

Chapter 6

Structuring Genetic Counseling Sessions: Initiating, Contracting, Ending, and Referral



Learning Objectives

1. Describe activities for initiating the genetic counseling session.
2. Define contracting and describe steps in the goal-setting process.
3. Describe genetic counselor activities for ending the session and the relationship.
4. Identify referral strategies for effective follow-up.
5. Develop skills at initiating, contracting, ending, and referral through self-reflection, practice, and feedback.

This chapter discusses four of the components of a genetic counseling session: initiating the session, introductions and contracting (setting goals), ending the session/relationship, and making referrals. The components described in this chapter correspond to several of the categories identified by the Accreditation Council for Genetic Counseling (ACGC 2015) for logbook case documentation.

6.1 Initiating the Genetic Counseling Session

Close your eyes and imagine that you are about to see your first genetic counseling patient. What are you feeling? What are you doing to prepare for your first encounter? Do you have a clear picture of how you will begin? What is the first thing you will say or do? Now ask yourself how your patients may feel about coming to genetic counseling and what they might say or do.

Many people have never heard of genetic counseling prior to becoming genetic counseling patients. They may be anxious, confused, frightened, and disoriented about the relationship they are about to enter with you. It is important that you try to alleviate their discomfort by providing guidance about what will happen in this relationship.

You can take several steps to set the stage for genetic counseling. These include case preparation, introductions and orientation to the session, contracting, and goal setting.

6.1.1 Preparation

Review Patient Records

Review any available patient records prior to the genetic counseling session. If information from a referring physician is missing, you should attempt to acquire it prior to seeing the patient. Reviewing the records not only better prepares you to assess patient goals for genetic counseling, it also indicates to the patient that you are interested and respectful enough to take the time to do this preparation. Uhlmann (2009) presents a detailed approach to case preparation and management in clinical genetic counseling.

Arrange the Counseling Environment

Surroundings are an important aspect of setting the overall tone. Keep your office or working space neat, uncluttered, and inviting.

- If possible, have chairs of approximately equal size and comfort available (Martin 2015).
- Position your chair so you face your patients and if possible move any desks so they are not between you. Have a box of tissues available.
- If you carry a pager or cell phone, turn it to vibrate mode and warn your patient if you expect someone to contact you during the session.

Prepare Yourself to Begin

- Minimize distraction. Be sure your manner of presentation is not distracting. Think about the type of impression you wish to convey, and then dress and behave accordingly. Wear clothes that are appropriate for your setting and for the patients with whom you are working. In genetic counseling, it is not appropriate to wear casual clothing such as jeans, hiking boots, and shorts. You should avoid clothing that could be regarded as provocative—short skirts, sheer blouses, low-cut shirts, thong-type sandals, and tight clothing. Cover up any tattoos. Also, as we discussed in Chap. 3, work on reducing or eliminating personal habits that might be distracting (e.g., twisting your hair, playing with jewelry, excessive use of filler words such as OK, right, uh-huh, you know).
- If you wear any obvious religious symbols (e.g., crucifix, yarmulke, burka), expect that some patients may react or even comment on them. Think about how you could respond if they do.

- If you have time between sessions, take a moment to psychologically prepare for the next session. Sit in a quiet room, take some deep breaths to calm yourself, try to put aside extraneous thoughts, and focus on the patient(s) whom you will meet in a few minutes. Visualize how you will greet your patient and what you might say at the beginning and end of the genetic counseling session.
- Begin on time, if possible, so as not to keep patients waiting. If your clinic is running behind schedule, explain the reasons for the delay.
- At any time during the session, if someone comes to the door, step outside and close the door to protect patient privacy. Handle the interruption quickly, come back to your patient, apologize, and briefly summarize what you were talking about before being interrupted (Fine and Glasser 1996).

6.1.2 *Introductions and Orientation*

Introductions

- Greet your patients and, if possible, escort them to the room. Remember there are cultural variations regarding touch. For example, some individuals from the Middle East do not shake the hands of members of the opposite sex. We recommend that you shake hands only if the patient initiates this behavior.
- Introduce yourself by first and last name. There is no clear protocol about how to address patients, but your institution may have one. For instance, in calling someone from the waiting area, you may be required to use only a first name. “At the start of the session, the counselor will want to greet everyone present, establish how they are related to the patient, and determine what each person wants to be called” (Spitzer Kim 2009, p. 73). There are cultural differences in how individuals wish to be addressed. For example, some older immigrants from Asia or from conservatively stratified societies may wish to be treated more formally rather than being called by their first names (Ishiyama 1995; Spitzer Kim 2009; Sue and Sue 2012). Also, when patients are older than you, it may be appropriate to address them more formally (Mr., Ms., etc.). Generally speaking, you should address people more formally until they invite you to do otherwise.
- Do not insist that patients address you in a certain way. For example, some patients may not be comfortable using your first name. Pay attention to any changes in the way a patient addresses you, as they may indicate a change in your relationship, either toward or away from trust and comfort (Fine and Glasser 1996; Spitzer Kim 2009).
- Allow your patients to choose the chairs in which they sit, and wait for them to be seated first so you don’t suggest you are rushing or directing them (Fine and Glasser 1996). When your patients are couples or families, where and how they position themselves provide important clues, for instance, about power dynamics and degree of closeness among family members (Schoeffel et al. 2018). Pay attention to who directs the action, who takes the most prominent seat, who sits closest to you, who sits next to whom, who speaks first and who speaks after

whom, whether individuals introduce themselves or are introduced by others, and how they refer to each other (Fine and Glasser 1996; Schoeffel et al. 2018). Additionally, you can gain important clues about individual patients by how they position their chair. For example, do they move it closer to or further away from you? Do they pick a chair that is closer to or farther away from yours?

- In general, you should limit your small talk to an amount that helps your patient relax a bit. Small talk also helps you to begin, "...assessing the client's level of comfort, mood, language skills, and a variety of other factors that can influence the subsequent interaction" (Spitzer Kim 2009, p. 72). A small amount of social conversation can be especially beneficial for individuals from certain ethnic backgrounds. For instance, some Asians, Native Americans, Hispanics, and African Americans may prefer a brief period of social conversation before proceeding to more intimate topics (Fine and Glasser 1996). In our experience, this is true of most patients regardless of their ethnic background. Too much small talk, however, is usually due to your own discomfort rather than for the patient's benefit.

Orientation

- First assess patients' understanding of the purpose of the visit. As part of this process, you could ask patients to describe their understanding of what will happen in the session. For example, "What was your doctor able to tell you about your appointment today?"
- Explain the genetic counseling process. Provide an overview of what will happen during the session (e.g., obtaining family history, reviewing medical history, physical examination, etc.) and who will be involved. Patients typically enter genetic counseling without knowing exactly what to expect or what will be expected of them. They may feel uncertain, vulnerable, or even embarrassed. By describing what will happen and by conveying a caring attitude, you can help them adapt to the situation (Spitzer Kim 2009).
- Bernhardt et al. (2000) found that patients often had few identified goals prior to a session due to their lack of familiarity with genetic counseling. They were unsure what the role of the genetic counselor was meant to be or how the session(s) would be structured. They appreciated receiving an orientation to genetic counseling.
- If you intend to take notes during the session (either with pen and paper or electronically), explain why you are doing so. Be aware that you may lose valuable nonverbal cues because you are not able to consistently look at your patients. Taking notes unobtrusively, while simultaneously paying close attention to your patient, is a skill that requires a fair amount of practice. You may wish to practice this type of note-taking outside of the genetic counseling session (e.g., role-playing with a friend). You will need to become proficient enough that your patients feel as if they have your full attention throughout the genetic counseling session.
- Consider developing and using an interview checklist outlining the topics you wish to cover during a session. A checklist may help you proceed in an unhurried but efficient manner, and it may be helpful for constructing post-session notes. A checklist may also serve as a stimulus for supervision (i.e., discussion of aspects

of the session that were difficult for you). When using a checklist, remember you will likely vary the order in which you raise topics, and you may not cover all topics with all patients. Also, as with note-taking, you should explain why you are using a checklist and allow the patient to see it. Finally, you can review your prepared checklist toward the end of the session to be sure you covered important topics (e.g., “I made a list of things I want to be sure we discussed during this appointment. Let me take a look to be sure we covered everything.”). This review can communicate to your patient that you prepared for the session. A *mental* checklist is always an option as well.

- If you plan to record a session, ask your patient’s permission, and request that she/he give permission in writing. Present the purpose of recording in a matter-of-fact way (e.g., “I’m doing this in order to receive supervision on my genetic counseling skills”), and assure your patients of the confidentiality of the recording (Martin 2015). We recommend telling patients that you will erase the recording at the end of your clinical rotation. If a patient is resistant to recording, offer to turn off the equipment if she/he wishes you to do so, at any point during the session. Note that you should always check clinic policies before recording a session, even with permission of a patient.
- Think about how you will respond if a patient wishes to record the session.
- Consider cultural factors in providing an orientation for patients, in particular, variations in how people communicate, possible culturally related obstacles, and how to overcome them (Oosterwal 2009). “The following factors need to be considered:
 - How do you greet and address each other, formally or informally, by first name or family name, looking each other in the eye or not?
 - What kind of relationship is expected between the [patient] and the counselor: paternalistic and hierarchical, or a more equal partnership?
 - When listening, is it acceptable to interrupt?
 - What types of questions are culturally appropriate?
 - How much time is available for the various activities that make up the process of counseling?

All of these issues are very different from one culture to another. What is appropriate or respectful in one culture may be offensive in another” (Oosterwal 2009, p. 352).

6.2 Contracting and Goal Setting

6.2.1 Contracting

Imagine yourself starting out on a vacation with a friend. The two of you are driving down the road, engaged in a lively conversation, as you head for Canada. About 30 min or so into the conversation, your friend looks around at the road signs and says, “Wait! I thought we were going to Florida!” You slam on the brake. What

happened in this situation? Evidently the two of you failed to discuss your intended destination. You did not develop a road map for your journey. A similar situation is likely to arise when you and your patients do not identify explicit and compatible goals for your session/relationship. Without a road map, sooner or later you'll have to pull over to the side of the road. In genetic counseling, the term "contracting" describes the process by which the genetic counselor and patient mutually reach agreement about the goals of the session. In this section, we will describe the contracting process and discuss goal setting in genetic counseling.

The Accreditation Council for Genetic Counseling (ACGC) defines contracting as "the two-way communication process between the genetic counselor and the patient/client which aims to clarify both parties' expectations and goals for the session" (ACGC 2015, p. 8). Genetic counselors "establish a mutually agreed upon genetic counseling agenda with the client" by doing the following:

1. Describe the genetic counseling process to clients.
2. Elicit client expectations, perceptions, knowledge, and concerns regarding the genetic counseling encounter and the reason for referral or contact.
3. Apply client expectations, perceptions, knowledge, and concerns toward the development of a mutually agreed-upon agenda.
4. Modify the genetic counseling agenda, as appropriate by continually *contracting* to address emerging concerns" (ACGC 2015, p. 4).

The first step in contracting and goal setting is to establish a "working agreement" or shared vision for the session with your patient (Spitzer Kim 2009, p. 76). This process begins by inviting patients to describe their understanding of why they were referred or the reasons they sought genetic counseling. Use your attending skills (Chap. 3), empathy skills (Chap. 4), and questioning skills (Chap. 5) to engage the patient in a conversation that will help you understand their reasons for seeking genetic evaluation/counseling. What do they hope to learn? What are their questions or concerns?

Invite patients to express their concerns about the visit. It can be very helpful to start by asking what questions or concerns are most pressing and addressing those first, if possible. Also, use this opportunity to tell them that the aim of genetic counseling is to be able to address those concerns. For example, the parents of a pediatric patient may start by saying "We're very concerned about our child's developmental problems and really need some answers!" In response, you could explain that this is a primary aim of a pediatric genetics evaluation, and describe the steps you will take to help achieve this goal.

An increasing body of literature addresses genetic counseling contracting and goal setting. Below, we briefly describe the findings and conclusions of several investigations of one or more aspects of contracting and goal setting.

Case et al. (2007) asserted that, "Informed decision-making, the foundation of prenatal counseling, rests on the practice of contracting with patients (the process of finding out what a patient knows and what attitudes she may hold and adapting information presented to that [patient's] knowledge)..." (pp. 655–656). They interviewed pregnant and nonpregnant women and found tremendous variability in their

knowledge and beliefs about genetic counseling. They concluded that this variability "...confirms the importance of contracting and taking time to understand an individual's personal beliefs, knowledge and attitudes about prenatal diagnosis" (p. 661).

Lafans et al. (2003) asked genetic counselors how they manage fathers' involvement in prenatal sessions. Their participants identified several strategies, including orienting and contracting (e.g., "...I usually start with defining what I am, and the process. Part of the contracting is to say, 'I'm not here to tell you what to do; and ... Usually the woman is the spokesperson, and she...has an agenda; she kind of tells him what it is, and he usually sits there and so, I turn to him and say 'Okay, so your wife says she wants to talk about this, this, and this. What about you? Do you have the same agenda, or is yours a little bit different?' ..." (p. 230).

Andrighetti et al. (2016) surveyed parents of children affected with obsessive-compulsive disorder (OCD) about their recommendations for genetic counselors. Their recommendations included, "thorough contracting with families upfront about what genetic counseling for OCD entails, as well as whether they are interested in knowing specific recurrence information" (p. 919). For example, counselors could ask parents, "'How involved do you want us to get? Do you want it right down to, 'these are the odds of it happening again' or do you just want to understand more of how it happens and why it happens?'" (p. 919).

Griswold et al. (2011) interviewed genetic counselors about how they counsel adolescents compared to how they counsel adults. Their participants reported "spending more time on case preparation, contracting, and psychosocial assessment with adolescents and more time on inheritance/risk counseling, pedigree, and discussing testing options/results with adults" (p. 187). The authors speculated that counselors may spend more time on case preparation when anticipating an adolescent patient in order to identify additional support and resources for them. Also, adults tend to have more questions and are more open to discussion with the counselor than adolescents because they may have given more thought to their options. In contrast, adolescents may be more focused on the here-and-now and less able to think about long-range outcomes (Berger 2005). Thus, discussions about inheritance and testing results may be more difficult with adolescents, and they may seem shorter. It also may be more difficult "...to engage adolescents in a conversation about emotions, and be more difficult for counselors to assess the needs of adolescents who are pregnant because adolescent girls are more likely to internalize problems..." (p. 187). It may require more time for genetic counselors to accomplish these goals. The authors concluded that contracting with adolescents and psychosocial assessment may be more difficult than with adult patients.

Pieterse et al. (2005) developed a measure of cancer genetic counseling patients' needs and preferences. They found that patients generally rated as most important the information about risk and prevention strategies and information about the counseling process (what happens and how) and, to a lesser extent, receipt of emotional support and discussion of feelings. The authors concluded that, "A primary goal of genetic counseling and testing is to educate individuals about cancer risk and cancer prevention, with the aim of reducing morbidity and mortality" (p. 361).

Importantly, however, you should always consider individual differences in patient needs and preferences and proceed accordingly.

6.2.2 *Setting Genetic Counseling Session Goals*

Goals are the road maps that bring focus and direction to the session and help to structure the relationship. Setting genetic counseling session goals is part of the contracting process. Goals are "...mental representations of desired outcomes to which people are committed..." (Mann et al. 2013, p. 488). They help counselors and patients identify precisely what they can and cannot achieve in genetic counseling (Hackney and Bernard 2017). Goals help you determine what information to present, how to structure the session, and the types of interventions to use. Goal setting encourages patients to be clear about what they want to accomplish in a genetic counseling session. Furthermore, goals can help patients feel motivated to take action, and they allow both you and your patients to evaluate the effectiveness of the genetic counseling session and relationship.

The importance of explicitly stated and agreed-upon goals is illustrated in a study of concordance between genetic counselors' and patients' views of the nature/type of patient concerns and the level/severity of their concerns. Michie et al. (1998) found that genetic counselors were sometimes inaccurate in judging patient concerns: "When there was not concordance, counselors were more likely than patients to think the patients' main concern was to get information or to find out about their risk status" (p. 228). Concordant sessions tended to emphasize more emotional issues and resulted in greater patient satisfaction with the information received and greater satisfaction with the extent to which their expectations were met.

6.2.3 *Goals of Genetic Counseling*

Genetic counseling is "the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease" (Resta et al. 2006, p. 77). Consistent with this definition, the Reciprocal-Engagement Model (REM) of genetic counseling practice (McCarthy Veach et al. 2007) identifies three overarching outcome goals. Specifically, the patient understands and applies information in order to make decisions, manage conditions, and adapt to her or his situation. To achieve these broad outcomes, there are 16 goals for genetic counseling sessions that reflect 4 major factors: *Understanding and Appreciation*, *Support and Guidance*, *Facilitative Decision-Making*, and *Patient-Centered Education* (Hartmann et al. 2015). The following list displays the REM goals associated with each factor (Hartmann et al. 2015):

Goals of Reciprocal-Engagement Model (REM) of Genetic Counseling

<i>Factor I: Understanding and appreciation</i>
Counselor and patient reach an understanding of patient’s family dynamics and their effects on the patient’s situation
Counselor promotes maintenance of or increase in patient self-esteem
Counselor facilitates the patient’s feelings of empowerment
Counselor integrates the patient’s familial and cultural context into the counseling relationship and decision-making
Counselor works with patient to recognize concerns that are triggering the patient’s emotions
Counselor establishes a working contract with a patient
<i>Factor II: Support and guidance</i>
Counselor recognizes patient strengths
Counselor and patient establish a bond
Counselor’s characteristics positively influence the process of relationship-building and communication between counselor and patient
Counselor helps the patient to gain new perspectives
Counselor helps patient to adapt to his or her situation
Counselor helps the patient to feel in control
<i>Factor III: Facilitative decision-making</i>
Counselor helps the patient to feel informed
The counselor knows what information to impart to each patient
Counselor facilitates collaborative decisions with the patient
<i>Factor IV: Patient-centered education</i>
Counselor presents genetic information in a way that the patient can understand
Good counselor-patient communication occurs

McCarthy Veach et al. (2007) distinguish between process goals and outcome goals in the REM of genetic counseling practice. “Process goals refer to the conditions that must be present during genetic counseling sessions in order to achieve desired genetic counseling outcomes...Outcome goals refer to the results of genetic counseling...” (p. 719). Process goals refer to the conditions necessary to establish the relationship (e.g., promoting patient autonomy, demonstrating good attending behaviors). Within genetic counseling, process goals tend to be fairly general, applicable to all genetic counseling relationships. They are primarily your responsibility to accomplish, and they are not necessarily verbalized to patients.

In contrast, outcome goals are unique to each patient and each situation. They are more specific, and you and your patients share a mutual responsibility for their establishment, through the contracting process. Outcome goals may change as the genetic counseling relationship progresses; therefore, a certain amount of flexibility is necessary in setting and sticking to goals. Although process goals are generally applicable to all genetic counseling relationships, outcome goals vary in their relevance for a given patient. Therefore, it is critical that you identify individualized genetic counseling goals with each patient.

6.2.4 *Characteristics of Effective Goals*

Greenberg et al. (2006) note that "... people will strive toward a goal, as long as they believe that the goal is within their reach" (p. 664). What makes a goal feasible? A feasible goal is specific, realistic, and mutually agreed upon; it defines the conditions necessary for reaching a desired outcome (e.g., making a decision, gaining genetic information); it is compatible with patient and counselor values; and it is qualified, that is, it tends not to have an all-or-nothing quality (Cavanagh and Levitov 2002; Stone 1994). For instance, a patient might say, "I want to know for certain that my child is OK." This is a very difficult, if not impossible, goal. Usually this type of certainty in genetic counseling cannot be achieved because of the complexity and the limits of genetic knowledge and testing (McCarthy Veach et al. 2001). A feasible goal is also open to revision as you and your patients reach new understandings (Martin 2015).

The goals that are established cannot be more specific than either the counselor's or the patient's understanding of the problem (Hackney and Bernard 2017). So, effective goal setting requires not only solid attending and empathy skills and good information-gathering skills, it also requires good inferential skills (i.e., advanced empathy—see Chap. 8). You may have to "look beneath" what patients are saying on the surface to identify more specific goals. Most patients will be general and will tend to talk about goals in problem language. Your challenge is to reframe these statements into specific, positive goal statements. For example, a patient says, "I don't want to make the wrong decision." You can reframe this goal as, "You want to learn about genetic risk factors, weigh your available options, and reach a decision based on that knowledge." Or, a patient says, "Because my mother had breast cancer, I'm afraid that I will develop breast cancer, too." You might reframe this goal as, "You want to pursue genetic evaluation in order to find out if you are at increased risk for an inherited form of breast cancer."

Sometimes you will need to use mild confrontation in addition to advanced empathy (see Chap. 8) to help patients set realistic goals. For example, it is not a realistic goal when a tearful prenatal patient who wanted the pregnancy says, "I want to feel good about my decision to terminate my pregnancy." You might say, "I wonder if it would ever be possible for you to feel good about this. Perhaps you're saying you want to feel confident that you made the best decision possible with the information we have?" Indeed, as Anonymous (2008) poignantly writes about the decision she and her husband made to terminate a pregnancy due to multiple serious anomalies, "My husband and I do not feel we made the wrong decision, but we are not entirely sure we made the right one either. We have to live with the decision we made" (p. 417).

6.2.5 *Strategies for Setting Goals and Attaining Goals*

Setting Goals

- Be responsive to the patient's concerns. Levack et al. (2011) take a patient-centered view of health care that values patient participation in decision-making, considers patients' unique life contexts, and respects them as individuals. They recommend that anything patients or families raise when talking about goals "should at least be considered for discussion. This might require clinicians to consider goals outside of their traditional scope... [of practice]. It may also require clinicians to consider goals that they consider to be 'unrealistic'" (p. 212). Acknowledging a patient's goals does not mean you have to fully address them in genetic counseling. Through sensitive provision of information, you can help patients see how some of their goals may be unrealistic. For example, a patient might ask if you can provide counseling to help with some marital problems. For goals outside your scope of practice, you can make a referral (described in more detail later in this chapter).
- Notice patient nonverbals and try to use that information to understand the patient's emotional state.
- Translate patient questions or concerns into specific statements of goals toward which you can orient the genetic counseling session.
- Try for patient agreement to work on these goals.
- Try to establish both immediate and longer-range goals, if appropriate. For example, an immediate goal would be, "To learn the risk for a genetic condition." A longer-range goal would be, "To make a decision about whether to be tested."
- Try to establish goals that build on the patient's resources and assets (Hackney and Bernard 2017; Stone 1994). As Stone (1994) says with respect to brief pastoral counseling, "It has been my experience that people who are going through difficult times tend to ignore their own strengths and resources... the focus of brief pastoral counseling is not to break down people's defenses; rather it is to build upon the counselees' own coping resources and strengths, latent though they may be. One of the quickest ways to help individuals begin to feel better about themselves, thus enhancing self-esteem, is to get them to use some of those latent strengths. Breaking down defense mechanisms, or gaining insight into one's own defenses, is generally not necessary for the management of a problem. It almost always is quicker to help people develop their own resident strengths than it is to break down their defenses-but even more importantly, it is more humane..." (p. 42). For example, a woman who is pregnant with a baby with anencephaly might say she's praying for a miracle and that maybe her baby will live. A genetic counselor might respond to say, "It's clear that your faith is important to you. Tell me about the support you might get from your church commu-

nity.” Sometimes patients express doubt in their ability to make a good decision. It can be helpful to ask patients to talk about other major decisions they made and think about how they approached those decisions. Their responses can help patients recognize both their strengths and their resources.

- Focus, when appropriate, on *approach goals*. Mann et al. (2013) state that “Goals can be oriented not only toward securing desired outcomes (approach goals) but also to avoiding unwanted outcomes...Because approach goals tend to be more effective than typical avoidance goals, one intervention strategy may be to reformulate avoidance goals into approach goals (e.g., ‘avoid being sedentary’ can be transformed into ‘take regular walks’)” (p. 490). So, for example, a genetic counselor might point out that if a patient’s goal is to avoid getting cancer, a positive BRCA test could be viewed as an opportunity to pursue surveillance for early diagnosis and management if cancer occurs (approach goal).
- Use an established framework for setting goals. Latham (2003) demonstrated the utility of SMART goals in organizational settings. SMART stands for specific, measurable, attainable, realistic, and timely. These may be especially relevant in management of genetic risks or conditions for which there is treatment, such as metabolic disorders.
- Keep in mind that not all patients will be forthcoming about their situations (Schema et al. 2015). In Chaps. 3 and 4, we discussed ways in which you can use attending and empathy skills to build rapport and trust that facilitates greater patient self-disclosure.
- Genetic counselors are frequently involved in evaluations to identify a genetic diagnosis and/or risk assessment. Yet, as genetic counseling becomes more integrated with other areas of medicine (such as cardiology, cancer), genetic counselors will increasingly help patients set goals for disease risk management through surveillance, adherence to treatment recommendations, and/or lifestyle modifications. Thus, you can play a role in helping patients determine action steps necessary to attain their goals. Mann et al. (2013) recommend that in order:

“To promote health behavior, people ideally should commit to health goals that are consistent with other personal goals, and they should give careful consideration to the desirability and feasibility of these goals...Once committed to a health goal, people need to think about how to implement these goals in the near and distant future. Attention should be paid to identifying goal-relevant opportunities and planning appropriate goal-directed behavior that capitalizes on these opportunities. Individuals should also think about obstacles, distractions, and temptations that may undermine goal-directed behavior and take prospective action to prevent their interference” (p. 494).

For example, a patient who is at risk for colon cancer avoids having a colonoscopy because it is unpleasant. A genetic counselor might help this patient recognize the long-term benefits of colonoscopy, early detection, and treatment, such as being around to watch his children grow up.

6.3 Obstacles to Goal Setting and Goal Attainment

Tryon and Winograd (2011) assert that, “Patients, particularly those who are new to psychotherapy, may have an inaccurate perception of the role they are expected to play in the treatment process. In their experiences with other health professionals such as physicians, patients tend to play a relatively passive, submissive role, presenting their symptoms and receiving treatment. The goals of such treatment typically do not involve much discussion, and there may be little collaboration regarding treatment beyond patient compliance in following professional directives” (p. 55). This is arguably true for genetic counseling. Thus, a common obstacle to patients’ active engagement in setting goals is their misperceptions about the nature of genetic counseling.

Danish and D’Augelli (1983) identify four major obstacles or roadblocks to patient goal setting and attainment, which we define in Table 6.1, along with examples and possible genetic counselor interventions. These obstacles, either alone or in combination, can prevent patients from achieving their desired outcomes. So, you need to assess patient roadblocks and take steps to reduce or remove them.

Here are additional examples of specific obstacles to setting and achieving genetic counseling goals:

- Some patients and genetic counselors may lack experience stating problems in positive, goal-oriented terms.
- As we said earlier, some patients have limited familiarity with the nature and scope of genetic counseling and therefore lack an understanding of appropriate goals. You can acknowledge their confusion and invite them to express goals at any point during the session. For example, “Don’t feel that you have to come up with something right now. Why don’t we begin with...Please let me know if you think of more goals as we go along.”
- There are other competing goals (Mann et al. 2013). For example, by avoiding setting a goal of deciding whether to have genetic testing, the patient may believe she can make the issue go away, avoid responsibility for the decision, and/or maintain an illusion that everything will be OK.

Table 6.1 Roadblocks to patient goal attainment

Roadblock	Patient example	Counselor intervention
Lack of knowledge	Patient does not know that there is a risk of passing a gene onto her child	Provide patient with genetic risk information
Lack of skills	Patient does not know how to approach his family members to persuade them to participate in genetic testing	Practice various scenarios for approaching family members
Fear of risk-taking	Patient fears that she could not handle a positive test result	Discuss fears and refer for mental health counseling if appropriate
Lack of social support	Patient has no supportive family members or friends, no religious/spiritual base, etc.	Refer to a support group or to mental health counseling/ psychotherapy

- The patient may be trying to set goals that actually belong to someone else (e.g., “My doctor wants me to have this test”; “My parents want me to terminate the pregnancy”; “Can you imagine what my neighbors would say if they knew I wanted to have a baby that has Down syndrome!”). Of course, if a patient is attending genetic counseling primarily to satisfy someone else, or is going through the motions in order to have testing, the goals will be quite limited and not as mutual as you would like. In such situations, you might say, “I know you would rather not be here. However, since you are, I wonder if there’s anything that might be beneficial to you. Is there anything you might want to discuss?” It is important to assess the motivation underlying patient goals, that is, whether the goals are for themselves or for doing what others expect of them (Mann et al. 2013).
- Patients may resist goals they perceive as being forced onto them, either by you or by someone else. For instance, McCarthy Veach et al. (1999) found that some former prenatal patients were dissatisfied with their genetic counseling because the genetic counselor insisted on presenting termination as an option after they had explicitly stated it was not an option for them. Clearly, these genetic counselors and patients were at odds over the goal of discussing all available options. Remember, you don’t always have to go into detail about every option merely because you think you must *cover all the bases*. It’s important to respect your patients’ views and feelings.
- Patients may only be considering short-term consequences. For example, a woman with a BRCA1 mutation might not want to share this information with her daughters because she is concerned about causing them to worry. A genetic counselor might help the patient modify her goal of not causing worry to address longer-term consequences (daughters may benefit from testing and appropriate surveillance).
- Cultural worldviews that outcomes are due to chance, fate, God’s will, etc. may not be compatible with self-directed goal setting. Patients with such worldviews may have difficulty seeing the value in setting goals. Nevertheless, you might say, “You’ve made the decision to come for genetic counseling. So, I assume you believe there’s something we could do that might be useful for you. How would you like to spend this time together?”
- Cultural variations in explanatory models for illness factors may present obstacles to goal setting. It is important to conceptualize patient concerns in ways that are consistent with the patient’s culture. Lewis (2010) suggests a series of questions to assess a patient’s explanatory model that can be adapted to genetic counseling:
 1. What do you call your problem? What name does it have?
 2. What do you think has caused the problem?
 3. Why do you think it started?
 4. What do you think the sickness does? How does it work?
 5. How severe is it? Will it have a short or long course?
 6. What kind of treatment do you think the patient should receive? What are the most important results that you hope she receives from this treatment?

7. What are the chief problems that the sickness has caused?

8. What do you fear most about the sickness? (p. 217)

- Cultural differences between the genetic counselor and patient may pose obstacles. As part of the goal-setting process, you may need to explicitly acknowledge ethnic and cultural differences (Cardemil and Battle 2003; La Roche and Maxie 2003).
- Some patients come from cultures that do not have a future time orientation, and therefore goals should be linked less to dates and more to social or natural events (Brown 1997). Also, Western views of change usually are linked to acting upon one's environment and taking control of one's situation, whereas for some patients from other cultures, change is regarded as establishing harmony within the family or tribe and learning to appreciate the ways things are and one's place in this reality (Brown 1997). Patients who hold Eurocentric views will tend to take a goal-oriented, self-expressive approach to dealing with their problems as will many African American and Asian-American patients, while Hispanic-American patients may tend to take a wait-and-see approach, and American Indians may prefer controlled self-expression characterized by thoughtful, rational, carefully controlled responses: "One implication of this value is that different groups may take longer to consider the problem and will have different propensities for action" (Brown 1997, p. 34). Keep in mind, however, that cultural and individual factors interact uniquely for each patient, so you should be careful not to make unfounded assumptions or stereotype patients (Hackney and Bernard 2017)
- Some patients lack an ability to conceptualize the void between where they are currently and where they would like to be (Hackney and Bernard 2017). For example, a patient (following the death of a child with a genetic conditions) says, "We wanted a big family, but now I don't think I will ever want another child." She fails to recognize that she might make a different decision through a series of smaller steps (e.g., gathering information about recurrence risks and available testing; consulting with genetic counselor and family members; seeking out personal counseling). Although these patients recognize where they are currently and where they ideally would like to be, they are unable to visualize what they would need to do to get from here to there. You could ask, "What are some things you need to do in order to make this happen? What will be your first step?" (Cormier and Hackney 2012; Hackney and Bernard 2017).
- Some patients may lack a clear awareness of their values, desires, priorities, etc. (Hackney and Bernard 2017), or they may be in conflict (e.g., wishing to determine if their child has fragile X syndrome, like their brother, but feeling responsible for this condition). You might address patient ambivalence by acknowledging it. For example, "You don't have to come up with a plan right now. Would you like to take a few minutes [or a few days, if feasible] to think about it?" You might try advanced empathy to identify the conflict. For instance, "I wonder if your indecision about fragile X syndrome testing is due to your feeling responsible for your son's condition?"

- When your patients are couples or families, you must simultaneously take into account several individuals' wishes, desires, and needs (Martin 2015; Schoeffel et al. 2018). This can make goal setting difficult, as their interests may be in conflict. Indeed, one of the major challenges experienced by genetic counselors when their patients have genetic concerns involves disagreements among family members about what to do (Abad-Perotín et al. 2012; Alliman et al. 2009; Bower et al. 2002; Gschmeidler and Flatscher-Thoeni 2013; McCarthy Veach et al. 2001). In such situations, you might say, "My goal is to assist you in finding the most satisfying solutions for all of you" (and then ask each individual to express her or his wishes) (Martin 2015; Schoeffel et al. 2018). One possible exception would be situations in which it is a cultural practice for one family member to speak for another (Schoeffel et al. 2018).

6.4 Genetic Counseling Endings

In genetic counseling, there are two types of endings: session endings and relationship endings. In situations where you have only one contact with a patient (e.g., many prenatal genetic counseling cases), these endings occur simultaneously. In other situations, you may have contacts that extend over a period of years (e.g., working in a specialty clinic such as a muscular dystrophy clinic, where patients are seen for ongoing care; patients who return with subsequent pregnancies; BRCA gene families). Ending the relationship in genetic counseling is similar to endings in psychotherapy, where the goal is to "...help clients successfully achieve their agreed-upon treatment goals and then end their work together in a planned and thoughtful manner" (Vasquez et al. 2008, p. 654). In this section, we offer suggestions for effectively managing both types of endings.

6.4.1 Guidelines for Effective Endings

In genetic counseling, you set the stage for successful endings from the outset by describing the nature of the contacts you anticipate having with your patients (number of sessions, session length, follow-up contacts, etc.). We recommend the following strategies:

- *Inform patients.* Explain what genetic counseling is, if they are unfamiliar with the service, and describe the process by which you will work with them. Determine mutually agreed-upon goals (Glasgow et al. 2006; Tryon and Winograd 2011; Vasquez et al. 2008). Include an explanation of how much time you have together so that it doesn't come as a surprise at the end (Kramer 1990).
- *Prepare patients for the end of a session.* Genetic counseling sessions may not adhere to a strict time limit. Nonetheless, you must remain sensitive to the overall

clinic schedule. For example, in prenatal genetic counseling sessions that precede a scheduled ultrasound, it is appropriate to let the patient know your time together is limited or ending (e.g., “I want to make sure that you get to your ultrasound on time, so we only have about 10 min left. I wanted to be sure we had enough time to talk about...”). Be careful, however, not to make patients feel rushed. To the extent that you can, try to maintain some flexibility in your schedule to accommodate the time requirements of an extremely complex and/or difficult case.

- *Summarize the session.* You can do this in different ways. You could provide an overview of the discussion and ask your patient how s/he feels about what you’ve discussed. Another option is to ask your patient to provide a summary (e.g., “Our time is about up. I’m wondering what stands out for you as far as what we’ve covered today”). You should fill in missing information and/or correct inaccurate statements; frequently you will need to correct technical/factual information. After the summary of the discussion, you might ask your patients to briefly describe where they are in their decision-making process. For example, “What are your thoughts and feelings about the next thing you will need to do in order to make a decision?” Finally, if appropriate, discuss how test results will be conveyed to them, and possibly walk patients through a discussion of *what if* the results are abnormal.
- *Discuss next steps.* Review what will happen next and what actions they can take. For example, “In about 10 days you will receive a letter summarizing what we discussed today. I will call you in two weeks with the results of your test. If you have not heard from me by then, please call the clinic. Also, if any other questions or concerns come up, please feel free to call me here.” Make a specific plan for communicating test results (e.g., What is a good time to call? If you are not in, may I leave a message?)
- *Arrange for follow-up.* If you will interact with the patient again, explain how future contacts can be made. Also, keep the door open, letting patients know they may return at some future time if they need to do so. But do this carefully, as this may be a way to avoid truly ending the relationship. Furthermore, patients may not have health-care coverage for additional sessions.
- *Try to end on a positive note, if appropriate* (e.g., “You seem very comfortable with the decisions you made today”). Be careful not to offer false hope and reassurances. Patients who receive bad news will experience any number of negative feelings (anger, grief, anxiety, shock, despair—see Chap. 9 for a discussion of patient affect). You may be tempted to try to make them feel better. This is probably not possible nor even desirable at this point. Be careful not to offer platitudes such as, “Everything will be fine,” “Things will look better after a good night’s sleep,” “You’ll get over this in time,” and “It’s all for the best.” In Chap. 7, we discuss communicating bad news to patients.
- *Reinforce patients.* Express confidence in their decision-making processes and in their ability to get through this difficult time. Be careful to reinforce their process and not their actual choice! For example, “You’ve done some very careful thinking about your options and seem to know which one is best for you,” rather than “You’re doing the right thing by pursuing this testing.”

- *Be sensitive to patient emotional state.* If patients are crying and/or otherwise visibly distraught, allow them a few minutes to compose themselves before leaving the room.
- *Observe social amenities regarding departure.* Hold the door for patients, escort and/or direct your patients to the exit, and shake hands, but *only* at their initiation.
- *Don't counsel outside of the room.* If you have to escort your patients any distance to an exit, some may attempt to continue counseling with you. Try to direct the conversation away from genetic counseling, instead engaging in social conversation about the weather or about where they had to park their car, etc.
- *Respect a patient's autonomy to end early* (Burwell and Chen 2006; Kramer 1990). Some patients may want to end before you believe everything has been adequately covered. There can be several reasons why patients might want to leave prematurely, including patient discomfort with difficult and/or painful information and/or patient denial that anything is wrong; you need to respect your patients' wishes to end early. Remember, however, there is certain information that you must present, such as risk. One option is to send a follow-up letter detailing information that you believe requires additional explanation.

6.4.2 Challenging Genetic Counseling Endings

There are a number of situations in which ending the genetic counseling relationship may be difficult. Generally speaking, the longer you've worked with a patient, or the greater number of contacts you've had with them, the more difficult the endings (Pinkerton and Rockwell 1990; Vasquez et al. 2008). Some patients may feel dependent on you, or they may have really enjoyed working with you (both are more likely when you've had more than one interaction). Research from counseling/psychotherapy also suggests that endings are more difficult when the process and outcome have not gone well; in other words, both the patient and the counselor are dissatisfied (Brady et al. 1996; Quintana 1993). You may have been the bearer of "bad news"; the patient may be angry; you may be a painful reminder of their disappointment; or the patient may not have adequately integrated information from the genetic counseling sessions. Even a skilled genetic counselor may be challenged by an angry, dissatisfied patient (Schema et al. 2015).

In addition to relationship endings, it can be challenging to end individual genetic counseling sessions, especially with highly verbose patients, emotionally distraught patients, patients who are making what you consider to be the wrong decision, patients to whom you've given bad news, and patients with whom you feel a strong connection (e.g., you wonder how things will turn out for them).

Regarding contracting and session endings, in a study of genetic counseling of deaf adults, Baldwin et al. (2012) recommended "Instead of including rapport building at the beginning of a session, the genetic counselor may wish to include rapport building at the end of the session. While in hearing culture, it is common for

conversations to terminate quickly, Deaf clients, may find this rude and often prefer a more prolonged good-bye. The genetic counselor may wish to include time at the end of the appointment for rapport building and an extended goodbye session and utilize time at the beginning for contracting and direct statements about the expected content of the genetic counseling session...” (p. 269). Based on their recommendations, we suggest that you spend a little bit of time to establish some rapport at the beginning of the session and save some time at the end of the session for further rapport building.

Perhaps one of the most challenging endings is with terminally ill patients where your good-byes are symbolic of their eventual deaths (e.g., a 17-year-old boy with Duchenne muscular dystrophy). Sometimes counselor difficulties with endings are related to unresolved endings in their own lives. Ending a genetic counseling relationship may represent these unresolved issues (see Chap. 12 transference and countertransference). Clues that you are having trouble with endings include consistently exceeding session time limits and looking for excuses to recontact patients.

Try to anticipate particularly difficult endings whenever possible and carefully plan for them. For example, you could discuss your feelings with your supervisor and brainstorm about how you might best proceed with saying good-bye. You could work on coming to terms with or accepting the limitations of genetic counseling, that is, accepting that it may not be the solution to every patient’s problems. We also recommend that you work on being aware of your reactions (see Chap. 12). Try not to let your personal feelings interfere with the ending (e.g., unreasonable fears about what the patient will do, your own feelings of not being helpful, etc.).

6.5 Making Referrals

Some of your genetic counseling patients may benefit from referrals to other sources of information, treatment, guidance, and/or support. In some situations, you might recommend additional medical evaluation (diagnostic or treatment/management). In other situations, you might offer referrals for therapeutic services, such as early intervention services for a child with special needs. You may also identify patients who would potentially benefit from social support services. Genetic counselors frequently provide patients with information about relevant support or advocacy organizations. Finally, you may recognize that your patient might benefit from additional counseling or mental health services. Reasons for this type of referral include patient issues that are beyond your expertise or scope of practice [e.g., patient is suicidal and in need of psychiatric care; intense marital conflict precipitated by the confirmation of a genetic condition (cf. Schoeffel et al. 2018)].

Schema et al. (2015) interviewed genetic counselors about their experiences of patient anger directed at them. Among the counselors’ recommended strategies, they suggested “Appropriate referral to other specialists including licensed psychologists is warranted when the psychosocial needs of the patient cannot be met by genetic counseling alone” (p. 728). Wool and Dudek (2013) assessed genetic counselor comfort with referral of prenatal patients to perinatal hospice and found

they varied in their comfort. This variation was partly due to level of familiarity with perinatal hospice services. They stressed, "...it is imperative that genetic counselors are aware of palliative care options in their organizations and communities" (p. 539). They identified several options, including written information and referral to support groups, accessing other parents who have experienced similar losses, and online resources that can help families through the decision-making process.

Sagaser et al. (2016) surveyed genetic counselors about their use of religious/spiritual language in sessions and their views about the importance of religion and spirituality. Based on the findings, the authors concluded that, "Just as recognizing traditional coping styles such as distancing, planning, or avoidance is useful in genetic counseling, recognizing a patient's utilization of positive or negative religious coping can be helpful for a genetic counselor, as he or she can either support the patient's use of positive religious coping or consider making a referral for chaplaincy or pastoral services... [Moreover] these data suggest that persons who are experiencing high levels of spiritual struggle are more likely to be receptive to religious actions and would especially benefit from a referral to receive pastoral services" (pp. 929–930).

Murphy et al. (2016) surveyed pediatric genetic counselors regarding their experiences with parents who ask them to provide sex education to their children affected with intellectual disabilities (ID). Based on their findings, they concluded that it is within the genetic counselor's role to "...assess individual sex education needs for patients with ID and provide suitable resources and referrals to those competent in sex education instruction" (p. 559).

Making an effective referral requires careful planning on your part. It is your responsibility to first assess whether your patients might benefit from referral to other sources of help and, if so, to explain how the referral is intended to be in their best interests (e.g., explain why you are suggesting additional support/help and what they might gain from using additional resources). We recommend the following referral guidelines:

6.5.1 Building a Referral Base

- Familiarize yourself with referral sources. You should build and continually update a referral file that contains the names, addresses, telephone numbers, and procedures for contacting various referral sources. Build a file by asking colleagues for recommendations, by checking with patients for sources that have been helpful to them, and by learning about local social services. You should update your file periodically (e.g., checking on which referral sources are currently accepting new clientele).
- In choosing referral sources for your file, select sources that are sensitive to and aware of cross-cultural issues, gender issues, and sexual orientation issues, and sources that are affordable and located a reasonable distance from patients (Owen et al. 2007; VandenLangenberg et al. 2012).

6.5.2 *Points to Consider When Making Referrals*

- Consider your patient's resources before making a referral. For example, be aware of expense, distance to the source, and whether the patient has insurance or some other means of paying for the referral source (Owen et al. 2007).
- Referrals do not always have to be made immediately. For instance, services may not be available, or the patient may not be emotionally ready. Let your patient know your referral sources are available in the future.
- Offer the referral tactfully so patients realize that it is to provide them with maximum assistance and not that their problems are so severe they need extra help. Start by focusing on the importance of their problems or needs and the desirability of resolving the problem.
- Prepare your patient. Provide details about the referral source (e.g., name, location, fees) to lessen anxieties about this new relationship. Describe the competencies and characteristics of the referral person(s) and how to contact the referral source. You are trying to enhance this person's credibility and expertise.
- Don't be too prescriptive with respect to the type of service or treatment the patient will receive from the referral source. For instance, do not suggest that your patient would receive a certain type of intervention or test.
- Check out patient feelings about the referral. Even patients who seem to readily accept a referral may be apprehensive. Normalize any fear. For instance, "Most people would feel hesitant to bring this issue to their minister." You could point out how the patient took the risk to come to see you and build on this to get the patient to take the referral (Cheston 1991). In some situations, you may decide to call and make the appointment, with the patient's permission.
- Anxious patients may ask a lot of questions about the referral source, and you should patiently answer their questions. In any case, ask them what they feel about the referral, and then what they think about it (Cheston 1991).
- Include the referral in a follow-up letter in order to remind patients.
- For some patients (e.g., a child referred to a special education professional), you may wish to follow up to see if the referral was taken and perhaps schedule another session with the patient after she/he has met with the referral source. Alternatively, you might ask the patient to call you in a couple of weeks to let you know how things went.
- Cheston (1991) cautions against leaving patients to their own resources. If your patient asks for additional help, and you are not immediately aware of any, tell your patient you will look into possibilities after the session and get back to her or him with whatever you find. Then follow through on your promise.

The following list displays the types of referral sources that might be appropriate for genetic counseling patients.

Common Referral Sources

Support groups (genetic condition)
Bereavement groups
Agencies (SSI, medical assistance, WIC, social services, respite care)
Services (infant stimulation, schools, The Arc)
Medical (genetics as well as other specialists)
Psychological (short-term therapy, long-term therapy, psychiatric, career/vocational counseling, family therapy)
Financial services
Adoption agencies
Social workers
Online resources
Clergy/spiritual leaders
Parenting classes
Drug/alcohol rehabilitation
Domestic abuse centers
Homeless shelters
Food banks
Developmental specialists
Unemployment center
Parents/individuals who are experienced with a condition and who are willing to talk with recently diagnosed patients/families

6.6 Closing Comments

You have a great deal of responsibility for beginning and ending genetic counseling sessions and relationships and for helping patients establish feasible goals. Advanced preparation, observing common courtesies, carefully listening to your patients, and setting goals and plans for achieving them will assist you in these important genetic counseling activities. As we've mentioned in other chapters, these responsibilities will become less challenging for you over time and with experience. You will gradually develop your style of structuring genetic counseling relationships and sessions.

6.7 Class Activities

Activity 1: Structuring the Session (Think-Pair-Share Dyads or Small Groups)

Students discuss the following:

- What concerns/questions do you think patients have about genetic counseling?
- What patient questions are you unsure about how to address? Afraid to address?