutch	1	0	1	2
++	Health AND genetics AND promotion	15	0	13	158
+++	Genetics AND health education AND Dutch AND effectiveness	014	0	1	7
++	Health information AND DNA diagnostics	015	0	0	1
++	Health information AND genetics	616	2	3	81
++	Health communication AND DNA diagnostics	017	0	0	0
++	Health communication AND genetics	118	0	0	1
++	Genetics AND health education	7	0	14	785
++	Health AND genetics	1136	17	421	17.992
+	Health promotion	5080	545	1349	18.920
+	Health communication	20119	70	26	231
+	Health information	152820	180	148	60200
+	Health promotion AND genetics	12	4	6	114
+	Predictive DNA diagnostics	1	0	0	30
+	Genetics AND education	356	4	62	3913
+	DNA diagnostics <sup>21</sup>	121	1	7	1254
++	Health promotion AND effectiveness	454	47	487	1033
++	Health education AND effectiveness	353	28	548	2636

<sup>10</sup> Web of Science search 31/5/2002 (all years with no limitations). Web of Science consists of: 1) Science Citation Index; 2) Social Science Citation Index; 3) Arts & Humanities Citation Index.

<sup>11</sup> Search for literature in Current Contents dated between 1999/10/02 – 2001/12/10.

<sup>12</sup> In Cochrane we used the MeSH term *health promotion*. This generated 1349 references, of which 58 were found in the DARE database (Database of Abstracts of Reviews of Effectiveness). The reviews are on different aspects of health promotion, such as smoking, diet, etc. When we added 'genetics' to the list of key words the number of hits was reduced to 6. If the number of hits cannot be reduced in this way, only the most recent articles were taken into account. The main practical restriction in searching literature databases like Cochrane is time. Although the aim of this research was not to review the health communication domain, we did try to duplicate some of the successes of health communication in a systematic way. For example, in the Cochrane Library we searched by using: health AND genetics AND promotion, which generated 13 hits, of which only 2 are relevant to our research question. An article on *Periconceptional supplementation with folate and/or multivitamins for preventing neural tube effects is less relevant to our research*.

<sup>13</sup> PubMed is a freely accessible database that includes MEDLINE. We conducted a full-text search with no limitations. We did not always search with MeSH terms, because the MeSH terms did not always correspond to our key words.

<sup>14</sup> Searched 24/08/2002: new key word.

<sup>15</sup> Searched 24/08/2002: new key word.

<sup>16</sup> Searched 24/08/2002: new key word.

<sup>17</sup> Searched 24/08/2002: new key word.

<sup>18</sup> Searched 24/08/2002: new key word.

<sup>19</sup> Searched 24/08/2002: new key word.

<sup>20</sup> Searched 24/08/2002: new key word.

<sup>21</sup> Primarily articles on applied biomedical science and fundamental biomedical science.

Our search of the unconsolidated literature showed that there was also little in the unconsolidated literature that was highly relevant (+++), though there are many publications (++) on health communication and effectiveness. The following section contains our analyses of the consolidated literature. It discusses the development of health communication as well as the theories and models used in this communication domain.

### 3.3 Health communication: the consolidated literature

Health has always been important for individuals (Kok and Van Empelen, 2000). Its importance is related to a social, cultural and physical context which plays a role in the effort taken by the individual to stay healthy (Pieterse et al., 2000). The social context consists of family, spouse and friends. The cultural context is influenced by nationality and physical context and consists, for example, of the health status of an individual. These contexts are constantly changing due to research or to societal and cultural changes. The expression safe sex was formerly connected to the warning not to get pregnant, now it is usually connected to AIDS prevention (Kok and Van Empelen, 2000). In addition, scientific knowledge concerning health is expanding, as is the need to disseminate this knowledge. Quality of life (Heuvelman and Van der Staak, 1992; Pieterse et al., 2000) has become an important driver for health communication, as well as the quality of health care (Holland et al., 1985), which includes unlimited access to public health services and protection from environmental hazards. By moving from purely physical health issues to communication on health in a broad sense, the communication process has also grown more complex in terms of the social and cultural aspects of health communication. On the one hand, this new complexity requires new communication strategies and processes for reaching the lay audience; on the other hand, it demands the innovative use of already existing strategies and means of health communication (Holland et al., 1985). This is in accordance with developments in biomedical science communication which has also had to cope with changes in the complexity of the process (as described in chapter 1). Due to developments indicated by medicalization and genetic essentialism, communication of factual information alone about genetics or predictive DNA diagnostics will not be sufficient to achieve a sustained behavioural response that is, a change or enhancement of behaviour.

#### 3.3.1 Definitions and modalities

Difficult as it is for public communication in general to generate a sustained definition - as depicted in chapter 1 - it is difficult for health communication in particular to generate a sustained definition as well. Although the use of multiple definitions indicates the plasticity of a domain it is confusing in formulating health communication aims, strategies, etc.

Health promotion, according to Thorogood and Coombes (2000), is slightly different from health education but is in accordance with the WHO's Ottawa Charter for Health Promotion (1986) which defines it as: the process of enabling people to increase control over and improve their health. Petersen and Waddell (1998) widen this definition and say health promotion is about how people function in a modern society with respect to their health. It concerns the sociology of illness, and deals with a shift from attention on the individual to attention on the individual in relation to society, where policy measures can be used or developed (Pieterse et al., 2000). Downie and Tannahill (1998) takes health communication somewhat further and writes: Health promotion comprises efforts to enhance positive health and reduces the risk of ill-health, through the overlapping spheres of health education, prevention and health protection. These are defined by Tannahill (1985) and MacDonald (1998) as:

- 1 health education: communication to educate both those in powerful positions and the community at large about positive health; for example, by means of health groups, campaigns and lobbies;
- 2 prevention of ill-health: measures to reduce the risk of disease, illness, disability or any other unwanted state of health; for example, screening for breast cancer;
- 3 health protection: stems from the more traditional public health approach: legal, fiscal and political measures, regulations, policies or voluntary codes to prevent ill-health and/or enhance wellbeing; for example, seat-belt laws, taxes on cigarettes and alcohol.

These different forms of health communication are not aims of health communication as such, as in improving health behaviour. Rather, they are to be considered as health communication *modalities*. Modalities are various ‘fields of action’ of health communication in which a distinct scope of aims is defined.

Using the multileveled character of biomedical science communication and its involvement with society as a starting point - as described in chapter 1 - we can make a similar categorization for biomedical science communication modalities: biomedical science promotion<sup>22</sup>, could be the overlapping sphere for biomedical science education, and prevention of biomedical science knowledge deprivation. Aims (like PUS, PAS, PES and PPS) and effects (like awareness and enjoyment) play a role in these three modalities.

However, in health communication the discussion of health communication modalities is still in full swing. Tones and Tilford (1994), for example, indicate that from an individual’s perspective health education might be synonymous with health promotion. Therefore we should carefully consider the idea of various modalities in the domain of biomedical science communication, by involving the notions of the target audience on health and predictive DNA diagnostics, for example. In the next section we focus on the interrelationship between the three modalities.

### 3.3.2 Three interrelated modalities

Due to the discussion on the differences between health promotion and health education we will focus first on health education to gain insight into different descriptions of this health communication domain.

From several definitions of health education it can be concluded that health education not only aims to increase the knowledge of individuals about health issues, but also aims to improve skills, such as information seeking. Green and Kreuter (1991, in Kok and Van Empelen, 2000) write:

*Health education is any planned combination of learning experiences designed to predispose, enable, and reinforce voluntary behaviour conducive to health in individuals, groups or communities.*

So health education is not only about increasing knowledge - it is also about lifestyle and individual behaviour in communities and society. The definition by Green and Kreuter also shows the planned nature of health education. Another definition, given by Simonds (1984), is:

*Health education is the process of assisting individuals, acting separately or collectively, to make an informed decision about matters affecting their personal health and that of others.*

This definition emphasizes the outcome of health education, whereas Green and Kreuter emphasize the process of health education. Moreover, the outcome of Green and Kreuter looks more like promoting healthy behaviour, whereas Simonds aims directly at making a decision (Pieterse, et al 2000).

Despite these differences, health education has clearly defined aims whereas health promotion focuses on more abstract aims.

<sup>22</sup> Biomedical science promotion should not be confused with the kind of promotion used within the marketing domain.

However, to make things even more complicated Tilford (1987) and Downie and Tannahill (1998) say that there is a seamless connection between the flow of information on the absence of disease (prevention/education), to health (education/promotion) to well being (promotion).

The same situation might exist between biomedical science promotion, biomedical science education and prevention of biomedical science knowledge deprivation. On the one hand, there is a clear difference between the aims of each; on the other hand, these different aims form a continuum of the possible aims and effects of biomedical science communication. This creates a continuity of biomedical science communication modalities and strategies, which is in accordance with the ideas of Van Ruler (1998). From Van Ruler's point of view these strategies do not need to be implemented in a linear way as we already described in chapter 1. In Fig. 3.1 this idea of a continuum of biomedical science communication modalities, aims, strategies and means is depicted:

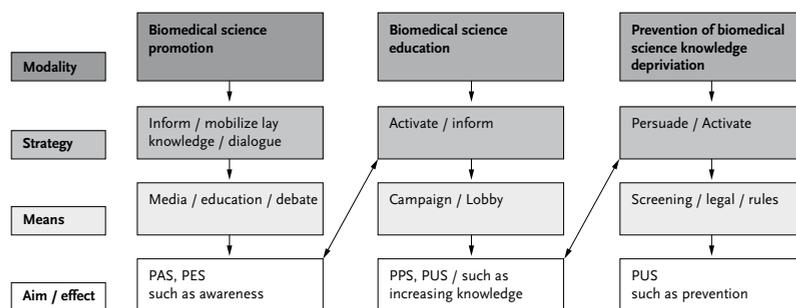


Fig. 3.1: The connections between the modalities of biomedical science communication suggested from descriptions and thoughts on health communication modalities. This flowchart provides one example of the way biomedical science communication modalities are different, as well as how they are connected in terms of aims and strategies. The aims are obtained from Van der Auweraert (2003) and the effects from different authors (described in chapter 1). The flow in this chart begins at the left: from biomedical science promotion, which can result in increased awareness by the target audience of the developments in predictive DNA diagnostics. From awareness it may be possible to activate the audience or to find a social basis from which to inform them, such as biomedical science education. When needed, where the knowledge of a target audience is increased, a prevention program may start in the case of prevention of biomedical science knowledge deprivation.

The modalities of biomedical science communication as depicted in Fig. 3.1 deepen and broaden the possibilities of biomedical science communication by making it possible to formulate more exactly the relationship and in time use of the different possible aims, effects, strategies and means. In other words, these modalities provide focus for the effort to construct an effective biomedical science communication process. The prevention modality does not often occur. In biomedical science there is a vague line between the prevention of ill health and the prevention of knowledge deprivation. For example the remark: '*contact with an electric current is bad for your health*', could be classed as the prevention of health damage or as the prevention of knowledge deprivation. So could a newspaper infographic warning hikers of the dangers of dehydration and the need to drink water during the *Avondvierdaagse* (a four-day, 40 km/day walking tour held in the Netherlands)<sup>23</sup>. Biomedical science communication or health communication? Where is the demarcation line? This question will become clearer in the following sections and is one of the main research questions of this thesis. Fig. 3.2 depicts a modification of Fig. 1.3, in which the different modalities of biomedical science communication and their aims are shown in a diagram of choices that makes the modalities and targets more dynamic.

<sup>23</sup> In 2006 two people died from heart attacks during the *Avondvierdaagse* due to extreme heat. The organization then decided to stop the popular hiking tour.

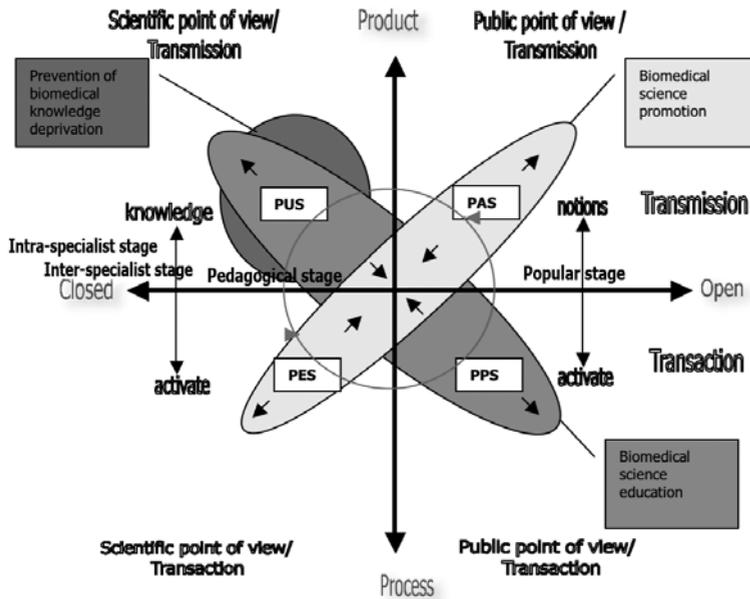


Fig. 3.2: Diagram of biomedical science communication choices based on Fig. 1.3 (targets of science communication, Auweraert 2003). In this diagram the different goals of science communication (PAS, PPS, PES, PUS) are placed into a biomedical science communication modality (biomedical science promotion, biomedical science education and prevention of biomedical knowledge deprivation). Continuity is depicted by the circle in the middle as well as the different stages of the communication process. These stages differ in their communication aims and their activation of knowledge and notions. One can see that transmission, transaction, open and closed communication are represented in every modality. One can even move from transmission to transaction and from open to closed quite easily on this axis because the space of complexity and the problem space will probably not change; only the communication aim (light grey ovals) will change. Only the modality of prevention of knowledge deprivation is locked to the closed/product quadrant. The figure also shows that if one wants to go from product to process in the domain of the public point of view one changes modality and aim and therefore space of complexity. A mistake on this point is easily made: When an item comes close to the middle of the diagram, the difference between the modalities becomes less discrete. This depends on the context of the communication process. The diagram therefore should be seen as a continuous flow of information and context. The biomedical science education and promotion ovals could therefore theoretically have different forms (indicated by little arrows). So there is a change in modality, stage, notion, knowledge, target and aims when one moves from transmission to transaction and therefore from product to process.

Following from the above, we propose these descriptions of the modalities of biomedical science communication:

*Biomedical science promotion:* in accordance with Petersen and Waddel’s (1998) sociology of illness, promotion has to do with the social and cultural aspects of biomedical science. All communication within this modality concerns the notions of the lay audience and other target groups and the meaning - holistic and utilitarian - biomedical research holds for them. It aims to increase public awareness and engagement with biomedical science.

*Biomedical science education:* has to do with informing the lay audience and other target groups about the facts of biomedical science, and aims to enhance public understanding of and participation in biomedical science.

*Prevention of biomedical knowledge deprivation:* has to do with preventing harm by providing the lay audience with necessary information. This modality can be embedded in legal means, and aims to increase public understanding of biomedical science.

Moreover, there are differences between the modalities of biomedical science communication at the level of urgency and the level of the complexity of the message's content. Due to the modality of prevention of biomedical knowledge deprivation, in which the message must be urgent and concrete, the messages of the other biomedical science communication modalities can be less urgent and less concrete. One could say that when the level of urgency is high (prevention of biomedical knowledge deprivation) the message will be more concrete, whereas, when the urgency is low the message will be less concrete. Fig. 3.3 shows the different terms described in chapter 1 combined. Figures 3.2 and 3.3 show that there is much to think about and to choose from when starting a biomedical science communication campaign, and that includes the content of the message.

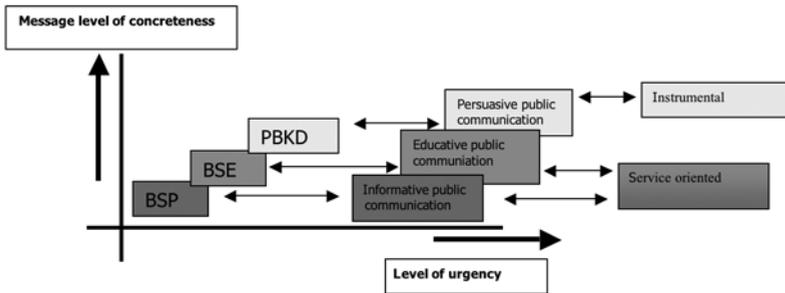


Fig. 3.3: Levels of urgency and concreteness. The diagram depicts Van Ruler's (as described in chapter 1) instrumental and service oriented point of view for public communication and Van Woerkum's persuasive, educative and informative ways of public communication in relation to biomedical science promotion (BSP), biomedical science education (BSE) and the prevention of biomedical knowledge deprivation (PBKD). A biomedical science communication professional must be aware of changes from one modality to another.

In conclusion, in this section we described some of the results obtained from the consolidated literature on health communication and three modalities of biomedical science communication in their relation to each other. Moreover, we described the difference between modality and aim which is necessary in order to depict the scope of possibilities in the biomedical science communication process. All of the modalities can function as a chain in time or as single actions, though we now know that there is some risk of a decrease in effectiveness in the latter. Transaction and transmission could be used within every modality, and PAS, PUS, PES and PPS are situated and fit into the concepts of Van Ruler and Van Woerkum. It is clear that biomedical science communication, with a complexity obtained from health communication, is closely related to thinking about public communication, as described in chapter 1. In the next section we will focus on the aims of biomedical science communication modalities as they can be obtained from the aims of health communication. From there we will seek a theoretical framework for biomedical science communication from health communication theories.

## 3.4 Aims

The modalities of health communication all have their own specific communication aims. Analysing a health communication process in which the different temporal aims are defined is quite difficult because there are so many levels of process. The complexity increases further as a result of the many intentions and perceptions of the target audience<sup>24</sup>, as we saw in chapter 1. For example, the sender's intentions could be attention, understanding, acceptance and application (Waarlo, 1997; Millar, 2000). This is different from the classical intentions of knowledge, attitude and behaviour. Changes in human behaviour definitely do not start from a rational basis; they are not constructed with knowledge and do not follow a linear process on the same level. This constraint has an influence on biomedical science communication as well. In the next three sections we describe the aims of the three modalities of health communication in accordance with similar modalities in biomedical science communication.

### 3.4.1 Aims of health promotion

The health communication aims and responsibilities with respect to Health promotion mainly concern a moral responsibility for the individual as well as for the benefit of society (MacDonald, 1998). Health promotion is about a broad (holistic) view of health and health issues by the sender and the target audience. The guiding question to be asked within the field of health promotion is, what do I have to do as an individual to be a healthy member of a healthy society? MacDonald refers to the international conference on health promotion held in Ottawa (1986), which made presented the holistic view:

- 1 any large-scale attempt to enhance people's health has to include many aspects which do not involve a biomedical orientation to the specific targeting of diseases;
- 2 health education is certainly an important component of health promotion, but is neither the same thing nor necessarily is it always in harmony with it. Health education involves the transmission of information relating to health (in section 3.4.2 we show that this is a restrictive notion of health education). As such, it need not involve people proactively;
- 3 health promotion involves empowerment, a process whereby individual people are encouraged to assert their own autonomy and bolster their self esteem sufficiently to be able to identify their own health agendas, rather than being told what to do or what is good for their health;
- 4 health promotion recognizes that health is both social and individual. Effective and healthy communities are sustained by 'neighbourhood advocacy' of various types – people identifying their health agendas as individuals and being sufficiently empowered to develop the necessary social and political skills to tie it in with the neighbourhood or a social health context.

MacDonald writes:

*Above all, the new health promotion must avoid the fundamental flaw of the old health education. The latter was based on an individualistic approach which 'blamed the victim', making people feel guilty about 'wrong behaviour', as though poverty, bad housing and other social pressures were non-existent [...]. The new health promotion in the contrary, starts from the fact that the main causes of ill-health are socially, culturally and economically constructed and, as with unemployment, are often outside the individual's control.*

<sup>24</sup> Dijksterhuis (2007) writes about the use of the conscious and unconscious mind in making decisions, saying that thinking does not often work in making decisions.

Downie and Tannahill (1998) defines health promotion as an overlapping sphere of health education and the prevention of ill health:

*Health promotion comprises efforts to enhance positive health and reduce the risk of ill-health, through the overlapping spheres of health education, prevention, and health protection.*

The WHO (1998) formulated five principles of health promotion, as follows:

- 1 health promotion involves the population as a whole in the context of their everyday lives, rather than focusing on people at risk for specific diseases;
- 2 health promotion is directed towards action targeted at the causes or determinants of health;
- 3 health promotion combines diverse, but complementary, methods or approaches, including communication, education, legislation, fiscal measures, organizational change, community development, and spontaneous local activities against health hazards;
- 4 health promotion aims particularly at effective and concrete public participation;
- 5 while health promotion is basically an activity in the health and social fields, and not a medical service, health professionals – particularly in primary health care – have an important role in nurturing and enabling health promotion.

In accordance with MacDonald (1998) biomedical science communication is no longer about making the audience feel guilty about not knowing, although this can still be an inconvenient result.

From the descriptions of health promotion above one could say that society as a whole has the obligation to promote a healthy life and society. This promotion is not aimed directly at health issues but at issues such as healthy communities and empowerment. These goals of health promotion could be added to what we described in Fig. 3.1 as biomedical science promotion, as a modality within biomedical science communication.

In the science communication literature in general there is also discussion about this issue, as described in chapter 1. Some authors speak of a paradigm change (Hanssen, et al 2002): the change from transmission (PUS/PAS) to transaction (PES/PPS) (as depicted in Fig. 3.2). When one is talking about transaction then the target audience becomes much more important within the process. It becomes a process of negotiation. But since biomedical science promotion is an overlapping sphere for biomedical education and the prevention of biomedical knowledge deprivation, the paradigm change is also important for these modalities. This means that communication aims such as PAS, PUS, PPS and PES could all be transaction or transmission based (Van der Sanden and Meijman, 2008). In Figure 3.2 PAS/PES and PUS/PPS could flow to the cross point of the diagram and from that point there would be a continuous shift from transmission to transaction within the different modalities. This enlarges the scope of possibilities for biomedical science communication. Biomedical science communication is to be seen as continuous process in terms of its modalities, aims, effects and strategies. Moreover, other communication tools are needed.

From the above, the aims of biomedical science promotion can be described as:

- 1 involving the audience by framing their social context with respect to their notions on biomedical science and technology and their social network;
- 2 a process of empowerment, whereby the members of a given audience are encouraged to assert their own autonomy and self esteem sufficiently enough to be able to identify their own agendas where biomedical science is concerned;
- 3 an overlapping sphere for biomedical science education and the prevention of biomedical knowledge deprivation. Biomedical science promotion aims to enhance effective and concrete public participation in science, public awareness of science, public engagement with science and public understanding of science.

### 3.4.2 Aims of health education

As we described in the previous section on theories of health communication, many theories have been developed for health education throughout the years. These theories could be categorized as traditional, transitional and modern (Downie and Tannahill, 1998). Moreover, there is a distinction between disease-oriented, risk factor-oriented and health-oriented health education (Downie and Tannahill, 1998). These processes, described in the traditional, transitional and modern theories together with the different orientations, form the basis for the definition of health education as Downie sees it:

*Health education is communication activity aimed at enhancing positive health and preventing or diminishing ill-health in individuals and groups through influencing the beliefs, attitudes, and behaviour of those with power and of the community at large.*

This underscores the idea that health communication as a whole is a multileveled, multipurpose process in which individuals and groups are involved in influencing beliefs and attitudes. Draper et al. (1980) describe a tripartite typology of health education:

- 1 type 1: education about the body and how to look after it;
- 2 type 2: provision of information about access to, and the most appropriate use of, health services;
- 3 type 3: education about national, regional and local policies and structures and processes in the wider environment that are detrimental to health.

For biomedical science communication these types resemble the targets of science communication as formulated in chapter 1, in part, and are additional in part. Type 1 health education can be the same as a vocabulary of scientific terms and concepts. Type 2 health education is additional to biomedical science communication in that access to services (websites, databases, organizations) and the proper use of these services also require effective communication. Type 3 health education can be the same as: a) insight into the process of science, even at the level of science policy and strategy; b) knowledge about the impact of science and technology on individuals and society.

When the above are taken together, the aims of biomedical science education become:

- 1 creation of a vocabulary of biomedical terms and concepts in the sense of disease, risks and health (insight into the scientific facts of predictive DNA testing, test usability and the validity of test results);
- 2 provision of information about access to, and the most appropriate use of, biomedical knowledge services such as libraries or patient organizations; access to databases like DISCERN and ACCE and the validity of the information supplied by such databases;
- 3 education about national, regional and local policies concerning biomedical developments and their impact on individuals and society in the wider environment; determining which are detrimental to biomedical science according to disease, risk and health; determining the variables of predictive DNA testing with regard to genetic essentialism, medicalization, legal and governmental issues.

### 3.4.3 Aims of prevention of ill health

As stated in section 2, the prevention modality of biomedical knowledge deprivation is similar to the prevention of ill health. Although this modality will not occur very often, it is an important modality in which transaction and moral issues are involved. However, the aim of the modality is much more directive.

For example, in the case of predictive DNA diagnostics, one should be aware of the consequences of genetic

knowledge. In chapter 4 (Medical Psychology) we describe how Galjaard (1996) and many other authors have warned about emotional breakdown that results from acquiring genetic knowledge. The risk of suicide is great in cases where a serious disease, such as Huntington's disease, is involved.

The audience should become familiar with the ethical and emotional constraints of biomedical science promotion, especially since it empowers them to ask questions about the ethical and emotional repercussions of genetic knowledge. This may form a social basis for the prevention of knowledge deprivation when a predictive test is encountered, either directly or indirectly. For ethical and moral reasons, this directive style of communication can only be carried out and be successful when it has an already empowered audience, one whose members are able to assess the impact of information and make their own decisions. Therefore, prevention should be considered as the ultimate phase in biomedical science communication.

The single issue aim of the prevention of biomedical knowledge deprivation is:

- 1 the directive provision of information to an audience that, will suffer emotional and physical ill health if it has, or if it does not have, the information.

#### 3.4.4 In conclusion

Taking all the aims of the three modalities of biomedical science communication together we see that the process of biomedical science communication has multiple purposes (see Box 3.1). This makes the analyses, the syntheses and the evaluation of an effective biomedical science communication process all the more complex, because all the aims are linked together in their modalities, as depicted in Fig. 3.2. In the next section we will focus on the different concepts, theories, models, constructs and variables of health communication that are useful for biomedical science communication. These theories help to make dynamic connections at the social, socio-psychological and the psychological level of biomedical science communication. They also make it possible to focus on variables and aims in biomedical science promotion, biomedical science education and the prevention of biomedical knowledge deprivation. From this we learn which variables should be considered and emphasized in the domain of biomedical science communication.

## 3.5 Theories and models of health communication

This section on the theories of health communication is categorized according to the elements of the communication process we described in chapter 1: structure, process, outcome and context. The theories are obtained from the consolidated literature and are to be validated by results from the unconsolidated literature search described in section 3.7.

### 3.5.1 Structure

Every communication process depends upon a structure. There are actors, means of communications, etc. Leger et al. (1992) extend Donabedian's definition (1980), which we described in chapter 1:

*It (structure, mvds) comprises the relatively stable characteristics of the services: the distribution and qualifications of the personnel, and the number, size, equipment and geographic distribution of hospitals and other facilities. It also includes the way that personnel are organized, and some important components of their relationships, such as hierarchical lines of command and the integration of quality review into day-to-day work. Taken together, these elements of the structure constitute the environment care.*

We have described this structure of medical science, strategy and policy using the case of predictive DNA diagnostics. We found no consolidated literature for the biomedical science communication process in the databases we searched. However, social marketing is mentioned by several authors in the consolidated literature (Boer et al., 1990; Fineman and Doyle, 2000; Khoury et al, 2000) and from social marketing we know that at least the price, place and activity are discussed. Kotler et al. (2002) write about product, price, place and promotion. Social marketing is also about the marketing of ideas. Social marketing is described by the authors as a scientific method to analyse, plan, implement and evaluate the programmes designed to fit to the parties in the market. In the following section we focus on the different aspects of price, place and activity.

#### Price and place

The price in a process such as predictive DNA testing can be seen as the mental price or physical price one has to pay, for example, to get information (Boer et al., 1990). Therefore the communication process needs to minimize these prices. Barriers such as waiting time and the effort it takes to complete a genetic service should be minimized. Also, the time required to travel to a clinic should be minimal. A mobile screening unit can be helpful in convincing the target group to take part in a screening programme, for example for breast cancer.

#### Activity

Activity includes the organized meetings, the brochures and meetings places needed. Fineman and Doyle (2000) use the Genetics Service Section of the Washington State Department of Health (DOH) as an example. The stakeholders in the process (who are therefore an element of the structure) are clients, primary care providers and genetic health care specialists. This is more or less comparable to the situation Nelis (1998) describes in the Netherlands. Clients find their way to the services with the help of patient organizations and other patients, family and friends. Primary care providers need to have access to the applicable genetic research, and they need some help to get the information across to the patients. Even the genetic specialists need more information on the subject.

The structure element is mainly concerned with access to information for the client as well as for the communication and genetic professionals. For the latter, training and education are needed to implement an effective biomedical science communication process. Lin-Fu and Lloyd-Puryear (2000) are somewhat more specific and sum up the following:

- 1 genetic information should be available: accessible and affordable;
- 2 educational material must be developed on the subject of genetics;
- 3 cultural barriers should be broken down.

What we learned from the scarce amount of material we found is that there is a need for well-trained professionals, and easy access to genetic information for the audience as well as for communication professionals. This is applicable to all modalities of biomedical science communication. The unconsolidated literature - as we will see - generates much more insight into the structure element of health communication and ultimately for the structure of biomedical science communication. In the next section we focus on the process of health communication and its meaning for biomedical science communication.

### 3.5.2 Process

Donabedian (1980) states that the quality of the process can only be defined in normative terms. Considered in isolation, matters of process are not very informative about service effectiveness. We should keep this in mind when considering health communication theories on process. Within the theoretical field of health communication a distinction is made between health models, models for planning and behavioural models. In general, models draw on a number of theories to help understand a specific problem in a particular setting or context. They are often informed by more than one theory as well as by empirical findings (Earp and Ennett, 1991, in Glanz et al., 2002).

Health models provide insight into the theories, concepts and constructs that constitute health and health behaviour. These elements form the basis for several behavioural models. Planning models generate insight into the dynamics of the process. The three categories of models are dependent on each other and form the context of the health communication process. We should keep this interrelatedness in mind when applying these models, or elements of them, to the domain of biomedical science communication and its different modalities. Of course the models, theories, concepts and constructs described in this thesis are not a complete list of all known theories. The models described are those which are most often discussed in textbooks. The connection between the different health communication models is depicted in Fig. 3.4.

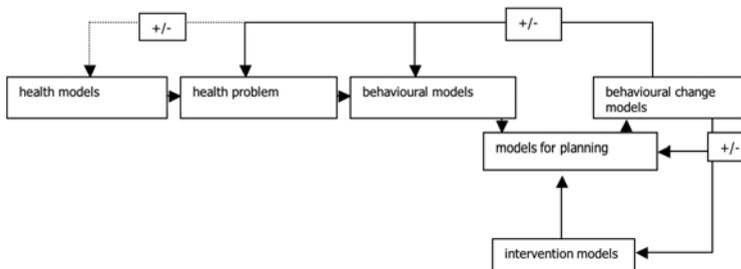


Fig. 3.4: Connections between health models, behavioural models, behavioural change models, intervention models and models for planning used in the process of health communication. The process starts with the health problem or the need to improve health. This problem or goal corresponds with health behaviour. The behaviour needs to be changed or enhanced in order for a person to stay healthy or to become healthy. These behavioural models not only provide insight into the existence of the health problem but also generate clues for the health communication actions needed to establish a behavioural change. This change could be effected by an intervention, which could be effective when using a model of planning. This process is of course steered by the different feedback loops. Possible feedback could come from the effects of the process to the models for planning, to the intervention, the behavioural models, to the health problem and potentially to the health models as well.

Such a scheme of interaction between the models for health communication can also be useful to structure the different steps of the processes of biomedical science communication. In the next section the different kinds of health models and their usefulness in view of biomedical science communication will be described, and the concepts, theories, models, constructs and variables from which these models are drawn become clear.

**Health models**

Downie (1998) depicts a model of health which describes the elements of health as: physical health, mental health and social well being. The health field concept of Tones and Tilford (1994) uses the same elements of health. Both refer to the health model of the WHO. Since the health model describes the different overall aims of health communication, is it also useful for the domain of biomedical science communication? Is there a difference?

The health model deals with the elements constituting good health. The meaning of the good health aim can not be translated to the domain of biomedical science communication, because there is no such thing as ‘good knowledge’. Knowledge can be appropriate and meaningful in a certain context; one could be knowledgeable in the field of predictive DNA testing. However, ‘appropriate’, ‘meaningful’ or ‘knowledgeable’ do not constitute a valuation of knowledge, good or bad. Knowledge is used by the individual whereas health is an intrinsic element of the individual. Therefore we should look for the different functions of knowledge accumulating in a *knowledge function model* (Van der Sanden, 2003; Van der Sanden and Meijman, 2008). What are the different functions of knowledge?

The perspectives of biomedical science communication described in chapter 1 are: democratic, economical, socio-cultural and life-long learning. Their elements regarding the function of knowledge can be described as follows:

- 1 democratic: use of knowledge (i.e. debating, making choices, social well being, co-construction of meaning);
- 2 economical: use of knowledge (i.e. valorization);
- 3 social cultural: notions of knowledge (as described in chapter 1);
- 4 life-long learning: growth of knowledge (i.e. learning).

So the knowledge function model consists of the use of knowledge, the notions of knowledge and the growth of knowledge. These terms should not be confused with the meaning of knowledge, attitude and behaviour, or with attention, comprehension, acceptance and utilization (Waarlo, 1997). The latter are useful within in all domains of the knowledge function model. See Fig. 3.5 for an explanation.

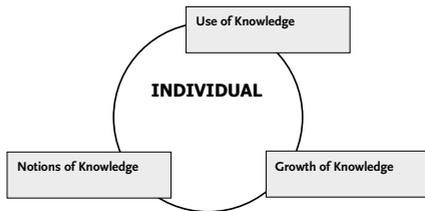


Fig. 3.5: The knowledge function model. The model depicts the different functions of knowledge for the individual. These functions form the basis of the formulation of different aims and effects of biomedical science communication, as physical health, mental health and social well being are used in health communication.

From this model one could abstract a biomedical science knowledge problem. For example there could be a knowledge problem which is based on a shortage of use knowledge, but which is mainly based on existing notions of knowledge already held by an individual. By trying to increase the base of specific knowledge, the knowledge ‘problem’ may be solved.

Formulating this model makes the potential aims and effects of biomedical science communication for the individual more explicit. In the next section the behavioural models for health communication will be discussed and framed within the domain of biomedical science communication.

### Behavioural models

According to the consolidated literature we studied this group of models is the most frequently discussed. Due to the practical restrictions we described in chapter 2 we may have missed some of the behavioural models that are important to the domain of health communication. A reader who is knowledgeable in the field of health communication will almost certainly find this section incomplete. Because of the vast number of models we will focus on the main models<sup>25</sup> we found. These models tell us which important changes have been made within the health communication domain. These changes in the development of the field might be illustrative for the theoretical ontology of biomedical science communication which is only in the beginning stages. From the theoretical ontology and the models, respectively, we can develop ideas for models, theories, concepts and constructs within the domain of biomedical science communication. Within health communication we distinguish between the models for action, prevention and so-called radical models. This is clarified in the following sections.

We start with the development of the model for planned behaviour by Fishbein and Azjen (1975) and the social cognitive theory of Bandura (1986). From the model for planned behaviour we learn that attitude, social influence and self-efficacy<sup>26</sup> are the main drivers of the intention of behaviour. From the intention of behaviour the eventual behaviour can be predicted, depending on skills and barriers to action (Brug et al., 2000; Kok and Damoiseaux, 2000). See Fig. 3.6.

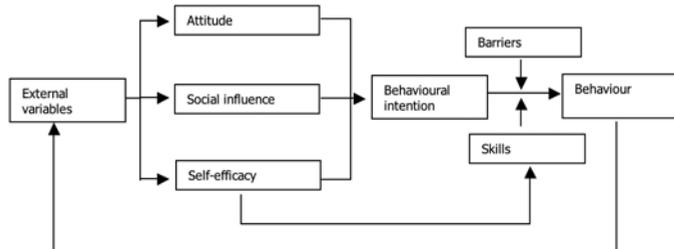


Fig. 3.6: Model of planned behaviour (Fishbein and Azjen, (1975) in Kok and Damoiseaux (2000)). The main determinants for behaviour are: attitude, social influence and self-efficacy. These three determinants form the basis for an intention of behaviour. This intention is influenced by barriers, like the absence of access to information, and by skills, such as being able to search for information. The behaviour exposed influences external variables which may subsequently change.

As one can see from this model of planned behaviour, knowledge is not a main driver of behavioural change (Kok and Damoiseaux, 2000). This was already clear from the work of Miller and Kimmel, described in chapter 1, but this health communication model generates insight into behavioural determinants that are also important to biomedical science communication.

<sup>25</sup> These are the models which were most often mentioned in the consolidated literature.

<sup>26</sup> Self-efficacy was added to the model of planned behaviour by Bandura.

Next to the model of planned behaviour, the *ASE model* (attention, social influence and expectation of self-efficacy) and Festinger's *theory of cognitive dissonance* (Damoiseaux et al., 1998; Brug et al., 2000) are described. The latter depicts three possibilities that could form a platform for change: 1) consonance: cognitions are positively related; 2) dissonance: cognitions are negatively related; 3) irrelevant relations. Cognitions are central in this theory, whereas constructs such as self-efficacy are central to the other models. In Bandura's model this becomes clearer. Central to Bandura's *social cognitive theory* is the connection between behaviour, person and environment as the three classes of determinants of behaviour (Brug et al., 2000). The behaviour strongly depends on the expectation the individual has of it. These are:

- 1 expectations about the consequences of actions in the social and physical environment: situation-outcome expectancies;
- 2 expectations of the consequences of personal actions: action-outcome expectancies;
- 3 expectations of being able to do something: self-efficacy. Self-efficacy is central to the social cognitive theory. The determinants in the model of Bandura can influence each other: reciprocal determinism.

When knowledge is not the main aspect, how do self-efficacy and situation-outcome expectancies fit in the process of biomedical science communication? Self-efficacy can function as a determinant of behaviour in the sense that an individual can see himself as capable of grasping mathematics, or understanding the explanation given in a science museum exhibit. For example, many people instantly feel helpless when they see a mathematical formula. 'Since secondary school I have not understood a thing about maths'. One could say that self-efficacy for maths is not generally strong. One of the factors for biomedical science communication is that communication starts to empower the individual to trust himself in understanding maths. Communication on the action-outcome and situation-outcome expectancies could probably be more successful in biomedical science communication than in health communication, so the model for learned behaviour and the social cognitive theory are quite applicable to the field of biomedical science communication. It broadens the insight into the process of knowledge dissemination by describing the driving variables of changing behaviour.

Now we come to the field of action theories. These theories aim to change behaviour determinants, behaviour itself and the environment (Kok and Van Empelen, 2000). Action theories indicate how the determinants of behaviour can be adjusted to the problem at hand. One of the action models is the model of communication innovation (Rogers and Schoemaker, 1971). They distinguish the well-known categories of the target audience: innovators, early adopters, early majority, late majority and laggards. These categories can also be useful for the domain of biomedical science communication. They are probably in line with the notions and cultural themes of society as described in chapter 1. Early adopters might form an audience that embraces new technology, and the laggards might be an audience that sees new technology in terms of 'future shock'.

Over the years the main models described above were extended and recombined. Much can be learned from these extensions in health communication models and theories. Kok (1985, in Damoiseaux et al., 1998) for example, combines the models by Fishbein (1975), Maddux and Rogers (1983) and McGuire (1985). Fishbein writes about the theory of planned behaviour, Rogers and McGuire about the different phases of the health communication process. This combination includes the following phases of the communication process: orientation, acceptance and integration (Kok and Damoiseaux, 2000), and forms the following model, shown in Fig. 3.7.

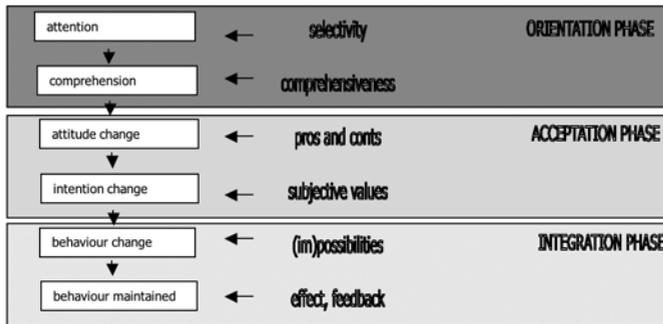


Fig. 3.7: Model of integration (Kok, 1985) with the phases described by McGuire added. This model includes Fishbein's model, which describes the relationship between attitude change and change of behaviour. McGuire's model adds the way the attitude has changed, from attention to comprehension, and integrates the different phases (orientation, acceptance and integration) of behavioural change. Rogers adds the change from behaviour change to change maintenance. The processes that occur in the individual are shown on the left of the figure, and the variables influencing the processes are shown on the right.

Taking this model of integration into account the biomedical science communication modalities, as well as their aims, could be sorted into three different phases of the communication process. Again, this is not a linear process. Biomedical science promotion aimed at PAS and PES could be a modality bound to the orientation phase, whereas biomedical science education aimed at PUS and PPS could be a modality bound to the acceptance and integration phase. Prevention of knowledge deprivation aimed at PUS could be a modality bound to the integration phase. Box 3.1 lists the constructs and variables obtained from theories and models of health communication that are relevant to biomedical science communication. These constructs and variables make the process of biomedical science communication more comprehensive and manageable.

### Box 3.1:

Biomedical science communication process constructs and variables now include (newly added variables are **bold**):

- o basic notions of technology; cultural themes;
- o **notions of knowledge; growth of knowledge; use of knowledge**
  - o biomedical science promotion; biomedical science education; prevention of biomedical knowledge deprivation;
  - o aims: PES; PAS; PUS; PPS;
  - o determinants of behaviour: **self-efficacy; expectations;**
  - o **different phases in the process;**
    - o effects of biomedical science communication: awareness, enjoyment, interest, opinions and understanding.

Tones and Tilford (1994) developed the health action model, which has been composed of different models. Within this model motivation, belief, self esteem and normative system, health locus of control and learned helplessness (the opposite of empowerment) are key terms. These variables and constructs provide insight into the dynamics of self-empowerment which is central to the model (Tones and Tilford, 1994). Self-empowerment is to be seen as being able to make decisions.

Health locus of control signifies how an individual sees the origin of his health problem or health improvement. There can be an external health locus of control: 1) *There is nothing I can do about not knowing about genetics. No one is telling me.* Or there can be an internal locus of control: 2) *I should ask for information on predictive DNA diagnostics myself.* The difference between learned helplessness and empowerment depends on self-efficacy, health locus of control, attitudes, beliefs and lay knowledge. The concept of the dynamics of self-empowerment within biomedical science communication shows that learned helplessness should be avoided and empowerment should be stimulated. Therefore, constructs and

variables such as health locus of control are useful to the domain of biomedical science communication. Again, this makes the process of biomedical science communication more comprehensive and manageable. Whether the communication process focuses on understanding or awareness of science the target audience needs to feel that they are accountable for learning about the problem they have. Moreover the target audience must have a basic feeling of empowerment. If individuals remain in a state of learned helplessness there are no grounds for effective biomedical science communication. There must be an internal locus of control for knowledge; if that is not the case the process of effective biomedical science communication needs to be designed to enhance the internal locus of control (see Box 3.2)

**Box 3.2:**

Biomedical science communication process constructs and variables now include (newly added variables are **bold**):

- o basic notions of technology; cultural themes;
- o notions of knowledge; growth of knowledge; use of knowledge
- o biomedical science promotion; biomedical science education; prevention of biomedical knowledge deprivation;
- o PES; PAS; PUS; PPS;
- o determinants of behaviour: self-efficacy; **internal locus of control for knowledge**; expectations;
- o different phases in the process;
- o effects of biomedical science communication: awareness, enjoyment, interest, opinions and understanding, empowerment.

Health communication specialists used to build theories and models as models for prevention (Tones and Tilford, 1994). However, when the determinants of behaviour (self-efficacy, health locus of control) became more complex over time, the thoughts and behaviour of individuals became more important. Therefore the interactive models for health communication, named radical models, were developed (Tones and Tilford, 1994; Holland et al., 1985; Downie and Tannahill, 1998). Within the preventive model disease is central, in the radical model empowerment is central. Downie and Tannahill (1998) added risk-factor oriented health communication to these models. The radical models of health communication generate new insights into the management of modalities and goals in a biomedical science communication process. From the literature we read the models (Downie, 1998) include: *health belief model* (Janz and Becker, 1984; Fig. 3.8); *persuasion communication model* (McGuire, 1985); *protection motivation theory* (Brug et al., 2000); *integrated model for determinants* (Pieterse et al., 2000). The health belief model is depicted in Fig. 3.8.

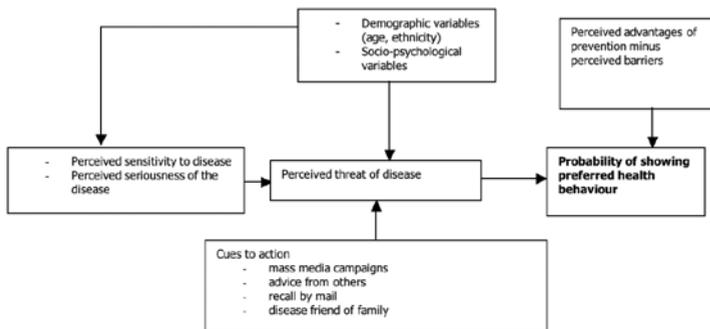


Fig. 3.8: Health belief model. In the model the individual makes a decision by balancing his background, which has a direct influence but also influences the perceived seriousness of the disease. The cues to action eventually trigger what to think or do. Then the advantages and the barriers to possible behaviour become clear. The balance between a perceived threat and perceived barriers and advantages culminates in an individual's choice.

The health belief model as well as the other models described above are models of checks and balances. The linearity found in classical health education (see section 3) is abandoned in these radical models. They are all based on balances between perceived threats, backgrounds, cues to action, etc. In the model for protection/motivation, the cost of behaviour is subtracted from self-efficacy. This eventually leads to a perceived feeling of protection which is an indicator of the probability of seriousness, and a perceived feeling of motivation which is an outcome of the probability of coping behaviour. The feeling of protection together with the feeling of motivation leads to coping or non-coping behaviour. Also, terms like 'voluntarily' (Tones and Tilford, 1994) become important (see Box 3.3).

### Box 3.3:

Biomedical science communication process constructs and variables now include (newly added variables are **bold**):

- o basic notions of technology; cultural themes;
- o notions of knowledge; growth of knowledge; use of knowledge
- o biomedical science promotion; biomedical science education; prevention of biomedical knowledge deprivation;
- o PES; PAS; PUS; PPS;
- o determinants of behaviour: self-efficacy; internal locus of control for knowledge; expectations;
- o different phases in the process;
- o **process of checks and balances**: voluntarity;
- o effects of biomedical science communication: awareness, enjoyment, interest, opinions and understanding, empowerment.

Now that the different variables are connected to different modalities, phases, aims and effects the communication process should be a manageable one. In the next section planning models obtained from the domain of health communication are discussed.

#### Models for planning

Planned communication is the most effective modus for public communication (Brug et al., 2000). One of the most-often mentioned models in the unconsolidated planning literature is the *precede-proceed* model from Green and Kreuter (1991, in Damoiseaux et al., 1998 and Brug et al., 2000). This model consists of different phases of planning. See Fig. 3.9.

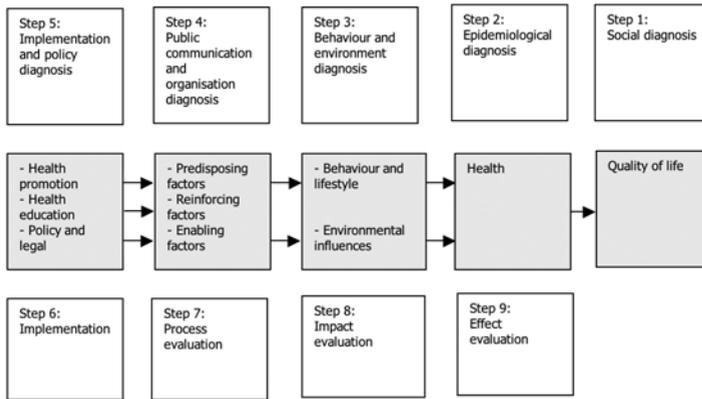


Fig. 3.9: Precede-proceed model for the planning and evaluation of health promotion. The model starts from the top right and runs to the bottom right. In the different steps (1 to 9) of the precede-proceed model the elements of models like the health belief model are recognizable (in grey). The different steps in the planning model 'circle' around the socio-psychological model above and under. The model is both linear and circular.

In the field of biomedical science communication these kinds of models for planning could enhance the effectiveness of the process while the socio-psychological models and the different steps of the communication process become recognizable and manageable. Other models for planning are the cybernetic model for planning from Knox (Damoiseaux et al., 1998) and the intervention mapping model (Brug et al., 2000). All of the models have a strong resemblance, however the starting points used for the analysis are slightly different. Green and Kreuter's precede-proceed model starts – like intervention mapping – with an analysis of the quality of life. The cybernetic model starts with an analysis of the environment. None of the models start with a communication question such as the communication aims.

As described before, the explication of different phases in the process of biomedical science communication is necessary in order to cope with the dynamics and complexity of the communication process. In the generic precede-proceed model by Green and Kreuter biomedical science communication could substitute for health communication.

McGuire (1985) has developed a matrix in which response steps, such as attending, liking, and becoming interested in, ending with post-behavioural consolidating, are matched with source, message, channel and receiver. This model resembles the science communication spectrum (Wehrmann and Van der Sanden, 2007). From this explication one can choose which step to take at a given time, corresponding with a given policy phase. The phase of communication must fit the phase of the individual's moment of decision making exactly (Pieterse et al., 2000).

When it comes to implementation, Rogers' model (1983) of the diffusion of innovations in which he describes the early innovators and the laggards, can also be mentioned as a model of planning and making the phases of the process more explicit. This model does not describe the effects of communication but instead the natural flow of the diffusion of innovations into society (Kok and Damoiseaux, 2000). Conclusions about the total process are shown in Box 3.4.

**Box 3.4:**

Biomedical science communication constructs and variables now include (newly added variables are **bold**):

- o basic notions of technology; cultural themes;
- o notions of knowledge; growth of knowledge; use of knowledge
  - o biomedical science promotion; biomedical science education; prevention of biomedical knowledge deprivation;
  - o PES; PAS; PUS; PPS;
  - o determinants of behaviour: self-efficacy; internal locus of control for knowledge; expectations;
  - o different phases in the process: **models for planning**;
  - o process of checks and balances: voluntarity;
  - o effects of biomedical science communication: awareness, enjoyment, interest, opinions and understanding, empowerment.

The scope of possibilities of the process of biomedical science communication has been strongly expanded. This leads to many other possibilities in terms of process, aims and effects (Van der Sanden and Meijman, 2008). The next section will focus on the different outcomes, which should match the different process variables.

**3.5.3 Outcome**

We did not find much regarding outcome in the consolidated literature we read. One of the main conclusions is that health knowledge is certainly not the only driver for changes in health behaviour (Downie and Tannahill, 1998). Moreover, as Downie and Tannahill write, health promotion must be enabling, articulating, crystallizing, refining, mobilizing and empowering.

As seen in the section on process the different phases can also have different outcomes at different moments.

Most of the time, the outcome of a process is the starting point for a next step in the same process (see Box 3.5).

**Box 3.5:**

Biomedical science communication variables of degrees of freedom within process now include (newly added variables are **bold**):

- o basic notions of technology; cultural themes;
- o notions of knowledge; growth of knowledge; use of knowledge
  - o biomedical science promotion; biomedical science education; prevention of biomedical knowledge deprivation;
  - o PES; PAS; PUS; PPS;
  - o determinants of behaviour: self-efficacy; internal locus of control for knowledge; expectations;
  - o different phases in the process: **models for planning**;
  - o process of checks and balances: voluntarity;
  - o effects of biomedical science communication: awareness, enjoyment, interest, opinions and understanding, empowerment.
  - o **different outcomes in different phases at different times.**

### 3.5.4 Context

As we stated in chapter 1, Miller and Kimmel (2001) have described numerous contextual variables for biomedical science communication. Tones and Tilford (1994) and MacDonald (1998) have also described contextual variables which are important to the communication process.

In addition to personal contextual factors Tones and Tilford and MacDonald write about political and mass contextual factors. When a political factor is concerned, there is a difference between a deliberated democracy and other political systems in terms of communication. The mass factors are notions like genetic essentialism, medicalization and cultural themes. Miller and Kimmel have described the personal contextual factors, notions, SES and the other aspects.

## 3.6 Conclusions from the consolidated literature

By comparing biomedical science communication with health communication, biomedical science communication's possibilities are expanded:

- basic notions of technology; cultural themes (chapter 1)
  - notions of knowledge; growth of knowledge; use of knowledge (obtained from **health communication**)
  - biomedical science promotion; biomedical science education; prevention of biomedical knowledge deprivation (obtained from **health communication**)
  - PES; PAS; PUS; PPS (chapter 1)
  - determinants of behaviour: self-efficacy; internal locus of control for knowledge; expectations (obtained from **health communication**)
  - different phases in the communication process models for planning (chapter 1 and obtained from **health communication**)
  - process of checks and balances (obtained from **health communication**)
  - context: individual and societal (obtained from **health communication**)
  - effects of biomedical science communication: awareness, enjoyment, interest, opinions and understanding (chapter 1)
  - different outcomes in different phases at different times (obtained from **health communication**)

All the above provide more insight into the variables discussed by Miller and Kimmel (2001) and the different aims and effects discussed by Auweraert (2003) and Bucchi (1998). If we follow the steps in a linear fashion we start with the basic notions of the target audience these were described in chapter 1. The foremost point is that cultural themes are connected to medical practice. Also, that genetic essentialism and medicalization play a role and form the contextual framework of the biomedical science communication process. From these contextual factors we come to the biomedical science communication problem or challenge in which knowledge must be formulated in a broad sense. The different determinants of behaviour can now be activated. We connected the different modalities of biomedical science communication to the different aims of biomedical science communication as PAS, PES, PUS and PPS. Furthermore we learned about the phases of attention, acceptance and integration connected to phases of changing behaviour from health communication, as shown in Fig. 3.7. Then the modality and goal of biomedical science communication could be described, depending on the level of urgency of the message, as depicted in Fig. 3.3, Fig. 3.7 and Fig. 3.9, and leading to a level of concreteness of the message communicated. From Fig. 3.2 we know that these different steps are dynamic in time and are not discrete but rather flow from one goal to another which makes biomedical science communication a dynamic complex process as well as one in which the communication strategy described by Van Ruler (1998) plays a role. This forms the starting point for analysing the unconsolidated literature. The degrees of freedom of the biomedical science communication process as described above, in combination with the results obtained from the unconsolidated literature, lead to a complex figure of biomedical science communication on predictive DNA diagnostics, model step 1.

### 3.7 Analysing the unconsolidated literature

The literature was analysed according to the method described in chapter 2. Table 3.2 shows the results from the databases. From the most relevant literature no relevant hits could be found. From the less relevant (++) literature we chose different articles. An electronic table on the thesis' website ([www.bscpa.tudelft.nl](http://www.bscpa.tudelft.nl)) shows the scores on relevance and validation, as well as text from the articles which describe success or failure on structure, process, outcome and context.

The distinct aspects (structure, process, outcome and context) of communication are discussed in the following sections. Every step described in the analysis starts with the most relevant and valid literature. Sometimes an article was chosen at face value, from a category of lower relevance (++) , but after analysis was considered to be highly relevant (+++). Also, articles taken from lists of references in the consolidated literature were read, as well as articles forwarded by colleagues. However, more than 95% of the articles were selected from the databases we searched.

#### 3.7.1 Structure

When reading the unconsolidated literature it became clear that we needed to divide 'structure' into its classical communication elements: sender, means and receiver. These elements have both a material (e.g. building, structure of the organization) and an immaterial side (e.g. the organization's philosophy, the brand). We now have the following sections within the element of structure:

**Material / sender**

- Success:
- (+++R/+V)
  - [...] call-centres [...] cancer information service (CIS) [...] The CIS endeavours to affect behaviour change by enhancing patients' competence and efficacy beliefs and making them more informed health care consumers. Callers to CIS report that contact with the CIS increased their knowledge, provided reassurance, influenced their decision-making, and improved their self-confidence, resulting in positive behaviour changes and in general helped them to better cope with their concerns [...] Computer-based health support systems are other examples of interventions that have been successful in reducing barriers to accessing health information and improving the quality of life of patients (Arora et al., 2002).
  - A majority of the respondents at all levels of knowledge accepted that gene tests should be available to everybody who wants them, and a minority stated that gene tests should not be done at all (Jallinoja and Aro, 2000).
- (+++R/-V)
  - The value of the test depends on the genetic disease for which the test has been developed, the effectiveness of the treatment and the costs (Condit et al., 2002).
- (+R/-V)
  - When genetic tests are in use it is important to be in close contact with health insurance companies (Leschot, 2001).
  - There should be a national group for predictive DNA diagnostics (Leschot, 2001).
- Failure:
- (+/R-V)
  - Geneclinics was established in 1997 to provide physicians and other healthcare providers with information on test usage in diagnosis, management and genetic counseling for specific inherited disorders. Hayflick et al. (1998) determined that a significant proportion (e.g. up to 25% of internists) did not know how to access local genetics services and had never referred patients for genetic services (Pagon et al., 2002).

**Material / mean**

- Success:
- (+++R/+V)
  - Sites for these enterprises could be the biology school curriculum, genetic counseling, media as well as health education and health communication in general and education starts in the primary school (Jallinoja and Aro, 2000)
- (++R/-V)
  - A health-promoting television series can increase health knowledge and enhance health beliefs, which in turn contribute to healthy behaviors (Chew et al., 2002).
- (+R/-V)
  - This article describes a rationale for Cochrane reviews as an evidence-based medicine tool for consumers [...] The Cochrane Collaboration's Consumer Network has established a separate website, with review synopses written for an audience of consumers. These sites (health and scientific information, mvds) offer convenient alternatives for people who have little time or desire to evaluate sites for themselves. Pre-evaluated sites may be helpful in providing introductory or background information. (Commentary in the same article: - Some physicians and health educators argue against evidence-based medicine for consumers, citing low literacy levels or lack of interest on the part of consumers in risk analysis. These arguments conflict with informed consent policies and the wishes of a growing number of proactive health consumers. More thought needs to be given to the work of consumers as referees) (White, 2002).
  - A successful bid for an LMEC was predicated upon making available relevant evidence-based material via the Internet to local primary and community care staff (Howard., 2002).
  - Public Health Informatics could be defined as the discipline that integrates public health with information technology. It deals with the storage, processing, dissemination and validation of information about public health practice and training. New genetic information technologies will make it possible to perform cost-effective screening (genetic tests) at the population level [...] A challenge is to transfer the knowledge of genetics to the field of public health.<sup>27</sup> (Martin-Sanchez et al., 2002).
  - The development and usage of two NIH-funded genetic testing information databases, GeneTests ([www.genetests.org](http://www.genetests.org)) and GeneClinics ([www.geneclinics.org](http://www.geneclinics.org)), now merged into one website, reflects the steadily increasing use of genetic testing and the expanding audience for genetic testing information [...] As genetic research has moved steadily out of research venues and into routine medical practice, the user audience for these databases has

become international and expansive and includes healthcare providers, patients, educators, policy makers, and the media. Gene Tests-Gene Clinics provides genetic counseling and testing information to a growing and diverse audience (Pagon et al, 2002a).

- Message credibility is generally agreed to result from an interaction of source characteristics (e.g. expertise, trustworthiness), message characteristics (related to message content, encompassing factors such as plausibility, internal consistency and quality) and receiver characteristics (e.g. cultural background, previous beliefs). The authors (Wathan and Burkell, mvs) conclude that there are seven criteria that affect credibility of Web information: source, content, format, presentation, currency, accuracy and speed of loading (Wathan and Burkell, 2002).
- Regarding predictive DNA diagnostics there are no identical situations that could occur. Laws could therefore easily miss their target (Leschot, 2001).
- Success: The authors introduce GENIS (Genetic Information-Seeking Skills), which is an intervention framework for helping people build genetic information seeking skills that will be useful throughout their lives. Genetics information pertaining to cancer is of vital importance for the management of the disease (Johnson et al., 2001).
- Failure:
- (+R/+V)
  - A conceptually sound evidence base for interventions that aim to promote health is urgently required. However the current research for evidence of effective health promotion is unlikely to succeed and may result in false conclusions being drawn about public health promotion practice in the long term. The reasons for this are threefold: lack of consensus about the nature of health promotion activity; lack of agreement over what evidence to use to assess effectiveness; and divergent views on appropriate methods for reviewing effectiveness. The evidence-based data must be accessible to and used by practitioners. While practitioners need to be more critical and to substantiate their decisions with evidence, key messages must also be disseminated clearly and unequivocally to influence practice (Speller et al., 1997).

**Material/receiver**

- none

**Immaterial/sender**

- Success:
- (++)R/-V)
  - The audience needing information could be easily found (Botorff et al., 2002)
  - In a number of well-designed randomized studies tailored print materials have been found to be more effective than non-tailored ones in helping individuals change health-related behaviours such as smoking, diet, physical activity and cancer and cholesterol screening [...]. (Kreuter and Holt, 2001).
- (+R/-V)
  - At the same time, community participation is held to be the 'cornerstone' of health for all strategy (Kelly, 1989).
- Failure
- (+R/-V)
  - In addition unhealthful behaviors are often predicated on a lack of information or on inaccurate information (Gostin and Javitt, 2001).

**Immaterial/mean**

- Success:
- (++++)R/+V)
  - The most important sources of information about HD (Huntington's disease) were given, in the questionnaire, as the neurologist/psychiatrist, family members, lay organizations [...] Lay organizations play an important role in informing the persons who are at risk (Kreuz, 1996). VSOP has an active role in preparing information for the general public and healthcare workers. 'We noted in our pilot clinic at Maastricht that couples were pleased to find a forum where they could discuss their questions and worries' [...]. Clinical geneticists are invited to play an active role [...]. (Schrandel-Stumpel, 1999: ++R/-V).

<sup>27</sup> Health informatics can be separated into distinct domains, such as: Molecular information level, Cellular information level, Tissue, Organ information level, Personal information level, Disease information level, Population information level.

- (++)R/+V)
  - Effective behavioural and educational interventions (smoking, mvds) include: physician advice; smoking cessation programmes implemented in pregnancy; smoking cessation advice and counseling given by nurses; training health professionals to provide smoking cessation interventions; group programmes and individual smoking cessation counseling. There was no evidence of difference in effect between individual and group counselling. Regarding diet: for the general population the more effective health promotion interventions were those based on theories of behavioural change, which may, for example, encourage clear goal setting. School-based sex education can be effective in reducing teenage pregnancy especially when linked to access to contraceptive services. All of the theoretically based interventions (multi-session programmes, which included skills training and strategies to modify perceived peer or partner beliefs about risk-taking behaviour) were effective in increasing condom use (Jepson, 2000).
- (+++R/-V)
  - An intermediary of this kind, termed the Research Liaison Officer (RLO), will clearly require a variety of skills [...] thus the RLO is a hybrid of journalist, teacher and researcher, who constitutes a unique two-way communication channel. Fundamental to an effective dissemination strategy are adequate resources. Researcher time and funds must be available in sufficient quantities to ensure that effective dissemination takes place (Crosswaite and Curtice, 1991:1994).
- (++)R/-V)
  - Although most of the patients had little knowledge of the genetic basis for the disease, most of them stated that if a diagnostic test for ET were to become available they would be interested in testing their gene status, suggesting that, from the patients' perspective, information on the genetic basis for their disease is viewed as important (Watner et al., 2002).
  - In communicating the impact of genetics on treatment and prevention, messages about gene therapy and pharmacogenomics need to be complemented with messages about the potential or behavioral and environmental interventions based on genetic information. Such messages could lead to a better appreciation of how behaviours can reduce disease risk. Risk reduction in the phase of genetic susceptibility is complex. It will require additional research in risk communication and the behavioural sciences to understand how to safely and effectively bring about the changes needed to improve health among those who have genetic susceptibility. Until such interventions are available for any given genetic trait, identification of genetic susceptibility may do more harm than good. Khoury et al. present three simple public health themes that can provide a basis for developing public health messages about genetics and disease prevention to various audiences: 1) human diseases result from gene-environment interaction; 2) population research is needed to determine the clinical validity and utility of genetic testing; 3) genetic testing can be used to target interventions that improve health and prevent disease. These messages underscore how knowledge of genetics presents an opportunity to prevent disease, and in showing these benefits, they aim to reduce fear of the misuse of genetic information (Conerly, 2001).
  - It is important to assess the knowledge of the lay audience. Assessment instruments like the Rapid Estimate of Adult Literacy have been developed, although this instrument should not be used in an automatic way due to the validity of the answers. This instrument could also be of importance for medical personnel (Conerly, 2001).
- Failure:
  - (+++R/-V):
    - The communication channels for health promotion research are generally less well-defined, as health promotion is served by various academic journals which represent a range of disciplines [...] This multidisciplinary context contributes towards widening the communication gap between researcher and research user. In health promotion, therefore, the task of targeting specific user groups for the dissemination of research findings is problematic [...] Practitioners and other users of research expressed concerns about access to research information and their difficulties in interpreting research findings in a manner that enabled them to implement findings in their daily practice and in policy making decisions.
    - The issue of access to research findings by the general public is an area that is rarely addressed in research (Kelly, 1992, in Crosswaite and Curtice, 1991).
- (++)R/-V)
  - There is not much research available when it comes to the differences of groups and individuals in their use of genetic services (Sorenson and Chevront, 1993).

**Immaterial/receiver****- Success:**

- (+++R/+V)
  - Sites for these enterprises could be the biology school curriculum, genetic counseling, media as well as health education and health communication in general [...] A majority of the respondents at all levels of knowledge accepted that gene tests should be available to everybody who wants them, and a minority stated that gene tests should not be done at all (Jallinoja and Aro, 2000).
  - [...] that they (patients, mvds) need a language they could easily understand (Arora et al., 2002).
- (+++R/-V)
  - Several websites provide information for geneticists on genetic disease, genetic services and professional training. Two UK sites act as gateways to information on specific diseases and support groups, suitable for patients and their caregivers. Public health professionals and policymakers are well served by sites maintained by the Department of Health and the NHS. Good web-based information on genetics for general practitioners and non-geneticist clinicians is lacking. Ethical, legal, and social issues are covered in sites maintained by national and international regulatory bodies in bioethics (Stewart et al., 2001).
- (++R/-V)
  - Members of the audience contribute to participatory action research. One might develop a system which monitors when a participational process is about to fail (Mittelmark, 2002).
- (+R/-V)
  - Elements of social marketing: 1) the product might be defined as 'good health' or 'self-empowerment'; 2) the price represents what the consumers must give up if they are to accept the health promoter's offering. Price might include money, time, psychological or physical costs to the consumer; 3) the place concerns the distribution channels used to reach the consumer; 4) promotion is the means by which the health promoter communicates the product to the consumer. The alternatives include advertising, publicity, word-of-mouth sales and sales promotion. Of these, advertising is probably most commonly used because it combines controllability with reach (Hastings and Haywood, 1991).
  - women's magazines are an important source of health information. The reach of women's magazines is enormous. The seven magazines in this study had nearly 22 million subscribers in 1995 (Gerlach et al., 1997).

**- Failure:**

- (+++R/+V)
  - Barriers to accessing health information include cost considerations, inability to devote time or effort, lack of awareness of sources, and literacy issues (Arora et al., 2002).
- (++R/-V)
  - [...] little is known about the optimal amount and timing of tailoring messages (Kreuter and Holt, 2001).
- (+R/-V)
  - A conceptually sound evidence base for interventions that aim to promote health is urgently required. However the current research for evidence of effective health promotion is unlikely to succeed and may result in drawing false conclusions about health promotion practice to the long term goals of public health. The reasons for this are threefold: lack of consensus about the nature of health promotion activity; lack of agreement over what evidence to use to assess effectiveness; and divergent views on appropriate methods for reviewing effectiveness [...] The evidence base must be accessible to and used by practitioners. While practitioners need to be more critical and to substantiate their decisions with evidence, key messages must also be disseminated clearly and unequivocally to influence practice (Speller et al., 1997).
  - [...] it really matters if an individual can obtain access to proper knowledge, health maintenance, proper diagnosis for complaints, and the most up to date treatment for disease and ailments (Lindberg, 2002).

**Conclusions: structure**

In this section we depict the most relevant and valid conclusions from the literature cited above. The less relevant and valid elements of structure found in the unconsolidated literature are used only when necessary. The most important advantage of showing the less relevant and valid literature is that its possibilities become apparent, and it becomes clear how much real convincing power exists in less relevant literature.

**Materialistic Sender**

The results for 'sender' are: a centre one can visit, a website, a centre to educate medical personnel, a genetic test kit, and contracts between the health care consumer and health insurance providers (Arora et al., 2002; Kreutz, 1996; Schrandel-Stumpel, 1999).

The usefulness of a centre was most strongly underlined by Pagon et al. (2002b). They write not only about centres open to the public, but also those that exist for the education of medical personnel. The Erfocentrum in the Netherlands is one example of such a centre. The authors found in their research that the centre for medical personnel's website was visited by members of the lay audience. Though these centres are desirable, only 25% of medical personnel were aware of their existence.

Another relevant and valid issue is the test itself. Condit et al. (2002) mention that the value of the test depends on the kind of genetic disease it has been developed to detect. What about the cost and the effectiveness of the test?

#### Materialistic Means

In the unconsolidated literature on communication means the more personal means are well studied in the literature we have read and validated. There exists less literature on brochures or other written materials. The main point recurring in the relevant and valid literature is the idea of beginning education on genetics at the primary school level (i.e. Jallinoja and Aro, 2000). Health informatics could be useful in supporting the learning process as explained in the less relevant and valid literature (Martin-Sanchez et al., 2002; Pagon et al., 2002; Speller et al., 1997).

According to Martin-Sanchez et al. (2002) this change to more personal means of communication is due to a shift from the genomic age to the post-genomic age. Now that the sequencing of DNA has been solved, researchers are focused on the functional elements of DNA. In accordance with this the production of custom-made medicines is possible. Personalized medicine is supported by tailor-made communication. Education on this point is important for the lay audience so that they may make an informed choice (see democratic principle, chapter 1, and the comparison with science education in chapter 7). The evidence-based information intended for professionals might be of use for the lay audience (Speller et al., 1997). The design and usability of websites, as described by Stewart et al. (2001) become increasingly important. In the less relevant and valid literature White (2002) and Howard et al. (2002) write about how the lay audience uses the Cochrane Library. Television programmes on health (Chew et al., 2002) and tailor-made information (Kreuter and Holt, 2001) are mentioned in the same class of literature.

Not all members of the lay audience are content with the development of electronic means of communication (White, 2002). The arguments for and against it have an equivalent convincing power, presented in the equivalent articles. An important issue is that there is less impetus for the lay audience to take serious scientific discussion into account. Moreover, no situation is identical to another (Leschot, 2001).

#### Immaterialistic / Sender

According to the unconsolidated literature read and validated in this research, there is not much that can be used within the domain of biomedical science communication on predictive DNA diagnostics. Costin and Javitt (2001) write that the sender has to take the following items seriously: 1) start with theory based campaigns; 2) repeat information at different moments; 3) take the target audience into account by using the Rapid Estimate of Adult Literacy.

#### Immaterialistic/ Means

The unconsolidated literature with the strongest convincing power depicts the following means: 1) biology education (Jallinoja and Aro, 2000; Walpole et al., 1997); 2) genetic counselling (Jallinoja and Aro, 2000). We read and validated one less valid but relevant special report, Crosswaite and Curtice's (1991; 1994) (+++R/-V) report for a Research Liaison Officer (RLO). This officer bridges the gap between health communication theory and practice. The RLO manages and implements the use of health communication knowledge in health communication practice. This is necessary in order to tear down the barrier between health communication researchers and health communication professionals. For example, both officers do

not read each other's literature. Due to this gap two-way communication on the dissemination of knowledge is not possible. Sorenson and Chevront (1993) subscribe the urgency of the need to take away this discrepancy between theory and practice.

**Immaterialistic/ Receiver**

In the most relevant and valid literature primary and secondary biology education is mentioned again as being important for target audiences. It for example deals with self-empowerment. Moreover, genetic testing must be available for everyone (Jallinoja and Aro, 2000). The less relevant and valid literature mentions social marketing (Hastings and Haywood, 1991).

**In summary: structure**

In general communication on health issues has a strong audience orientation. It is about education, tailor-made messages<sup>28</sup>, and research liaison officers, going far beyond the scope of the stand-alone brochure or website. The contours of a far more personalized form of communication are depicted, one in which the health consumer searches for information by himself. In our opinion, such a personalized form of communication is not a strong presence in the consolidated literature, which is where social marketing comes in.

In order to communicate in a personalized way, a great deal more theoretical information is needed in order to develop theoretically based campaigns: evidence-based campaigns, so to speak. Although it is not valid, the idea of the RLO deserves some attention (see Fig. 3.10).

This view of a more personalized structure as an element in the communication process is likely to be translated in relation to biomedical science communication on predictive DNA diagnostics. It is no longer found in brochures and on TV programmes; rather, it is about education, centres that people can visit and tailor-made messages and websites. It is about evidence-based campaigns.

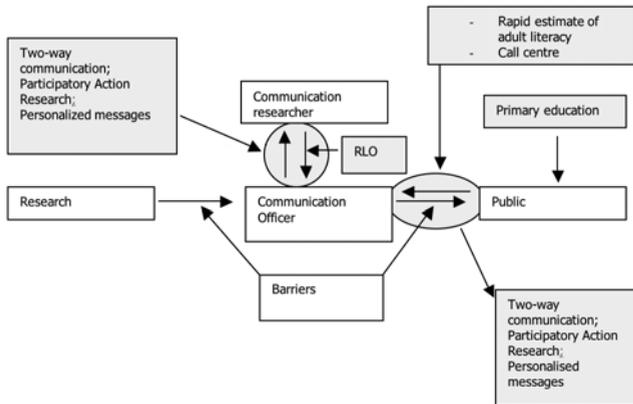


Fig. 3.10: An extension of the structure of biomedical science communication.

**3.7.2 Process**

The communication element process can also be divided in the processes corresponding to sender, receiver and means. Obviously the various processes interact with each other, therefore some processes can be linked to sender, receiver and means.

<sup>28</sup> Health informatics can be separated into distinct domains, such as: Molecular information level, Cellular information level, Tissue, Organ information level, Personal information level, Disease information level, Population information level.

**Sender**

## Success

## (+++R/+V)

- Information can play an important role in enhancing patients' efficacy and competence expectations. Johnson's self-regulation theory suggests that information, by virtue of decreasing the discrepancy between patients' expected and actual experiences and enhancing patients' understanding of their situation, is likely to result in an increase in their confidence in their ability to handle encountered problems [...] Lazarus's cognitive appraisal theory provides additional support to the above assertion. This theory suggests that when faced with the fear and uncertainty of a life-threatening illness, patients cognitively appraise their own resources and options for dealing with the threat. Patients who perceive that they have more control over the threat are better able to reduce the negative consequences of the threat (Arora et al., 2002).
- While health competence and self-efficacy are highly related constructs, we (authors, mvds) note that Bandura conceptualizes self-efficacy to be individually task-specific, such as self-efficacy for smoking cessation (although there are a few researchers who have studied self-efficacy at a more global level) [...] Perceived health competence, on the other hand, has been conceptualized to be a domain-specific efficacy construct where the domain of interest is health. Perceived health competence measures the degree to which an individual perceives him/herself to be capable of effectively influencing his/her health outcomes. Given that women with breast cancer are likely to engage in a variety of tasks and behaviours that might enhance their health outcomes, we used the domain-specific measure of efficacy (perceived health competence) in our study (Arora et al., 2002).

## (++R/+V)

- Information given should be repeatedly (Bratt et al., 2000).
- Public communication on sex behaviour: AIDS risk reduction interventions can be effective in improving knowledge, attitudes, and behavioural intentions and in reducing risky practices. The most effective approach to HIV/AIDS risk reduction among young people is one that provides practical information and support in a non-didactic way (Jepson, 2000).

## (+++R/-V)

- Effective interventions to change behaviour after the provision of information on risk need to be developed (Marteau and Lerman, 2001).
- Behavioural change is most likely in motivated people who participate in effective interventions [...] behavioural change may be more likely if people are persuaded that changing their behaviour can reduce the risk of an adverse health outcome and they are given access to evidence-based interventions. Further research is needed to evaluate programmes in which information about genetic risk is given, including evaluation of different ways of giving information [...] theories of behavioural change suggest that motivation to change a health-related behaviour is influenced by two sets of beliefs: 1) beliefs about current behaviour (is it putting me at risk?); 2) beliefs about the ability to change behaviour (how easy will it be for me to change my behaviour?). Most studies use the intention to change behaviour as the measure of motivation [...] Interventions with evidence are available for smoking, physical activity, and participating in screening programmes. The human genome project shows what can be achieved with sufficient resources and concerted international effort. Perhaps what is needed now is a human behavioural change project to ensure that applications from the human genome project are realized in practice (Marteau and Lerman, 2001).

## (++R/-V)

- Long multifaceted communication (Walpole et al., 1997).
- Communication campaigns must be driven by theory. Without theory a campaign could be successful, but it does not contribute to the development of the domain (Ziglio et al., 1998).
- The strategy of preventive medicine; 1) Risk factors for a large number of diseases and health problems are distributed in populations in a graded manner; 2) there is often no obvious and clinically meaningful risk factor threshold that differentiates those at risk and those not at risk for a chronic disease; 3) for many chronic diseases, there are many more people in a population at a relatively moderate level of risk than at the highest level of risk; 4) addressing only the very high risk (clinically recognized) segment of a population misses the opportunity to improve the risk profile of the entire population; 5) modest risk reduction among many persons with moderate risk factor levels will shift the risk factor profile of the entire population in a favourable manner; 6) a population-wide approach to intervention is thus called for, the objectives of which should be to reduce the average level of the population's risk through intervention for all and to intervene intensively for those few at the highest level of risk (Mittelmark, 2002).
- This paper argues that health communication needs to look at personality as a segmentation variable for audience selection and message designing purposes (Dutta and Vanacker, 2002).
- Several groups of authors have recommended that all health communication materials be written at the fifth-grade level (Doak et al., 1996) [...] Although simply written materials may cause concern that individuals with higher levels

of literacy may be offended, research has demonstrated that such materials are received favourably and preferred by people at all literacy levels [...] Doak et al. (1996) proposed the following guidelines for developing effective health education materials at the fifth grade level: 1) assess the educational needs of the target audience; 2) limit the number of educational objectives to one or two; 3) base content on behaviors rather than on facts or principles; 4) present the context first so readers have a framework on which to build the new information that follows; 5) increase the complexity by providing information in smaller 'chunks', with interaction after each chunk; 6) include reader interaction in the form of questions or checklists directed to the reader; 6) select visuals and layouts that match the culture and gender of the target population (Conerly, 2001).

(+R/-V)

- Disease prevention campaigns are often considered less than effective since the benefits are attained in the future rather than in the present [Rogers and Storey, 1987]. However, many have succeeded and the elements of a successful media campaign include the following: 1) specific attainable objectives; 2) recommended behavioral changes that are easy to perform; 3) message accessibility and appeal. Four implications are proposed regarding the steps involved in healthy behaviour: 1) one strategy to promote healthy behaviour is to increase perceptions of efficacy, susceptibility, seriousness and salience; 2) a television series focused on improving health through disease prevention can increase health knowledge and in so doing boost viewers' efficacy and salience; 3) the optimal opportunity for stimulating efficacy is to produce messages that provide respondents with information that enhances their confidence in their ability to differentiate accurate from inaccurate reports as well as help them recognize the dearth of reliable information around (Chew et al., 2002).
- Once a causal relationship has been established between individual behaviour and an increased risk of disease, it also becomes viable to consider whether health education might be a feasible intervention strategy, drawing on the established theoretical base for achieving personal or social change. This might include, for example, social learning theory, diffusion of innovation theory, social marketing principles, community development and so on. It is equally crucial that more recognition is given to the importance of understanding the process of change within interventions, and including this dimension as a control component in the evaluation task (Nutbeam et al., 1990).
- Rather, we simply want to examine whether social marketing, like other disciplines such as education and social psychology, can contribute in some way to the work of health promoters in general and their attempts to communicate through the media in particular [...] commercial marketing is essentially about getting the right product, at the right price, in the right place at the right time, presented in such a way as to successfully satisfy the needs of the consumer. The so-called 'marketing mix' [...] The four elements should be applied in conjunction with one another, rather than in isolation (Fox and Kotler, 1980) [...] The marketing mix and the role of communication within it should be subject to continuous monitoring and evaluation so that it can be designed and developed to meet these needs. Indeed pragmatism – the 'can do' philosophy – is perhaps another important insight that health promoters can gain from marketing [...] At the very beginning of a project, consumer contact can help define the nature of the problem to be tackled, determining whether the media has a role to play and, if so, what objectives it might fulfil [...] Assuming initial contact with the consumer does define a role for the mass media, further contact can help determine the relative merits of different creative ideas or approaches on which to base a campaign [...] Ideally the progress of an initiative should be continuous, tracking the progress of an initiative over time and feeding back information that can help executive decision making [...] This type of understanding is fundamental to effective communication (Hastings and Haywood, 1991).
- [...] fear is most likely to be effective if the campaign allows for the desired behaviour to be reinforced by a reduction in the level of fear. This entails five requirements: 1) fear onset should occur before the desired behaviour is offered; 2) the event upon which the fear is based should appear to be likely; 3) a specific desired behaviour should be offered as part of the campaign; 4) the level of fear elicited should only be such that the desired behaviour offered is sufficient to substantially reduce fear; 5) fear offset should occur as a reinforcer for the desired behaviour, confirming its effectiveness [...] In general a positive reinforcement approach may prove to be more effective than the use of fear [...] If fear is to be employed as the basis of a health promotion campaign, then research must be undertaken before intervention is implemented. This preliminary research should ensure that, in the relevant target audience: 1) the level of fear aroused is not so high as to make it unlikely that the prescribed action will alleviate the fear; 2) the prescribed action does, in fact, largely eliminate the fear aroused; 3) other inappropriate reactions (denial, perceived personal invulnerability) are not occurring and being reinforced by fear reduction (Soames, 1988).
- 1) conduct communication surveillance-examination of media trends, professional deliberations, Internet rumours, cultural myths, etc.; 2) educate at all levels – develop social norms, reiterate key messages and develop health literacy; 3) advocate with key leaders including the media, academic and government communities, not just the health sector; 4) create dialogue opportunities for public understanding of science/health in the media and in public settings; 5) integrate scientific knowledge and 'truth' in sustainable systems (media, academia, government, etc.) (Ratzan, 2002).
- Dissemination is about the communication of knowledge, this being either a planned and systematic process or a

passive and unplanned diffusion process. It is argued that researchers have a duty to share new knowledge with a wider audience including the general public. Effective dissemination requires an active and systematic approach that is adequately resourced throughout. Researching the complex area of dissemination has involved examining three key areas: 1) defining dissemination and identifying barriers to effective dissemination; 2) describing the audiences for health promotion research and defining their needs; 3) identifying appropriate strategies to implement (Crosswaite and Curtice, 1994).

- It is argued that health promotion research faces three critical problems: 1) defining adequate research questions; 2) identifying appropriate areas for research; and 3) developing a theoretical basis for problem formulation [...] if health promotion research is to be distinguished from epidemiology, sociology, psychology, politics or economics with a health promotion angle, then these three problems must be resolved [...] The Ottawa Charter therefore identifies the building of public health policy, the creation of supportive environments, the strengthening of community action, the development of personal skills and the reorientation of health services as the key strategies in the overall process [...] The ideals of improvement and change also formed the core of an earlier WHO document entitled *Health promotion: Concepts and Principles in Action: A Policy Framework* (Nutbeam n.d.). Here the principles of health promotion are identified as: 1) involving the population as a whole (rather than populations at risk from particular diseases) in the context of their everyday lives; 2) being directed towards action on the determinants of, or causes of health; 3) being diverse in methods and approach; 4) involving effective and concrete public participation; 5) not being a medical specialism [...] These principles are the basis for what Nutbeam calls the subject areas of health promotion. These are: 1) access to health; 2) development of an environment conducive to health; 3) strengthening social networks and social support; 4) promoting positive health behaviour; 5) increasing knowledge and dissemination of information (Kelly, 1989).

#### Failure

(++R/-V)

- Traditional health communication theories such as the health belief model, the theory of planned action, self efficacy, and the theory of reasoned action have consistently focused on functional needs, without paying attention to other types of need (social and sensory, mvds) [...] The normative model (underlining, mvds) provides a more holistic approach to the understanding of the persuasive processes in health communication [...] optimizing the effectiveness of the public health messages (Dutta and Vanacker, 2002).
- The AIDS pandemic continues to expand despite community, national and international prevention and education efforts. One reason for this expansion may be that early AIDS campaigns tended to focus on rational rather than emotional arguments (Dutta and Vanacker, 2002).

#### Means

##### Success

(++R/-V)

- An assessment is needed in which the following questions could be asked: 1) attitude regarding health care; 2) knowledge of the genetic essentials of, for example, breast cancer; 3) trust and credibility of diagnosis (Kinny et al., 2001).

##### Failure

(+++R/-V)

- The direct use of research in policy is rare. Research is more likely to form part of a general information background for policy makers, practitioners and the public. Direct use though is necessarily supported with evidence-based health communication databases (Crosswaite and Curtice, 1991; Khoury et al., 2000).

(+R/-V)

- Public health authorities distrust the free market to inform the public accurately and objectively concerning risk behaviours and appropriate measures for healthy living. Their reason is that the market is a cacophony of explicit and implicit messages about health, many of which are not based on science but on uninformed opinion (Gostin and Javitt, 2001).

#### Receiver

##### Success

(+++R/-V)

- Providing people with personalized information on risk is not new. The question is whether responses will be any different if the information is based on DNA [...] Genetic risk information could both increase and decrease motivation to change behaviour. It might increase motivation by strengthening the belief that current behaviour, combined with a genetic predisposition, is putting a person at increased risk of disease. It could also increase motivation by strengthening belief in the effectiveness of a treatment recommended on the basis of genotype information. Alternatively, given a common perception that genetic risks are immutable, it might decrease motivation by weakening beliefs that changing behaviour will reduce risks. Genetic risk information may also weaken belief in the ability to change

behaviour, for example among people who learn that they have genetic vulnerability to nicotine addiction [...] (Cancer): However initial data show no significant changes in screening behaviour after testing [...] (Smoking): These preliminary results suggest that genetic information may not lead to behavioural changes, even when there is an unequivocal risk reduction strategy available [...] The current evidence suggests that providing people with DNA-derived information about risks to their health does not increase motivation to change behaviour beyond that achieved with non-genetic information (Marteau and Lehmann, 2001).

(++R/+V)

- More systematic and efficient ways need to be found to translate and disseminate research results to the public. The failure of the public cannot be written off simply as the fault of their ignorance [...] when the public acts without sufficient evidence professionals and scientists blame the public for ignorance of scientific facts. Scientists and health professionals have only themselves to blame for public misunderstanding of scientific facts. Health educators have a responsibility not only to translate scientific information to the public in palatable and behaviourally relevant ways, but also to pull the information from the always diffident scientists and their forever incomplete research (Green, 1987).
- high self-monitoring, high idiocentrism is the only combination that produced a significant effect on the attitude toward the advertisement. Considerable work has been done with self-monitoring [...] self-monitoring is a personality trait that conveys the extent to which an individual is likely to monitor and control his/her expression in situations which contain reliable cues to social appropriateness. High-self monitoring is typically concerned with projecting social images that allow them to meet the varying needs in various social situations. They are being concerned with being the right person in the right place at the right time, and therefore sensitive to images of self that they project in social situations [...] Low self-monitors are more concerned with being consistent with their internal feelings and preferences rather than with social appropriateness. They do not attempt to mould their behaviour to fit situational and interpersonal considerations (Dutta and Vanacker, 2002).
- Disease prevention campaigns are often considered less than effective since the benefits are attained in the future rather than in the present (Rogers and Storey, 1987). However, many have succeeded and the elements of a successful media campaign include the following: 1) specific attainable objectives; 2) recommended behavioral changes that are easy to perform; 3) message accessibility and appeal [...] Four implications are proposed regarding the steps involved in healthy behaviour: 1) one strategy to promote healthy behaviour is to increase perceptions of efficacy, susceptibility, seriousness and salience; 2) a television series focused on improving health through disease prevention can increase health knowledge and in so doing boost viewers' efficacy and salience; 3) the optimal opportunity for stimulating efficacy is to produce messages that provide respondents with information that enhances their confidence in their ability to differentiate from inaccurate reports as well as help them recognize the dearth of reliable information around (Chew et al., 2002).
- Studies have shown that messages processed in this way (central routing, Elaboration Likelihood Model, mvds) tend to be retained for a longer period of time and are more likely to lead to permanent change than messages that are not elaborated upon (i.e. peripheral processing) (Kreuter and Holt, 2001).

(+R/-V)

- message credibility is generally agreed to result from an interaction of source characteristics (e.g. expertise, trustworthiness), message characteristics (related to message content, encompassing factors such as plausibility, internal consistency and quality), and receiver characteristics (e.g. cultural background, previous beliefs) (Wathan and Burkell, 2002).
- One of the criteria we use to filter information is its credibility, or believability [...] A key early stage in the persuasion process is the receivers' judgement of the credibility of the information [...] Sources are judged as credible based on perceived competence, character, composure, dynamism and sociability [...] Tseng and Fogg (1999) identify four types of source credibility: 1) presumed credibility arises from the assumptions of the perceiver; 2) reputed credibility is based on source levels. Those sources labelled 'Doctor' or 'Professor', for example; 3) surface credibility is assigned based on a user's simple inspection of superficial characteristics, i.e. judging a book by its cover; 4) experienced credibility is based on user's experience [...] The Science Panel on Interactive Communication and Health (SciPICH) identified the following advantages of interactive health communication: 1) improved opportunity to tailor messages; 2) improved use of media to match the learning styles of users; 3) increased possibility for users to remain anonymous, which may increase their willingness to engage in frank discussions; 4) increased access to information and support and demand; 5) increased opportunity for interaction with health professionals and/or support from others; 6) enhanced dissemination capabilities and opportunity to keep content current [...] Consumers of health information identify credibility as an important aspect of useful information (Wathan and Burkell, 2002).
- an important role of health information seeking is that it allows individuals to cognitively and behaviourally attempt to gain control over health-related events (Lenz, 1984).
- The GENIS focus on information seeking contrasts directly with most health information campaigns that view the world as rational and known, and which concentrate on controlling individuals to seek values of efficiency and effectiveness.

Instead GENIS addresses issues similar to notions of way of life and mastery of life by focusing on the process of information seeking rather than just on the results of the search [...] Self-efficacy in information seeking facilitates an individual's development of lifelong skills that can be applied in the ever-changing health information environment, rather than forcing the individual to rely on being 'spoon-fed' (brackets in original text, mvds) perishable content [...] It is believed that if a person's previous intent to seek information (which is generally higher) can be sustained when they are actually confronted by the disease [...] At each stage, people are faced with different information needs and with different levels of emotion that impact their information seeking: 1) a casual level is characterized by a general lack of concern or interest; 2) a purposive-placid level is characterized by questions such as, 'What can I do to prevent cancer?'; 3) a purposive-clustered level describes a situation where an individual is in somewhat greater proximity to cancer.; 4) a directed level includes individuals who have been diagnosed as having cancer [...] As mentioned before, studies indicate that people are less likely to look for information as their proximity to cancer increases, meaning that people in the third and fourth stages are less likely to look for information (Johnson et al., 2001)

Failure

(++R/-V)

- Disease prevention campaigns are often considered less than effective since the benefits are attained in the future rather than in the present (Rogers and Storey, 1987, in Chew et al., 2002).

### Conclusions: sender

From the literature on the sender as a facet in the communication process, we learn that most of the time the use of theories by the sender (theory-based interventions) is dealt with, but ways to reach out to different target groups are also discussed. The most valid and relevant literature covers the importance of information which causes an increase in expectations of competence and the efficacy of the target audience. Arora et al. (2002) use Johnson's theory of self regulation in which the gap between expectations and actuality diminishes, which causes the target audience to understand the situation in a more comprehensive way. Lazarus's theory of cognitive appraisal is also discussed by Arora et al. (2002). This theory states that when people in a threatening situation find enough information they obtain control over the threat. Moreover Arora et al. (2002) say that self-efficacy goes beyond the individual, also exerting an influence on a group or at a population level. Self-efficacy, as Arora et al. (2002) write, could be considered as perceived health competence. For the use of theories in intervention Chew et al. (2002) (less relevant/not valid) mention the Health Belief Model (see Fig. 3.8). They write:

*The positive results support the model's heuristic in explaining and predicting disease prevention behavior. Consequently, the study emphasizes that the Health Belief Model variables of efficacy regarding the benefits and barriers to healthy behaviour, susceptibility, seriousness, salience and cues to action are important dimensions in promoting healthy behaviour.*

The Health Belief Model (HBM) could be seen as an instrument for biomedical science communication policy and strategy. Hastings and Haywood (1991) (less relevant/not valid) write that it is useful to incorporate the ideas of social marketing, about which they write:

*Social marketing is the design, implementation, and control of programmes seeking to increase the acceptability of a social idea, cause or practice in a target group(s). It utilises market segmentation, consumer research, concept development, communication, facilitation incentives and exchange theory to maximise target group response.*

According to Hastings and Haywood health promotion involves social changes. The lay audience becomes aware of a health issue and starts changing its behaviour. This behavioural change is part of a social change. Effective marketing is marketing that fulfils the customer's wishes.

This movement into social marketing for health communication is part of a change in thinking in health communication, one which we read about in the consolidated literature. In this context, Dutta and Vanacker (2002) (relevant/not valid) state that the traditional theories of health communication, such as HBM, the theory of planned action, and the theory of reasoned action, have functional needs as their target for effectiveness, whereas there is no attention given to the social needs of the target audience. This normative model of health communication might be a more holistic approach but according to Dutta and Vanacker it contributes to the optimization of the effectiveness of the health communication message. In the next section we will focus on the distinctive stages that constitute the health communication process.

In the literature we have read and validated, a few authors describe the different steps that can be taken to design an effective communication process (Conerly, 2001; Soames, 1988; Johnson et al., 2001; Kelly, 1989; and Ratzan, 2002) (relevant, less relevant / not valid). The ideas of these authors can be combined into the following steps, although one must be careful when using them, as they are presented in the relevant but not valid literature. After assessment the convincing power of the unconsolidated literature indicates: 1) relevant and valid (+++R/+V): development of capacity and a focus on the emotions of the target audience; 2) less relevant and not valid (++R/-V): communication process between biomedical science communication researcher and biomedical science communication professional; 3) relevant and not valid (+R/-V): all other cited elements. Taking this into consideration, the different steps are:

- 1 assess the educational level of the target audience and their learning styles. See the target audience as a whole and start the communication process from an emotional point rather than from a functional, rational angle;
- 2 restrict the subjects of the message and get close to the wishes of the target audience. Give the target audience insight into where to find additional information and try to build social networks that provide social support for the process of searching, finding and interpreting information;
- 3 start from the context of the health communication issue and generate a framework from which the target audience can start;
- 4 make the information manageable for the target audience by providing small, relevant elements of the whole health issue;
- 5 introduce interactivity with health professionals and other members of the health communication network of the target audience. This enhances the dissemination of knowledge and keeps information up to date;
- 6 use repetitive messaging if it is useful in reaching the target audience (Jepson, 2000; Bratt et al., 2000) (relevant/not valid);
- 7 make use of different means of communication, which leads to multifaceted health communication (Walpole et al., 1997) (relevant/not valid);
- 8 evaluate the process once it is started (Marteau and Lehrmann, 2001) (relevant/not valid).

#### Conclusions: means

The means and channels of process and communication are of course intertwined. There is no effective process without an integrated means of communication, and there is no useful means of communication without the context of a process. Hence, the designing of an effective communication process is a communication tool as such (Crosswaite and Curtice, 1991; Khoury et al., 2000) (relevant/not valid). Also, an evaluation process is a means of communication means (Kok et al., 1997) (relevant/not valid).

One of the means of the communication process – in addition to elements of structure, which are described in

the former section – is a needs assessment (Kinney et al., 1997) (relevant/not valid). This can be easily worked in a manageable questionnaire. These kinds of instruments need to be introduced quickly to the practice of health communication (Crosswaite and Curtice, 1991; Khoury et al., 2000b).

#### **Conclusions: receiver**

In the unconsolidated literature we have read that health promotion and health education are closely related. Health education is fundamental to health promotion, as Green (1987) (relevant/not valid) writes. In this situation of strong relatedness increasing self-efficacy, susceptibility and visibility are of most importance (Chew et al., 2002) (relevant/not valid). The GENIS system helps to search for h information by supporting a target audience in their way of searching for information. Aspects such as self-efficacy are important in searching for information, as the process of searching for information is more important than the search target as such. The object here is having competency in searching for information (Johnson et al., 2001) (relevant/not valid). Aspects such as credibility and convincing power are also important.

To summarize all of the conclusions on the process of biomedical science communication on predictive DNA diagnostics we conclude that the theoretical models obtained from the consolidated literature are also used in the unconsolidated literature, or are subject to research. Although a few of these models are slightly modified or criticized, they are obviously quite useful. As we concluded from the consolidated literature the models are useful for the practice of biomedical science communication and their use is theoretically justified. However, most of the literature is not valid, therefore introduction of these models into the domain of biomedical science communication should be carried out carefully. When a model is used, for example, in a campaign based on HBM an evaluation study should follow, in which the criteria are related to elements of the HBM model. Fig. 3.11 shows a synopsis of the models and theories in their use to biomedical science communication on predictive DNA diagnostics.

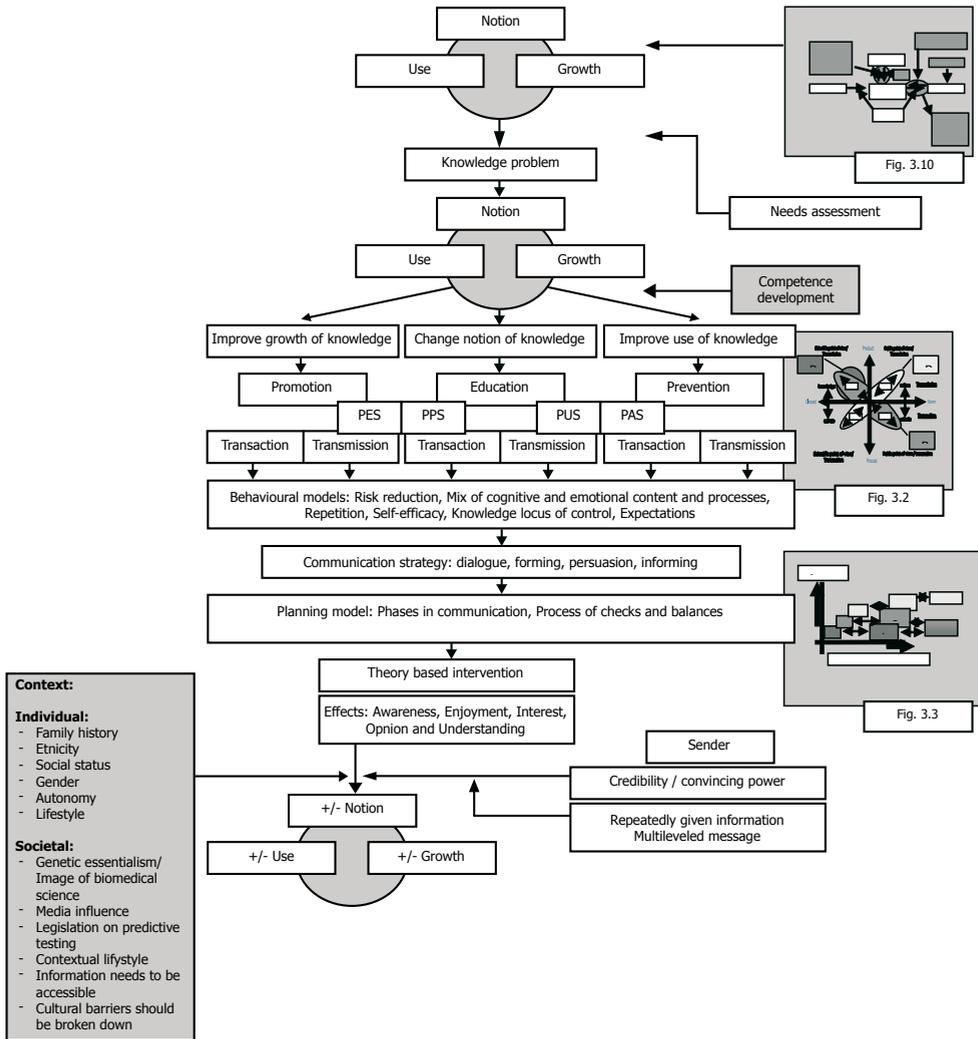


Fig. 3.11: Preliminary model of the process of biomedical science communication on predictive DNA diagnostics. New angles and definitions from the unconsolidated literature on process are used. The process starts with gaining insight into the knowledge problem or challenge (cognitive and affective) of the target audience (needs assessment). The process could be made evidence based by using the RLO as described in Fig. 3.10. Then one has to decide whether this is a problem or challenge to the notion, growth or use of knowledge. From there the different modalities of biomedical science communication should be chosen. Within these modalities one can choose transaction or transmission. The choice made might be supported by the interaction between different modalities and goals, as described in Fig. 3.2. In accordance with this a model for intervention like HBM could be used to reformulate one's question on a biomedical science communication intervention from a theoretical perspective. Moreover this question could be supported by insights into the level of urgency, modality and level of concreteness as described in Fig. 3.3. Once the intervention model has been chosen a strategy (Van Ruler, 1998, described in chapter 1) can be implemented. From this strategy the biomedical science communication professional should make a decision about the timing of the process and the message, the latter of which could be multileveled.

### 3.7.3 Outcome

The element of outcome can be defined in light of: 1) knowledge and competences; 2) susceptibility; and 3) behavioural change (see Fig. 3.12). In the analysis of the unconsolidated literature the elements of knowledge depicted are the analysis domains.

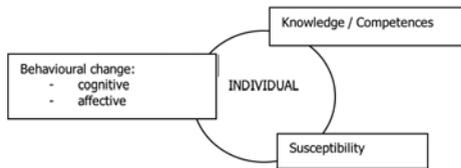


Fig. 3.12: Knowledge in relation to the individual (see text for explanation).

#### Knowledge

##### Success

(+++R/+V)

- Individuals use their knowledge on affective responses differently. This depends on the way the message is interpreted by the target audience (Dillard and Peck, 2000).
- Our (authors, mvds) results showed that a majority of the Finnish population generally approved of gene tests. A considerable proportion believed that genetic testing will have positive consequences but also had worries related to the development of gene tests [...] The general public sees new developments in genetics as a double-edged sword (Michie et al., 1995, in Jallinoja and Aro, 2000).
- It is often taken for granted that worries and ideas accompanied by fear of new technologies are due to a low level of knowledge. Many studies on the public understanding of science have equated public appreciation of and support for science with the public's accurate knowledge of it (Davidson et al., 1997; Wynne, 1995). This would mean that with improvement of the level of knowledge among the general population attitudes toward gene tests would become more favourable. However, it might be that the association between knowledge and attitudes is not so straightforward (Evans and Durant, 1995, in Jallinoja and Aro, 2000).
- We measured attitudes on the following issues: general acceptance of gene tests; privacy; voluntariness; positive and negative consequences of gene tests; control and financing of genetic testing; and informing the public about gene tests (Jallinoja and Aro, 2000).

(+++R/-V)

- The utility of a predictive genetic test will therefore depend on whose point of view is considered [...] Success: the ideal context, therefore, is a highly predictive test for a disease that is serious and incurable but preventable by means that are imperfect or expensive [...] Family history and experience are important factors in determining how an individual perceives the utility of predictive genetic testing [...] The complexity of these factors calls for discussions about testing that are highly tailored to the testing context and the individual's needs and preferences (Evans et al., 2001);
- Responses to any information on risk are shaped by pre-existing perceptions and by the way the information is presented (Marteau and Lerman, 2001);

(++R/-V)

- The LMEC (Local Multidisciplinary Evidence Centre) gave access from the workplace to both physical and electronic resources to support clinical governance and lifelong learning, with a strong emphasis on evidence-based material (Howard, 2002);
- Reports answer the following frequently asked questions: 1) for which diseases is clinical testing available?; 2) for which diseases is prenatal testing available?; 3) for which genes does a test exist?; 4) for which diseases is direct DNA testing used? Linkage?; 5) for a given disease, how many searches are performed?; 6) how many labs provide DNA-based services, such as genotyping? DNA banking? (Pagon et al., 2002b);
- Among women who have 1-11 years of education (i.e. have not completed high school), the probability of expressing interest in genetic testing is lower for women with breast cancer than for women without breast cancer. Among women with more education (14+ years), the effect is reversed, with the probability of interest in genetic testing being higher among women with breast cancer compared with those without [...] This finding reflects women's interest in obtaining categorical information (will I get the disease or not?) rather than probabilistic information about their risk for breast cancer, and their unrealistic expectations of what genetic testing for breast cancer risk can provide (Bottorff et al., 2002).

(+R/-V)

- [...] suggest potentially significant demands for genetic testing and related information, which can affect the individual and his or her family or biological network (Johnson et al., 2001).

Failure:

(+++R/-V)

- Responses to any information on risk are shaped by pre-existing perceptions and by the way the information is presented (Marteau and Lerman, 2001).

(++R/-V)

- Better information alone will not produce more equity (Braveman and Tarimo, 2002).
- More than 40% of adults in the USA have low literacy skills. Unfortunately, many health communication materials are not culturally relevant and are written at a level of literacy that is too high [...] Faal: Inadequate health literacy suggests that people can often misread simple materials, including prescription bottles and appointment slips (Conerly, 2001).
- We (authors, mvds) surveyed 50 essential tremor (ET) patients about their knowledge of the genetics of ET. Many patients, including those who reported having a family history of the disease, did not reply that ET was a hereditary disease (Watner et al., 2002).
- Regardless of their breast cancer status, almost two-thirds of the women surveyed did not know that one's paternal family history of breast cancer is important [...] For the most part, women with breast cancer did not express superior knowledge of breast cancer genetic testing [...] Critical gaps in the knowledge essential to understanding hereditary breast cancer and genetic testing appear to persist and point to the need for better educational strategies (Bottorff et al., 2002).
- People who had seen the pamphlets or the poster were about three times more likely to have chosen the correct definition of genetic disease [...] However, there were few significant improvements in knowledge after the interventions among male or female respondents and the overall level of knowledge was not high (Walpole et al., 1997).
- More systematic and efficient ways need to be found to translate and disseminate research results to the public. The failure of the public cannot be written off simply as the fault of their ignorance [...] when the public acts without sufficient evidence professionals and scientists blame the public for ignorance of scientific facts. Scientists and health professionals have only themselves to blame for public misunderstanding of scientific facts. Health educators have a responsibility not only to translate scientific information to the public in palatable and behaviourally relevant ways, but also to pull the information from the always diffident scientists and their forever incomplete research (Green, 1987)

## Behavioural change

### Affective

Success

(+/-V)

- Regardless of whether fear of genetic discrimination is based on perception or reality, we must find a way to ensure public confidence in genetics research and the use of genetic information (Rothenberg and Terry, 2002).

Failure

(+++R/+V)

- [...] it is also possible that lower psychosocial outcomes may in turn result in greater difficulties in accessing information [...] 'I needed information but I couldn't afford the time or effort it took to get it' (Arora et al., 2002).
- Persons at risk for HD would not change their attitudes regarding indirect or direct predictive and prenatal DNA analysis. They have a confirmed opinion about molecular genetics mostly depending on familial and social factors (Kreuz, 1996).
- Our (authors, mvds) results showed that a majority of the Finnish population generally approved of gene tests. A considerable proportion believed that genetic testing will have positive consequences but also had worries related to the development of gene tests [...] The general public sees new developments in genetics as a double-edged sword (Michie, et al 1995, in Jallinoja and Aro, 2000).
- Research shows that lively use of language can lead to 'perceived effectiveness' but not to a change in attitude (Collins et al., 1988, in Dillard and Peck, 2000).

### Cognitive

Success

(+++R/+V)

- Breast cancer patients often report dissatisfaction with the extent to which their information needs are addressed by their health providers. Our findings (authors, mvds) underscore the need for designing and implementing interventions that would aid providers in better meeting the information needs of their patients [...] greater difficulty in accessing needed information is significantly associated with poorer psychological health. (Arora et al., 2002).
- A slight feeling of anxiety could help healthy behaviour: fear-arousing theory (Bratt et al., 2000).

(++R/+V)

- After hearing about the outcome of a genetic test, four reactions can be distinguished: 1) I do have a genetic predisposition, so who cares about smoking; 2) I do have a genetic predisposition, so I should be careful about smoking; 3) I do have a risk for heart disease. I should stop smoking; 4) I have a low risk for heart disease so I do not care about smoking (Hunt et al., 2000).

(+++R/-V)

- Behavioural change is most likely in motivated people who participate in effective interventions [...] Behavioural change may be more likely if people are persuaded that changing their behaviour can reduce the risk of an adverse health outcome and they are given access to evidence-based interventions (Marteau and Lerman, 2001).
- [...] the first generation of research on the effects of tailored communication demonstrated that such materials could promote greater behavioural change than non-tailored materials could [...]. It appears that tailored materials generated greater elaboration among participants, and other studies have found that such elaboration is associated with subsequent behaviour change (Kreuter and Holt, 2001).
- People who had seen the pamphlets or the poster were about three times more likely to have chosen the correct definition of genetic disease [...] However, there were few significant improvements in knowledge after the interventions among male or female respondents and the overall level of knowledge was not high (Walpole et al., 1997).

(++R/-V)

- [...] high self-monitoring, high idiocentrism is the only combination that produced a significant effect on the attitude toward the advertisement. Considerable work has been done with self-monitoring [...] self-monitoring is a personality trait that conveys the extent to which an individual is likely to monitor and control his/her expression in situations which contain reliable cues to social appropriateness. High self-monitoring individuals are typically concerned with projecting social images that allow them to meet the varying needs in various social situations. They are concerned with being the right person in the right place at the right time, and therefore sensitive to images of self that they project in social situations. [...] Low self-monitors are more concerned with being consistent with their internal feelings and preferences rather than with social appropriateness. They do not attempt to mould their behaviour to fit situational and interpersonal considerations (Dutta and Vanacker, 2002).

(+R/-V)

- What is needed is a strategy that does not rely on perishable content but instead helps people gain lifelong skills to find and assess cancer genetic information on their own (Johnson et al., 2001).
- It was intended that dissemination activities would be enhanced through networking and 'ripple' effects – hence participants at the workshops could return to their own workplace and conduct further workshops and presentations. Mutter's (1989) approach to dissemination was intended to act as a catalyst for change in the health education sectors. It resulted in raised awareness and had a significant effect upon intended targets (Crosswaite and Curtice, 1994).
- Employing programmes soundly based on three learning principles, effective persuasion was achieved during the 1980s in the area of smoking. The persuasive messages evaluated have been soundly based on three learning principles: 1) The level of fear employed must be relatively low, so that inappropriate responses (such as denial) are not required to deal with the fear. This has been achieved by concentration on the immediate physiological effects of smoking, such as blood pressure and lung capacity; 2) This concentration on short-term effects also allows for a more immediate result from the cessation of smoking, i.e. the results of increased lung capacity, rather than the very long-term reinforcer of possible avoidance of an earlier death. It is a well-established principle of learning that a reinforcer of shorter delay is more effective than one of long delay and even with long delays of reinforcement less time for 'associative interference' enhances learning; 3) The principle of behaviour shaping is employed as specific responses are offered rather than naive advice to simply not smoke. Typically this has involved teaching specific skills to resist the social pressures to smoke. These principles have been employed in numerous studies reporting positive results (Soames, 1988).

Failure

(++R/-V)

- The current evidence suggests that providing people with DNA-derived information about risks to their health does not increase motivation to change behaviour beyond that achieved with non-genetic information (Marteau and Lerman, 2001).
- Research shows that the mass media have succeeded in increasing factual knowledge and public awareness of health issues although they are less successful in changing established attitudes and behaviour (Rogers and Storey, 1987) [...] It is interesting that perceived efficacy and seriousness did not significantly contribute to health behaviour among non-viewers. This could have been attributed to the lack of available health information apprising them of symptoms of health contradictions and the benefits of and barriers to good health (Chew et al., 2002).
- Inadequate health literacy suggests that people can often misread simple materials, including prescription bottles and appointment slips (Conerly, 2001).

**Susceptibility**

## Success

(+++R/+V)

- Perceived effectiveness leads to better measurement [...] Effects belonging to emotion as well as to attitude are determined by 'perceived message effectiveness' [...] Happiness is associated with improved message acceptance [...] Vivid language does improve 'perceived effectiveness' but does not automatically lead to a change of attitude (Collins, Taylor, Wood and Thompson, 1988, in Dillard and Peck, 2000).

(+++R/-V)

- Four main factors have been found to influence the way in which a consumer receives information. These are: the type of information offered, the manner of data presentation, the type of media channel used and the credibility of the message (Dennis, 1990, in Crosswaite and Curtice, 1991).

(++R/-V)

- [...] high self-monitoring, high idiocentrism is the only combination that produced significant effect on the attitude toward the advertisement (Dutta and Vanacker, 2002).
- [...] Strong support for the HBM (Health Belief Model, mvds), increases factors of efficacy, susceptibility, seriousness and salience in their contribution toward health behavior among television viewers compared with non-viewers. Cues to action variables (including television viewing) and health knowledge boosted efficacy among viewers. Without the advantage of receiving health information from the television series, non-viewers relied on their basic fears on one hand, and interest in good health on the other to take steps toward becoming healthier [...] When respondents feel their health is susceptible and that they highly value health, they will practice health behaviors. This applies to both viewers and non-viewers (Chew et al., 2002).
- Improvement of the social context and the economical and political criteria of health. This is about empowerment and capacity building (Mittelmark, 2002).

(+R/-V)

- For example, creating awareness may be achieved purely through communication whereas changing behaviour will probably require a more extensive intervention using both communication and other types of initiatives (marketing mix) (Hastings and Haywood, 1991).

## Failure

(+++R/+V)

- The relation between reviewing a message (perceived effectiveness and attitude toward message) and other 'persuasion outcomes' (change in attitude, intention of behaviour) is complex and a subject for further research (Dillard and Peck, 2000).

**Conclusion: knowledge**

The most relevant and valid literature claims that an increase in knowledge is important for the target audience when they appreciate and support new developments (Jallinoja and Aro, 2000; Evans and Durant, 1995). Though this is also supported by less relevant and non-valid literature from Johnson et al. (2001), the dissemination of knowledge is not enough (Conerly, 2001) (relevant/not valid). Forty percent of Americans lack the literacy skills needed to benefit from the health communication targeted toward them. Communication and messages therefore assume too high a knowledge level to be understood by the target audience (Conerly, 2001) (relevant/not valid). An example of this is the fact that women suffering from breast cancer do not have more knowledge about cancer than others have. Some of them do not know it can be inheritable (Bottorff et al., 2002) (relevant not valid). It is the many different ways that a target audience reacts to the different messages and their content that show that there is much more to an effective message. Marteau and Lerman (2001) (relevant/not valid) describe two types of reaction: 1) information on genetics can possibly change the motivation of the target audience in a positive way, by changing behaviour that diminishes the cancer risk, or in a negative way, when the target audience believes that they are the victim of their genes and therefore does not change their behaviour. In this there is a difference between men and women. Women are more interested in categorical information ('Will I get cancer or not?') whereas men are more interested in probabilistic knowledge ('What is my chance of getting cancer?') (Bottorff et al., 2002) (relevant/not valid). Pagon et al. (2002) (relevant/not valid) did research on which questions the lay audience has: 1) for which diseases is clinical testing available?; 2) for which diseases is prenatal testing available?; 3) for which genes does a

test exist?; 4) for which diseases is direct DNA testing used?; 5) for a given disease, how many searches are performed?; 6) how many labs provide DNA-based services, such as genotyping? DNA banking?

#### Conclusions: affective behavioural change

One of the main aims of communication on affective aspects is the idea of gaining the trust of the target audience. This depends on mental well being, which in turn depends on the effort one has to make to find information, for example. The more effort one has to make, the less effective the message is. Moreover, it leads to a decrease in mental well being (Arora et al., 2002) (relevant and valid). Mental well being depends (in a broad sense) on a context. When people are for example tested on Huntington's disease their attitude toward predictive testing does not change. Their opinion is strongly based on what happens in the family and in other social networks (Kreutz, 1996) (relevant and valid).

#### Conclusions: cognitive behavioural change

A few authors have carried out research on the different behaviours of people who have undergone genetic testing. According to Hunt et al. (2000) (relevant and valid) four outcomes are possible: 1) I have a genetic predisposition, so who cares about smoking; 2) I have a genetic predisposition, so I should be careful about smoking; 3) I have a risk for heart disease. I should stop smoking; 4) I have a low risk for heart disease so I do not care about smoking.

The questions are due to certain characteristics of the individual. For example, research has been carried out on the self-monitoring of the individual (Dutta and Vanacker, 2002) (relevant not valid). High self-monitoring individuals are people who are worried about being the right person in the right place at the right time. High self-monitoring individuals change their behaviour when it is socially appreciated, whereas low-self monitoring individuals are focussed on fulfilling their own needs and feelings and will not change their behaviour when it is socially polite to do so.

Within this frame of social behaviour fear and fear arousal can enhance or weaken the effect of a message (Soames, 1988) (relevant not valid). When fear arousal is used in a campaign the target audience needs to know how to handle it. One can, for example, ask oneself why drivers do not buckle up: 1) there is too much difference between buckling up and dying due to a car accident: the paradigm of punishment; 2) a driver does not see the seat belt as an instrument for avoiding being killed in a car accident; 3) one perceives the possibility of dying in a car accident due to not using the seat belt as being quite unlikely. How to improve on this: 1) fear arousal should be manageable by the individual; 2) it should be associated with specific behaviour, not just punishment for not buckling up; 3) it should teach that driving safely is about more than surviving a car accident. When fear arousal is too strong the target audience grows immune to fear by communication, an idea that is also supported by Bratt et al. (2000) (relevant and valid). When this happens the knowledge level of the target audience is important. A low level of health literacy may cause a poor assessment of fear arousal because members of the target audience have difficulty interpreting the information obtained (Chew et al., 2002) (relevant not valid).

#### Conclusions: susceptibility

Although 'perceived effectiveness' is seen as a powerful aspect of the health communication process it is still not an indicator for straight success in changing attitudes (Dillard and Peck, 2000) (relevant / valid). There are so many aspects of the communication process to be mentioned and monitored that it remains unclear which aspects are actually responsible.

Dennis (1990, in Crosswaite and Curtice, 1991) (relevant/not valid) describes four factors that determine the way a target audience receives a message: 1) the type of information; 2) the way the information is presented; 3) the means of communication; and 4) the credibility of the message sent.

In addition to these factors, elements of the respondents' characters are important. Therefore according to Dutta and Vanacker (2002) (relevant not valid) high self-monitoring (being aware of one's own actions and thoughts) and high idiocentrism (the self is more important than the group) is the only combination that leads to a significant effect on attitude. The relation between judgment of the message (perceived effectiveness and attitude toward message) and other persuasion outcomes remains complex and constitutes an interesting subject for further research (Dillard and Peck, 2001).

#### Conclusion: outcome

The most important question regarding information is: what is in it for me? Perceived effectiveness is important with respect to the development of competences. Behavioural change can be made measurable by using these competences. One competence could be: knowledge susceptibility.

When information is used by members of a target audience they can change their behaviour or they can ignore the information as a result of feelings of fatalism. These insights into knowledge susceptibility could be a first step in formulating criteria for outcomes that are part of an effective biomedical science communication process.

The unconsolidated literature does not generate a completely different angle on success and failure as obtained from the consolidated literature. Many items have been more profoundly studied but the results of these studies are in line with the consolidated literature. What we learned from the literature is that the outcome of the communication process is not at all defined. The audience has questions but the answers provide too many different directions.

### 3.7.4 Context

After reading the unconsolidated literature the element of context can be separated into individual context and societal context.

#### Individual context

##### Success

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

- Most individuals are aware of their lifestyle and the risk [...] Perception of familiar heart diseases is important in the individual risk perception [...] We (the researchers, mvds) thus argue that understanding people's construction of familial risk of heart disease is important for health promotion as it is common and linked to behavioural risk factors for coronary disease (Hunt et al., 2000).

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

- The utility of a predictive genetic test will therefore depend on whose point of view is considered [...] The ideal context, therefore, is a highly predictive test for a disease that is serious and incurable but preventable by means that are imperfect or expensive [...] family history and experience are important factors in determining how an individual perceives the utility of predictive genetic testing [...] the complexity of these factors calls for discussions about testing that are highly tailored to the testing context and the individual's needs and preferences (Evans et al., 1997).
- Responses to any information on risk are shaped by pre-existing perceptions and by the way the information is presented (Marteau and Lerman, 2001).
- There is a strong tendency to focus on individual behaviour, but the social and physical environment is also seen as an important target for health education interventions [...] Quality was measured by: 1) relevance 2) individualization 3) feedback 4) reinforcement 5) facilitation (Kok et al., 1997).
- Age was found to be a factor mediating health beliefs (Chew et al., 2002).

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

- Background factors included: age, gender, family identification number, marital status. Education, household income, history of cancer and number of first-degree relatives with breast and/or ovarian cancer [...] younger age was associated with interest in genetic testing, as were a prior history of breast or ovarian cancer and one or more first-degree relatives with breast and/or ovarian cancer (Kinney et al., 2001; Spruijt-Metz and Gageldonk, 2001).

- For adolescents the basis for communication processes should be made of affective theories rather than rational theories (Spruijt-Metz and Gageldonk, 2001).
- Familial hereditary knowledge or upcoming pregnancy are reasons for attention given to genetic diseases (Sorenson and Cheuvront, 1993).
- In promoting healthy behaviour, two additional mediators seem appropriate in the context of a recently democratized society, health motivation and salience. These variables provide a measure of an individual's sense of participation in and responsibility for his or her own health [...] In the HBM, five basic factors influence disease prevention behaviours: 1) perceived susceptibility. This refers to a person's beliefs about the possibility of getting the disease or being harmed by the condition; 2) perceived seriousness of the consequences of the disease or health constitution such as a disability or mortality; 3) perceived benefits of performing the recommended behaviour, which includes feeling healthier or living longer; 4) perceived barriers to the suggested actions, which may include cost, time or inconvenience; 5) cues to action, which may consist of a physician's advice, print or electronic advertisement, or television programme. Previous researchers have also included a motivational factor [...] Five sets of variables derived from the HBM were measured: 1) efficacy (index of barriers and benefits); 2) readiness (susceptibility separate from seriousness); 3) health motivation; 4) salience; 5) cues to action [...] The study's main contribution has been its application of the HBM with its entire array of health belief factors in assessing the influence of a television series on health behaviours. The positive results support the model's heuristic in explaining and predicting disease prevention behaviour. Consequently, the study emphasizes that the HBM variables of efficacy regarding the benefits and barriers to healthy behaviour, susceptibility, seriousness, salience and cues to action are important dimensions in promoting healthy behaviour. Viewing a health promoting television series shown to enhance health knowledge, health beliefs and ultimately health behaviour (Chew et al., 2002).

#### Failure

(+R/+V)

- Overall a structured programme in its present form did not appear to be an effective programme for use in general practice (Slama et al., 1990).

(++R/-V)

- None of the socio-demographic variables had any effect on health behaviour (Chew et al., 2002).

#### Societal context

##### Success

(++R/-V)

- The drive towards what is described as a more efficient health service goes hand in hand with the purported upholding of consumer choice, underpinned by an expressed belief in the value of autonomy (Chadwick, 1993).
- We (the authors, mvds) propose a theoretical model, entitled collective lifestyles, which brings together three concepts from practice theory: social structure, social practices and agency [...] we (the authors, mvds) suggest that a different conceptualisation of accessibility and lifestyle in contextual studies may enable us to improve our grasp on how differential rates of disease come about in local areas [...] Later studies have also confirmed that the type of local neighbourhood is associated more strongly with perceived health than the larger region in which the neighbourhood is located (Baxter, 1990) [...] These studies converge to suggest that it may be fruitful to examine features of local areas that are potentially health damaging [...] To produce a richer framework for understanding the relationship between agency, structure and health behaviours we have chosen to explore 'place' as the location within which social structure impacts on people's lives [...] The pairs of smoking-discouraging resources tend to be more present when either a territory has higher proportions of university-educated people or a higher proportion of single, female-led households [...] It would be tempting to conclude that more advantaged territories tend to have more smoking-discouraging resources and therefore, probably have lower rates of smoking initiation amongst their pre-adolescents [...] Given that each of the territories studied here exhibited different social practices, norms and cultures in relation to smoking, it would be critical for health promotion and public health programmes to tap into these 'collective lifestyles' in order to understand where and why pre-adolescents are willing to stop smoking (Frohlich et al., 2002).
- The social and psychological levels of the community have a significant influence on the well being of the individual who in turn influences others (Mittelmark, 2002).
- Numerous studies are currently addressing the issue of contextual effects on health and disease outcomes. The majority of these studies fall short of providing a theoretical basis with which to explain what context is and how it affects individual disease outcomes [...] For the most part current studies tend to conceive of context in four ways: 1) as the defined area within which we capture variation by analysing the aggregate characteristics of individuals that happen to live there; 2) as a location for particular environmental factors that influence disease outcomes; 3) as a location for community-level resources such as parks, stores, etc; 4) as a location for social capital [...] While it is critical to be able to describe physical, material and psycho-social features of areas, it is also key to capture the meaning that people ascribe

to their local neighbourhoods, their resources and people's actions [...] Three major aspects of social theory enable a greater articulation of context's components: social structure, social practices and agency [...] Social structure is not directly observable but is the objectification of a system of meaning. While well aware that there are numerous ways in which structure may be conceptualized, we choose to operationalize some aspects of structure in this paper using a few commonly used indicators of structure: 1) aggregate characteristics of individuals, which in most of the literature on context include indicators such as income, deprivation or inequality indices, percent poverty (Duncan et al., 1993 (for example, mvds)); 2) other instantiations of the social structure are what we entitle social 'agents' and 'resources' [...] We developed a heuristic tool entitled 'collective lifestyles' which brings together notions of social structure, social practices and agency to explain how health outcomes may come to be differentially distributed [...] we therefore define collective lifestyles as not just the behaviours that people engage in, but rather, as the relationship between the social structure and social practices (Frohlich and Potvin, 1999) [...] Collective lifestyles can thus be viewed as local ways of being, which work through individual and collective involvement in local rules, resources and practices [...] Thus suggesting that the pattern of resources in a territory is in part a function of the education levels of its population [...] the point being that context is neither just the reflection of the distribution of individual characteristics nor just the attributes of the area, but also the significance that these characteristics and attributes have for people (Frohlich et al., 2002).

- There is also considerable misinformation about genetic disease in the community, often aggravated by inaccurate media coverage (Walpole et al., 1997).

(+R/-V)

- [...] suggest potentially significant demands for genetic testing and related information, which can affect the individual and his or her family or biological network [...] Cancer genetics is an important health context because information acquisition can positively impact an individual's morbidity and mortality while also affecting an individual's family network (Johnson et al., 2001).
- Health public policy provides a legislative and economic framework within which 'healthy choices' may be made (Kelly, 1989).
- Developments in the Human Genome Project will lead to an increase in genetic testing at the level of genetic effects on newborns and on possible carriers of genetic disease. Moreover genetic research leads to genetic programmes and changes in society concerning knowledge about heredity (Sorenson and Cheuvront, 1993).

Failure

(++R/+V)

- An increase in genetic essentialism in society contributes to an increase in feelings of anxiety and fatalism, which in turn can undermine initiatives (Hunt et al., 2000).
- These uncertainties (regarding the test, mvds) contrast with the presentation of predictive genetic testing in the popular media, which often fosters an illusion that genetic risk is highly predictable and determinative [...] The value of a predictive test depends on the nature of the disease for which testing is being carried out, how effective treatment is, and the cost and efficacy of screening and surveillance measures. (Evans et al., 2001).
- Socially constructed gender roles and gender inequalities may adversely affect the health of men as well as women (Braveman and Eleuther, 2002).
- None of the socio-demographic variables had any effect on health behaviour among viewers (Chew et al., 2002).

(+++R/-V)

- [...] the term 'mutation' has become increasingly negative in its connotations though time. Although it has been used more frequently than alternative terms such as 'variation' and 'alteration' it is more likely to bear negative connotations than these alternatives. Clearly, further research is necessary to develop more precise understandings of the affective linkages of scientific and lay interpretations of terms associated with genetics. Such research would further assist with the important process of communicating about genetic variation and change with the lay public, policy makers and even fellow scientists (Condit et al., 2002).

(++R/-V)

- Many people, regardless of their socioeconomic status, may feel uncomfortable discussing colorectal cancer because of its location. Therefore, communication about colorectal cancer may need to take into account the embarrassment associated with the disease (Conerly, 2001).

(+R/-V)

- Generally, behaviours advocated by health professionals must be culturally acceptable [...] This is an especially important perspective for genetic information since there are sensitive social issues associated with it (Johnson et al., 2001).
- Genetic testing of individuals cannot take place when a treatment is missing (Leschot, 2001).
- Health damaging behaviours tend to cluster in the lower social classes and to contribute to inequalities in health. Age, gender, race, ethnicity, historical period and social context shape the operation and importance of all these processes [...] The importance of social context needs continually to be taken into account and is likely to result in more differential models (MacIntyre, 1997).

**Conclusions: individual context**

All of the authors stated that context is the most difficult element to analyse when developing an effective communication process. The most important aspects of individual context we found in the unconsolidated literature are:

- 1 family history (Hunt et al., 2000; Evans et al., 2001; Kinney et al., 2001; Spruijt-Metz and Gageldonk, 2001; Sorenson and Chevront, 1993);
- 2 earlier experiences and the way information was presented then (Marteau and Lerman, 2001);
- 3 important in the area of breast cancer (for other diseases no causal relationship was found: Kinney et al., 2001; Spruijt-Metz and Gageldonk, 2001) contextual factors regarding the individual are: 1) age; 2) gender; 3) family; 4) married or not; 5) level of education; 6) income; 7) individuals with cancer in the family (Kinney et al., 2001; Spruijt-Metz and Gageldonk, 2001).

To our knowledge, at this time there is no profound understanding of how individual aspects in a communication process are linked or levelled to each other. The unconsolidated literature seems to indicate that it strongly depends on the genetic disease in question.

**Conclusions: societal context**

Even more complex to handle, use or manage in a communication process is the societal context, which is, according to the unconsolidated literature we read: 1) a defined context in which people live; 2) a context that is influenced by other contexts; 3) a context with structural elements such as shops, schools, admission procedures, etc; 4) a place with social capital, like communities and other forms of interaction between individuals. In these kinds of context the important elements in social theories are 1) social structure; 2) social practice; 3) agency (Frohlich et al., 2002) (relevant/not valid). This means that there are different levels to cope with. One of the main questions, which also pertains to biomedical science communication on predictive DNA diagnostics is, what are the main factors to take into account when designing a communication process? As described in chapter 1 the medical context in which genetic essentialism plays a role is important. But the influence of genetic essentialism on the communication process is not clear in the literature we have read. Moreover, communication steers genetic essentialism as well which makes it a complex system that feeds forward and back.

Frohlich et al. (2002) write about collective lifestyles:

*Collective lifestyles can thus be viewed as local ways of being, which work through individual and collective involvement in local rules, resources and practices.*

This level of collective lifestyles might be a manageable one for the design of a biomedical science communication process. It could be seen as an abstract form of individual lifestyles. But what is the difference between, for example, socio-economic status (SES) and these collective lifestyles? For biomedical science communication on predictive DNA testing, knowledge about collective lifestyles, SES, and societal knowledge such as systems of genetic essentialism and the developments in the Human Genome Project (Sorenson and Chevront, 1989) (relevant/not valid) (results from the domain of social studies of science) should all be taken into account.

When one sees these similarities together it becomes clear that these developments form the basis for potential individual or collective feelings of fatalism and the undermining of future initiatives (Sorenson and Chevront, 1998) (relevant/not valid). Another strong element within the societal context is political and governmental influence (Kelly, 1989; Leschot, 2001). Kelly (1989) (relevant not valid) states that it is a governmental task to establish legislation to guarantee good health care in terms of structure and process, which support the public as they make their choices (informed consent). This can be done by starting from the archetypes of the *homo economicus*, *homo psychologicus* and the *homo sociologicus*.

### 3.8 In conclusion: theoretical framework step 1 for consolidated and unconsolidated literature

In Fig. 3.13 the conclusions obtained from the consolidated literature as well as the unconsolidated literature are depicted. The main changes to the framework for biomedical science communication can be seen in the contextual elements, and in the outcome elements of the biomedical science communication process (in green). In addition, new questions arise from the unconsolidated literature concerning the different levels, or system levels, of the biomedical science communication process. Overall one can see that the ideas of Miller and Kimmel and Van de Auweraert are wider and deeper than the ideas of others. Now it becomes more clear which of the many variables from chapter 1 construct the process described by Miller and Kimmel and the aims described by Van de Auweraert.

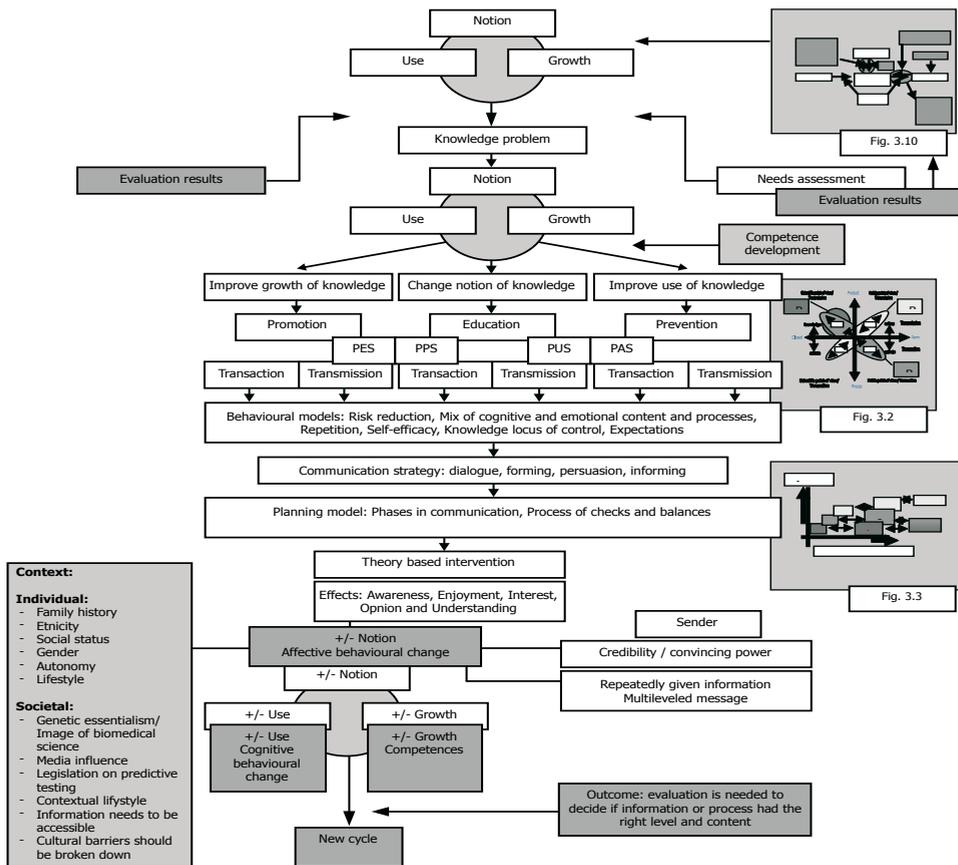


Fig. 3.13: Expanded process model of biomedical science communication on predictive DNA diagnostics. (See text below for an explanation using an example from a utopian situation). This is still a rough model. In the next chapters of this thesis we shall focus on subject, object and target group.

The following example describes the main elements of this model in light of predictive DNA diagnostics. A new predictive test has been developed based on DNA technology to test for susceptibility to colon cancer. This test replaces the current test, which is based on a Faecal Occult Blood Test (FOBT) in which traces of blood in the faeces can be seen. These traces indicate the possible presence of malignant tumours in the colon. This new predictive DNA test is to be implemented widely<sup>31</sup>. Regarding Fig. 3.13 the following could occur:

<sup>31</sup> We wrote an article for MAGMA on the subject of FOBT and public communication (Van der Sanden and Meijman, 2005).

- 1 In a meeting with the communication departments of several hospitals and other stakeholders involved in the implementation of the test, the organization and aims of the test are discussed in relation to the target audience, their beliefs and SES.
- 2 On the basis of the goals defined in this meeting the biomedical science communication officer and the health communication officer (see section 17: discussion) direct their communication policy and strategy in accordance with the targets of the test. Part of this communication policy and strategy is talking with the research liaison officer (RLO) to hear about the newest theoretical insights into the structure, process, outcome and context of the biomedical science communication process. Also, available information on the different stakeholders could be obtained from the RLO or allied research agents.
- 3 The communication officers (biomedical science communication/health communication) try to establish the different target groups and their level of involvement. Is knowledge about colon cancer important for the target group at the level of knowledge growth, knowledge use or beliefs about knowledge of colon cancer? What is the capacity to be developed and what are the competences?
- 4 Now the communication modalities can be established: are they about health education, health promotion or the prevention of ill health? Or are they about biomedical science promotion, biomedical science education or the prevention of biomedical knowledge deprivation? Which is the main modality? Which arguments are helpful in differentiating between health education and/or science communication? Supported by insight into the relation between level of urgency and level of concreteness of the message and goals like PAS, PUS, PES and PPS, the biomedical science communication officer can make some well-argued, explicit choices, choices that remain implicit in current practice.
- 5 Now the biomedical science officer should try to find out which communication strategy would best fit the communication problem: transaction or transmission. Since transmission could be a rare format for communication in this case (though it is possible!), transaction could be a strategy. Transaction though can be performed in the form of a dialogue form or in the form of persuasion, according to the communication intersection described by Van Ruler (1998). Because of the complex context at both the individual level and the societal level mistakes involving trust and credibility could easily be made. To put it another way, the risk of miscommunication increases. Dialogue could be therefore the most effective strategy for low-risk communication.
- 6 Now that the context and the content of the communication process have been established, the intervention model could be chosen. As the consolidated literature especially shows, this could be based on the Health Belief Model (HBM), Protection Motivation Theory (PMT), or the Elaboration Likelihood Model (ELM). Every model has its own specific emphasis on the psychological or psychosocial aspects of the biomedical science communication process. HBM could play a role when there are questions about the legitimacy of the process and the ownership of the predictive testing problem. ELM could play a role when legitimacy is established, but the complex message needs to be communicated in an alternative way (ELM is discussed in detail in chapter 5). For example, when people first need to learn how to search for information by themselves (i.e. learning to learn, see chapter 7 for an expanded explanation), 'Questions about genes/colon cancer? Grow up and sort it out for yourself!' could be a teasing campaign to urge an audience to be responsible for its own health. Finally:
  - a. organizational target: introduce test and get people to have the test done;
  - b. communication target: try to convince them that they are responsible for their own health;
  - c. communication modality: biomedical science promotion;
  - d. communication strategy: dialogue.

### 3.9 Discussion

In this chapter we have tried to answer two questions. The first is, are there concepts, theories, models, constructs and variables to be obtained from health communication that are relevant and useful to the domain of biomedical science communication on predictive DNA diagnostics? This question was answered in the text above: there were many concepts, theories, models, constructs and variables to be found in health communication. The other question is about the position of biomedical science communication with regard to health communication. Is health communication a part of biomedical communication or *vice versa*? We will end the discussion with reflection on this subject.

#### Theories and concepts

For biomedical science communication, there is lot to learn from health communication. There are many more angles for communicating than there were before this analysis. Biomedical science communication on predictive DNA diagnostics and science communication in general are in the phase of formulating communication targets in which information, enjoyment, emotions, etc. play a role. However, a strategy for communicating about emotions was missing. Models and concepts like HBM and PMT generate possibilities to begin new research. Developments in new theories must be closely monitored. For example, De Vries et al. (2005) have developed the Integrated Change Model (previous versions of this model are referred as the ASE Model) in which the theories of Planned Behaviour, Social Cognitive Theory, the Transtheoretical Model, Health Belief Model and Implementation and Goal-Setting theories are combined. This synthesis of different theories forms a new starting point for further research with regard to biomedical science communication on predictive DNA diagnostics. There are many more angles from which to start and from which to define proper research questions and research.

However, not everything can simply be translated from health communication to the domain of biomedical science communication on predictive DNA diagnostics, due to individual and societal contexts concerning health. As we have seen in the unconsolidated literature, family history, age, etc. are important elements in communication when it comes to medical topics. So the system and the elements of the system shown in Fig. 3.13 stay the same, only their colour and sparkle in the light of context might change. In other words, the accents in the figure will be different in various contexts.

The context determines the freedom of choice one has and the level of perceived anxiety and urgency. When one is a patient there is a different realm of possibilities than when one is not a patient or not yet a patient. In other words, when members of the target audiences are not patients, the communication process is totally different than when they are patients.

In the health model as used in this chapter the variables are physical, mental and social. These are items which are directly related to well being. For biomedical science communication the variables are: beliefs and the use and growth of knowledge, which are far less urgent than the health communication items. Health communication has a more intrinsic character, one cannot escape from one's health. Biomedical science communication has a more functional character: knowledge or the awareness of knowledge is not an intrinsic physical value but has a functional character. This difference means that biomedical science communication could be communicated differently. One can escape from biomedical science communication targets. One cannot escape as easily from targets concerning health. This could mean that the theories and concepts obtained from health communication might be too rigid for biomedical science communication. There is a difference between 'I do not want to understand this' and 'I don't want to go to the dentist' or 'it is not my fault that I have colon cancer'. Where is the intersection between health communication and biomedical science communication on predictive DNA diagnostics? *'The structure of our DNA forms the basis of our health'* could be health communication as well as biomedical science communication. It depends on the context. In

Fig. 3.14 we attempt to show the difference in different quadrants of the contexts of possible problems (see figure for explanation and text below). Different target groups must be selected.

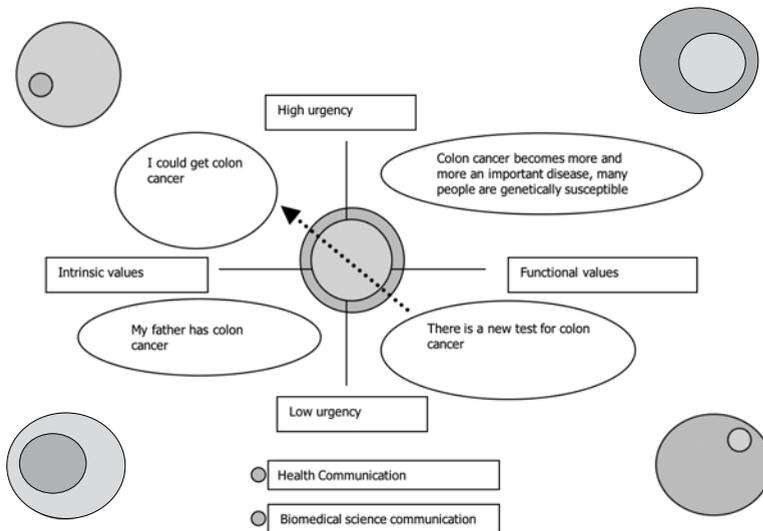


Fig. 3.14: Shift from functional values to intrinsic values and shift from low to high levels of urgency. The figure consist of four quadrants: 1) intrinsic value/high urgency, when one is probably best served with health communication (health education) which could contain an element of biomedical science communication (an explanation of colon cancer); 2) functional value and high urgency, when one is probably best served with biomedical science communication; 3) functional value with a low urgency, when one probably is best served by biomedical science communication; 4) intrinsic value with a low urgency, when one probably needs health communication.

Now it is possible to follow a strategy and determine if one is dealing with biomedical science communication or health communication. If one shifts from the lower right to the upper left then the health locus of control could be an anchor point for communicating to people that they are responsible for their own well being at any level. In the case of a target audience that might shift this way (those who are not yet patients) the biomedical science communication professional could include a prelude to the next step in health communication and help the health communication professional.

In summary, in accordance with the descriptions in chapter 1, a rough draft of a 'protocol' to establish the difference between health communication and science communication in a given context can be formulated:

- step 1) Medical context? No?: science communication / Yes?: health communication / biomedical science communication / doctor-patient communication.
- step 2) Aim of medical intervention? / compulsory?: doctor-patient communication or health communication / facultative?: biomedical science communication.

In the following chapter on medical psychology, different variables such as health beliefs and compliance will be discussed. The main focus of chapter 4 is to deepen the insight into the different variables in order to assess which are most important to an effective biomedical science communication process.