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Mini-review article

Comparing genetic counseling with non-genetic health care interactions: Two of a kind?

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Abstract

Objective: Increasingly clinicians other than genetic counselors will advise people with genetic risks. Although some express concerns about this development because of the need for non-genetic clinicians to have additional training, we argue that genetic counseling has more in common with other health care interactions than is generally assumed.

Methods: In this narrative review we investigate the health communication literature taking the perspective that all provider–patient/client interactions share the following goals: forming a relationship, the exchange of information, decision making, promoting health-related behavior and providing support.

Results: We found that both non-genetic and genetic 'disciplines' endorse an egalitarian relationship, based on a patient-centered approach and both have difficulties with attuning to the patients' agendas and enhancing patient understanding. Shared decision making is increasingly the preferred model for geneticists and non-geneticists alike, and both need skills to constructively discuss patients' risk-reducing behavior and provide emotional support.

Conclusion: Rather than developing separate vocabularies and research traditions, the discipline of genetic counseling may benefit by drawing on non-genetic patient–provider interaction research.

Practice implications: Since geneticists face the same challenges as non-geneticists, medical training should continue to improve basic consultation skills, regardless of whether the consultation involves genetic information.

Keywords: Genetic counseling; Patient–provider communication; Relationship; Information; Decision making; Health behavior; Emotional support; Review

1. Introduction

Discussion of genetic information has traditionally been the domain of professionals trained in human genetics, i.e., clinical geneticists and genetic counselors. Increasingly, other health professionals such as non-genetic medical specialists, general practitioners, pharmacists, nurses and midwives will inform patients about genetic risks. This is a result of the rising availability of genetic risk information, the growing use of genetic tests for common multifactorial diseases, the implementation of genetic screening programmes, and the increased availability of prenatal screening and diagnosis of fetal abnormalities [1,2]. Eventually, many individuals may undergo genetic testing not provided by genetic counselors alone [2].

Recent surveys have shown limited genetics knowledge, clinical skills and support for a directive method of counseling in non-genetic health professionals [3–5]. This is of concern to those who consider genetic testing requires specific knowledge and counseling and therefore specialist training. However, not all non-geneticists will be motivated or have the opportunity to undergo such training. A study of UK primary care physicians, for instance, found that the majority did not view genetics to be important, because of the perceived rarity of genetic conditions [6]. In the Netherlands, continued courses on genetics are offered irregularly, with the exception of training in midwifery [7].

Training non-geneticists may prove difficult because some tenets of genetic counseling are controversial, for example, the

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feasibility and desirability of nondirectiveness [8]. Nondirectiveness assumes that, in making decisions about reproductive options or undergoing genetic testing, the opinions and preferences of the counselor should not be expressed in order to influence clients. This is increasingly being questioned [9,10] on the basis that nondirectiveness is not always possible nor in the best interest of the client.

In addition, the effectiveness of communication in genetic counseling lacks an extensive evidence base. Few studies have described the genetic counseling process, most of them being published relatively recently [11]. This is most likely the result of genetic information being afforded a special ethical status with a strong representation of bioethicists in this discipline [12]. Consequently, the focus has been predominantly on what should occur during counseling rather than on what actually occurs and how this relates to relevant outcomes such as clients' satisfaction, understanding and decision making, health behavior and psychological distress. The field of genetic counseling evolved in relative isolation, developing its own teaching methods, terminology and research base concerning the interaction between counselor and client.

We suggest that genetic counseling can be seen within the context of regular health care interactions, rather than as a separate case. The aim of this paper is to demonstrate the commonalities in the communication process between genetic counseling and other health care interactions to challenge the unique character contributed to interactions which involve genetic information. By showing what genetic counseling shares with other medical interactions we intend to build the argument that the tendency towards separate research and training into 'genetic communication' is unproductive in terms of understanding and improving the counseling process.

2. Method

This paper is a narrative review, using a communication framework and taking the perspective that communication serves several goals. Such a goal-oriented approach makes the clinical process explicit and can be used independently of the type of consultation involved [13]. It offers a useful framework for comparing non-genetic and genetic interactions despite differences in their content.

Lipkin distinguishes three functions of medical interactions: the gathering of information, developing a therapeutic relationship and patient education [14]. Others consider the clinician's influence on patients' behavior as crucial to effective health care [15] or put decision making forward as a separate function of the medical consultation [16]. Educating and informing patients, facilitating decision making, promoting health behavior and providing support were advocated as relevant goals for genetic services [17]. Integrating these approaches, we consider the following goals as pertinent to the analysis of health care communication: (1) forming a relationship, (2) the exchange of information, (3) decision making, (4) promoting health-related behavior and (5) providing emotional support [18]. We used these five goals to structure our search of the literature. For each goal, central themes from the health care communication literature are discussed, followed by an appraisal of the genetic counseling literature. We refer to 'clinicians' and 'patients' when discussing health care interactions in general, and 'counselors' and 'clients' when discussing genetic counseling specifically.

3. Results

3.1. Forming a relationship

The quality of the patient–clinician relationship is essential to the quality of health care [19]. Most authors agree that therapeutic qualities positively affect this relationship [16], creating a 'therapeutic alliance'. Its core components such as empathy, respect, genuineness, unconditional acceptance and warmth, are seen as fundamental requirement of a patient-centered communication style [16]. To date, a patient-centered approach is the dominant paradigm in medical communication research and skills training [20,21]. In a statement issued by 21 leaders in the field of medical communication, it was asserted that the fundamental communication task would involve 'a patient-centered or relationship-centered approach to care' [22]. Patient-centeredness is generally described as clinicians' behavior which enables patients to add to the content of the consultation by expressing their perspective and which allows the patient some control over the agenda and the decisions to be made [23,24]. By including the patient's perspective and sharing power and responsibility, patient-centered health care promotes the ideal of an egalitarian relationship [20].

Studies into actual consultation behavior suggest room for improvement in clinicians' patient-centered behavior. A recent study defined clinicians' patient-centeredness as the presence of facilitating and absence of inhibiting behavior. Facilitating and inhibiting behaviors were observed in 100% and 49% of general internal medicine visits, respectively. Yet, on average 70% of all facilitating behavior had a medical content, whereas only 8% had a psychosocial content [25]. This raises the question to what extent the clinicians actually tried to obtain the patients' perspective. In a study among general practitioners, the mean patient-centered score for audio-recorded consultations ($n = 143$) was 0.51 (S.D. 17) on a scale from 0 to 1 [26].

Based on a review, Stewart et al. [27] concluded that a patient-centered approach is desirable given that a patient-centered approach was associated with increased patients' satisfaction, adherence to health advice and better health outcomes. More recently, the effectiveness of patient-centeredness has been questioned, on the grounds of negative or no associations with health outcomes or health behavior [21].

In the genetic counseling literature, a similar client centered approach is advocated [28,29]. Although its therapeutic character is generally emphasized, genetic counseling is commonly defined as a combination of as a *teaching* and a *counseling* model [30]. The relationship is unequal in the teacher model: the 'teacher' is the more knowing one and the 'student' the learner, whereas the counseling model aims for an egalitarian relationship. Although the counseling model is generally advocated, two recent studies in cancer genetic

consultations found information giving to be predominant [31] and highly standardized [32], which suggests that the educational approach still prevails.

Trust is a vital aspect of any patient–provider relationship. Patients remain dependent on health professionals for knowledge of, and access to, medical treatment, despite increasing patient autonomy and greater access to medical information making the relationship more egalitarian. Therefore, patients depend on a trusting relationship with their clinician, allowing him or her considerable control [33]. Such trust comprises perceived fidelity, competence, honesty and confidentiality [33] and is in part dependent on the clinician's communication skills [34].

Interestingly, in the genetic counseling literature, trust refers predominantly to the dimension of confidentiality. Indeed, clients have to trust their counselor to deal sensitively with personal information because accidental disclosure can have far reaching implications for their relationships with relatives, for example, when false paternity is disclosed to an unsuspecting husband, or when information is provided to institutional third parties, such as employers and insurers [35]. Yet, we feel the other dimensions of trust, such as fidelity and competence to be equally important for relationship building in genetic counseling.

Genetic counseling often involves forming a relationship with several members of a family and promoting communication among family members, including from parent to child. Genetic information differs from other health information in its potentially direct implications for other family members: DNA material may be required from family members to form a diagnosis and genetic test results have implications for the risk status of family members [36]. Consultations frequently involve more than one client. Reproductive counseling for example involves couples most of the time. It may be difficult for counselors to build a relationship where preferences and needs of each individual client can be taken into account. In case of conflicting interests, it will be even more difficult for the counselor to have each individual feel that his/her interests are equally served.

3.1.1. In conclusion

A patient-centered approach with its egalitarian relationship and trust as an essential element is generally advocated, although not always practiced, in health care interactions, regardless of whether genetic issues are discussed. Hence, genetic counseling is not unique in this respect. The involvement of family members is however more specific to relationship building in genetic counseling.

3.2. The exchange of information

The patient–provider relationship is the background for the second function of health care consultations: the exchange of information. Clinicians need information from their patients for diagnosis and treatment. Patients have a need to know and to understand their illness and its treatment. In order to fulfill their needs, clinicians and patients alternate between information giving and information seeking [14]. Studies show patients to generally want much information (e.g. [37]) and to be more satisfied and have greater trust in physicians who are informative [38]. At the same time, a sizeable proportion of patients prefer more limited information [39–41]. Matching information giving to patients' desired level of information is considered preferable over a strategy of providing everyone with as much information as possible [21,41,42]. Such a match is related to greater patient satisfaction, less surgery related anxiety, lower self-reported pain and more problem-oriented coping [41].

Unfortunately, clinicians often misjudge patients' information needs and do not always establish what these are. Generally, clinicians' question asking and information giving is cure oriented, and accounts for a considerable part of the medical interaction [16,23]. Patients' active participation is mostly limited. For example, patient question asking has been found to be the least frequent category of verbal behavior in medical visits [43,44]. Their participation is however related to physicians' facilitative behavior [45].

There is a similar picture in genetic counseling consultations; for example, a study of 131 genetic counseling consultations found that counselors spoke twice as much as clients [44]. These results are confirmed by findings from more recent studies [47,48]. A lack of concordance has been reported between what clients wanted to discuss and what genetic counselors thought they wanted to talk about [49,50]. Clients want to know for example about available and developing treatments, which receives limited attention in counseling [50,51]. Recent results in cancer genetic counseling suggest more effort, with counselors asking clients about their agenda in 69% of the consultations in an Australian sample [52], and in 95% in a Dutch sample [47]. However, low client involvement and a lack of influence of clients' pre-visit needs on the content of the interaction suggest room for improvement [47].

Understanding and recall are requirements for adequate information exchange. Unfortunately, this is frequently hampered by insufficient communication skills [16]. Clinicians generally overestimate the degree of medical knowledge of their patients [53] and their use of medical jargon impairs the ability of patients to understand the information provided. Explicitly asking for patients understanding is one of the least conducted communication activities (e.g. [54]). If the information has profound implications for the patient, it may lead to stress and anxiety, which in turn may cause ''attentional narrowing'' whereby the stress-inducing information becomes the primary focus, limiting attention for other relevant information. This latter information is consequently often not stored in memory and cannot be recalled [55].

Similar difficulties have been reported in genetic counseling [55,57]. Understanding and recall are particularly important in index patients, i.e., the first members within a family in whom the hereditary condition is diagnosed. They serve as a gatekeeper of genetic information and their understanding is critical in determining how and whether this information reaches other family members [58]. Yet, understanding was checked in less than half of the consultations [46]. General

problems with understanding and recall may be augmented in the context of genetic consultations because most information concerns risks. Providing this can be fraught with difficulties (e.g. [59–61]). First, there are many levels of *uncertainty* involved. The diagnosis may not be reliable because some genetic conditions are extremely rare. Genetic tests do not always provide reliable or conclusive results. In the case of a negative test result, it may be unclear whether the counselee is a non-carrier or whether he/she carries a so far unknown gene mutation. There is also uncertainty about how the genotype is related to phenotype, i.e., whether, when and how a condition will develop.

Secondly, risk information is notoriously difficult for patients to understand [62]. Because risk information is central to genetic counseling, the issue of how to present such information has attracted considerable research attention. In a UK study, one in five people who received genetic counseling did not recall their personal risk figure or category (e.g. low or high) [56]. An analysis of transcripts of 144 counseling sessions found that, of all the risk expressions used, approximately half were words and the other half were numbers [61]. Counselors assessed comprehension on only a quarter of occasions, less often following the use of words than numbers, and on only 9% of occasions when there was no response from the client to their risk communication. Since clients did not respond to 43% of risk communications, there is a concern that patients may not have understood the risk [61]. An Australian study found accurate risk perception to increase from 50% at baseline to 70% after counseling. This increase was however unrelated to the way that risk information was presented [63].

3.2.1. *In conclusion*

Information exchange is equally vital to genetic and non-genetic health care interactions. In both types of interactions clinicians face the same difficulties: attuning to the agenda of the patient/client and enhancing understanding and recall. Risk communication is more common in genetic as compared to non-genetic consultations, but is prevalent in the latter also, as when discussing complication risks or comparing different treatment strategies. Hence, health care professionals in general need good information giving skills.

3.3. *Decision making*

The patients' contribution to decision making is increasingly advocated on the basis that participation leads to better adherence and health status and serves the ethical principle of autonomy [64,65].

Charles et al. [66] distinguished three models of decision making: in the *paternalistic model* the clinician is seen as acting in the patient's best interest, in the *professional as agent* model, the clinician also makes the decisions, having solicited the patient's views, and in the *informed model*, the clinician increases the patient's knowledge so that decision making control can lie with the patient and the clinician's preferences are disregarded. When a clinician has an opinion on the 'best' way to proceed, it may be difficult not to reveal this preference to the patient [67]. Therefore, Charles et al. developed the model of *shared decision* making [66] in which both patient and clinician participate in discussions of treatment options by expressing what they feel is the right option and collaborate to reach a mutually agreed decision. Depending on the specific clinical context and preferences of patients and providers, either one of the four forms of decision making can occur. The need for shared decision making is most compelling when the stakes are high and there is no clear best solution because several options exist, with different benefits and risks [68]. As a result of the advancement of modern medicine, clinicians and patients are increasingly confronted with such decisions, most particular when treatment is provided as part of a clinical trial needing patients' informed consent. Although 'shared decision making' is currently the most advocated model for decision making in health care, at least two studies, involving oncology and primary care consultations, suggest the application of its principles not to be common practice yet [69,70].

Facilitating decision making is a central goal of genetic counseling [17], with nondirectiveness as the traditional model for decision making. Disregarding differences between definitions of nondirectiveness, the common position is that the opinion and preferences of the counselor should not influence the patients' decision. Nondirectiveness is espoused not only because it assumingly serves the client's autonomy best, but also because it protects the profession from associations with the eugenics movement [67].

The model of nondirectiveness has been the topic of much debate [9,10,71–74]. According to some, counseling will always have directive elements, explicit or implicit. The choice of which information is provided and how the information is provided (choice of wording, timing, intonation etc) can itself have a steering effect. Moreover, nondirectiveness may not always be desirable as when a counselor wants to recommend a course of action not only for medical reasons but also for ethical considerations, for example when it would be in the interest of other family members for the client to disclose information about him/herself [67]. Additionally, a nondirective stance could be used by counselors for self-interest purposes, e.g. to secure them against involvement in the moral and ethical dilemmas that their practices raise [10]. From the client's perspective, they may ask the counselor for their opinion because they consider this to be valuable information. When a counselor fails to provide a clear answer to their request, out of concern for being too directive, the client may feel abandoned [75] or feel that the counselor has a negative view about e.g. having a test [74].

Two studies which actually addressed the degree of directiveness found neutrality not always attained, for example with counselees whom counselors considered more concerned or of lower socio-economic status [73,74].

Shared decision making has been proposed as an alternative model in clinical genetics, because it provides guidance as to how a degree of directiveness can be negotiated [67,76]. This model may also fit genetic counseling because the stakes are often high in the decisions to be made and commonly there is no one best solution [68]. Since genetic counselors come from a

tradition of nondirective counseling, they may be less resistant to the concept of shared decision making than other health professionals [77]. Although the paradigm of shared decision making seems a promising alternative for nondirectiveness, it seems to have received only scant attention in the genetics literature, so far.

3.3.1. In conclusion

In times of increasing patient involvement and medically equivalent treatment options, shared decision making has become part and parcel of good medical care. Traditionally genetic counseling has been more open to patient involvement in the decision making process. Increasingly, patient choice is seen as important and all health care professionals are being encouraged to negotiate with their patients in an attempt to reach decisions that do justice to the perspectives of both the professional and the patient/client. Thus, genetic counseling is no longer exceptional in this regard. Moreover, since the traditional paradigm of nondirectiveness is increasingly being questioned, geneticists may consider using a shared decision making approach, making counseling more comparable to non-genetic interactions. Both geneticists and non-geneticists then face the challenge of how to integrate the model of shared decision making into actual practice.

3.4. Promoting health-related behavior

Because patients' behavior is important for the prevention, recovery and management of many medical conditions, discussing health-related behavior with patients should be part of the routine work of health professionals. Although brief information and simple advice is better than no information about the benefits and risks associated with certain actions such as smoking cessation [78], more sophisticated strategies are needed to effectively motivate patients to change health-related behavior and maintain that change. Social cognitive models indicate that behavior change is a process, and that health-related actions broadly depend on patients' goals, attitudes, social influences and feelings of mastery [79]. Providers should take these mediators of behavior change into account when trying to help their patients to change their health behaviors. Examples of such approach are behavior change counseling [80], a technique derived from motivational interviewing [81] and the model for individual health counseling proposed by Arborelius [82]. Yet, health professionals are more inclined to educate rather than discussing patients' motivation or ability to change [80]. To illustrate, content analysis of videotaped consultations of 125 new general internal patients showed that 57% of the clinicians educated and 62% provided general advice about the solution, whereas only 19% assessed patients' motivation to change and 7% discussed the patients' ability to follow a specific plan [83].

One of genetic counseling's aims is to identify individuals at risk so that they may take preventive action to reduce their health risks [15,84]. Clients' reason to seek counseling is usually to get information about the possibilities of prevention of future disease or having a child with a genetic condition. In most common, multifactorial diseases, lifestyle factors such as smoking or diet usually have an important role. The goal of genetic counseling for common diseases thus resembles that of many other health care interactions, namely understanding personalized disease risk and enhancing health promoting behaviors [85]. Hence, discussing such behavior as smoking cessation in the case of carrying the ApoE4 gene, the preventive use of statins in the case of Familial Hypercholesterolemia (FH), or screening and the removal of detected polyps in the case of familial adenomatous polyposis (FAP), has its place in genetic counseling.

A common assumption among genetic clinicians is that providing clients with genetic risk information will motivate them to take appropriate actions. However, research findings suggest that such information does not necessarily lead to increased preventive behavior [17,84], and genetic risk information may even lead to a false sense of reassurance, when clients initially overestimated their risk or test negative [17]. There have even been concerns that detection of genetic risk may discourage adherence to advice concerning health behaviors, as the risk may be perceived as beyond personal control, resulting in a sense of fatalism. For example, 54% of clients who tested positive for familial hypercholesterolemia (FH) qualified as being 'fatalistic', i.e., they believed that their cholesterol level could never be low. Of those who tested negative for FH, 23% were 'falsely reassured' because they believed that their cholesterol level could never be too high. The 'fatalistic' and 'falsely reassured' clients more often reported unsatisfactory cholesterol level, body mass index or smoking status at 7 months follow-up. Furthermore, the 'falsely reassured' were less often inclined to have their cholesterol checked in the future [86]. Other findings suggest that genetic test results do not affect the extent to which people feel they have control, but rather how control is best achieved [87]. These and other findings [87,88] suggest that attention to psychological mechanisms is justified during genetic counseling in order to promote risk-reducing behaviors.

Little is known about the extent to which relevant behaviors are addressed during genetic counseling and whether counseling helps individuals to take actions which contribute to subsequent risk reduction. Koch and Nordhal Svendsen [89] observed that in genetic counseling, direct proposals such as 'you should stop smoking' are rarely made because individual autonomy is more explicitly respected than in other health care interactions. Nevertheless, as more treatments and preventive options become available, the counseling approach may become more directive and increasingly similar to approaches in general health care where the provider may recommend participation in preventive programmes or other life style changes [90].

3.4.1. In conclusion

Both non-genetic and genetic health care professionals are increasingly recommended to discuss health-related behavior with their patients/clients. Only few professionals, however, seem to apply skills to motivate and instruct patients in such a manner that increases the chance that they will indeed act upon

the advice. Geneticists probably do not differ from non-geneticists in this regard.

3.5. Providing emotional support

Sensitively dealing with emotions promotes the achievement of all the aforementioned goals of health care encounters. It enhances the patient–provider relationship by generating trust [35], improves patient comprehension of information by removing emotional occupations [55], allows for decisions to be influenced by information rather than emotions alone [90] and may improve health behavior by reducing patients' defensive reactions [80].

Finally, paying attention to emotions and concerns allows the clinician to help support patients, which may contribute psychological adaptation. Moreover, emotions and their adverse consequences may be the patients' primary reason for consulting a clinician.

In an experimental setting, women were found to be significantly less anxious when they saw a videotape of a breast cancer consultation in which the clinician showed compassion during two segments of approximately 40 s, as compared to women who saw the same consultation, without these segments [91]. Compassion involved the physician acknowledging the patients' psychological concerns, expressing partnership and support, validating her emotional state, touching her hand and trying to reassure her. A positive impact on patient satisfaction has also been found [92].

Despite their apparent importance, health professionals are generally reluctant to enquire actively about patients' concerns and feelings [93]. This is partly because they feel ill equipped with the necessary interviewing skills and they fear causing psychological damage [94]. Additionally, they may find it difficult to endure other people's sadness, anxiety, confusion, anger, or consternation. Consequently, they may be inclined to use defensive strategies to avoid or soften reality, for example by postponing bad news, using euphemisms or jargon, or by prematurely stressing treatment options [95]. Conversely, patients only seldom explicitly express their feelings; they rather hint at an underlying unpleasant emotion, i.e., they present cues but not an explicit message. In primary care and surgical settings, patients presented cues in about half of the consultations that were predominantly emotional in nature [96]. Finally, caregivers may fear that discussion of emotions would be too time consuming. In a palliative care setting for example, emotional problems were found to be less frequently discussed during consultations that took place behind schedule [97].

Negative emotions are to be expected in the context of genetic counseling because learning about genetic disorders, in common with other health conditions, can be stressful and threatening due to characteristics as unpredictability, uncontrollability, novelty, potential burden and loss adversely affecting the lives of patients and their families [98,99]. Most commonly investigated emotions are anxiety, depression and (disease-specific) worry [51,100,101]. Typical for genetic disorders is that such feelings are often not prompted by current symptoms or medical procedures but by the awareness of future risks. In families with inherited conditions, such awareness is influenced by previous experience with relatives' illness. The fact that genetic diseases are 'family diseases' may also contribute to the emotion of (survival) guilt [102]. Survival guilt, the feeling of guilt that one has not (yet) the disease, while other relatives have [103], has been described in non carrier members of Huntington's disease families [104] and in women at high risk of developing breast cancer [105,106]. Counselees may also feel coerced by family members to engage in counseling and/or testing to reduce uncertainty about their future [107].

A recent review and a meta-analysis suggest that during counseling for predictive genetic testing, psychological distress generally decreases after testing to a level normal for the general population [108,109]). However, we do not know whether counselor behaviors contribute to these effects. One of the few studies in which the interaction between client and counselor was recorded found that, in 56% of the consultations with women from high-risk breast cancer families, counselors checked for clients' concerns and in 57% discussed emotional concerns [51]. Feelings about being at risk, about having a genetic test and about breast cancer in the family were discussed in 44%, 36% and 63% of the consultations, respectively.

These results might suggest that supportive communication is more common in genetic counseling as compared to other medical consultations. However, Biesecker and Peters suspect that, as in medicine in general, more value is placed on diagnosis and prognosis, recurrence risks and treatments rather than on attending to the concerns and emotions of clients [29]. This is supported by evidence in a variety of studies that show relatively limited engagement in social or emotional issues by genetic counselors [72,75,109]. More important perhaps is how the interaction links to client adjustment. Two studies found attention given to emotional matters to be positively associated with anxiety on the short term [51,110]. Another study found variation between counselors to be associated with greater change in clients' post-consultation depression, but the skills that could explain this effect could not be identified [32].

3.5.1. In conclusion

All the aforementioned reasons for considering the provision of emotional support hold for any health care encounter, genetic or non-genetic. Yet, we are aware of the specifics of genetic counseling in this regard. This discipline deals with issues that are morally loaded in our culture such as reproductive choices and individual decisions with far reaching implications for relatives. Moreover, genetic health care professionals generally realize that decision making involves emotions and that medical interventions (e.g. genetic testing) can significantly affect the psychological wellbeing of the individuals involved, which may in turn have far reaching implications for others. Emotions may for example influence clients' willingness to approach other family members. Or they may affect the decisions about testing among their at risk family members [111]. Consequently, it is an explicit goal of genetic counseling to provide support and to help clients cope (psychologically and

socially) such that psychological stress is minimized and personal control maximized [19,29]. In this regard, we consider that genetic counselors differ from clinicians in most other medical specialties.

4. Discussion and conclusion

4.1. Discussion

With the advances of genetics since the mid-1980s, new possibilities for prevention of hereditary disease have emerged and certain hereditary conditions are now preventable if diagnosed in time. As a result, the purposes of consultations in clinical genetics and other medical specialties have been becoming closer to each other [90], leading to increased involvement of non-geneticists in informing and testing individuals on their genetic susceptibility for disease. One may see this as an unwanted development; non-geneticists' unfamiliarity with specific requirements of genetic counseling may impair the quality of care for clients. On the other hand, one may question the uniqueness of genetic counseling, as we have done in this paper.

4.2. Conclusion

Clearly, genetic counselors differ from non-genetic health professionals in their highly specialized genetics knowledge. Yet, in terms of the interaction with clients, research suggests that the communication of health professionals involved with genetic counseling has more in common with that of non-genetic health professionals than is often assumed. Both 'disciplines' endorse an egalitarian relationship, based on a patient-centered approach and have difficulties with attuning to the patients' agenda and enhancing patient understanding. Shared decision making is increasingly the preferred model for decision making, for geneticists and non-geneticists alike, and both need skills to constructively discuss patients' risk-reducing behavior. Finally, providing emotional support is not unique to genetic counseling. Thus, rather than developing a new 'vocabulary' and research tradition, the discipline of genetic counseling may benefit from joining non-genetic patient–provider interaction research. One such benefit is that those who want to investigate the process of genetic counseling can build on existing concepts and methodology used in the general study of patient–provider interaction. Available measures, including interaction rating systems such as the Roter interaction analysis system [11] or patient-centered behavior coding instrument [26] can be used (see [17] for a review of other outcomes measures). A better understanding of how the process relates to various outcomes will help identify areas for intervention. Moreover, by using similar concepts and methodology to other areas of health care, genetic researchers broaden their possibilities to exchange results with others involved in the study and training of medical communication. Finally, the use of a similar vocabulary will make it easier to identify what is unique to genetic counseling and what is shared. By not integrating genetic communication research with other medical communication research, the discipline runs the risk of isolating itself rather than building a strong case for what lessons might be learned from, and for, the special case of genetics.

4.3. Practice implications

Based on our comparison of research addressing genetic and non-genetic consultations, we fully agree with Roter et al. who state that: ''the challenges [for training of genetic counselors] are the same as those faced by our medical colleagues—to listen more and speak less, to engage and empower clients, and to be emotionally present when they are needed'' [11]. While genetic counseling training commonly stresses both the presentation of clinical knowledge and attention to the client's psychosocial needs, available data suggest that the educational approach predominates within counseling. This means a focus on providing information rather than on seeking the clients' involvement and perspective.

Perhaps the most salient difference between genetic and non-genetic consultations is the form and degree of family involvement. Genetic counselors need to discuss the implications of clients' actions for their relatives and genetic clinicians are responsible for sensitively dealing with these issues. If non-geneticists need additional communication training, it is probably in the area of family involvement, e.g. when and how to inform family members, the implications of the messenger role for the proband and family dynamics.

Additionally, genetic counselors are more experienced in risk communication, facilitating decision making and providing a supportive role in these processes. This may result from the fact that information exchange and providing support are their main 'tools', rather than initiating a treatment as in other medical specialties. It is important that these skills are not lost with greater involvement of non-geneticists. However, these skills are valuable for all health care interactions and as such are not exclusive to genetic counseling. Since geneticists face the same challenges as non-geneticists, medical training should continue to improve basic consultation skills, regardless of whether the consultation involves genetic information or not.

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