Opening the psychological black box in genetic counseling

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Chapter 12

Addendum:

Theoretical and practical implications

1. Introduction

'Tout est bien dit, mais il faut cultiver notre jardin.' (Voltaire in 431)

The eleven previous chapters of this thesis have described how the disclosure of DNA-test results may influence the counselees' perception, their medical decisions and psychological well-being. Moreover, we have demonstrated that the counselee-oriented processes may explain the impact of DNA-testing better than information-oriented processes.

What do these outcomes precisely mean? In this chapter, we discuss several theoretical and clinical implications of our studies. They create an answer to questions that several researchers, genetic-counselors, psychologists and social workers have asked us about our study results.

We describe these implications in this addendum and not in the discussion chapter, because they could not directly be derived from our results. This chapter has a more theoretical and clinical nature than the discussion, and will not be restricted to the published results from our studies but will also include other theoretical and empirical articles and will also present some additional results of our studies. These implications should be regarded as hypotheses to be confirmed in future studies.

Several researchers have asked us what the results of our studies precisely mean. For instance: how are the information-oriented and counselee-oriented processes related? Why did we find that the counselees' need for certainty is so important, and that their perceived uncertainty is so frightening? Are counselees able to live with their unfulfilled need for certainty? These questions will be discussed in paragraph 2. Paragraph 3 will discuss ethical implications of the counselee-oriented approach in the practice of genetic counseling. After this, suggestions for future studies are sketched on the basis of a discussion of the limitations of our studies (paragraph 4). In paragraphs 5 and 6, we will propose a number of concrete psychosocial interventions, because several genetic-counselors, psychologists and social workers have asked us for practical suggestions how to apply a counselee-oriented approach in clinical practice.

2. Theoretical implications

This paragraph 2 describes how the information-oriented and counselee-oriented processes may be related to each other: are they different or do they interact, etc.? Before going into these explanations, I clarify the terminology that I will explicitly use in the following paragraphs: 'approach', 'process', 'practice' and 'ethics'. These are nouns to which the adjectives 'counselee-oriented' and 'information-oriented' may be applied.

In chapter 1, I have described that many researchers have a dominantly information-oriented approach. In response to that, I tried to develop a counselee-oriented approach in this thesis. My counselee-oriented 'approach' means that I focused on different phenomena, i.e. on counselee-oriented processes instead of on information-oriented processes. These 'processes' are the counselee-oriented processes inside a counselee ('her experience'), such as the way how she provides a subjective meaning to the DNA-test result and how she embeds it in her life; these are not merely cognitive information-incorporating processes but these are also about the subjective interpretation, meaning-making and embedding of the DNA-test result in the counselee's life (cf. chapters 9 and 10). Genetic-counselors and psychologists may also focus on these counselee-oriented processes in their clinical sessions which may be called 'counselee-oriented practice'.

Why did I focus on counselee-oriented processes in this thesis? In the first place because the current goals, policy and practice of genetic-counseling imply a counselee-oriented approach but in contrast, the psychological literature seems to dominantly focus on information-oriented processes (see chapter 1). In the second place, I did not neutrally describe the counselee-oriented processes, but – like many genetic-counselors – I assumed that it is *good* to focus on these processes in my research. That is, my counselee-oriented approach was not merely descriptive but also normative, i.e. the norms and values of me as a researcher and psychologist were counselee-oriented. This may be called a 'counselee-oriented ethics', which I will describe in paragraph 3.

Thus, both my approach and ethics have been oriented on counselee-oriented processes. This paragraph 2 starts with discussing on counselee-oriented *processes*.

2.1. How are the information-oriented and counselee-oriented processes related?

> *How my life has changed after the DNA-test result? I started to think differently about heredity. I started to realize that other relatives could also undergo the same cancer-experience as I have. I'm not thinking that simply and rationally about the heredity anymore. I've learnt that these are not mere facts, but it contains a real story about the heredity, and its consequences. (…) This information has changed my life. It is as if you cannot trust your own body any more after the DNA-test result. It leaves you alone. It makes you uncertain, because it increased my risk of developing cancer again. It took me a long time before I regained some trust. (…) Due to the confrontation with your death and deepest vulnerabilities, you start appreciating life more. Such as living in the here and now, and taking priorities in relationships. I'm not saving money anymore to go on holiday over 20 years; I'm going on holiday now. I became much more aware of everything that happens in my life. (...) Uncertainty had never existed in my vocabulary before genetic-*counseling*, I was always self-confident. Now, I cope completely*

> *differently with uncertainties in life. (…) How? I feel uncertain about my self. Frankly, I cannot deal with it. I find it unbearable.* (Based on interview RL-027)

The communication of a DNA-test result starts many information-oriented and counselee-oriented processes inside the counselee. Previous chapters showed that the DNA-test result is not only taken up as 'mere facts', but it has a personal, existential meaning of 'a real story' for the counselee, as this counselee said. But how are these 'mere facts' and this 'real story' related to each other? Generally speaking: how are the information-oriented and counselee-oriented processes related to each other?

We have found that the counselee-oriented processes mediated the effects of the information-oriented processes on outcomes such as the counselees' risk-perception (chapters 5-9). Thus, all information-oriented processes influenced the perception indirectly via the counselee-oriented variables. It was unthinkable that the information-oriented processes would directly have influenced the counselees' perception (chapter 1, 1.3.3.4.). It was only the counselees' interpretation that directly influenced their lives. But what does this mediation precisely mean? What are the precise differences between the information-oriented and counselee-oriented processes, and how do they interact?

The answer to these questions are relevant to understand the impact of DNA-testing on the counselees' lives, it may offer clues for the psychological care of counselees who experience distress in aftermath of DNA-testing, and it may generate hypotheses for future studies (see paragraphs 4 and 6). I will roughly sketch five possible answers that are given by other authors in psycho-oncology, and I will conclude with the remark that there is yet not enough evidence to decide which answer is most likely to be true.

2.1.1. Background and foreground

The information-oriented and counselee-oriented approaches differ in focus. The information-oriented approach has a relatively specific, narrow focus, because it examines processes in a specific small part of the counselees' life that is only related to the genetic-counseling, such as cancer-risks or the counselees' cognition about her illness. The counselee-oriented approach has a broad focus on larger processes; it examines for instance how counselees embed the DNA-test result in their lives, and how their personal and existential context of their lives influences the perception of the genetic-information, and vice versa. The counselees' need for certainty and vulnerability has already existed before the counselee visited the department of clinical genetics, and are probably triggered or intensified by genetic-counseling.

Thus, counselee-oriented factors –the counselees' life in general- seem to be the background or context which gives the specific DNA-test result at the foreground its ultimate meaning for the counselee (cf.432). The specific experiences of genetic-counseling may be at the foreground of the counselees' experience at one specific moment; the counselee for instance pays attention to the communicated risks and uses a specific style to cope with these risks. But this specific experience and this coping style can only be understood against the background of the counselees' whole life.

Many different names are used in the literature for this background that defines the meaning of the foreground, such as 'field' (432), 'foundations', 'meaning' or 'horizon' (e.g.433). It has been suggested that the background, and its relationship with the foreground, is most effectively uncovered when qualitative, phenomenological research methods are used (e.g.6).

In summary, the counselee-oriented processes may be described as the background against which the foreground of the information-oriented processes can be understood.

2.1.2. Different perspectives or modes

It has been said that psychology started when Wundt, Freud and others discovered that psychological phenomena could be described from multiple perspectives (i.e. point-of-view, cf. 'approach'; cf. 'Zweideutigkeit', 434). Genetic-counseling may also be described from different perspectives. For instance, researchers may describe that a DNA-test result changes the counselees' well-being (that is how it 'functions'), but that does not tell how the DNA-test result feels for the counselee and what consequences she has in mind (that is what it 'means' to her). Thus, we use a different perspective when we describe the function ('syntax') of the DNA-test result, than when we describe the meaning ('semantics') of that result. We find totally different answers when we ask counselees from a functionalist perspective or from a meaning-oriented perspective. The same DNA-test result ('function') may have totally different meanings for different counselees. This could be compared with a linguistic sentence: its grammar and spelling may not have the same meaning for the speaker and the receiver of the sentence.

What different perspectives may a counselee have regarding her own processes? Counselees do not seem to merely have a cognitive 'perspective' on themselves, they also *experience* themselves. To express this self-experience, one may use the term 'modus' instead of 'perspective' (433,435). For instance, one third of all counselees in our studies had reported that their 'self-experience of their body' and their 'self-experience of their personality' had significantly changed due to the DNA-test result (chapters 3, 5 and 6). The interviews suggested three different ways in which the counselees experienced themselves: living-mode, reflection-mode and physics-mode.

The interviews with the counselees revealed that they did not experience their body – especially their breasts – in the same perspective or mode as they did in the past. In everyday life, healthy people may not be aware of their body functions: they do not feel the beating of their heart and the streaming of their blood, and their breasts just feel as a normal part of themselves, thus: they are simply living their lives. They are in the everyday life mode of ‘living’ (living-mode) (433,435).

People may take a moment to stop, think and talk about how their body functions: at that moment, they are not simply living but talking, and they are in a different mode (reflection-mode). For instance, counselees told in the interviews that after DNA-testing, they had started reflecting about their body instead of merely experiencing and living their lives: ‘I started thinking, thinking and thinking. My body became a continuous stream of thoughts and worries.’ (Based on interview RL-009)

When we are confronted with an illness, we may experience our body in even another mode, that is: we regard our body as a mere physical, biological thing that is not functioning and that may not feel ‘us’ (physics-mode) (389,390). Counselees spoke about their body as a mere physical thing: ‘my breasts are time bombs’, ‘I cannot trust my body anymore’, ‘my body feels distant’ and ‘I cannot get connected with my body anymore’. The majority of all counselees felt a fundamental physical vulnerability regarding their body, which may suggest that they are in the physics-mode and not in the living-mode (chapter 6; 75). To return to their daily life mode, counselees said that they had to ‘regain trust in the body’ and to ‘do activities that make my life feel meaningful, so that I can start living a normal daily life again, to get in a flow, and to forget about my uncertainties’. (Based on interview RL-012)

The information-oriented approach speaks about medical facts and risks, that is: the reflection-mode or the physics-mode. In contrast, the counselee-oriented approach seems to discuss how the counselees’ experience of their living-mode has changed due to the communication of the genetic-information.

In summary, the information-oriented and the counselee-oriented approaches may be regarded as different perspectives or modes to describe the counselees’ experiences of the communicated genetic-information and their selves. The disclosure of the DNA-test result seems to have changed the counselees’ mode or perspective, but counselees said that they were able to return ‘to a higher mode’ (cf.436).

2.1.3. Meaning-based coping

In the previous chapters, I used the term ‘interpretation of a DNA-test result’. Another expression for this is ‘the meaning of a DNA-test result for the counselee’. Generally, psychologists differentiate between situational/specific meaning and global meaning (131,137). Global meaning, or the sense that one's life has meaning, involves one’s subjective general conviction that one is actively fulfilling a unique role or purpose in life, in which one is able to live to one’s potential as a human being (130). This should not be mixed with faith or religion, which involves one's belief in a higher transcendent power, and one's connectedness with this power (132). The information-oriented approach may regard the specific meaning of genetic-counseling, and the counselee-oriented approach the global meaning in the counselees' life.

Situational meaning, or appraised meaning, is the meaning that an individual attaches to a specific situation such as DNA-testing, and is regarded as an essential element in coping with stressful life events (131,137,437). When confronted with such a situation, people may first appraise the situation as relevant or irrelevant to them (primary appraisal), and evaluate their personal sources to deal with it (secondary appraisal).These appraisal processes strongly interact with the counselees' global meaning (3^{ary} appraisal). E.g. a counselee may try to create a clear-cut, certain answer in reaction to the actually communicated, uncertain DNA-test results (2^{ary}), because she fundamentally assumes that life is certain and predictable (3^{ary}) (cf. chapter 10).

When people experience a situation as incongruent with their global meaning, distress may arise. E.g. when a counselee highly values having certainty, she may experience distress when she receives an uncertain DNA-test result. The level of distress has shown in our studies to be unrelated to the information-oriented facts, but is strongly related to the meaningful (re)appraisal of the information, i.e. the counselees' interpretations (cf.438). Well-being is assumed to depend on the extent to which a patient is able to integrate a stressful life event, like the DNA-test result, in her life/global meaning via 3^{ary} appraisal (439,440). This was confirmed in our study that showed that counselees who experienced an unfulfilled need for certainty, experienced distress (chapter 10).

Incongruence between situational and global meaning can be solved by reappraisal of global meaning. E.g. a counselee may reorder her fundamental values in life: how I look in the mirror is not as important as my risk to develop cancer, therefore I may undergo PBM; despite being a mutation-carrier, I still experience meaning by being a mother and friend. Thus, after a period of perceived anxiety or meaninglessness (126), a counselee may undergo a personal transition by developing new meaning, and by doing so, she learns to live adequately with the fact that she may be at risk to develop cancer, and/or that she carries a PM which she may have transmitted to her children (441).

In summary, the information-oriented approach seems to primarily focus on the specific meaning of the DNA-test result, and the counselee-oriented approach on the global meaning in the counselees' life. Differences between this specific and global meaning may be experienced as stressful, and may be solved by either changing the specific meaning (e.g. changing the interpretation), or by changing the global meaning (e.g. actively creating certainties and meaning in life).

2.1.4. Confrontation with the ultimate concerns of life

We have found large existential changes in life since DNA-testing (chapters 3, 5-6), which confirms other studies about familial cancer (153,442,443). There is a large literature on the positive existential impact or so-called ‘post traumatic growth’ after cancer diagnosis (e.g.127,130,137,141,444), which may be applied to genetic-counseling.

Many post-traumatic growth studies seem to assume that when a person is confronted with a certain theme in a specific situation, this teaches her about life in general, e.g. it may shake her fundamental ideas about the world. For instance, when a counselee is confronted with the uncertainty over the DNA-test result, she may subsequently generalize this result to her general experience of her body and her self-experience (cf.445,446). Thus, the genetic-counseling situation may be a teacher or ‘boundary situation’ to the counselees, which may teach them that not only the DNA-test result is uncertain, but also life itself (cf.447). Existential lessons may be an inherent part of genetic-counseling. For instance, the communication of genetic-risks tells a counselee about the physical limitations of life (she cannot change her DNA), the cancer-risks may indirectly refer her to the possibility of death, she may not feel free regarding her ‘genetic fate’, and may feel fundamentally stigmatized and ‘different than other people, as being a mutation-carrier’ (60,126). The fundamental ideas that a counselee has about life may also be shattered. A counselee may say: ‘I have always assumed that the world is a predictable, just and benevolent place to live, in which good things happen to good people. But these have proved to be false assumptions, because it is not just that I and/or my relatives have received this unexpected DNA-test result’ (448).

In summary, the communicated information (i.e. information-oriented) may teach the counselee general lessons about life or may shake her fundamental ideas about the world (i.e. counselee-oriented).

2.1.5. Am I my genes?

It has been suggested that individuals in our western society have a strong focus on the body and may develop and define their identity according to their physical characteristics (449,450). If this is true, we can expect that especially counselees from families with many cancer patients have developed their self-identity in relationship with their cancer-experiences in their family. From a young age onwards, they may implicitly or explicitly have been defining themselves as ‘a person from a cancer family’ and/or as ‘a person who is at risk to develop cancer’. This identification with their genetic background seems to be strengthened by the communication of DNA-test results (cf. 2.1.2.) (61). That is, their genetic status may become a small or even large part of who they are. We also found in our studies that the counselees’ self was related to the communicated genetic information (chapter 10).

What does it mean when the communicated information is pessimistic in an individual who identifies strongly with her physical and genetic characteristics? Her self-image may become negative, and an existential identity crisis may be evoked: who am I? Am I my genes? Am I a cancer patient? (61) Her self-image may become completely focused on the past (i.e. genetic background of her family) and her future (i.e. possible development of recurrence of cancer), and she may not experience the present in its totality (449, p. 29). Like a cancer diagnosis, the genetic diagnosis may cause a one-sided focus on being-a-patient and forgetting that one also is a mother, an employee, etc. (138)

In summary, a counselee may identify with her genetic status. Thus, she uses the information-oriented facts to create her counselee-oriented sense of self.

2.1.6. Summary

I have presented five ways to describe how the information-oriented and counselee-oriented processes may be related to each other, such as background and foreground, different perspectives or modes, meaning-based coping, genetic counseling as a teacher about life, and identification of one's self with the genetic information. Which answer is true? Or are all true? I have provided some evidence and arguments for each possibility. But the precise relationship between information-oriented and counselee-oriented processes has not been a main research question of our studies, and has to be examined in more detail in future studies. It may be useful to analyze these five hypothetical relationships in conversation with a counselee, e.g. when she reports psychopathology in aftermath of DNA-testing. This analysis may yield clues for a better understanding of the counselee and for possible psychological treatment (see also paragraphs 2.3. and 6).

2.2. Why is Need for Certainty so important and is Perceived Uncertainty so frightening?

> *I asked for genetic counseling, because I wanted to have certainty about the reason why I had developed cancer, and to know my daughters' risks. (…) I was certain that they would find a pathogenic mutation that would explain everything. (…) I had expected to hear the genetic-counselor communicating either 'yes' or 'no'. After the result, I felt that they had only communicated a little 'yes'. The result was not certain. I had not expected that it would bring so much uncertainty! (…) But I did not let the uncertainties control my life. I wanted to be in control: I had to be. Therefore I started thinking: 'it is true, I have the mutation'. But I know that this idea is not true.* (Based on interview RL-013)

Why do counselees have such a strong need for certainty, like the counselee in this example? Why do they seem so anxious for uncertainty? Why do they seem to react to an unfulfilled need for certainty by avoidance, denial and renaming coping strategies, and not by acceptance (chapter 10)? I will hypothesize sociological and psychological answers to these questions.

Individuals in modern western countries live in a society that is full of risks, risk communication and choices based on risk calculations (451-453). For instance, population-wide health education consists of the communication of health risks, such as that of smoking. Despite the fact that western people are confronted with many risks and their associated uncertainties, we find it often difficult to make decisions (454). Possibly as a reaction to these difficulties in decision-making, we may cling to techniques, and wait until instruments – such as DNA-tests – tell us what to do. If these instruments do not give a clear-cut answer we may become frustrated (449,452,455). For these reasons, we may also have high expectations of medical care and of medical techniques, and may feel frustrated when these do not provide clear-cut answers to the question 'what do I have to decide?' (449,450,455). These sociological trends seem to be reflected in the high demands that many counselees have regarding DNA-testing (1,5,6,148,216,359-361). Thus, counselees may demand certainty and control over DNA-testing, as they always cope with risk information, and like everybody in the population does.

However, genetic risks seem to differ from of other types of risks, which is psychologically processed in a different way. For instance, despite the fact that everyone has to deal with risks, counselees who undergo genetic-testing for hereditary breast and/or ovarian cancer experience more distress and show more active health-improving behavior than the general population (325). Possibly more than other risks in life, genetic risks seem to be inherently related to existential and identity questions (61,62,389,390). A logic reason for distress and active behavior may be that genetic risks may confront counselees with the possibility of illness, reduced quality-of-life and eventually death; other health risks may not directly confront counselees with such existential threats (e.g.101,363,456). In contrast with other risk information, counselees may also experience an existential plight to undergo DNA-testing and disclose the result to their relatives (425). Genetics may also be more personal than other risks, because this risk is already part of them, and other health risks are less 'embodied' (cf. 2.1.5.1.; 62).

Moreover, genetic risks are not changeable or avoidable, in contrast with health risks, such as smoking. The fact that one's own genetic risks are not controllable, and that the genetic status may be felt as being 'unjust', 'not right' or 'not what they deserve', may interfere with the counselees' fundamental assumption in life that 'bad things only happen to bad people'; the possible undermining of this fundamental psychological assumption by genetic information may add to the difficulties for counselees to accept the genetic risk information (448). Thus, genetic-risks seem to be more fundamental, personal, and unavoidable than other health risks. This may give the high emotional and existential value to genetic-risks for counselees.

Counselees may not able to live their daily lives when they are continuously aware of their genetic risks (cf. 2.1.2.). Like all people, they may need certain fundamental 'assumptions', 'schemas' or 'illusions' to fulfill their daily lives, such as a basic feeling of certainty (448,448,457). For instance, we have to believe that we are to some extent invulnerable when we cross the street. We have to believe in the meaningfulness of the world, in which events ‘make sense’. The world is benevolent and just: good things happen to good people, and bad things to bad people. We have to believe that we are valuable persons (self-worth). Finally, we have to believe that we are in control of our own lives, even if this is an obvious illusion to other people (454).

These fundamental assumptions are very resistant to change, because they are the invisible fundament and guarantee of our daily lives. We do not want to transform such fundamental assumptions, not even when we are confronted with genetic-risk information (458). When a counselee is confronted with such threatening risk-information, she may realize that she is *not* invulnerable, and that the world is not always predictable, just and benevolent, and that she cannot trust herself anymore (cf.390,448). Staring into this existential uncertainty may be emotionally overwhelming (e.g.101,363,456). For that reason, when she is confronted with such feelings, -instead of acknowledging this existential uncertainty- she may start avoiding and denying this information, distorting her perception of reality (e.g. inaccurate risk-perception), and start actively coping by making radical medical decisions such as PBM and PBSO (cf.chapter 10; 126,459).

Thus, people are said to have an important, inborn –possibly even evolutionary- tendency of being cognitively conservative regarding fundamental psychological assumptions in life. This may also be shown in the counselees’ reactions to the DNA-test result, because they may experience the DNA-test result as dangerous to their fundamental assumptions. In reaction to that potential danger, they may react in a conservative manner.

How are the counselees’ conservative tendencies shown in the context of genetic-counseling? Counselees may use information-oriented cognitive mechanisms to assimilate the information in their pre-existing schemas. For instance, they may underestimate the likelihood of negative events and overestimate the likelihood of positive events, and appear to operate on the basis of an illusion of invulnerability, like many people do (216,302,358,448,460). Our results also suggested that counselees do not adjust their interpretations to the actually communicated risks, but they seemed to assimilate the risks in their possibly pre-existing fundamental assumptions (cf. chapters 3-6; 461). Whether counselees accommodate their schema to the communicated risk, depends on the personal and existential situation of the counselee (cf.448,462), such as social resources and attachment style (cf.448), personality weaknesses and strengths/resilience (cf.463) and the amount of physical limitations (cf.464). We have found that the more previous experiences of uncertainties a counselee had in life, the more did she adjust her interpretations adequately to the actually communicated risk-information (chapter 10). Possibly, previous experiences with uncertainty may have made her schemas more flexible, and/or enabled her to experience the new uncertain situation as not-being a threat for herself.

In summary, counselees who undergo DNA-testing seem to have a strong fundamental need for certainty, like all people have, but possibly even stronger because genetic risk information is more personal, fundamental and unavoidable than other health risks.

2.3. How can counselees live with their unfulfilled need for certainty?

> *I had received the result, but I still knew nothing. The result was uncertain, and consequently I felt uncertain as a person. Usually, I am a person who wants to have certainty, and to know what to do. But now, I was uncertain what to do. Is it a mutation, or isn't it? Shall I wait for the genetic-counselor or not? Am I able to wait? That is the question. Can you leave it and wait until you develop cancer, until they give you an advice what to do? I started to think. (…) I made the decision to have my ovaries removed. Because I shall not live with uncertainty! Even if surgery meant that I would only have two children in life. No breasts, no more children. (…) It just stops all the bothering. I knew that it would help, because this decision fitted my personality. (…) I still do not regret the decision. Because I have prevented the worst case scenario: living with uncertainty, which would have made me restless, knowing the recurrence risks. (…) Eventually, the DNA-test result has turned out to be the best scenario: the DNA-test result was OK, I would not have developed cancer. Despite that, it was a good decision, because it provided me with inner peace.* (Based on interview RL-034)

'Thou shalt not live with uncertainty.' This seems to be one of the commandments of this counselee, which created an awkward predicament for her because she had actually received a UV-result which could not provide her with certainty. Her situation was similar to that of many other counselees: her need for certainty stumbled upon the actual uncertainty of the DNA-test result (chapter 10). This raises the question: are counselees able to live satisfactorily with the paradoxes of DNA-testing, such as this contradiction of the counselees' need for certainty versus their actual uncertainty? Are counselees able to accept both realities in such a discrepancy? I will try to answer this question by means of psycho-oncologic literature.

Having cancer, or being at risk to develop cancer (again), has been associated with many contradictions/discrepancies, as our study confirms (401). Examples in our study were: certainty versus uncertainty, positive versus negative emotions, objective risk-information versus subjective perception, recollections versus interpretations, physical/medical facts versus the own body experiences, and so on.

Patients are assumed to cope optimally with their illness experience, when they are able to acknowledge and/or integrate the co-existence of these 'dual realities', without collapsing one or both of these realities (401). However, we found that the majority of counselees did not seem to accept such dualities. For instance, only 6% of all counselees who experienced the paradox of the need for certainty and the perceived uncertainty used an accepting coping style, and most counselees used avoiding coping (chapter 10). Moreover, the discrepancy of objective risk-information versus subjective risk-perception was ‘solved’ by the dominance of the counselees’ subjective perceptions.

What would acceptance of a contradiction/discrepancy look like? It would mean that people have more than one evaluation about the same subject, e.g. they respect their need for certainty and at the same time they acknowledge that they have actually received much less certainty. In the ideal situation, both sides –need for certainty and perceived uncertainty- would be fully acknowledged; neither one of these sides would be dominated by the other side. This could be called a ‘dual attitude’ (465,466).

Are counselees able to accept two opposite feelings or thoughts about the DNA-test result at the same time? Wilson et al describe that all of us have dual attitudes regarding many topics (466). Usually, one aspect is more salient or explicit on the foreground, but that does not deny that another implicit aspect may exist at the background (cf.2.1.1.). For instance, in their daily lives, counselees may act as if everything is normal, but in the back of their mind there may be a feeling of vulnerability and uncertainty. They may act as if they have certainty, but still acknowledge the actual uncertainty when we ask them about that. Counselees may put their experiences of certainty in front to avoid being overwhelmed by anxiety in their daily lives (cf. 2.2.). This dual attitude may explain that counselees do not report severe distress or limitations to their daily lives, but at the same time do experience significant changes in their feelings of vulnerability and uncertainty. One counselee explained to me:

> *‘Everyday I feel, up to my bones, that I will die eventually… soon… but while acknowledging this, I know that I want to use the time that I still have. I have to! In the beginning, I could only experience the meaninglessness of it all, the loss of expectations. I have learnt that meaninglessness is not the only and the last possible that I could experience during the remaining time of my life. I appreciate life more, social relationships, the birds in the tree… Now, I feel the meaninglessness of it all… but I also feel deeply connected to it all, and I feel the value and meaning of every day that is given to me.’*

Accepting the discrepancy of the unfulfilled need for certainty means that a counselee learns to create certainty and meaning in every day life, e.g. stay focused at her job, friendships, moments of happiness, etc. At the same time, she acknowledges that she stands in a larger landscape of genetic uncertainty and possible physical limitations. Counselees may learn to switch between this certainty and uncertainty; for instance, they may try to stay with one of both sides while not being afraid that the other side will return (cf.432). Counselees may learn to trust themselves in their ability of switching and returning to the other side.

Several psychotherapeutic intervention studies have provided evidence that counselees may benefit from a dual attitude. For instance, existential group therapy helps BRCA1/2-counselees to integrate the communicated risks in their lives, and as a side-effect they may also improve the accuracy of their risk-perception (467,426). The aim of such existential interventions is to help counselees to find ways to live a meaningful life, despite the limitations and uncertainties of their illness (145,378,384,468,469). They are stimulated to explore their feelings of ambivalence and uncertainty, but with a positive focus on finding meaning. As two parallel processes, deepening of existential feelings goes hand-in-hand with active positive meaning-making. Counselees are stimulated to explore a broad range of possible meanings, priorities and identities in life, which helps them to acknowledge explicitly that they are not only a patient or person-at-risk (like many patients; 138), but that they are also a mother, a friend, an admirer of classical music, and so on (cf. 2.1.2.).

Not all individuals may be able to develop a dual attitude to the same extent, because some may not adequately have learnt as a child to have a dual attitude (e.g. Piaget, Kohut and Kernberg in: 470, cf.428). More research is required to understand which counselees are able to develop a dual attitude. For instance, new instruments may be developed to predict which counselees are able to develop a dual attitude and who may not. Such instruments may help geneticists and other physicians in tailoring their communication to their patients. For instance, they may use a more directive, reassuring communication style when they speak with patients who do not have sufficient skills to accept ambiguous, uncertain medical information. In the consultations of other patients, they may have a more nuanced, non-directive style and may focus more on the existentence of dual realities. Such new instruments may be aimed at helping genetic-counselors to attune to the counselees' needs, and may not be used 'as a trick'.

3. Implications for a counselee-oriented ethics applied to practice

3.1. Counselor-oriented ethics

In this dissertation, I have described the (further) development of a counselee-oriented, integrative approach in genetic-counseling. In the discussions of the chapters, I have advocated several counselee-oriented suggestions for clinical practice and further research. Underlying these suggestions was often a counselee-oriented ethics that may be experienced as new by some readers. Therefore, I will provide some ethical reflections in this paragraph.

In general, a counselee-oriented ethics means that the counselor, psychologist, social worker or researcher is not primarily focused on how genetic information is transfered, but they primarily focus on the counselees' needs (see 3.3.). Their attitude/approach can be described as being attuned to counselee-oriented processes. Thus, counselee-oriented ethics is not merely 'a theory' or a 'dogmatic set of norms and values', but it is manifested in the approach and the practice of genetic-counselors. Therefore, it would be inconsistent to focus in this paragraph on the theory instead of on the practice of counselee-oriented ethics. For that reason, I discuss the counselee-oriented ethics in relationship to the counselee-oriented results from our studies, and I examine whether genetic-counselors are actually able to develop a counselee-oriented approach in clinical practice.

To explain the meaning of counselee-oriented ethics, I will start describing how it differs from two different ethics that seem to dominate the current literature and clinical practice, i.e. counselor-oriented and information-oriented ethics. The information-ethics overlaps with Kessler's 'content-orientation' and also elements from his 'person-orientation' (419). The counselee-oriented ethics includes elements from Kessler's 'person-orientation', and is an extrapolation of our study results in combination with recent trends in the literature. See De Wert for a discussion of the limitations of the counselor-oriented and information-oriented ethics, especially regarding the many different forms of directivity and non-directivity (429).

Before the start of genetic-counseling as a formal medical discipline in the 40s of the 20th century, counselor-oriented ethics dominated the practice of eugenic programs (36,43,429). People who followed such ethics were paternalistic and coercive in their communication style, made decisions for the counselees or forced them to make decisions.

From its origin as a formal discipline, genetic-counseling explicitly followed non-paternalistic and non-coercive ethical ideals, possibly to avoid these abusive practices in the past (see chapter 1; 43,44,471). Despite these ethic ideals, some counselors –especially in the beginning years- have been described as following their own aims in counseling instead of using a non-paternalistic approach (43,44).

3.2. Information-oriented ethics

Information-oriented ethics follows a 'consumer model of autonomy' (472), 'in which the genetic-counselor has to provide the counselee with all the information that she needs to make an autonomous decision' (471). This ethics forms the basis of the non-directive counseling style that has been adapted by the Dutch departments of genetic-counseling from the beginning (471).

Is an information-oriented ideal actually attainable in clinical practice? This ethics assumes that the provision of information causes autonomous decisions by counselees. We found indeed that genetic-counselors communicate a wide range of information (e.g. chapter 6) and that counselees indeed make their own decisions. However, most of these decisions were not directly caused by the communicated information, but seemed to depend on the interpretations and personal context of the counselee (chapters 5 and 6). Thus, the disclosure of genetic information did not seem to 'cause' autonomous decisions, but counselees seemed to be already autonomous before genetic-counseling: they seemed to already have their own 'autonomous' perception of cancer and genetics before they underwent genetic-counseling, and they processed the communicated information in an autonomous way (359). One may argue that genetic-counseling did respect the counselees' autonomy by providing them with information and letting them have their own interpretations and make their own decisions (cf.429).

Thus, it is unclear whether genetic-counseling can stimulate the counselees in their autonomy to make their own decisions. One may also argue, that counselees should not only be autonomous in the final decisions that they make, but also in the decision making process (429). This means for instance that the counselor adjusts the information to the counselee and provides the counselee – as the definition says – with 'the information *she needs*'. Thus, not only the provision of information may be ethically relevant, but the tailoring of information to her needs may be. I identify tailoring information to the counselees' needs as an essential practical consequence of counselee-oriented ethics, because that ethics focuses on the counselee, and information-oriented ethics focuses on the information transfer.

The 'consumer model of autonomy' also assumes that 'communicating all information' is by definition good; this ethical ideal of open communication has also been integrated in national and international guidelines that warrants the counselees' 'right to know' (e.g. World Health Organization). However, not all counselees may want to receive 'all information'. Information-oriented ethics may not provide a satisfying answer to the question whether tested counselees and their untested relatives have the 'right not to know' the DNA-test result (154,473,474). Should the counselees' and relatives' wishes of not-wanting-to-be-informed be respected, or should information be disclosed, even if the information does not have large medical consequences and many counselees seem to experience difficulties in coping with this result (e.g. UV-result)? The information-oriented ethics cannot answer this question, because it is a *contradictio in terminis*; that is, information-oriented ethics seems to consist of two possibly conflicting elements: the open communication of all information and respecting the counselees' autonomy (including their desire not-to-know) at the same time.

The information-oriented, nondirective ethics has been criticized for assuming that counselors communicate information in a value-neutral way. This is not actually possible, because genetic-counseling involves a human-to-human encounter which is inherently value-laden; for instance, counselors decide what kind of info should be given and in what kind of format, and this involves a value judgment (475,476).

Moreover, like in other medical disciplines (477), several studies have suggested that it may be difficult for genetic-counselors to always adhere to the ideal of non-directiveness, which may be due to the fact that some counselees need or ask for a more directive approach (e.g.475,471).

In summary, information-oriented ethics tells that genetic-counseling should provide counselees with much relevant information to make autonomous decisions. But despite the fact that all information is communicated, this does not seem to *cause* counselees to make more autonomous decisions. It may be paternalistic to communicate all information and not listen to the counselees' 'right not to know', and it may be difficult for counselors to adhere to an information-oriented ethics.

3.3. Counselee-oriented ethics

Counselee-oriented ethics is attuned to the counselees' needs, and assumes that the genetic-counselor takes care for the totality of a counselee and not only for informing them. This ethics also seems to be applied by many genetic-counselors in the Netherlands, and also by many other physicians (45,46).

The counselee-oriented ethics implies that not each patient may need autonomy and non-directiveness of communication, i.e. the main information-oriented ideals. Counselee-oriented ethics may also imply that not all counselees may need DNA-testing as a means to fulfill their need for certainty; alternatives for DNA-testing may be explored, such as waiting or referral to a psychologist or social worker.

To which needs of the counselee may researchers focus on? Previous studies mainly described the counselees' wishes for information provision and assistance with decision-making (53-56). However, this kind of research has been criticized for being too information-oriented by mainly asking about knowledge, plans and behaviors (37). Also more personal and existential needs may be explored, such as the counselees' need for certainty, feeling of closure about the family history of cancer, developing mastery over cancer, undermining anxieties, etc.

How can a genetic-counselor practically explore these needs in the counseling sessions? A genetic-counselor may pay explicit attention to the needs, context and perception of the counselee, by asking questions about this (see paragraph 4). A counselor may use this conversation to 'tailor the communication of information'. That is, the genetic-counselor may tailor the communication of genetic-information to the counselee's needs, situation and perception (cf.430). In previous studies, genetic information was often tailored to information-oriented processes, such as the counselees' understanding skills and questions about their medical decisions. It has been suggested to broaden the assessment of the counselees' needs to a broader range of personal and existential issues, such as the personal meaning of genetic-testing in the context of the counselees' lives (38,476).

How can a genetic-counselor adjust the session to the counselees' needs? It has been suggested that the genetic-counselor and counselee 'share and struggle together' with opinions, thoughts and feelings to determine the aims and procedure of counseling for this individual counselee (471). This assumes that the genetic-counselor creates an open atmosphere in which reflection can occur and in which the counselee feels free to express her ideas and feelings (471). It has been suggested that an open communication may be fostered when the counselor shows her own vulnerability and humility, that is: when the counselee experiences that her needs and interpretations are equally valued by the genetic-counselor as the counselor's own ideas (471). The counselor and counselee may try to be personally engaged in the counseling process 'as a team', that is: a personal responsiveness to the other, a relationship between individuals that is grounded in ambiguity, uncertainty, openness, trust and respect (471). In such an atmosphere, the genetic-counselor may also communicate her own uncertainties about the situation; openness of the counselor may foster openness of the counselee. Additionally, instead of being a unidirectional process, counselee-oriented genetic counseling may be a reciprocal dialogue (283), which includes listening, hearing and sharing information (471).

How can a genetic-counselor introduce the counselee-oriented approach to a counselee? Counselees may not expect a counselee-oriented ethics, may feel unequal to the counselor, and may even be afraid to express their true feelings. Genetic-counselors may try to overcome this problem by not only explaining the procedure of genetic-counseling, but also by discussing the relationship between the counselor and counselee, and asking the counselee's wishes regarding their relationship.

Can a counselee-oriented ethics be attained in clinical practice? In contrast with information-oriented ethics, counselee-oriented ethic goals seem better attainable in practice. Several interventions have been developed on the basis of a counselee-oriented ethics, and these seem to yield better results than studies following information-oriented ethics. For instance, tailoring has shown to be effective in enhancing the counselees' knowledge, the accuracy of the counselee's perception and well-informed decision-making (430). The process of 'sharing and struggling together to find the appropriate decision has shown to facilitate the decision making process, enhance self-determination, promote autonomy, and advance beneficence' (471). Explicitly addressing the counselees' perception lowers distress and raises satisfaction (cf.312,313) and enhances the accuracy of the counselees' risk-perception (282). The positive regard and empathic confrontations during the dialogues may also improve recollections (cf.309-311,478). It has also been suggested, that all types of interventions are effective in improving genetic-counseling because of the counselee-oriented elements of these interventions (284).

3.4. Examples of the counselee-oriented approach

A first example of counselee-oriented ethics has been discussed in chapter 10. The question was raised whether genetic-counselors are ethically justified to try to give counselees an accurate perception of the communicated information. It was argued that counselees may have their own justified reasons to have a perception that deviates from their genetic-counselor (I do not use the paternalistic term ‘inaccurate perception’ here). Genetic-counselors may invite counselees to discuss and to test their interpretations for their accuracy. But genetic-counselors may not provide corrections in reaction to the counselees’ expressed perceptions, when counselees have not fully provided them with informed consent to do so. To get this informed consent, genetic-counselors may discuss in the beginning of the first genetic-counseling session what their expectations are about the counselor-counselee relationship (e.g. providing ‘corrections’ in the counselee’s perception?), and ask whether the counselee agrees with this.

A second example is the question whether UVs should be communicated or not to counselees. A counselee-oriented ethics would use the counselees’ needs as criterium. Counselees seem to request for genetic counseling to fulfill their need for certainty about the heredity and the cancer-risks of themselves and their relatives, to be able to make well-informed medical decisions (i.e. ‘knowing what to do’), reduction of distress –and uncertainty in particular-, and facilitate communication with relatives (e.g. chapters 9 and 10).

However, the counselees’ need for certainty was not fulfilled by the UV-result (chapter 10). Well-informed decision-making was not shown, because UV-counselees misinterpreted the communicated genetic-information as ‘false alarm’. On the basis of this inaccurate perception, they made poorly-informed medical decisions (chapters 3-6). Many experienced distress; on the long-term, the communicated UV-result directly predicted symptoms of depression (chapter 4). UV-counselees communicated more indirect and less reassuring information to relatives compared to PM/UR’s; consequently, these relatives felt more at-risk to develop cancer (chapters 7- 8). In contrast, PM/UR-counselees, reported more fulfillment of their needs for certainty after DNA-testing, experienced less distress, had a fairly accurate perception of the PM/UR-result and cancer-risks, and had communicated the DNA-test result more neutrally to relatives.

In summary, the UV-result did not fulfill the needs of the counselees, and at the same time, this result did not have other medical implications than UR. For that reason, we proposed in chapters 3, 5, 6 and 10 that it is justified according to the counselee-oriented ethics to communicate unclassified-variants as uninformatives, i.e. 'we did not detect any mutations explaining the occurrence of cancer' instead of 'we detected a mutation/genetic-change with unknown clinical consequences'. An exception to this ethical decision of non-communication would for instance be a situation in which additional genetic investigation in the family is needed, such as cosegration-analysis and functional testing.

We may extrapolate these findings about UVs to low penetrance genes or whole genome sequencing. A mutation in a low penetrance gene is associated with a relatively small cancer-risk, e.g. 2% to 15%, in contrast with the high penetrance of the two major susceptibility alleles, BRCA1/2. Whole genome sequencing means that not only BRCA1/2-mutations may be detected but also mutations which may be associated with diseases other than breast and ovarian cancer. One may hypothesize that counselees may also experience an unfulfilled need for certainty and/or may experience distress when these ambiguous and/or unexpected test results are communicated, because - like UVs - this communicated information may be perceived as ambiguous, uncertain or unexpected. On these grounds, it may be argued that these results should not be communicated, as long as these genetic results do not imply a difference in the medical care of the counselees. More studies are required to examine the ethical foundation of communicating low-penetrance genes and unexpected results from whole genome sequencing.

A third example is the so-called 'duty to recontact' (e.g.479). Genetic-counselors are assumed to have the duty to recontact counselees when new genetic information becomes available. Does a counselee really need to be recontacted, if there is new information without medical consequences? What does recontacting do psychologically with a counselee? How may they benefit from it? It could also be argued that recontacting may re-evoke uncertainty and distress which the counselees may perceive as unwanted at that moment. Recontacting may also go against their need for being in control and setting the agenda, when the initiative for recontacting is in the hands of the genetic-counselor.

It may also be argued that counselees create a better perception, experience decision-making as easier and may consequently experience less distress, when the genetic-counselors help them during a follow-up session in interpreting the DNA-test result and reflecting on its medical consequences. For instance, many counselees in our study said that they liked being contacted by us –the researchers- at a long-time after DNA-test result disclosure; they said that talking and reflecting about their DNA-test result helped them 'to put things straight in their minds'. Thus, recontacting a counselee may not only be a 'medical duty' (e.g.479) but also a 'psychological duty' for the genetic-counselors. More research is needed to examine the ethical basis and the balance between medical and psychological benefits and costs - i.e. cost effectiveness - of organizing a follow-up session.

3.5. Limitations of the counselee-oriented approach

The application of a counselee-oriented ethics in clinical practice may also raise many questions. Are counselees able to reflect on themselves, and express what they need? Do they know what they need? Do they know enough about genetic-counseling to express what they precisely need from the genetic-counselor? When counselees say that they need something, is that also what they really need: is a genetic-counselor able to make a distinction between the real needs of a counselee and her psychological resistance to discuss certain needs? Does a genetic-counselor have to follow a counselee when she is avoiding important feelings and needs? Does the genetic-counselor have enough skills to explore these counselee-oriented needs? Is she able to assess which counselees are able to have a non-paternalistic, equal relationship with the genetic-counselor and who are not? Is the genetic-counselor herself able to fulfill a non-paternalistic role? And to what extent does the genetic-counselor passively have to follow the counselees' needs?

The most extremist variant of a counselee-oriented ethics would imply that the counselee is left alone in her process, and the genetic-counselor only follows the counselee and does not explicitly discuss the meaning and the medical consequences of the DNA-test result if the counselee does not start speaking about this. A softer variant claims that the aim of this physician-patient interaction is 'to elucidate the patient's values and what he or she actually wants, and to help the patient select the available interventions that realize these values' (480). This means that the genetic-counselor has a more active role in helping the counselee to explore her interpretations. The counselor may fulfill her most active role when she 'helps the patient determine and choose the best health-related values that can be realized in the clinical situation' (480). The latter means that the genetic-counselor shows alternatives to the counselees' interpretations, and helps the counselee to weigh multiple possibilities. Thus, there are many different gradations in which the counselor can be directive or non-directive in counseling, while focusing on the counselees' needs (429). Which model should be followed? A counselee-oriented ethics would suggest that the genetic-counselor and counselee discuss and determine the relationship during the intake session (see 5.2.). At least, the counselor should ask for permission to discuss alternatives to the counselees' perception, and make clear when she is speaking about her opinion instead of merely speaking about the medical facts (429).

One of the biggest practical limitations to the counselee-oriented ethics may be the relatively limited time and funds available for genetic-counseling. This may hinder genetic-counselors to perform an extensive assessment of the counselee's situation and to thoroughly discuss the possible meanings and consequences of the DNA-test result for the counselee. Moreover, for financial reasons, it may be useful when genetic-counselors help counselees to have 'an accurate perception' and to follow the suggested medical risk-reducing options; however, this paternalistic and directive approach is contradictory to a counselee-oriented ethics.

Time and fund restrictions may not limit genetic-counselors in developing a counselee-oriented attitude. Counselors may not be able to perform a large number of extensive counselee-oriented interventions, but their counselee-oriented attitude may help them in attuning better to the counselee and to perform a small number of counselee-oriented interventions, within the time limits. For instance, one Dutch study suggest that genetic-counselors are able to discuss some psychosocial issues, without making the counseling sessions longer, when they had followed a short skills training (56). As examples, we suggest in paragraph 4 several questions that genetic-counselors may use to start such a dialogue. More research is needed to help genetic-counselors to optimally develop a counselee-oriented approach within the given time limitations.

These limitations seem to suggest that in practice, genetic-counselors have to find a balance between the needs of the counselees on the one hand, and the practical possibilities of genetic-counseling on the other hand. They may for instance include their own ideas about what is needed most in the counselees' situation (481; cf. discussion in chapter 5). For these reasons, the implications that we discuss in paragraphs 5 and 6 do not merely follow a counselee-oriented ethics, but also information-oriented ethics such as improvement of the counselees' perception. But in the end, the counselee-oriented ethics assumes that it is the counselee who defines when the balance feels 'right'.

4. Implications for genetic-counselors

4.1. Genetic-counselors 'do a good job', and may do it even better

> *'The genetic-counselor has done a good job. She has explained everything very well, and I know all the facts now. But I am just not convinced that this is the only truth.'*
> (Based on interview RL-02)

The results of our study may be disappointing for genetic-counselors. Because we have shown that the actually communicated information only has a small, indirect effect on the counselees' perception, medical decisions and psychological outcomes. The counselees' own interpretations seem to be more important in explaining the impact of genetic-counseling than the genetic-counseling process itself. Do these results imply that genetic-counselors do not 'do a good job', and that they should reduce their activities to taking a blood sample, testing the DNA, and communicating that either a mutation has been found or has not been found? No. Beside ethical reasons (3.3.), our study provides several reasons why genetic-counselors 'do a good job'.

Despite the fact that many counselees felt that their fundamental needs were not fulfilled after genetic-counseling, they were very satisfied with genetic-counseling as such. For instance, unpresented results from the prospective study showed that 96% of all counselees evaluated genetic-counseling as useful, 91% evaluated the counseling as 'good' and 79% as 'pleasant', 95% evaluated the explanations as good, 57% reported that they had received new information that they did not have before genetic-counseling, and 93% would request for DNA-testing again. Thus, there is some evidence that genetic-counselors 'did a good job' from a counselee-oriented perspective.

Our studies also provided several information-oriented arguments why genetic-counselors were successful in their counseling sessions. Counselees were enabled by genetic-counseling to make medical decisions with more medical information than they probably had before genetic-counseling, regardless of the fact that they may 'misinterpret' this information. Our family study has suggested that the genetic-counselor is the most reliable factor in the 'whisper game of genetic-counseling', because the communicated information correlated about .40 with the counselees' recollections, and the relationships between all other steps in the whisper game were much lower (chapter 7). The counselees' recollections and interpretations of their cancer-risks and heredity-likelihood also changed after the DNA-test result 'in the right direction' of the actually communicated DNA-test result (but these changes remained small and differed from the actual result) (chapter 6). When counselees were counseled by phone instead of face-to-face, their perception was slightly more inaccurate, which may suggest that the interaction between the genetic-counselor and the counselee actually influence the counselees' perception (chapter 9).

In summary, from an information-oriented perspective, genetic-counselors had a positive influential role in helping counselees with their need for information. But their influence seemed to be restricted to a certain bandwidth in which the counselee changed her perception. The counselees' personal and existential background seems to have determined this bandwidth even before they had met the genetic-counselor for the first time. Can genetic-counselors change this bandwidth? A recent review suggested that many interventions can indeed significantly improve the counselees' perception, especially thanks to the counselee-oriented elements of these interventions (284). Moreover, several studies showed that counseling based on counselee-oriented ethics may improve the counselees' perception (see paragraph 3). But the extent to which the counselees' perception can be influenced has still to be determined, and the size of the bandwidth may vary among counselees.

In this paragraph, I will describe several possible implications of our studies for genetic-counseling. The aim of these implications is not to change the counselees' bandwidth – which seems ethically unjustified (3.3.) –, but its aim is to make genetic-counseling even more counselee-oriented than it often already is. Thus, these suggestions should not be followed as 'a trick', but as a way to start a dialogue with the counselee. Table 1 provides an overview of these implications, which should not be regarded as a complete overview or guideline for genetic-counseling, but as examples in addition to existing counseling guidelines. All of our suggestions are loosely based on our study results in combination with previous studies, and their efficacy still has to be confirmed in empirical studies.

4.2. Implications for the counseling of counselees

4.2.1. Interventions before counseling

Many counselees had high expectations of genetic-counseling after the intake session. This raises the question whether the possible outcomes of genetic-counseling had been discussed sufficiently with the counselees. Before they have the first genetic-counseling session, counselees may be prepared by provision of information, e.g. via a flyer, letter, group-wise instruction or the internet. Pre-counseling explanation may help counselees to develop more realistic expectations about genetic-counseling, which may prevent disappointment and misinterpretation at a later stage of genetic-counseling. Provision of a flyer (e.g.484) has indeed shown to improve the accuracy of the counselees' risk-perception (chapter 9).

We suggest focusing this pre-counseling information on the discussion of certainties and uncertainties that genetic-counseling may yield. Additionally, the possible psychological consequences of the outcomes may be discussed, such as feeling uncertain and distressed. Examples are the likelihood to find a PM, and uncertainties that may arise after a result, for instance regarding medical decisions, telling relatives, the sensitivity of DNA-testing, and the inherent uncertain meaning of risks, i.e. the uncertainty whether and when the counselee may develop cancer (chapter 10). When the policy is to communicate UV's, the counselees' perception and distress may be lowered when the possibility of finding a UV is mentioned during the intake (chapters 3 and 9).

4.2.2. Interventions during the start of the first session

We suggest that the main focus of genetic-counselors during the intake session is to create a positive counselor-counselee working alliance that satisfies the counselees' needs. Several studies have shown that a positive working alliance is associated with patient adherence and satisfaction (485,486,487). It has been suggested that it is the depth of the relationship that helps counselees to actively explore their own ideas and feelings (e.g.488). All interventions that we provide below should be regarded as a means to foster the working alliance.

Previous studies have shown that counselees do not know what to expect from the counselor-counselee relationship, and some counselees may expect a traditional hierarchy between patient and doctor. The genetic-counselor may break this expectation by discussing several possibilities how to work together (cf. 3.3.). For instance, the genetic-counselor may ask what the counselee wishes, and may explain that genetic-counseling may differ from other medical disciplines because the intention is to have a discussion/dialogue and not to give a lecture/monologue, and the geneticist is the counselee's companion and is not the person who makes the decisions. Additionally, the counselor may tell that genetic-information is 'not a standard story' and does not have standard consequences for each counselee; it has always a personal, subjective meaning and consequences. Which medical options is the best for a counselee, depends on her counselee's medical situation but also on her own thoughts and feelings. The counselor may explain about the counselor-counselee relationship, that the counselor may ask questions about the counselee's thoughts and feelings, and explores the possible meaning of the communicated information in the counselees' life. An explicit agreement should be made how the counselor-counselee relationship will be (see: 'informed consent to correct inaccuracies', 3.4.). Which psychosocial interventions may follow, depends on this agreement.

The counselor may be better able to follow the counselee's needs, when she explicitly explores the counselee's personal and existential context during the beginning of the first session. This exploration may also be important from an information-oriented perspective. For instance, our studies have shown that the counselee's personal context predicts her interpretations, distress and her medical decisions (chapter 9). Tailoring of information to the counselee's context is predictive of a more accurate perception and better attention/focus by the counselee; to be able to do this, the genetic-counselor has to know some basic information about the counselee's situation (430,476).

A broad range of questions may be asked. We mention a few in table 2 that have been derived from our studies, and that may be used as a means to start a conversation, to strengthen the working alliance and to attune to the counselee's needs. For instance, the counselee may reveal her experience of her context when she is asked about their motivation to undergo genetic-counseling, and why she wants to do it at this moment in her life. Her expectations may be explored by means of the question how much certainty she wants and expects to receive from genetic-counseling, and what this certainty may be about. We also suggest asking questions about the way how a counselee copes with her cancer, and with the cancer in the family.

4.2.3. Interventions later in the first and second sessions

Counselors may be better able to follow the counselees' needs, and to help them in expressing their wishes, when they ask counselees about their perception at three moments during genetic-counseling: at the beginning and at the end of the first session, and at the end of the DNA-test result disclosure session. The perception at the beginning of the first session may be used to tailor the genetic information that is discussed in the session, and that may immediately give the feeling to the counselee that she can discuss her feelings and interpretations with the genetic-counselor. Exploring perceptions at the end of sessions may inform the genetic-counselor how well the counselee has understood the information, and to start a discussion about the meaning of the DNA-test result.

Table 2 provides examples of risk-perception questions that may be effective. Our studies have shown that general questions, such as 'how well have you understand this?'

and ‘which DNA-test result category have you received?’ may not be useful, because the answers to these questions were unrelated to the actual understanding, perception and outcomes of genetic-counseling. Questions should be specific and cover the personal meaning of the DNA-test result. It is important to make an explicit difference between the counselees’ recollections –i.e. their understanding of the information- and their interpretations –i.e. giving the result a personal meaning and embedding it in their lives. These questions about the counselees’ interpretations have shown to be strongly related with the outcomes of genetic-counseling (chapters 3-8). Counselees may be stimulated to express their interpretations, by explaining that the communicated risks may feel differently compared to what has been communicated; the genetic-counselor is interested in these feelings and personal ideas, because she would like to explore what consequences may be most suitable for the counselee.

Some counselees may experience questions about their own perception as a ‘school examination’ which will be ‘judged’ by the genetic-counselor. Moreover, ‘discussion on the part of the counselor has the potential to function as coercion in the life of the client’ (489). The counselor should therefore be very explicit about the intention behind these questions, and emphasize that all feelings and thoughts may be expressed, and that there are neither good nor bad answers. When the counselor asks additional questions or offers additional explanations in reaction to the counselees’ perception, she may explicitly ask for permission to avoid giving the counselee the feeling of ‘being wrong’. For the same reason, asking questions may be preferred over giving an additional ‘lecture’; questions may help the counselee exploring her own interpretations, and test the accuracy and applicability of these interpretations (this is called a ‘Socratic dialogue’ (490).

At the end of each session, the genetic-counselor may explore the possible medical and psychological consequences and the involvement of the family after DNA-testing. This may help the counselee to embed the DNA-test result in her life, and the genetic-counselor may provide her with additional explanations and suggestions if needed. If there is a follow-up session (e.g. via the Internet,cf. 98) these questions may also be asked to explore changes in the counselees’ ideas and feeling about the meaning of the DNA-test result and possible consequences.

The counselor may use the information about the counselees’ personal context and perception when she tailors the genetic-information. Both the content and the presentation of information can be tailored (430). Usually, tailoring will be an automatic subconscious process when there is a reciprocal dialogue between the genetic-counselor and counselee. Tailoring may also include the format of communicating risks, e.g. in words and/or in percentages. We suggest to be careful in communicating UR/UV-results in multiple formats and mirroring the risks (i.e. 80% at risk also implies 20% not at risk), because this has shown to make the counselees’ perception less accurate. It may be helpful when the risks for PM-carriers are mirrored (chapter 9).

4.2.4. Limitations

As we discussed in 2.5., the genetic-counselor's possibilities to perform a 'perfect counselee-oriented session' may be limited by for instance time restrictions. However, the literature is optimistic: many interventions by genetic-counselors have shown to be effective, even when the intervention was relatively small (56,284). This may suggest that the general attention for counselee-oriented ethics, or the awareness of possibilities to start a dialogue, may already improve the genetic-counseling sessions.

4.3. Implications of the counseling for relatives

Our family study has shown that relatives often feel strongly involved in the genetic-counseling process, and may experience significant changes in their perceptions, medical decisions, and psychological well-being. Their perception was often inaccurate, which seemed to be caused by the 'noise' that had occurred within the counselee/proband during the 'whisper game of genetic information'. Most of all, some relatives wished to be more involved in genetic-counseling (chapters 7 and 8). This suggests that it may be relevant – i.e. it may fulfill the needs of untested relatives –, when genetic-counselors pay explicit attention to the meaning of DNA-test results for untested relatives.

Genetic-counselors may explore together with the counselee for which relatives the genetic-information may be relevant, and to whom and how the information may be communicated by the counselee. In this exploration, the counselor may provide suggestions on how to communicate the results, or provide a flyer with suggestions for family communication of DNA-test results.

Currently, genetic-counselors often suggest the counselee that she may copy her own summary letter that the counselor sends her. We suggest that genetic-counselors write or copy a letter specifically created for relatives, and provide this to the counselee for further distribution in the family (this can be a standard letter for relatives). The counselee's own summary letter often includes personal information which she may not want to share with her relatives; this may prevent her from distributing the letter. Many summary letters include little or only ambiguous information for the untested relatives (unpresented data in studies 3-10). We expect that having to copy the letter for their relatives may create an additional threshold for counselees to share the letter. For these reasons, it seems more likely that summary letters will be distributed when the counselor provides the counselee with specific letters for specific relatives. This letter may include an invitation for relatives to ask the genetic-counselor for additional explanation if they need.

Providing counselees with specific letters for relatives is common practice when a PM is detected. We also suggest doing this in UR/UV-families, because the communication of DNA-test results within families may be even more indirect and inadequate than PM-results due to the ambiguous nature of these results (cf. chapters 7 and 8).

Table 1. *Recommendations for genetic-counseling*

Discussions for national and international policy

- development of a sound and reliable BRCA1/2-terminology (chapter 2)
- ethical foundations of genetic-counseling (3.1.-3.3.)
- ethical and psychological acceptance of communicating UV's (3.4.)
- ethical and psychological acceptance of communicating results for low penetrance genes and whole genome sequencing (3.4.)
- ethical issues regarding the duty to re-contact counselees (3.4.)
- direct communication with untested relatives (chapters 7 and 8)
- re-define criteria for referral to a psychologist or social worker (6.1.)

General counselee-oriented ethics / attitude (3.4.)

- following the counselees' needs
- exploration of alternatives to DNA-testing
- flexible adjustment of directiveness/non-directiveness to the counselee's needs
- tailored communication
- exploration of the counselees' context, needs and perception
- exploration of the meaning and consequences of the DNA-test result
- open, responsive atmosphere
- equal counselor-counselee relationship
- reciprocal dialogue
- empathic confrontations
- balance between counselees' needs and medical possibilities
- ask informed consent to correct inaccuracies in the counselees' perception
- discuss possibility of recontacting

Pre-counseling preparation of counselees for uncertainty

The preparation of counselees may include an explanation of genetic and psychological aspects of counseling*, including uncertain DNA-test results and their psychological consequences*:

- preparation by flyer, letter, group meetings, internet
- mentioning of the possibility of detecting UV-results (if communicated)

Intake session

- preparation by explanation of counseling: general procedure, relationship, uncertain outcomes
- global exploration of the personal and existential context of the counselee, e.g.: motivation to undergo DNA-testing, motivation to request testing at this moment in life, coping with cancer
- at the beginning of the session: exploration of the counselees' perception (cf. table 2)
- tailor genetic information to the context and perception of the counselee
- at the end of the session: exploration of the counselees' perception
- exploration of consequences: whether DNA-testing suits the counselees' context best (discuss alternatives); involvement/consequences of relatives; intended medical consequences; current or expected psychological impact

DNA-test result disclosure session

- tailor genetic information to the context and perception of the counselee
- if the counselee is emotional, explore these emotions by means of questions
- at the end of the session: exploration of the counselees' perception
- exploration of consequences: involvement/consequences of relatives; intended medical consequences; current or expected psychological impact

follow-up

- exploration of the counselees' perception
- exploration of consequences for medical decisions and psychology
- exploration of the involvement/consequences/contacting of relatives
- additional explanation, tailored to the counselees' context and perception
- psychological individual or group meetings (6.1.-6.5.)

Table 2. *Examples of questions for counselee-oriented counseling, derived from interviews and instruments in our studies; questions may be used to start a dialogue and attune to the counselee*

Counselee's motivation

- What made you request for genetic-counseling at this specific moment in your life?
- What is the possible meaning of genetic-counseling for you?
- Who else has influenced your decision to undergo genetic-counseling? (partner/kids/relatives; degree of coercion)
- When did you become aware that the cancer in your family is hereditary? (when, how, by whom)
- Given the occurrence of cancer in your family, how do you feel about your personal risk of cancer?
- Are there others in your life that you getting this genetic counseling for? (self versus others)
- What information do you think is important for me to know about you and about your life?

Counselees' expectations and wishes

- What are your expectations and hopes about me/the counseling? (counselor-counselee relationship and information)
- How do you think that the result may help you and/or your relatives to cope with your/their cancer or your/their risk to develop cancer?

Counselee's perception

- Recollection: How would you tell your partner, relatives or friends what I have told you about the information/DNA-test result/pedigree?
- Interpretation: Regardless of what I have communicated, what do you think and feel yourself about your own risk/your relatives' risk to develop cancer/for the likelihood that cancer is heritable in the family?
- Interpretation: How is it to receive this (un)expected information/result/pedigree?

Consequences of DNA-test result (subsequent to exploration of emotional reaction)

- How do you think this information may be of any help to you?
- What do you intend to do with this information/result/pedigree? (e.g. medical decisions, informing relatives)
- How certain do you feel now about the heredity of your cancer/your cancer-risks/relatives' cancer-risks? (e.g. understanding, preventive management options, future expectations, communication with others)
- How are you going to deal with the uncertainty of the information/result/pedigree?

Familial context

- Which of your relatives have you informed about you undergoing genetic-counseling? And how did they respond? (at intake/pretest)
- Who in your family will you inform about this DNA-test result? What (content) and how (process) are you going to tell them?

At the end of a session

- How do you feel about this session?
- What has felt most important to you from our conversations that you take home with you?
- What do you need to support you as you process this result?

5. Implications for the psychological care of counselees

5.1. Who needs psychological care?

> *In the past, I was a perfectionist who wanted to be in top of everything and who always wanted to have certainty in life. For that reason, I became very depressed after the DNA-test result, which confronted me with lots of uncertainty. I was not in control. I started to question the meaning of life and the justice of carrying this mutation* (i.e. UV result-JV). *But I have changed since then. I've learnt to accept things as they are. All things have to go their own way and all people have to live their own lives. Of course, I still want to be in control of my life –and I usually am!- but it is not an inflexible urge anymore. I'm not afraid of uncertainty anymore, I just let it be and live my own live. I know the meaning in life and there is inner peace. I feel complete again as a human being. (…) Yes, I was severely distressed after the DNA-test result. But no, I did not need professional help for that.* (Based on: RL-06)

Which counselees may need referral by the genetic-counselor to a social worker or psychologist? It is common practice in the Netherlands, that genetic-counselors automatically refer counselees who have decision problems, problems with coming to terms with the test result, problems in the partner-relationship, problems with informing children or relatives, etc. (e.g.491).

This common practice seems to assume a simple, information-oriented model, similar to the underlying model in previous studies in which distress was correlated with information-oriented variables (cf. chapter 4). In the discussion-sections of chapters 5 and 10, we suggested on the basis of non-presented results that the personal and existential meaning of the DNA-test result may be a better explanation of who needs professional psychological care. Table 3 shows these results (cf.507). The counselees' self-reported wish for psychological help was *not* correlated with the actually communicated DNA-test result category, cancer-risks and heredity, but it was correlated with their intentions to undergo surgery, their symptoms of psychopathology, and being a young mother. Independently from these psychopathological problems, the need for psychological care was also equally strongly predicted and completely mediated by several counselee-oriented variables, such as having an inaccurate perception, using passive coping styles, existential concerns, high need for certainty and low perceived certainty, feeling and thinking that they and/or their relatives have a high risk to develop cancer, and problems in family relationships (see table 3).

What does this mean? Neither the actually communicated information nor the counselees' medical intentions and psychopathology was directly correlated with counselees needed psychological care, but the counselees' interpretations and the personal meaning of these facts did (cf. chapters 5 and 6). For instance, some counselees seemed to experience strong distress after DNA-testing but they did not wish to receive psychological care. Others did not show severe distress, but they strongly wished psychological care. The main difference between counselees who want and who do not want to receive psychological care can be defined by their way of embedding the DNA-test and the distress in their lives, for instance by the creation of an inaccurate perception, or having a strong need for certainty.

In the past, several authors and probably also policy makers seemed to assume that the absence of pathological levels of distress in the large majority of counselees implied that ‘these counselees do not require psychological help’ (492; cf. chapters 5-6). However, the absence of psychopathology may only say that the distress/psychopathology instruments were too insensitive or a-specific to describe the specific and personal concerns of counselees (cf.74,323,492). Psychological care may not only be restricted for counselees with psychopathology. Our studies have shown that, despite the absence of severe psychopathology, many counselees feel uncertain, vulnerable, and stigmatized and may experience difficulties interpreting the DNA-test result ‘correctly’.

Of all counselees, one in 6 actively reported to need psychological care (both in the retrospective and prospective studies). But only one in 25 had actually received that help. This may be due to the fact that counselees may not have expressed their psychological needs to the genetic-counselor (cf.493), or to the inadequacy of current referral criteria. We recommend developing and using other referral criteria which may be further operationalized in future studies (e.g. table 3). Psychological screening instruments may be used, but we suggest that these should also include items other than psychopathology and which are oncology-specific and genetics-specific. (cf.507)

Table 3. *Criteria for referral to a social worker or psychologist, defined by the correlations between the counselees' wish for help and these criteria.*

1. **surgery intentions**
   intention to undergo surgery of breasts and/or ovaries (.57, .66) *

2. **large 'inaccurate' perception**
   large difference between the counselees' interpretation and the actually communicated DNA-test result (.56) **

3. **passive coping styles**
   distraction, renaming, avoidance and denial (.50, .25, .25, .25) *; **

4. **psychopathology**
   negativity and worries (.48, .43) *

5. **existential concerns**
   vulnerability, uncertainty, lack of purpose in life, lack of self-acceptance (.30, .26, .30, .28) **

6. **high need for certainty and low perceived certainty**
   need for certainty and perceived certainty (.21, .34, .31, .27; ,22, .34, .27, 30)**

7. **interpretations of high risks and heredity**
   feeling and thinking of being at high risks to develop cancer (again), and high heredity; feelings of large vulnerability (.28, .21, .27)

8. **young woman with children**
   number of children living at home (.29) *

9. **familial problems**
   lack of trust and justice in the relationships within the family (.25)

*Unpresented results from the prospective study (chapters 6, 9 and 10), confirming the criteria discussed in and based on data the retrospective study (chapter 5). Figures are correlations and partial correlations. Only R>.20, p<.01 are presented. All items are measured three months after the DNA-test result (i.e. T2). All criteria are linear scales (see chapter 6, 9 and 10). Wish for psychological help was measured on a 1-7 semantic differential, ranging from 1, no wish, to 7, strong wish; 16% of all counselees mainly reported wishing to receive psychological help >4, 68% mainly reported not wanting to receive psychological help. All criteria have been corrected for psychopathological symptoms (i.e. partial correlations). All results were comparable with non-parametric tests. * When these information-oriented variables (criteria 1, 3, 4 and 8) are included in mediation regression analyses together with counselee-oriented variables, they do not directlycorrelate with the need for psychological help anymore, and the counselee-oriented variables remain as the only significant correlations, (i.e. complete mediation; see chapter 6 for explanation). ** When the results are not corrected for the psychopathological symptoms, the correlations are significantly higher, with larger effect sizes.*

5.2. Counselee-oriented interventions

Several psychologists and social workers have asked me to provide suggestions how counselees may 'optimally cope' with an unfulfilled need for certainty. The counselee-oriented ethics would suggest that each counselee may need an individual approach, and that the counselee's needs are followed in psychological care. It has been suggested that counselees may benefit from a psychologist or social worker who does not provide answers but mainly asks questions to help the counselee to discover her own truth, i.e. a Socratic dialogue (490). However, I will describe some general therapeutic interventions that may assist in individual cases. Similar to the suggested interventions for genetic-counselors, all interventions should be regarded as a means to foster the working alliance and to help the counselee fulfilling her needs.

For instance, it may help to explore the counselee's interpretations and embedding of the DNA-test result in her life, by means of questions such as suggested in tables 1 and 2. A counselee may also be stimulated to explore what she really needs at this moment in life. For instance, DNA-testing may not be the most suitable option, for instance because the counselee may not be ready yet to undergo DNA-testing due to her personal and existential life situation. To assess this, psychologists may develop a model regarding 'existential stages of readiness for genetic-counseling' (cf.377). This may be operationalized by means of a 'needs questionnaire' for the counselee, or a checklist for the genetic-counselor.

In 2.3., we described that many counselees experience difficulties with living in dual realities, such as needing certainty on the one hand and not having received certainty about the DNA-test on the other hand. I suggested that counselees can learn to accept the existence of both realities without denying one of both, and can learn to trust themselves in switching their focus from one reality to the other, and back. Many psychotherapeutic interventions may be used to help them to develop a dual attitude, such as existential-therapeutic interventions (467,426). On the basis of literature, I suggest several therapeutic interventions to explore the dual attitude (e.g.494,378,468,145,495,440).

Firstly, existential experiences may be explored with the counselee, for instance about existential anxiety, death, being at-risk, being a cancer-patient, being 'guilty' or 'responsible' for transmitting a PM to her children, identity questions, etc. Counselees may be assisted to stay focused and to deepen/intensify these existential themes, and not automatically avoiding them. Research has shown that deeper explorations in therapy may help counselees in detoxifying existential feelings and cause better therapy outcomes (496,497,126).

Secondly, counselees may be stimulated to not solely focus on the negative, existential, limited side of life, but to broaden their focus. Counselees may be inclined to identify their identity with their risk-status, and 'forget' that they are not only a person-at-risk, but also a mother and a friend, and so on (see 2.1.5. and: 61). They may be stuck in this mode of being at-risk or being a patient (see 2.1.2). Therefore, therapists have suggested to stop reflecting and concentrating on their existential issues: they may take time for 'dereflexion' (cf.498) and 'decentration' (499).

Concretely speaking, a counselee may be stimulated to pay attention to the certainties, meanings and meaningful goals that she currently experiences, has experienced or may experience in life. She is asked for a broad exploration of meanings, and to subsequently revalue, reorder and reorganize these, and to finally make steps to realize these meaningful goals. These certainties and meanings may range from a practical level – e.g. listening to music, being together with her partner– to an abstract level – e.g. defining the ultimate meaning in life. Research shows that cancer-patients who are able to reengage in meaningful goals despite their uncertainties and physical limitations, experience more positive affect (143). Otherwise formulated, they are helped in meaning-based coping as described in 2.1.3. (131). Thus, the psychologist or social worker may explore both the uncertainties and existential questions on the hand, and the certainties and meaningful experiences in the counselees' daily life on the other hand.

Third, the psychologist or social worker may pay explicit attention to the switching between these two realities, such as the switch that counselees may experience when they are meaningfully living their daily lives and suddenly feel vulnerable and uncertain about their genetic status. Counselees could explore previous 'switching experiences' in previous periods of uncertainty in life, and explore how they may actively switch between both realities. For instance, the psychologist or social worker could explore which situations automatically trigger a switch between two realities, and what reason is behind this (cf.458).

Fourth, several studies have shown that counselees may benefit from psycho-education, that is from explanation of their situation (e.g.500). Didactics may lower distress and may facilitate a normalization process, i.e. they may help a counselee to experience her situation as a normal reaction to an abnormal situation. Information from this thesis may be included in this psycho-education, e.g. the fact that many counselees may feel uncertain and vulnerable. It may be explained that dual realities may exist next to each other and that for instance being at-risk does not necessarily mean that one's identity has to change. Didactics may not only be provided during a session, but also by means of flyers with explicit psycho-educational information (e.g.484).

Fifth, psychologists and social workers may explicitly recognize the counselees' needs, situation and perception, for many counselees in our pilot study said that they felt 'seen' and 'recognized' thanks to our interview, and they experienced this recognition as valuable (see quote in 1.1.). The psychotherapist Boszormenyi-Nagy writes that it is important to give explicit recognition to an individual who is struck by an unchangeable fate, such as one's genetic background (501). He would say that an individual will not be able to develop a 'dual attitude' and to cope actively with her situation, when her victimhood is not first recognized. Thus, the creation of a dual attitude may assume the explicit recognition of the counselees' worries and needs.

Sixth, explicit attention may be given to the untested relatives of the counselee. We found that relatives are involved in the genetic-counseling process. But this involvement may not be without emotional and relational consequences for the counselee. For instance, counselees wished to receive psychological help when they had the feeling that they could not trust their relatives, and that they did not receive the care from relatives that they actually felt they deserved (see table 3). Additionally, unresolved family myths may be revived, loyalty conflicts may occur, and family-conflicts may start (112-114). Other studies have also shown that the counselees' family-experiences with cancer may predict their level of distress (491). Creation of a dual attitude may also be helpful in such family situations. More specifically, counselees may be helped to combine their loyalty towards and identification with their family with being autonomous, such as asking relatives for their opinion and at the same time making their own medical decisions (114,501).

Finally, our studies suggested that counselees did not make their medical decisions on the basis of the actually communicated facts or of their recollections, but on the basis of their own interpretations (chapters 5, 6 and 10). Therefore, we suggest that a psychologist or social worker explores the subjective, emotional ways of reasoning when a counselee wishes to receive psychological care about her decision to undergo surgery of her breasts or ovaries. We recommend to not only use cognitive techniques during this exploration - as is often suggested (502-503) -, but also to use techniques that may help counselees to deepen and to stay focused on their feelings, such as mindfulness (504-506).

> *'My life has changed due to genetic-counseling. It was a difficult process. But it was worth it. I have learned much, I know what to expect from my cancer, what medical decisions to make and what to tell my children. And above all, I have learned to be myself, and not to be distracted by uncertainty.'* (Loosely based on interview RL-006)

6. Main conclusions

1. BRCA1/2-counseling can be compared with a children's whisper game. The genetic-counselor has actually communicated 'A', the counselee recalls 'B', interprets this as 'C', and experiences distress and makes medical decisions on the basis of 'C'. The counselee communicates this information to her relatives, who recall 'D', interpret 'E' and experience distress and make medical decisions on the basis of 'C'.
2. The disclosure of BRCA1/2-results has a far-reaching impact, which includes medical, psychological and existential changes in life (1.2.1.).

3. The counselees’ perception of the BRCA1/2-result deviates significantly from the actually communicated information, and consists of multiple elements such as recollections and interpretations of cancer-risks and heredity-likelihood (1.2.2.).
4. The communication of BRCA1/2-results do not directly correlate with the far-reaching impact of genetic-counseling, but the counselees’ perception does correlate with and mediate this impact (1.2.3.).
5. Relatives feel strongly involved in the genetic-counseling process. They experienced a significant impact of the DNA-test result on their lives. This was only correlated with their own subjective perception that deviated from the actually communicated information (1.2.4.).
6. The unfulfilled need for certainty may be frightening for counselees, possibly because of the personal and fundamental meaning of DNA-test results for counselees (2.2.).
7. Few counselees seemed to accept the unfulfilled need for certainty, which may cause denial and distress; acceptance may be increased by helping counselees to acknowledge both the uncertainties and the certainties in their life (i.e. form a dual attitude) (2.3.).
8. We suggest genetic-counselors to follow a counselee-oriented ethics in their clinical practice, which focuses on the counselees’ needs, and assumes that the counselor takes care for the totality of the counselee and not only for the disclosure of information; examples to start a dialogue have been provided (3.3.; 5.1.).
9. The communication of UV’s may not be in line with this counselee-oriented ethics because it does not fulfill the counselees’ needs and it seems to evoke significant distress in many counselees, but at the same time it does not have important medical implications 3.4.).
10. Genetic-counselors seem to be the most reliable factor in the communication process of genetic-counseling, and the counselees’ and their relatives’ interpretations seem to predict the noise in the ‘whisper game’ (5.1.).
11. We suggest revisiting national and international policies, for instance regarding DNA-terminology, ethical foundations of genetic-counseling, and recontacting counselees (5.1.).
12. Genetic-counselors are advised to provide counselees with letters for their relatives which explain the DNA-test result (5.2.).
13. Most counselees do not develop psychopathology after DNA-testing, but the majority do feel vulnerable, and about one-sixth would like to receive psychological help, especially those intending to undergo surgery, having an inaccurate perception, asking existential questions and feeling uncertain (6.1.).
14. Psychologists and social workers may help counselees by developing a dual attitude, for instance by acknowledging that they need certainty and that they may not actually experience certainty at the same time. (6.2.).