Summary

Cancer genetic counselling represents a very special situation of interaction between the geneticist and the counselee, marked by a number of specificities that account for its complexity. Cancer genetic counselling has multiple repercussions, such as identification of a deleterious genetic mutation associated with a high probability of developing breast and/or ovarian cancer, the implementation of preventive measures ranging from close surveillance to the decision to perform mutilating prophylactic surgical procedures, or the impact of the information on the other members of the counselee's family also concerned by the genetic risk. This chapter is based on a review of the literature that has been rapidly growing over recent years and on our clinical expertise as psycho-oncologists and geneticists. We will first present the reasons that make the information so critical. These reasons are both objective (complexity of the genetic information per se, difficulties of understanding the concept of risk) and subjective (information given to people with an emotionally charged family history and a perception of risks closely linked to their representation of cancer). At the same time, the counsellees are charged with the transmission of this information to members of their own family. We will then discuss the various modalities of communication in this setting. While unidirectional transfer of information from the geneticist to the counselee has been the preferred method in cancer genetics for a long time, a model based on patient-centred communication is more adequate in predictive medicine and allows shared decision making. In all cases, the different professionals involved in the process have to learn how to work in a performing cohesion. We also present the main guidelines on the subject and the various underlying objectives with regard to information delivery and the subject's personal experience. Although the psychological impact of genetic counselling consultations raises a number of questions, the results of preliminary studies are reassuring, demonstrating psychological benefits. However, a number of aspects concerning communication in predictive medicine remain to be investigated and improved.

3.1 Introduction

The discovery of the BRCA1 cancer-susceptibility gene in 1994 (Miki et al. 1994) and BRCA2 in 1995 (Wooster et al. 1995) now allows identification of individuals with a cancer predisposition mutation by performing DNA mutation analysis. There has always been a popular belief concerning hereditary transmission of breast cancer, which has been supported by this scientific progress and mediatization of this breakthrough has led to an increased awareness of the concept of family risk, resulting in a growing demand for genetic counselling and genetic testing (Bottorff et al. 1998; Holloway et al. 2004).

However, known inherited gene mutations are only involved in 5% of cancer cases (King et al. 1993). Presymptomatic genetic testing is therefore not appropriate for the majority of women with a family history of breast cancer. The indication for gene mutation testing first has
to be discussed in preliminary genetic counselling consultation.

Breast cancer genetic testing was initially proposed in the context of research protocols. In this setting, sustained follow-up of the counselees not only helped them to anticipate the outcome of the genetic test, but also allowed interventions in the case of psychological distress. Meanwhile, breast cancer genetic testing has become available in routine clinical practice, despite the fact that it is not yet clear how to adequately inform patients about their personal breast cancer risk and the pros and cons of genetic testing (Green et al. 2004). Moreover, the long-term impact of genetic counselling on psychological well-being and health behaviour is still largely unknown.

In this chapter, we will discuss the psychological aspects of cancer genetic counselling and review the current knowledge concerning its psychological impact. We will try to define the optimal modalities of communication between geneticist and counsellee, and demonstrate that the subject's understanding of a risk can be modified by individual psychological characteristics, which must therefore be taken into account.

### 3.2 Complexity of Cancer Genetic Counselling

Genetic counselling is a highly complex process due to both objective and subjective factors. The information provided in the context of cancer genetic counselling, including the concept of risk, is objectively complex. More subjectively, this information must be provided to an individual, mostly a woman, who is often emotionally affected by a family history of cancer and who will have to consider the pros and cons of the necessities of surveillance or preventive surgical options. In addition, the counsellee also has to act as a messenger to the members of the family, whose relationships might subsequently be modified by the information.

#### 3.2.1 Objective Factors

##### 3.2.1.1 Complexity of the Information

The primary goal of genetic counselling is to inform individuals about cancer risk and cancer prevention in order to reduce morbidity and mortality (Pieterse et al. 2005). More specifically, genetic counselling should enhance their knowledge and encourage favourable health behaviours, i.e. by adequate objective risk perception with a level of anxiety that does not impair understanding or appropriate medical surveillance.

The information provided in cancer genetic counselling is complex for different reasons. First, the counsellee is faced with a very large quantity of information. The various national guidelines for cancer genetic predisposition management (see in Bortoff et al. 1998; Richards et al. 1995; Eisinger et al. 2004) represent a considerable amount of information that must be presented to and understood by the counsellee. After the genetic counselling visit, the subject should know: (1) the purpose of the test; (2) the risk of the test (e.g. consecutive insurance problems); (3) the uncertainty of the test; (4) the risk that the test may reveal an unexpected finding; and (5) the consequences of a positive test (e.g. impact on family members) (Butow et al. 2004). Therefore, one can expect that the counsellee is often overwhelmed by such a body of information and that psychosocial aspects are neglected in the consultation.

The information is also based on a very abstract and unusual medical terminology; it is in fact difficult to translate molecular genetic findings into lay terms and the general population has a poor understanding of Mendelian genetics. Another element of complexity is the rapidly growing scientific progress and the still existent methodological limitations and lack of long-term follow-up of current methods (Eisinger et al. 2004). Finally, the information concerning the consequences of genetic testing is also complex. Genetic testing for breast/ovarian cancer susceptibility offers a potential benefit of early detection of cancer, reduction of uncertainties, and relief if the test provides negative results. However,
genetic testing also entails potential risks, such as the risk of failure of preventive interventions, adverse psychological reactions, social and occupational discrimination or inappropriate health surveillance behaviour (Brédart et al. 1998). When discussing these aspects, the genetic counselling consultation should allow individuals to make informed medical decisions about whether or not to be tested and the adoption of appropriate preventive strategies.

3.2.1.2 Concept of “Risk”

The information provided in a cancer genetic counselling consultation essentially concerns risks. The concept of risk is traditionally defined as “the probability of (occurrence of) a negatively valued event” (Julian-Reynier et al. 2003). In the context of cancer genetics, information about risk is particularly complex, as cancer risk information concerns multiple risks (e.g. all epidemiological and personal risk factors, risk of the predisposing gene running in the family or of inheriting a genetic mutation, risks associated with the prognosis of cancer and preventive/early detection interventions), and most risk estimators are associated with uncertainty. For example, if a person in a cancer family is found not to carry the predisposing gene, the probability of developing a sporadic cancer (i.e. not linked to a hereditary component) remains equivalent to that of individuals in the general population. Risk estimators also comprise uncertainty, particularly for penetrance of genes. Estimates of penetrance values of BRCA genes appear to vary between 60% and 85% at age 70 for breast cancer and between 10% and 40% for ovarian cancer (Struwing et al. 1997; Ford et al. 1998; Antoniou et al. 2003).

Certain non-contributive or unexpected results can lead to a highly paradoxical situation, because the subject expects a result which should decrease uncertainty about her genetic status, but the results sometimes increase uncertainty by information she does not know how to use. A good example is the discovery of variants of uncertain clinical significance (VUCS). VUCS refers to alterations of genetic sequences whose risk consequences are often unknown (they differ from inconclusive results in that inconclusive results mean that no BRCA1/2 mutation is detected) (van Dijk et al. 2004b).

3.2.2 Subjective Factors

Cancer genetic risk information must be integrated by individuals who are often emotionally affected by a family history of cancer, life experiences and psychological characteristics which determine the understanding of the information and the perception of the risk.

3.2.2.1 Impact of Prior Experiences and Emotions

The experience of a family history of cancer is frequently associated with feelings such as fear, low self-esteem, anger, guilt, grief, and embarrassment. This experience must be taken into account as a possible barrier in the education about cancer genetic risk.

On the one hand, studies of women with a high risk for breast cancer due to a family history of the disease in first-degree relatives have found that these women experienced high levels of worry about their risk (Lerman and Schwartz 1993; Audrain et al. 1997). Levels of anxiety about cancer, on the other hand, have been shown to be associated with inaccurate perception of breast cancer risk in women at risk (Hopwood 2000).

While the emotional impact of a family experience of cancer is variable, it is likely to generate a certain amount of distress during counselling (van Dijk et al. 2004a).

3.2.2.2 Perception of Risk

Prior to genetic risk counselling, only a minority of women have an accurate perception of their risk of developing breast cancer, and the majority either overestimate or underestimate their risk (Hopwood 2000). Cross-cultural differences have been demonstrated, with a much greater risk overestimation in the USA than in the UK.
Risk overestimation is also high in Latin countries (Huiart et al. 2002; Gil et al. 2003).

Cognitive biases, individual preconceptions (and misconceptions), life experiences, cultural context, the subject’s general outlook (e.g. pessimism, locus of control), as well as social biases, such as family history and related beliefs of being vulnerable, may also influence the interpretation of risk information (Bottorff et al. 1998).

Providing up-to-date and accurate risk estimates to the counselee is one of the main goals of genetic counselling; but how is cancer risk perceived after counselling?

Studies evaluating risk perception vary widely in their definition of risk accuracy leading to inconsistent results (Hopwood et al. 2003b; van Dijk et al. 2004a). In a 1-year prospective study of 158 women aged 18–45 years with a confirmed lifetime risk of breast cancer of 1 in 6 or greater, the proportion of women with accurate personal risk perceptions based on “gambling” odds (1 chance in x) significantly improved after risk counselling (Hopwood et al. 2003b). “Gambling” odds was the method of reporting perceived risk with the best level of risk accuracy and women preferred this format. However, the concept of lifetime risk was understood by only 44% of counselees.

Using open-ended, semi-structured face-to-face interviews, van Dijk and coworkers (2004a) showed that the level of risk perception accuracy depended on the leniency of the criterion applied, being either an exact match with the verbal label or more global high versus low level of risk estimation.

In a prospective study performed on 108 women receiving genetic counselling, women’s risk perceptions after counselling were significantly lower than pre-counselling, but still significantly higher than the actual risk information communicated (Gurmankin et al. 2005).

Kelly and coworkers (2004) examined changes in perceived breast cancer risk from post-counselling (1–2 days after counselling) to post-result (1 week after receipt of test results), and found that the perceived risk decreased in those tested negative, but remained unchanged in those tested positive. They concluded that individuals may assume that they have a hereditary mutation until they receive contrary test results; this may be interpreted as a coping method of assuming the worst in order to manage anxiety or as defensive pessimism.

In conclusion, van Dijk and coworkers (2004a) emphasized that the level of perceived risk accuracy might be a limited outcome for assessing the effectiveness of genetic counselling and that it would be preferable to identify which emotions, cognitions, and behavioural intentions are elicited by the risk information and whether they are congruent with the goals of counselling (i.e. adopting medically appropriate behaviours, reporting a moderate level of distress after counselling).

3.2.2.3 Messenger Role

A further difficulty involves communication of cancer genetic information within the family. The counselee becomes a messenger of sensitive information to other family members. However, little is known about this process (Tercyak et al. 2001, 2002; Blandy et al. 2003).

While cancer genetic counselling is addressed to an individual, it also concerns the whole family. At first sight, the person who consults may appear to be the person primarily concerned, but the implications obviously surpass the individual case. As already discussed, the subject expects a result from the visit (answers to questions about the cause of the disease, reduction of the anxiety related to uncertainty, information concerning prevention, etc.), but there are no genetics without family and the information therefore inevitably concerns the person’s descendents, ascendants, as well as other members of her own generation.

This observation raises the very complex question concerning ownership of the information: does this information belong exclusively to the one who consults or does it immediately belong to the whole family? Is the person aware of this twofold ownership and/or has the rest of the family already questioned a possible genetic predisposition?

These ethical issues have a number of consequences on the practical organization of cancer genetic counselling and must be investigated before performing the test, especially before pro-
viding the results. A thorough investigation of the personal motivations, as well as perception of the implications for the rest of her family, has therefore to be an integral part of genetic counselling.

3.3 Communication in Cancer Genetic Counselling

The three main objectives of doctor–patient communication in medicine are: the creation of a trustful interpersonal relationship, exchange of information, and treatment-related decisions (Ong et al. 1995). The primary objective of cancer genetic counselling is exchange of information. However, to obtain an adequate level of informed consent, to minimize distress, improve satisfaction, and promote appropriate preventive behaviour, other aspects must also be taken into account, especially an evaluation of the patient’s understanding of the information provided and of the emotional reactions induced by this information.

3.3.1 Communication Models

Various communication models have been described in general medicine. In cancer genetic counselling, the “rational” model now appears to be predominant. This model emphasizes the importance of the information derived from the medical profession, which must enable the counselee to take an informed decision. This model only partly satisfies the expectations of counselees. As Pieterse and coworkers (2005) stressed, the major issues for counselees were to discuss their own and/or their family members’ risk of cancer, to receive information about early detection of cancer and preventive actions, and to determine the risk for their children, or of transmitting an increased susceptibility to their children. Other important expectations included the need for emotional support, to reduce anxiety, to obtain help in discussing genetic risk issues in the family and to receive information about the counselling and testing procedure. The “rational” model therefore appears to be fairly limited.

Borttoff and coworkers (1998) described a model of “shared medical decision-making”, which advocates a partnered decision-making in which the professional engages with the client to achieve an understanding of the meaning of the genetic risk, by taking into account the individual’s expectations and representations, and to reach a medical decision considering the various available medical solutions and their consequences.

In the particular setting of cancer genetic risk communication, probability and contextual approaches have been proposed. The probability approach provides numerical information in the form of a numerical risk, such as absolute risk (assessing a discrete estimate of risk), relative risks (assessing risk in comparison to another individual or group), odds ratio or ratios (frequency of events, proportions, percentages, probabilities) and verbal descriptions of risk magnitude (unlikely, higher risk than average, higher risk than another woman in the population). Visual displays, such as line graphs, pie charts and bar graphs reveal data patterns and may also communicate uncertainty. A preference for quantitative information has been highlighted and a combination of visual displays and numerical and written information improves the perceived usefulness of the information and the perception accuracy (Julian-Reynier et al. 2003). The contextual approach communicates risk with reference to the patient’s medical history and the consequences of the health problem, providing, for example, information about the causes of the disease and the severity of its consequences, or using testimonies or videos.

3.3.2 Communication Guidelines

Various guidelines for risk counselling are now available (Richards et al. 1995; Eisinger et al. 2004). A multistep process has been proposed (Julian-Reynier et al. 2003), starting with assessment of the counselee’s preconceptions, knowledge, preferences, expectations, anxiety and coping style in order to tailor the risk communication process. The information to be given to the counselee (risk, magnitude, uncertainty, for-
mat) is then selected and ordered so that it can be put in perspective with other disease risks, using several formats. Lastly, feedback from the consultation is provided by means of standardized tools that complement the consultation (leaflet, videos, CD-ROM), and a personal letter summarizing the consultation.

Bottorff and coworkers (1998) also highlighted strategies such as relationship and trust building, history taking, explanation of risk, and risk assessment. Efforts are made to help counselees understand the meaning of risk estimates in relation to other life events, and to emphasize that the risk of developing the disease is not the same as the risk of dying from the disease.

We underline the considerable role, both technical and emotional, played by the clinical geneticist and genetic counsellor (Lobb et al. 2004), as well as their multiple tasks. They routinely initiate contact with the family, obtain a pedigree, obtain consent from living relatives to access medical records, confirm relevant medical data, ascertain family beliefs about the inheritance pattern, advise family members of these risks and options and arrange clinical screening (Richards 1993). From a subjective point of view, counselees are confronted with the difficulty of providing complex medical information while dealing with the emotional repercussions of belonging to a family with a cancer history and learning about one’s own risk status and its consequences. Management of all of these dimensions, even in a 1h consultation, is a challenge.

3.3.3 Organization of Cancer Genetic Counselling in France

Various models of cancer genetic counselling, depending on national or regional expertise and resources, have been developed (Hopwood 2005).

In France, for example, the various professionals working in the field of cancer genetics, forming the “Genetics and cancer” group, have proposed guidelines for cancer genetic counselling, based on a multidisciplinary organization in which the various healthcare professionals meet with the counselee at various times.

The first meeting is a long consultation, for which the counselee is encouraged to attend with a certain amount of preparation (maximum of information about the family history of cancer). The counselee is invited to attend the visit with one or several members of the family. The counselee’s family tree is constructed and a maximum of information is obtained about all cancers in the family; then, the geneticist describes the objectives of genetic counselling, the existence of genes and their possible alteration, the concept of risk, the implications of genetic testing, the various expected results and their consequences, the concept of specific surveillance and possible prophylactic surgical procedures aimed to decrease the risk of developing cancer. Finally, the geneticist provides information about the risk of the family members and advice concerning the transmission of this information. At the end of the visit, the geneticist provides the counselee with a fairly precise estimate of the probability that she carries the BRCA1 or BRCA2 genetic alteration. The counselee is given an information brochure, summarizing the information provided orally, which can be read at home and shared with other members of the family.

Usually, it is proposed not to take the blood sample for genetic testing immediately, as the counselee is given a period of reflection of about 2 months during which she is encouraged to attend a visit with a member of the psycho-oncology team. The psycho-oncology interview is an opportunity for the counselee to review her motivation to undergo genetic testing, to explain her expectations and to investigate the subject’s representations of cancer, especially in the light of her family history, and to share her level of information and her integration of the information presented at the first meeting with the geneticist. The psycho-oncology interview investigates the counselee’s perception of risk, her capacity to anticipate the results of genetic testing, her desire to transmit the information received to her family, and, more globally, the model of family communication. It also assesses the psychological impact of the genetic risk and the possible risk of psychiatric disturbance related to this situation. The interview sometimes leads to the decision not to perform the genetic test or at least to postpone it.
The second meeting with the geneticist, often shorter than the first, confirms the counselee’s motivation and reinforces the main information. After understanding how the counselee and her family experience this period of reflection, the geneticist answers any of the patient’s remaining questions. A letter summarizing the genetic information provided during the consultation is then handed to the counselee; this can be especially helpful for the counselee to recall this information and to transmit it to the family.

The psycho-oncologist may follow the counselee during this period, but is usually only consulted at the time of delivery of the genetic test results.

In every case, geneticists and psycho-oncologists meet regularly to pool their information in order to achieve a global understanding of the counselee’s expectations, values, and choices and the possible psychological difficulties. Written summaries are included in the counselee’s file, allowing sharing of information collected by the various professionals involved.

It should be underlined that the geneticist not only informs on the genetic situation but also takes part in the organization of the next steps of the process. After presenting the different possibilities to reduce the counselee’s risks, surveillance or preventive surgery, he participates in the practical organization of the medical exams or further consultations with members of the multidisciplinary medical team.

This cancer genetic counselling model is continually evolving, especially in view of the recent arrival, in France, of newly trained genetic counsellors, which will modify the distribution of roles between the various professionals involved.

3.3.4 Impact of Organization on Outcomes

Although cancer genetic counselling services vary in terms of staffing and/or organization, evidence suggests that the context of risk counselling has a less important impact on psychological outcomes than expected (Hopwood et al. 2003a). In terms of organization, a multidisciplinary team achieved a significantly greater improvement of risk knowledge than cancer genetic counselling administered by a surgical department (Brain et al. 2003). The different models currently implemented should be further evaluated, looking for the most convenient one.

3.3.5 Process and Content of Familial Breast Cancer Genetic Consultations

Butow and Lobb (2004) conducted a major study, examining in detail the process and content of genetic counselling in initial consultations with women from high-risk breast cancer families. Over 158 consultations of women unaffected and affected with breast cancer, conducted in 10 familial breast cancer clinics throughout Australia, were audiotaped and transcribed. A detailed coding system was developed to cover all facts thought to be important to be elicited from or conveyed to the consultant, and all behaviours thought to facilitate active involvement and expression of emotional concerns.

This analysis evidenced that the average genetic counselling session was 61 min [comparable to that of European clinics (Hopwood et al. 2003a)], that patients spoke on average one-third of the session and consultants demonstrated consistently good practice in providing detailed information on essential aspects related to familial breast cancer. The authors noted that, although the woman’s agenda was frequently elicited, other subjects were tackled less frequently, namely the women’s decision to discuss the results with other family members or emotional concerns such as those relating to prior experiences of loss and grief. Considering the predominant role played by information processing in cancer genetic counselling, it has to be stressed that passive listening reduces understanding and interactivity should therefore be stimulated. Moreover, training in or self-monitoring of behaviours known to facilitate understanding (checking women’s medical knowledge, checking understanding, explaining medical terms, inviting questions, summarizing, and using diagrams) may assist clinical geneticists and genetic counsellors to further develop these skills.
3.4 Consequences of Cancer Genetic Counselling

3.4.1 Psychological Impact

Major questions still remain unanswered: What is the psychological impact of genetic counselling? Does cancer genetic counselling induce psychological morbidity? What is known about the short-term and longer-term impact?

In a systematic review (Butow et al. 2003), genetic counselling and testing appeared to produce psychological benefits. Carriers of mutations in cancer predisposition genes did not experience any significant increase of depression and anxiety after disclosure of their mutation status, while non-carriers experienced significant relief. If general distress levels for counselees are comparable with community samples, cancer-specific worries are increased in women at risk compared with those without a family history (Hopwood, 2005). On the other hand, women who were tested, but who refused to be informed about the results, seemed to be at greater risk of poorer psychological outcome (Lerman et al. 1998).

3.4.2 Satisfaction with Cancer Genetic Counselling

Assessing the satisfaction of 36 counselees with cancer genetic counselling in The Netherlands, Bleiker and coworkers (1997) found generally high levels of satisfaction with the different aspects assessed. The areas identified as needing further attention were related to the information regarding the possible impact of genetic counselling and testing on daily life, communication between the clinical geneticist and other healthcare workers, and psychosocial support during and after genetic counselling.

3.4.3 Psychological Consequences in Relation to Communication Style

Two factors appear to be particularly important when communicating risk information: the individual’s affective response to risk information and the communicator’s skill and sensitivity in disclosing the results (Borttoff et al. 1998).

3.4.3.1 The Individual’s Affective Response to Risk Information

Greater attention should be paid to ways of coping with test results at the very first contact with the genetic counselling service. Younger women, those without a history of cancer, and those who are first in their family to apply for genetic counselling for breast/ovarian cancer, have been shown to withdraw prematurely from cancer genetic counselling (Bleiker et al. 2005). They do not appear to have elevated levels of distress, but they seem to have doubts about their (in)ability to cope with a possible unfavourable test outcome.

3.4.3.2 Communication Skills in Disclosing Genetic Test Results

Various skills should be considered when communicating cancer genetic information or test results, such as the counsellor’s sensitivity to individual and cultural differences, the language used (avoiding medical jargon), the ability to provide emotional support, and the counsellor’s own anxiety level, which has been found to be inversely correlated with the counselee’s capacity for understanding (Lobb et al. 2001).

Further research is needed to examine the counsellor’s communication style in relation to the psychosocial impact of cancer genetic counselling (Hopwood 2005). The few available studies are presented below.

In a multicentre study, Lobb and coworkers (2005) showed that clinical geneticists and ge-
nitalic counsellors achieved a certain degree of standardization in communicating information, but showed a diversity of skills, i.e. communication behaviours that facilitate understanding, active involvement, partnership building, and addressing emotional concerns. These variations in counselling style resulted in differences of patient's depression, 4 weeks after the counselling session. However, there was no association between the way genetic risk was communicated and women's accuracy of risk recall or satisfaction with the consultation.

Butow and coworkers (2004) highlighted that increased use of supportive and counselling communications increased anxiety about cancer, suggesting that emotional issues may be raised without adequate resolution. It may be helpful for consultants to be able not only to assess psychological stress, but also to keep checking how the woman is coping during the consultation and to provide adequate support.

3.4.4 Communication in the Family

The effect of risk communication is also reflected in subsequent disclosure of risk information in the family (Hopwood 2005). There is a need to improve knowledge about communication strategies within the family and their impact on family relationships and family members' reactions. Very few studies have been conducted in this field.

Tercyak and coworkers (2001) evaluated the psychological impact of the parental communication of the result of BRCA1/2 testing. Mothers (versus fathers) and subjects with the highest levels of general emotional distress more easily informed their children about the test results. Coping strategies after the test (both active and avoidant) were positively correlated with the post-counselling distress level. However, communication of the result to the children did not modify the counselee's level of distress, but increased their children's level of distress.

The same authors also evaluated the parent–child relationship and its impact on the communication of test results to the children (Tercyak et al. 2002). Older children appeared to be more frequently informed about the test results, and the communication style within the family seemed to predict the way mothers shared the information with their children (the test result was more frequently shared when the communication style between parents and children was more open), and was not modified by revelation of the result.

Blandy and coworkers (2003) showed that results of BRCA tests were generally adequately transmitted to the family; difficulties of transmission, however, correlated with a poorer understanding and a higher level of anxiety and avoidance. First-degree relatives were most frequently informed about the test results, but they only rarely requested genetic testing, which was essentially requested by sisters and daughters. The quality of family support and the level of understanding of the risk of transmission were positively and significantly correlated with the decision to perform the test in first-degree relatives.

In France, the bioethical legislation has recently considered this medical situation in which information elicited in one individual of a family concerns all its members. The latest bioethical law sets that the biomedical agency takes the responsibility to confer this information to the different family members: the transmission should proceed from doctor to doctor, and from them to family members (Public Health Policy, Biomedicine Agency, 2004).

3.5 Improvement of Cancer Genetic Counselling

Studies indicate that cancer genetic consultants present generally good practice in terms of the information they provide; however, they less frequently demonstrate attention or skills to deal with the subjective aspects of the genetic counselling, i.e. verifying the counselee's understanding of the information, assessing emotional reactions or attitudes of informed family members.

Biesecker and Peters (2001) proposed a working definition for genetic counselling consultations that defines the goals as “promoting understanding, achieving informed consent, fa-
cilitating decision-making, reducing psychological distress, restoring feelings of personal control and advancing adaptation to stress-inducing events”.

These objectives are much more exhaustive than those regarding patient information. However, this definition raises new questions: What is the exact role of the geneticist or genetic counsellor, especially concerning the evaluation of emotional reactions or the provision of psychosocial support?

There is a growing number of guidelines for communicating risk, suggesting the need to develop and evaluate innovative communication strategies (Bottorff et al. 1998; Hopwood 2005). Genetic counsellors should also be encouraged to explore idiosyncratic risk beliefs, personal theories of inheritance, and personal or social support that underpin coping. Integration of risk information may be enhanced when emotional issues are addressed. Geneticists or genetic counsellors are confronted with the challenging task of providing objective information which is adapted to the individual, taking into account the individual’s concerns and preferences. Counselees often express a marked need to receive more attention and information with regard to the possible impact of cancer genetic risk on their daily life and the availability of psychosocial support (Bleiker et al. 1997). These aspects do not seem to be sufficiently addressed in genetic consultations. Several key elements can improve communication.

### 3.5.1 Develop Aids to Recall and Transmit Information

We have stressed the double role of the information provided at the cancer genetic counselling visit, allowing the counselee to understand the risk for herself, before having to transmit the information acquired to her own family.

A growing number of field experiences and studies have reported the benefit of proposing on the spot or by means of documents (written documents or videos) a summary of the complex information presented during the visit. Hallowell and coworkers (1998) showed that counselees feel a duty to share the information they obtain during genetic counselling to relatives, and warned about the risk of miscommunication (due to the counselee’s difficulty to recall information). In a series of 400 interviews, 92% of subjects reported that the written summary facilitated their understanding and/or recall of the information.

Tools should be developed to alleviate the burden of information provision within the cancer genetic consultation; for example, information personally tailored to the individual’s needs, characteristics and coping style (personalized letter, audiotape, computer-generated information, telephone services) or information/decision aids.

Even when the counselee is accompanied by other members of her family, she remains responsible for the information received and its transmission to the rest of the family. It is therefore important to develop ways of helping her to anticipate the information that he/she has to transmit, as well as in the transmission process itself.

Several modalities can be proposed, such as letters to families that can be sent by the doctor with the patient’s consent, discussion with the patient during the visit about the content of the information to be transmitted and the way to transmit this information, or meetings with other members of the family to inform them during a consultation.

### 3.5.2 Improve Communication Style

One motivation for attending genetic counselling is to receive reassurance. Unaffected women cited information as reassuring, whereas affected women perceived the skills of the geneticists in listening, appearing caring and relaxed, as providing an independent source of support. It may therefore be more important to actively reassure affected women.

This supposes relational capacities which are not only innate, but which can be acquired by specific training, the so-called communication skills training (CST), which are based on analysis of fictional clinical situations (with actors simulating patients or as role plays between
healthcare professionals) or real clinical situations which are audio-recorded and/or filmed and complemented by role play and supervisions (Balint groups or equivalent).

It is therefore important to increase the awareness of healthcare professionals, as early as possible, about CST or other ways of improving communication techniques.

3.5.3 Further Promote Multidisciplinary Collaboration

Various healthcare professionals are in contact with the counselee during the cancer genetic counselling process (geneticist, genetic counsellor, psycho-oncologist, etc.). Multidisciplinary meetings between healthcare professionals of these various fields enhance the understanding of the counselee: his/her values, motivations, capacity to integrate the information, personal perception of the risk, anticipation of the consequences of the test results, desire to transmit the information to other members of the family—all elements that contribute to the decision-making process.

3.5.4 Take Time

Although no data on these aspects are available, we can assume that the time devoted to assess the counselee’s knowledge, perceived risk, information/emotional needs and preferred modalities of risk information is an important element of genetic risk counselling.

During a consultation, the geneticist or genetic counsellor should help counselees demystify genetics, and highlight how expertise in this field may answer many of their actual medical questions although some will remain unresolved and some will raise further issues still unaddressed. Such an approach may require time, which may be well invested, since it increases efficient information sharing.

3.6 Conclusions

There are insufficient data concerning optimal risk communication strategies. Recent research shows both consistency in information provision and deficiencies in specific communication skills. The need for personally tailored risk information seems a key element of successful genetic risk counselling (Hopwood 2005). Outcome studies on risk perception and psychological distress are insufficient to understand the complex communication and decision-making process in this context. Assessment of the risk counselling process is a new field and evaluation and comparison of various approaches therefore constitute a research priority. Outcome measures must also include decision-making and subsequent healthcare behaviours. In addition, communication within the family raises a number of difficulties that have not been sufficiently investigated yet.

There is a need to provide clear directions about how to ensure that the probabilistic nature of risk estimates is accurately transmitted and understood, and especially how the error-proneness of genetic tests is sensitively communicated (Bottorff et al. 1998).

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