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Resistance and Adherence: Understanding the Patient's Perspective

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OBJECTIVES

- Define patient resistance, adherence and non-adherence
- Identify individual and social factors that contribute to resistance and non-adherence
- Develop skills for addressing resistance and adherence

Resistance is a challenging, but not uncommon dynamic that arises in genetic counseling. Whether it is the patient who asks, "Why do I even *need* this information?" or the young woman who repeatedly reschedules her genetic counseling appointment, resistance contributes to the psychosocial complexity[1] inherent to genetic counseling (Shugar 2017). In its many forms, resistance directs genetic counselors to address individual patient attributes outlined in the Reciprocal Engagement Model (REM) of genetic counseling practice – *Patient emotions matter*, *Patient autonomy must be supported,* and *Patients are resilient* – and assess and explore what lies beyond the patients' inability to engage in the genetic counseling session (McCarthy Veach et al. 2007).

To better understand resistance, this chapter defines patient resistance and the related concepts of adherence and non-adherence to medical recommendations – including the different perspectives from which the patient and the genetic counselor experience resistance and non-adherence. It then addresses the interacting personal, social and medical factors that contribute to resistance, with attention to the self-protective role of resistance. Techniques are then presented by which the genetic counselor can respond effectively and empathically to resistant behavior and non-adherence to medical recommendations.

1 Shugar (2017) defines psychosocial complexity as "the patient-specific social, emotional and psychological barriers that interfere with the usual process of genetic counseling" (p. 217).

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Definition and Concepts

Resistance

Resistance refers to attitudes, behaviors, emotions and ways of thinking by which a patient limits full engagement with the process of genetic counseling. Resistance has many forms and degrees of intensity (McCarthy Veach et al. 2018). Examples include:

- The patient may say that he or she does not understand the reasons for referral or has no relevant questions or concerns.
- The patient provides incomplete or inaccurate information or fails to recognize the severity or significance of a situation.
- The patient may avoid meaningful discussion about important issues or make decisions without appropriate deliberation.
- The patient may express anger, hostility, withdrawal, inappropriate humor, or implicitly or explicitly question the genetic counselor's competence or the value of genetic counseling.

Some degree of patient resistance is relatively common, and the genetic counselor must be prepared to address it. Resistance can result from a wide variety of inter-related personal, family, social, and cultural factors. Nevertheless, it is important to discern the reason for a patient's resistance in order to manage it. For instance, while the above examples may indicate patient resistance, there are many potential reasons other than resistance to explain a patient's behavior (e.g. fear, resentment, confusion, or misunderstanding or disconnection with counselor or medical providers; McCarthy Veach et al. 2018). Thus, care must be taken in defining and responding to patient behavior solely as resistance (Beutler et al. 2001; Djurdjinovic 2009; McCarthy Veach et al. 2018).

Adherence and Non-adherence

Adherence and non-adherence reflect behaviors that may indicate the degree of a patient's resistance (Scaturo 2005). Adherence refers to the extent to which a patient follows the advice and recommendations provided in genetic counseling. Examples of non-adherence include: lack of follow-through with recommended health care referrals; less than full compliance with exercise, dietary, or weight recommendations; failure to strictly follow medication instructions; procrastination regarding cancer screening tests; and missed or late-canceled appointments. Although adherence is difficult to measure, and empirical findings vary, a wide variety of studies show that non-adherence is a significant problem in the practice of medicine (Kennedy and Llewelyn 2003; Shearer and Evans 2001) including genetic counseling (Hadley et al. 2003; Humphreys et al. 2000; Peters et al. 2001).

From the patient's perspective, resistance and non-adherence often involve an attempt to protect oneself and/or family under difficult circumstances, and this motivation may be at least partly unconscious. From the genetic counselor's perspective, resistance and non-adherence may appear to impede the process of genetic counseling and the provision of optimal genetic services (McCarthy Veach et al. 2018). The issue of perspective is critical, because the differing circumstances of the genetic counselor and the patient are key to understanding and addressing resistance and non-adherence.

Resistance and non-adherence in genetic counseling lie within the far larger domain of discrepancies between the expectations or recommendations of health care providers and the responses of their patients (Kennedy and Llewelyn 2003; Shearer and Evans 2001). To illustrate these differing perspectives, consider the process of genetic counseling: The genetic counselor works with a deep understanding of medical genetic information and procedures, in a familiar professional setting, with the responsibility to focus for a limited period of time on the patient's needs. Thus, it is relatively easy for the genetic counselor to recognize the value of genetic counseling and the recommendations that may ensue. By contrast, the patient's experience of genetic counseling typically involves new and complicated information as well as complex decisions. Genetic counseling takes place in an unfamiliar setting under circumstances in which stress, confusion, anxiety, uncertainty, fear, or anger are common. Once the session is over, the genetic counselor's support and focus recede, and subsequent steps take place within the full complexity of the patient's individual, family, social, and cultural life. Thus, in addressing patient resistance, the genetic counselor must strive to understand the long-term, multifaceted circumstances under which the patient responds to the exploration, information, and recommendations of genetic counseling. The genetic counselor must also avoid allowing his or her own clarity about the value of genetic counseling to interfere with the ability to address the patient's resistance empathically.

Resistance

Factors Contributing to Resistance

Resistance to genetic counseling in general or to specific aspects may occur for many reasons both on an individual and social level (Djurdjinovic 2009; McCarthy Veach et al. 2003; Weil 2000).

Individual Response to the Genetic Counseling Process

At any point, resistance may be due to emotional or psychological responses to the genetic counseling process. From the start, the manner in which a referral was made may cause confusion, anger, or resentment. For example, if the nature and potential consequences of prenatal screening have not been clarified, a patient may feel that s/he was misled when informed of a screen-positive result. Before genetic counseling begins, patients may be anxious or concerned about possible test results, diagnoses, medical recommendations, emotional responses, or the responsibility of making decisions.

Resistance can arise during the session. The information presented may be anxiety-producing or, although not unduly threatening, presented in a manner that overwhelms the patient's ability to understand or process it. It may also be inconsistent with the patient's perceived risks and create resistance to further information provided during the session. For instance, Gurmankin and colleagues (Gurmankin et al. 2005) studied women at risk for breast cancer and BRCA1 mutations. They found that patient worry not only impacted post-counseling risk perception, but it also was a factor in the women's resistance to communicated risk information, especially when unexpected risk information was presented. This resistance can result in an inaccurate risk perception that ultimately impacts medical decision-making and care.

Other emotions and psychological responses can also lead to resistance. Patients may experience changes to identity or self-esteem, a perceived loss of independence and self-determination, and/or narcissistic

injury (which involves an impaired sense of self-worth and ability to appreciate one's own activities and achievements) (Weil 2000). Psychoanalytic psychologists view resistance as the client's innate protection against emotional pain (Cowan and Presbury 2000). In genetic counseling, emotional pain can range from guilt and shame, to anger and sadness about the process of genetic counseling or aspects of a disorder and its impact on the family (Kessler et al. 1984; McAllister et al. 2007). Notably, an individual's temperament (e.g. high vs low anxiety) and personality (e.g. optimism vs. pessimism) may affect the extent to which a patient experiences and expresses resistance.

Resistance may indicate a weak working alliance or patient-counselor "bond" (McCarthy Veach et al. 2007). Patients may feel the genetic counselor failed to meet their expectations and thus, the counselor rather than the patient may be the source of resistance (Bannink 2006; Cowan and Presbury 2000). The genetic counselor may seem insufficiently engaged emotionally or appear to respond non-empathically (Djurdjinovic 2009), or the patient may feel powerless in a relationship where the "power" lies within the genetic counselor's knowledge (Guilfoyle 2002). As Okun and Kantrowitz (2015) state,

> "Resistance is often the helpee's response when a trustful relationship has not yet been established and the helpee is feeling threated, whether by the relationship, the material being explored, or the helper's probing or interpreting of sensitive issues before the client is ready to talk about them" (p. 99).

The genetic counselor must not take the patients' reactions personally, and they need to remain aware of their own reactions to the resistance that may contribute (or not) to the working alliance (Newman 2002). Bannink (2006) suggests that clinicians adopt a stance of finding out what the patient would like to achieve through their relationship with the professional, assuming the patient has a good reason for their resistance, and being unconditionally accepting of the patient. The counselor can then, (i) Acknowledge the patient may not want to be at genetic counseling ("Since you are here for your appointment, how can we make the most of our time together?") and (ii) Ask the patient what s/he would like to achieve in the session and accept the answer.

Individual Beliefs and Values

The patient's individual perspective, specifically beliefs and values, are another important consideration in resistance. Patients' beliefs and values may underlie their resistant behaviors. Religious, spiritual, or moral values may conflict with potential decisions concerning reproduction, abortion, genetic testing, and invasive or heroic medical measures (Ano and Vasconcelles 2005; Pergament and Pergament 2012). Patients may feel burdened by medical genetic procedures and social expectations that previous generations did not face: complex reproductive decisions, a high level of responsibility for one's own health and that of one's present and future children, and the introduction of medical genetics into the highly personal areas of reproduction and intimate relations (Beeson and Dokusm 2001; Mills and Haga 2014; Rapp 1993, 2004, 2011; Rothman 1986).

Social Milieu

Patients' larger social and cultural background or milieu has an essential role in how they relate to genetic counseling. The beliefs, values, and practices of family members, peers, religious institutions, and/or the community may cause a patient to enter genetic counseling with some degree of resistance or with heightened sensitivity to perceived failings in how he or she is treated during the session. For example, Chin et al. (2005) studied motivators and barriers to cancer risk genetic counseling in Singaporean

women. While women were receptive to genetic counseling, traditional cultural and family beliefs, including attitudes toward cancer and doctor–patient relationships, influenced their attitudes to medical care. Cultural beliefs that precede a patient's experience in genetic counseling can ultimately result in resistance to genetic information and/or testing (Eisenbruch et al. 2004; Glanz et al. 1999).

The interaction between a patient and their social milieu is complex. The patient may agree with values of his or her community that conflict with the goals of genetic counseling. These cultural differences may contribute to resistance; either the patient may have mixed or conflicted feelings, or the patient may be unconflicted but hesitant to act against the values of family and community (Shaw et al. 2018). Generational differences can exist in medical beliefs and thus, older or younger patients may differ in how they present their opinions or values (Chin et al. 2005). In situations such as this, the patient's resistance may be a desire to avoid conflict – internal and/or with others. The resistance may also involve ambivalence due to social milieu, leading to an inability to make decisions in the face of mutually conflicting possibilities, each of which has value to the patient.

Ethnocultural differences between genetic counselor and patient may also lead to a sense of unfulfilled expectations or disrespect in areas such as the role of the family in healthcare decisions, the amount and type of guidance provided during decision making, healthcare beliefs and practices, and social practices such as how individuals are addressed and the order in which family members are greeted (Cura 2015; Greb 1998; Huff 1999; Weil 2000).

The Interplay of Individual and Social Factors

In reality, patient resistance may result from the interplay of any of the factors discussed previously. Furthermore, as discussed in detail later in this chapter, the manner in which the genetic counselor responds to early indications of resistance plays a role. The factors described above can contribute directly to resistant behavior:

- Guilt or shame may cause the patient to withdraw emotionally or withhold relevant information.
- Conflicted beliefs and loyalties concerning ethical and moral issues or other social/cultural norms may cause the patient to limit their investment in the genetic counseling process or avoid difficult issues that raise painful personal or interpersonal conflicts.
- Anger or resentment may be expressed overtly, disrupting the relationship between genetic counselor and patient and preempting meaningful discussion, or covertly, leading to withdrawal and withholding.

Patients may express resistance in a cyclic dynamic in which their feelings, thoughts, and interactions with the genetics clinic oscillate between approach and withdrawal (Schneider 2002).

Functions of Resistance

Resistance serves an important self-protective function. Patients are grappling with discussing difficult information and experiencing uncomfortable emotions; as such, resistance is one way of coping and adapting to these difficult and complicated situations. Functions of resistance include:

- Avoiding one's primary fear (namely, exposure) by withholding information or limiting discussion of guilty or shameful feelings (Kessler et al. 1984).
- Relieving and/or avoiding deeper painful feelings by venting anger; angry withholding behavior prevents the object of anger from responding in the feared, retaliatory manner (Schema et al. 2015).

- Limiting the anxiety and pain of individual conflict and potential interpersonal conflict by skirting issues that involve beliefs, values, and loyalties.

Self-protection occurs in part through coping mechanisms that individuals develop throughout their lives. Coping mechanisms include psychological defenses such as intellectualization, denial, and displacement. These are mental processes through which individuals avoid painful or threatening emotions, wishes, or fears by keeping them out of conscious awareness. Although they are often discussed in the context of psychopathology, defenses that function flexibly and in a mid-range of intensity are normal and essential to adaptive psychological functioning (Weil 2000).

Given their importance, genetic counselors must exercise caution in assessing patient resistance as a defense mechanism. For instance, Lubinsky (1994) identified three forms of patient resistance – disbelief, deferral, and dismissal – that superficially resemble the defense mechanism of denial, yet differ from it and from each other with respect to causal factors, patient behavior, and appropriate interventions. This valuable paper is discussed in greater detail later in this chapter. However, it is introduced here to indicate the importance of carefully and flexibly assessing patient resistance and avoiding the facile overuse of terms such as "denial." As De Shazer (1984) suggests in a paper, "The Death of Resistance," counselors must view resistance as a unique way in which the client chooses to "cooperate" by sending the message that something is not working in the session – the approach, relationship, or the counselor's ability to read the client's cues. The counselor's job is not to dismiss the resistance but rather to ask what the resistance is telling them.

Strategies for Working with Resistant Patients

Addressing resistance can facilitate the process of genetic counseling and, equally important, may enhance the patient's ability to understand and adapt to the circumstances they face. As with any psychosocial intervention, the genetic counselor should begin to address patient resistance by attempting to understand its nature and origins. Newman (2002) suggests helpful questions to understand the patient's resistance in psychotherapy that can be adapted for genetic counseling.

- What is the function of the patient's resistance?
- What might be some of the patient's beliefs that are feeding into resistance?
- What might the patient fear would happen if s/he engages in genetic counseling?
- How might the patient be misunderstanding the genetic counselor's suggestions, methods, or intentions?
- What does the genetic counselor need to understand or learn about the patient to make sense of his/her resistance?

These questions may serve as an internal dialog to help the genetic counselor assess the patient's resistance and identify and understand the underlying problem leading to resistance (Nystul 2001).

At the same time, the genetic counselor should assess her or his own emotions and thoughts. Patient resistance can be discouraging, angering, or seem like an assault on one's sense of professional efficacy and desire to be helpful. These reactions can be exacerbated if resistance is a persistent issue with the patient, if the genetic counselor has other recent or current difficult cases, or if he or she faces professional or personal stresses. Attention to one's own feelings reduces the likelihood of the counselor's

emotional withdrawal, subtle retaliatory statements, or other counterproductive responses. Furthermore, as with countertransference (See Chapter 8), the genetic counselor's emotions may provide valuable clues about the patient's thoughts and feelings (Djurdjinovic 2009; Kessler 1992; McCarthy Veach et al. 2018; Weil 2000).

Assessing a patient's resistance, as well as the genetic counselor' own reactions, can then lead to psychosocial interventions using basic counseling skills such as primary empathy (reflecting the patient's thoughts or feelings underlying the resistance); closed- and open-ended questions to explore the patient's resistance; and advanced empathy to help the patient gain insight about their resistance. Consider the following situation and how the genetic counselor uses reflective counseling skills to address the patient's resistance:

> Following a diagnosis of limb-girdle muscular dystrophy, an adolescent patient withdrew into angry silence. Looking at her own feelings, the genetic counselor found, among other emotions, an increased desire to be helpful to him [countertransference identified through self-reflection]. This was an intuitive, empathic reaction to the pain and cry for help that lay beneath the patient's angry behavior. The counselor was thus able to say, "It must be so hard to think about how this is going to affect you at this stage in your life [primary and advanced empathy]." The patient, who had expected and unconsciously hoped his behavior would push her away, was moved by her concern and cautiously began to interact with her.

If the genetic counselor has established a sufficiently trusting relationship with the patient and the patient appears open to discussion, the genetic counselor should attempt to explore the resistance directly. Essential elements of this approach are empathy and a focus on the self-protective aspect of the patient's behavior, as discussed earlier. Equally important are support for the patient's attempt to handle the situation and a genetic counselor's willingness to provide the time needed in the session to support the patient's adjustment. For example:

> *Genetic counselor, to a woman who is knowledgeable about BRCA1/2 testing for familial breast and ovarian cancer but is vague when asked what her thoughts are about having genetic testing and avoids a question as to whether she has discussed it with family members*: "You have obviously investigated testing thoroughly and know a lot about it, but it seems like you're reluctant to talk about it now. I know some women have concerns about where testing will lead in terms of their own feelings about cancer management, specifically prophylactic surgery. I wonder if you are feeling some of that."
>
> *Patient*: Well, ... Most of the people I know are so sure testing is the right thing to do. But sometimes I wish I didn't have to face such big decisions.
>
> *Genetic Counselor*: So your feelings are different from those of the people you talk to. [primary empathy] Do you have some uncertainty yourself, too? [closed-ended question]
>
> *Patient*: Yes, it's actually both. It seems like such an important decision, and I don't know which is right.
>
> *Genetic Counselor*: I don't think there's a right or wrong answer. Maybe you should take some more time to think about it [influencing and advice]. We can talk about it here. But, I also wonder, are there any family members or friends you can talk to who would understand both ways of looking at it? [close-ended question]

In acknowledging and exploring a patient's resistance, the genetic counselor should, whenever possible, affirm the patient's dignity, integrity and sense of responsibility (Lentz 2016). As previously mentioned, guilt, shame, narcissistic injury, and anger about what has befallen and/or about needing help can undermine patients' self-esteem and sense of efficacy. Responding empathically and providing the patient with positive feedback and support about aspects of the patient's life and functioning allows the patient to have choices and an active say in their care (Newman 2002). Direct statements (e.g. "I can see you have been doing your very best to try and deal with this difficult situation"), as well as through the primary activities of genetic counseling – providing relevant information, promoting informed decision making, and facilitating the patient's role in planning and implementation – can communicate support of the patient's autonomy. Genetic counselors can also highlight aspects of how the patient is coping, adjusting and caring for self or family through strength, courage, thoughtful planning, etc. (Kessler 1999). For example, a genetic counselor can state, "Even though it's been hard for you to come here and talk about this, I can see you are really trying to do what's best for yourself/ family member."

Addressing Specific Types of Resistance

Lubinsky's (1994) discussion of the three "mimics of denial," introduced earlier in this chapter, provides guidance for addressing three specific types of patient resistance:

- *Disbelief* involves accurate perception of the information, but a failure to accept or believe it because it does not appear to make sense given prior information and expectations. For example, parents of a newborn initially reject a diagnosis of Down syndrome based on minor clinical stigmata when there are no major medical problems, the pregnancy has appeared to be normal, and the parents have taken appropriate precautions during pregnancy. Disbelief allows patients to remain hopeful in the early stages of adjustment. Genetic counselors can address disbelief by prioritizing and promoting only the essential interventions. They might present preliminary findings or a clinical diagnosis as suggestive evidence that requires further assessment, while making definitive data concrete (e.g. providing a copy of a karyotype and normal control). These approaches address immediate needs while providing time for the patient to adjust and accept the information and its implications.

It is also important to acknowledge the patient's perceptions even when they seem contrary to the presumed diagnosis. As Lubinsky stresses, adaptation to the new situation is a process that involves acceptance coupled with the need to maintain hope and to "say goodbye, to let go of one world and move on to another" (p. 7). The following example illustrates patient disbelief:

> *Genetic counselor, to a sullen, withdrawn new mother referred with a clinical diagnosis of Down syndrome in her newborn daughter*: I can understand this is a big shock. You must have a lot of feelings going on, including wishing you didn't have to be here and I would just go away. We can take as much time as you need to talk about what is going on and to help me understand how I might be helpful to you.
>
> *Patient, teary and speaking softly*: I'm so scared for my daughter. And my husband, who had to work today, says he doesn't believe the doctor. The baby looks okay to him.

Genetic counselor: So, you want to do the very best you can for your daughter, but you don't know where to go or who to trust.
Patient: Yes, that's how it feels.

Genetic counselor: Let me explain to you how we might be helpful. I'll tell you why the doctor thinks your daughter has Down syndrome and what we're doing to find out if he is right or wrong. I'll try and explain it so you can tell your husband, too.

Patient: Okay. I do want to do what's right. And if there is a problem, I know my husband does, too.

After further discussion, the patient agreed to blood being drawn for a karyotype. There was no further discussion of the implications of Down syndrome, and the patient was prepared to tell her husband that the blood test was the only way to find out if the doctor was right or wrong.

- In *deferral*, information is accepted as *correct* but its implications are not. Deferral helps prevent the emotional impact of the information from overwhelming the patient's psychological resources and allows time for adaptation and coping before fully acknowledging the consequences. Examples include missed and canceled appointments following the diagnosis of a severe disorder, and delayed follow-up after a determination of high risk for breast cancer. Genetic counselors can address deferral empathically by acknowledging that the information is scary or difficult to face while helping the patient obtain or mobilize social and psychological resources for coping. The primary danger of deferral is that patients will delay an essential diagnosis or treatment. Thus, it is important to discuss the value of the proposed services in a manner that supports and encourages the patient's desire to do what is in fact needed. Consider the following example of addressing patient deferral:

  Genetic counselor, on the phone with a cancer risk patient who has missed an appointment: It's normal to be scared when you've learned that you and your daughters may have a high risk of breast cancer. So, I can understand why you decided you just couldn't face the appointment yesterday. Is there a friend who could come with you, or that you could talk to beforehand? I ask because, if you could come in, we can certainly answer some of your questions and help figure out what to do next.

- With *dismissal* the patient denies or attacks the genetic counselor's or the institution's credentials, professional competency, and/or areas of medical expertise. This form of resistance provides relief from a seemingly unbearable situation by dismissing information and expertise and providing a rationale for disengaging. Dismissal often involves anger, and genetic counselors can address it by acknowledging the difficult circumstances the patient faces, as well as the normality of feeling angry, if relevant. If there are aspects of diagnosis or treatment that the patient does accept, at least tentatively, they should be emphasized while the genetic counselor sensitively continues to explore areas of disagreement. The counselor must maintain a non-judgmental attitude and pay attention to countertransference (Schneider 2002).

Lubinsky's analysis illustrates two previously discussed issues: First, the importance of accurately assessing the nature of resistance, as different forms require different responses and involve different aspects of genetic counselor countertransference; second, the central role of empathy in addressing resistance in a sensitive and patient-centered manner. His analysis also introduces the temporal aspect of resistance as part of patient adaptation. Adaptation is a complex process that involves multiple steps and may be cyclic (Weil 2000). It may take place over months or years and often involves other family members and their interactions (Rolland 1994). Thus, resistant behavior may change during a genetic

counseling session or evolve over the course of repeated contacts with a patient. The following example illustrates how resistance may evolve:

> An adolescent boy with a diagnosis of Marfan syndrome angrily dismissed the referring physician's competence and was distrustful of the genetic counselor. Careful exploration identified his panic about the risk of early death and dismay at the need to curtail his active involvement in mountain biking. By the end of the session, he was more trustful and clearly appreciated the genetic counselor's non-judgmental reactions to his feelings and behavior. At a two-month follow-up visit with his mother, he was not distrustful but was quite withdrawn. Exploration revealed an inwardly directed anger that his body had betrayed him and conflict with his mother over his continued level of physical activity. Building on the trust developed in the previous session, the genetic counselor drew him more fully into the discussion. However, he remained resistant to detailed consideration of appropriate physical activity, and the parent-child conflict was only partially resolved. A three-month appointment was made, which he agreed to attend.

Addressing Culture and Resistance

As in all aspects of genetic counseling, attention to ethnocultural issues is essential (Greb 1998; Huff 1999; Lewis 2002; Warren, n.d.; Weil 2000) (see Chapters 11 and 12). Failure to understand patients' actions and their expectations regarding healthcare (e.g. the questions they do or do not ask), or making recommendations that appear disrespectful of their social mores or healthcare beliefs can cause significant resistance. General knowledge of the beliefs and practices of a given ethnocultural group is important. Experience working with members of a particular population is invaluable. Such knowledge and experience must always be tempered, however, by respectful inquiry concerning the individual patient's beliefs and practices. The genetic counselor should be prepared to explore the following issues, both to avoid resistance and to address it if it occurs.

- What do patients expect from healthcare providers? This includes expectations for guidance in making decisions and/or expectations for medical recommendations (Browner et al. 2003).
- What is the role of family or social institutions? Does the patient wish to include family members or other individuals in the decision-making process? Should family or other social supports be incorporated into the treatment plan?
- What is the patient's understanding of the cause of the condition or problem? Do the medical-genetic explanations conflict with the patient's beliefs, or with those of the family or community? (Kleinman 1980).
- What are the patient's understanding and expectations of proposed tests or treatments? Do the medical procedures conflict with the patient's healthcare beliefs and practices?
- What other ethnocultural issues are relevant (e.g. respect for family and elders; distrust of Western medicine)?
- Are there language barriers? If so, what is the best way to reduce them and facilitate communication?

Adherence and Non-adherence

One gauge of a patient's resistance may be the degree to which they adhere (or not) to recommended care. In addition to addressing patient resistance in the session, the genetic counselor must promote the patient's accurate and timely adherence to referrals and recommendations following the session. Studies

of adherence in genetic counseling identify relevant issues including: attendance at scheduled appointments (Humphreys et al. 2000), use of medication and modification of physical activity (Peters et al. 2001), and cancer screening and testing among individuals in families carrying predisposition alleles for hereditary forms of cancer (Gurmankin et al. 2005; Hadley et al. 2003; Shaw et al. 2018). Patient adherence to treatment recommendations comprises an area of active research in many branches of healthcare (cf. Bosworth et al. 2018; Shearer and Evans 2001). While much of the concern with non-adherence involves underutilization, overutilization is also a concern regarding medication (Shearer and Evans 2001), and in genetic counseling, with respect to colon cancer screening among family members found not to carry a predisposition allele (Hadley et al. 2004). Measurement of adherence is difficult both conceptually and practically. Yet it is clearly a significant problem in many areas of healthcare (Bosworth et al. 2018; Shearer and Evans 2001).

A continuation of the example of an adolescent boy with Marfan syndrome, presented earlier in the discussion of the psychological defense of dismissal, illustrates the issue of non-adherence relevant to genetic counseling.

> The adolescent attended the three-month follow-up genetic counseling appointment accompanied by his mother. A discussion of his physical activities since the preceding session revealed that, against medical recommendation, he continued mountain biking. Peer pressure and a desire to fit in with his biking friends had largely negated the sense of trust he had begun to develop with the genetic counselor. A discussion focused on the relationship between Marfan syndrome, excessive exercise, and the risk of aortic dissection, rekindled his concern with the implications of his disease and the importance of adjusting his physical activities.

Factors Affecting Adherence

Similar to resistance, a wide range of individual and societal factors influence adherence, and they are important to assess and understand in order to improve medical adherence (Bosworth et al. 2018):

Individual Factors

- Beliefs and Values
  - The personal, social, familial, and cultural meanings of healthcare behaviors such as exercise, smoking reduction, safe sex, and use of prenatal diagnosis influence adherence, as does the support, or lack thereof, of family and peers (Hadley et al. 2004; Kennedy and Llewelyn 2003; Rapp 2004, 2011).
- Characteristics of the disorder and treatment
  - Severity as well as greater visibility of symptoms are associated with increased adherence
  - Poor prognosis, complicated regimens, adverse effects of medication, lengthy or costly treatments, and alleviation of symptoms before the end of treatment are associated with reduced adherence (Kennedy and Llewelyn 2003; Shearer and Evans 2001).
- Reaction to medical care
  - Anxiety, fear, and other emotions and perceptions may lead to active avoidance of information, as in the case of non-participation in cancer screening (Donald et al. 2005; Schneider 2002) and non-engagement in decision-making regarding genetic testing (Shaw et al. 2018).

  - Lack of information regarding the illness (Shearer and Evans 2001), fear of test results (Hadley et al. 2003), and failure to perceive the importance or potential benefits of healthcare visits (Humphreys et al. 2000).

Social Factors

- The financial challenges and lack of or inadequate healthcare insurance coverage that patients face, especially those of lower socioeconomic status.
- The need for childcare, lack of transportation, and uncompensated work leave reduce adherence to appointments and are related to socioeconomic status.

In addition to individual and social factors, the relationship with the genetic counselor and/or genetic counseling process may affect adherence or lack thereof. Adherence to referrals to genetic counseling has been found to be influenced by patients' perceptions of the genetic counseling process, whether due to the amount of information received at the point of referral, as well as the level of information provided within the genetic counseling session (Shaw et al. 2018). Once patients attend genetic counseling, their trust in the genetic counselor and the information presented influences the way in which they understand and adopt (or not) recommendations for medical management (Bosworth et al. 2018).

Theoretical Models of Adherence and Non-adherence

A number of theoretical models attempt to identify the more dynamic, interactive aspects of adherence and non-adherence (Donald et al. 2005; Shearer and Evans 2001). The *Health Belief Model* (Rosenstock 1977) focuses on perceptions and motivation. Adherence requires that the individual believes the risk of the condition, symptom, or disorder is personally relevant (susceptibility), and believes it is sufficiently serious to warrant a response (severity). The *Comprehensive Model of Information Seeking* (Longo 2005) has three sets of components: antecedents such as gender, ethnicity, education, and experience with and beliefs about the disorder; the individual's assessment of the nature and value of various sources of information; and decisions about which sources to use based on conscious assessment as well as emotional, social and other factors. The *Transtheoretical Model* (Prochaska et al. 2008) addresses the initiation and maintenance of healthcare behaviors. It includes stages of change such as preparation, action and maintenance, and the processes of change including consciousness-raising, self-reevaluation and stimulus control. Individuals preferentially use different processes at different stages. Unlike the other more static models, the Transtheoretical Model introduces the all-important aspect of time and changes over time.

The variety of models, and the fact that each addresses a different set of factors, illustrates the complexity of the actual process of responding to healthcare recommendations. This process involves information and beliefs, cognitive assessment, decision-making, emotional responses, coping mechanisms, psychological defenses, and familial/social/cultural environment influences. In addition, any or all of these, and their interactions, may evolve over time.

Strategies for Increasing Adherence

Although adherence refers to the patient's actions and behaviors outside the genetic counseling session, there is no strict dividing line between what occurs within and outside of the session. The rapport, trust, empathy, adequately explained information and informed decision making that occur in the session will

affect the patient's subsequent actions. In addition, through return clinic visits, follow-up phone-calls, clinic reports and reminder letters, the genetic counselor may continue to have opportunities to interact in a manner that affects patient adherence. Thus, the first step in promoting adherence is preparation for and effective work in the genetic counseling session, including all aspects of working with resistance discussed earlier in this chapter.

The strategies for increasing adherence discussed in the medical literature are identical to central components of genetic counseling. These include (Kennedy and Llewelyn 2003; Shearer and Evans 2001):

- Provide information about the disorder and proposed treatments tailored to the patient's knowledge and concerns.
- Explore and address when appropriate the patient's questions, concerns, sources of support and healthcare beliefs and practices.
- Include and support the patient in decision making and planning, which may involve multiple steps under evolving circumstances.
- Support patient autonomy and competence.
- Provide appropriate written materials and follow-up.
- Acknowledge the context of the patient's social and cultural environment in providing referrals and recommendations.

The concordance between these recommendations and the practice of genetic counseling suggests that, in addition to improving their skills for enhancing adherence within the genetic counseling session, genetic counselors play a key role in adherence both with in-session work and follow-up. Discussing the importance of including the patient in defining and implementing the treatment plan, Kennedy and Llewelyn (2003) state, "Working collaboratively [with the patient] <u>may demand new skills from staff</u>" (p. 32, emphasis added). As genetics expands into new areas of genomic medicine (Epstein 2006), genetic counselors have the opportunity to present, among their many skills, those relevant to the all-important issue of patient adherence and non-adherence.

Motivational interviewing (MI), a well-known and validated method of enhancing patient motivation for change in other healthcare contexts, has been proposed as an effective method to address patient' resistance and adherence to behavior change in genetic counseling (Ash 2017; de Geus et al. 2016; Eijzenga et al. 2018). MI has been found to be effective in building relationships with patients who present with ambivalence regarding genetic counseling and the information/recommendations presented. The MI approach or "spirit" utilizes a host of person-centered counseling skills (e.g. reflection, open-ended questions, affirmation) to elicit change talk with patients and guide them to a resolution of ambivalence and ultimately, behavior change (i.e. adherence; Westra and Norouzian 2018). Genetic counselors can adopt four distinct but related processes from MI in addressing patient adherence:

- *Engaging:* The genetic counselor builds a working alliance with patient to contract and understand the patient's perspective. This allows the counselor to meet the patient where they are at and assess factors that may contribute to resistance and ultimately, adherence and non-adherence to medical recommendations (Daly 2014).
- *Focusing:* An agreed upon session agenda, collaborative goals, and information exchange occur between genetic counselor and patient. Focusing is where the genetic counselor can actively engage the patient in information and identify patient "change and/or sustain talk" (i.e. defined in MI as the patient's expression of ambivalence or desire, ability, reason or need for behavior change).

- *Evoking:* The genetic counselor identifies areas of the patient's desire or ambivalence and then validates, explores, or clarifies these perspectives so the patient can either further their commitment to change or resolve their ambivalence.
- *Planning*: Finally, the genetic counselor continually summarizes the patient's comments and asks for collaborative commitment for the next steps and plan of action. Key questions are often: So where does this leave you? What do you see as your next steps?

Ash (2017) presents additional MI strategies and illustrations for genetic counselors to "Roll with Resistance" to facilitate patient behavior change or action.

A limited number of studies demonstrate the value of addressing adherence and non-adherence in genetic counseling practice. Timely, appropriate follow-up has been shown to increase parents' utilization of genetic counseling following newborn detection of heterozygous (trait) status for sickle cell and other hemoglobinopathies (Kladny et al. 2005) and to reduce delays in colonoscopy screening for individuals at high risk for colorectal cancer (Bleiker et al. 2005). In a study of delayed colorectal screening among members of Finnish families at high risk for colon cancer, Bleiker et al. (2005) also found that delays in colon screening may be reduced by acknowledging the potential discomfort and embarrassment about the procedure.

Research on the use of genetic counseling by first-degree relatives of individuals with hereditary non-polyposis colorectal cancer (HNPCC) (Hadley et al. 2003, 2004) indicates that a discussion of concerns about the emotional impact of test results on the individual and other family members, as well as fears of loss of health insurance, would increase use. However, the emotional concerns that patients identified on the research questionnaire were often not expressed in face-to-face sessions. The fact that these concerns were not expressed in face-to-face sessions demonstrates the importance of carefully pursuing such issues during genetic counseling (Hadley et al. 2003).

Peters et al. (2001) investigated perceptions of and adherence to medication and modified physical activity among individuals with Marfan syndrome. They found that respondents' concerns about medication went beyond harmful physical effects and included the implications of treatment for the patients' lives and self-perceptions. "The daily ritual of taking cardiovascular medication serves as an uninvited reminder of respondents' lack of control over the condition precipitating medication use" (p. 289). Self-reported medication adherence was high in this study (up to 80%). Nonetheless, the researchers concluded that, when discussing medication with a patient in order to promote adherence, the genetic counselor should include its potential impact on the patient's self-perception and sense of efficacy and control. The latter two studies make clear the importance of thoughtful, empathic exploration to identify patient concerns that are initially unexpressed as well as to detect sources of anxiety and self-definition that may underlie their specific concerns.

Summary

- Resistance refers to attitudes, behaviors, emotions and ways of thinking by which a patient limits full engagement with the process of genetic counseling. Adherence, with the converse non-adherence, refers to the extent to which patients follow advice and recommendations provided in genetic counseling. Resistance and non-adherence are common and normal, and the genetic counselor must be prepared to address both types of behavior.

- Resistance can occur at any stage of genetic counseling and/or in response to the circumstances that make genetic counseling necessary or desirable. Emotional responses, beliefs and values, and the individual's social milieu interact to evoke resistance.
- Resistance serves an important role in protecting the individual from painful or potentially overwhelming emotions, personal or interpersonal conflicts, and decisions. Recognition of this protective role is essential for responding effectively to resistant behavior.
- Empathy, attempting to understand the source of resistance, and careful attention to one's own emotional responses (countertransference) are central to working with resistant patients. Discussing the reasons underlying resistant behavior; affirming the patient's dignity, integrity and sense of efficacy; and supporting feelings of control and autonomy may reduce resistance.
- Disbelief, deferral, and dismissal are specific types of resistance that involve different behaviors, may evoke different forms of genetic counselor countertransference, and require different responses from the counselor. Resistance may evolve over time, thus requiring continual evaluation and flexible responses by the genetic counselor.
- Adherence and non-adherence to medical recommendations are related conceptually to resistance, and they are directly relevant to genetic counseling. A wide variety of factors interact to influence adherence to medical recommendations. These factors include the nature, severity, and social meaning of the disorder and of recommended treatment or prevention; practical limitations such as transportation or child care; and patient lack of information as well as anxiety or fear about treatments or test results. The patient's response to medical recommendations involves interacting cognitive, emotional, and psychosocial processes.
- Empathic counseling in the session, including addressing resistance, is central to promoting adherence. The genetic counselor should discuss with the patient the actions and procedures involved in the recommended treatment or referral, potential outcomes with and without treatment, and the relationship between the treatment and the nature and causes of the condition. The patient should be an active participant in this discussion, which includes identifying relevant resources, setting realistic goals, and addressing anxieties and concerns about the physical, emotional, and psychosocial consequences of the treatment.
- Motivational Interviewing is one approach that integrates various counseling skills to address resistance and facilitate patient commitment to behavior change and adherence. Through processes of engaging, focusing, evoking, and planning that are compatible with genetic counseling components and interventions, a genetic counselor can collaborate with the patient to facilitate or direct their motivation or ambivalence regarding change.

Learning Activities

Activity 7.1 Discussion

Students discuss in dyads or as a group the following questions: Have you ever been in less than full adherence concerning a medication, diet, exercise, weight loss, smoking reduction or other medical or healthcare recommendation? If so, what were factors that contributed to your resistance and decreased adherence? What might a healthcare provider have done that would have increased your