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Cultural Factors and Concepts of Pollution:  
Colorectal Cancer and Health Behaviors among Ashkenazi Jewish Women

by

Karen Besterman-Dahan

A dissertation submitted in partial fulfillment  
of the requirements for the degree of  
Doctor of Philosophy  
Department of Anthropology  
College of Arts & Sciences  
University of South Florida

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Keywords: cancer prevention, Judaism, purity, Mary Douglas, disparities

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## Dedication

I dedicate this dissertation to my family and biggest cheerleaders; my husband, Emad Dahan, my children, Jared and Kyra, and my mom, Phyllis Besterman, for their encouragement, love, support and patience that sustained me through this process. In loving memory of my father, Dr. Gerald Besterman.

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## List of Terms

The following terms are used as operational definitions for the purposes of this dissertation.

### **Hebrew/Jewish/Yiddish Terms**

Ashkenazi – Jews whose families come from Europe (central/Eastern) referred to as Ashkenazim. *Ashkenaz* is the Hebrew word for Germany. (Telushkin, 1991: 206)

Bracha – Blessing; comes from the word *berekh*, meaning 'knee', thus suggesting a bended knee is the proper posture for one who is approaching God. (Telushkin, 1991; 670)

Chabad – (Chabad-Lubavitch) Hasidic movement founded in Russia at the end of the eighteenth century. Headquartered in Crown Heights, Brooklyn. Tremendous emphasis placed on outreach, particularly on influencing nonobservant Jews to accept Jewish ritual observances. Services are Orthodox, with an emphasis on singing and joyous praying. (Telushkin, 1991: 430-1)

Conservative Judaism – Denomination which strikes middle ground between Reform and Orthodox. Unlike Reform, it considers itself bound by almost all of the Torah rituals as well as Torah ethics. Unlike Orthodoxy, it considers itself free to introduce innovations in Jewish law, particularly as the laws formulated in the Talmud. Promoted Jewish legal innovations, including permission to drive on the Sabbath, calling women up to read from the Torah, and allowing women to be invested as cantors and ordained as Rabbis. (Telushkin, 1991: 397)

Halacha - The collective body of Jewish religious law, including biblical law (the 613 *mitzvot*) and later Talmudic and Rabbinic law, as well as customs and traditions. These laws legislate precise modes of behavior for virtually any situation in which a person finds himself. (Telushkin, 1991: 241)

Kashrut - Jewish dietary laws. *Torah* associates *kashrut* with holiness (Leviticus 11:44-45, Deuteronomy 14:21) The laws regulate that Jews are not permitted to eat whatever they want, and even permitted foods must be prepared in a special way. Certain animals may not be eaten at all. This restriction includes the flesh, organs, eggs and milk of the forbidden animals. Some of the rules include the following broad categories:

1. Of the animals that may be eaten, the birds and mammals must be killed in accordance with Jewish law.
2. All blood must be drained from the meat or broiled out of it before it is eaten.
3. Certain parts of permitted animals may not be eaten.

4. Fruits and vegetables are permitted, but must be inspected for bugs
5. Meat (the flesh of birds and mammals) cannot be eaten with dairy. Fish, eggs, fruits, vegetables and grains can be eaten with either meat or dairy. (According to some views, fish may not be eaten with meat).
6. Utensils that have come into contact with meat may not be used with dairy, and vice versa. Utensils that have come into contact with non-kosher food may not be used with kosher food. This applies only where the contact occurred while the food was hot.
7. Grape products made by non-Jews may not be eaten. (Telushkin, 1991: 634-6)

Mikvah - A ritual bath used for spiritual purification. It is used primarily in conversion rituals and after the period of sexual separation during a woman's menstrual cycles. Most *mikva'ot* are located in buildings, however any body of natural water (ocean, pond, lake) can serve as a valid *mikvah*. Women go to the *mikvah* on the first evening on which they are permitted to resume sexual relations according to family purity laws. No men are present when the woman uses it; the woman undresses and immerses herself in the waters while unclothed. She then recites a blessing to God. Only after thoroughly immersing herself is a woman permitted to resume sexual relations with her husband. Some Jewish men immerse themselves in the *mikvah* especially before the Jewish holidays, on Fridays to prepare for Shabbat, or even daily. *Mikvahs* are also used in the conversion to Judaism. (Telushkin, 1991: 618-19)

Mishaberach – A special prayer recited during the reading of the Torah in synagogue, which petitions God for the speedy recovery of an ill person. (Telushkin, 1991: 531)

Mishegas (meshegaas, mishegaas) – craziness, madness (Yiddish dictionary online, 2008)

Mitzvah - . Commandment. Any of the 613 commandments in the Torah that Jews are obligated to observe. While commonly considered a good deed (voluntary) *mitzvot* are actually obligations. (Telushkin, 1991: 495)

Niddah -. Separation, as in separation of the menstruant in the family purity laws (*taharat hamishpacha*). As these laws are commonly understood, they proscribe all physical contact when a woman is in *niddah* (separation) This occurs not just during blood flow, but extends until she goes to the mikvah and consciously changes her status. The word “niddah” is a functional term whose application is not limited to women, but can include anyone who is exempted from society for a short period of time. This exemption can be either positive or negative; in itself it does not have any value connotations. (Jewish Virtual Library, 2008)

Orthodox Judaism – Orthodox literally means ‘correct belief’. Jewish Denomination whose faithfulness to the practices of Judaism and to Jewish law as in its traditional formulation. Granted that the Torah is of divine origin.

(Telushkin, 1991: 437)

Pikuach nefesh - The obligation to save a life in jeopardy; considered a major value to uphold. In most circumstances, all Jewish laws are to be suspended when human life is at stake. Based in Leviticus 18:5, “You shall keep my statutes and my ordinances, which if a man do he shall live by them.” Rabbis understood this to mean “You shall live by them and not die by them.” (Yoma 85b) (Telushkin 1991: 521-22)

Reform Judaism – Denomination that arose in Germany in the late 1800’s as both a reaction against Orthodox rigidity and a response to Germany’s liberal, political climate which was open to Jews dropping rituals that isolated them from their German neighbors. Reformed synagogue services and Jewish laws, declared the *Torah*’s ritual laws no longer binding. This included dropping obligations for rules of *kashrut* and Sabbath restrictions which isolated Jews from their non-Jewish neighbors. Coined the term ‘ethical monotheism’ to convey the belief that the world is ruled by one God whose primary demand of humans is ethical behavior. Introduced many changes into Jewish life, including being the first denomination to ordain women as rabbis. Also, dropped requirement for a religious divorce (*Get*) and altered traditional matrilineal definition of a Jew to include anyone born with a Jewish father and a non-Jewish mother as long as they are raised with a Jewish identity. (Telushkin 1991: 230-2, 394)

Shul - Yiddish term for a Jewish house of worship; also means school. (Telushkin 1991: 641)

Tameh/Tumah – Commonly translated as ‘impure’; ancient term applied to anyone who is forbidden to have contact with sacred food, or to enter the Temple precincts in Jerusalem; a state when certain ritual acts are forbidden. State of a woman who is menstruating. (Telushkin, 1991: 617)

Taharat Hamishpacha – Laws of family purity, concerning sexual separation. The Torah categorically prohibits sexual relations between husband and wife during the woman’s menstrual period (Leviticus 18:19 and 20:18) as well as during other times of uterine bleeding. The rabbis, concerned that women would not be able to distinguish the sources of the bleeding, collapsed all distinctions (Leviticus 15:25-33) and decreed that sexual relations be prohibited for a full seven days after the woman has experienced the last drop of blood. (Telushkin, 1991: 617)

Tanakh - Acronym of the three categories of books that make up the Hebrew bible: *Torah* (Law), *Nevi'im* (Prophets) and *Ketuvim* (Writings). Written *Torah*; what non-Jews call the Old Testament. (Telushkin, 1991: 23)

Torah - The first five books of the Hebrew Bible: Genesis, Exodus, Leviticus, Numbers and Deuteronomy. Regarded as Judaism’s central document. Along with stories about the Patriarchs, Matriarchs, Moses, Exodus from Egypt, they contain 613 commandments, which are the backbone of all subsequent Jewish law (*halacha*). Also called *Chumash* – from the Hebrew *chamash* (five) - and the

Pentateuch. According to Jewish tradition, the books were dictated to Moses by God around 1220 BCE, after the Exodus from Egypt. (Telushkin, 1991: 23)

### **Colorectal Cancer Terms**

Colonoscopy - An internal examination of the colon (large intestine), using an instrument called a colonoscope. The colonoscope is a small camera attached to a flexible tube. Unlike sigmoidoscopy, which examines only the lower third of the colon, colonoscopy examines the entire length of the colon. (MedlinePlus Medical Encyclopedia, 2008)

Flexible sigmoidoscopy - An internal examination of the lower large bowel (colon), using an instrument called a sigmoidoscope. (MedlinePlus Medical Encyclopedia, 2008)

Fecal occult blood test (FOBT) - a noninvasive test that detects hidden (occult) blood in the stool. Such blood may come from anywhere along the digestive tract. Hidden blood in stool is often the first, and in many cases the only, warning sign that a person has colorectal disease, including colon cancer. (MedlinePlus Medical Encyclopedia, 2008)

Cultural Factors and Concepts of Pollution:  
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Karen Besterman-Dahan

ABSTRACT

The colorectal cancer (CRC) incidence in Ashkenazi Jews has been found to be highest of any ethnic group in the world (Feldman, 2001). It is currently unclear how culture and religion influence health behaviors of U.S. Ashkenazi Jews, as well as what other socio-cultural factors influence AJ women's attitudes towards CRC risk and screening practices. This study aimed at exploring and describing the cultural and religious influences on health behaviors and beliefs related to CRC in Ashkenazi Jewish women. Research participants included seven key informants (rabbis) and forty-two Ashkenazi Jewish women ages 50 and up. Methods included in-depth, qualitative interviews and focus groups. The study also utilized a demographic survey which included questions about baseline knowledge of colorectal cancer in Ashkenazi Jews, and a ten-item *American Cancer Society's Questionnaire on Experiences with and Attitude toward CRC Screening*. Participants were recruited from Tampa synagogues and community using non-probabilistic sampling. Results revealed only 5% of participants were aware of the increased prevalence of colorectal cancer in Ashkenazi Jews; still, most participants (88%) were up to date on colorectal cancer screening. Judaic purity laws did not resonate with many participants, and for those who did follow them, they did not take a view of bodily functions as being impure. A consistent description of a 'Jewish way' of looking at health emerged, involving both the push for education, which increases knowledge

about and access to healthcare, as well as the core Jewish tenet of the infinite value of life. No significant differences were found among the screening practices of the three self-identified denominations, and only breast and cervical cancer screening were found to be significantly different between those who have ever had a CRC screening and those who have not. Recommendations highlight the need for future research in this area including larger samples, further exploring core Jewish tenets as related to health behaviors in this population, partnering with the Jewish community for interventions, and addressing ways to better track CRC incidence, mortality and screening in this population in order to raise awareness.

## **Chapter One**

### **Introduction**

This chapter will introduce the problem of colorectal cancer incidence in the Ashkenazi Jewish population, and review the relationship between culture and religion. The rationale for conducting this study will next be described, and the research questions will be explained. Finally, the significance of this study will be discussed.

### **Statement of the Problem**

The colorectal cancer (CRC) incidence in Ashkenazi Jews (AJ) has been found to be highest of any ethnic group in the world (Feldman, 2001). Although CRC screening rates of AJ in the United States are not tracked, several studies of AJ have found overall compliance with CRC screening to be low in North America, despite being vigilant about screening for other cancers (Friedman, et al, 1999, Cappelli, et al, 2002). Additionally, due to the categories of race and ethnicity in which national CRC statistics are tracked in the United States, the burden of CRC in the AJ population is poorly publicized. Health research is based on OMB Directive 15 categories of race and ethnicity. Interpretation of the research findings often is on the "variables" of race and ethnicity from these categories, despite these categories being noted for their absence of "scientific or anthropological" foundations in its formulation, without explanation of what was

meant by "race" or "origin," or what distinguished these concepts, or standardized for self-identification or determination by others (American Anthropological Association, 1997). Ashkenazi Jews are included in the 'white' category; therefore their CRC screening rates, incidence and mortality are diluted in the overall 'white' rates, and not known on their own. CRC screening in Israel is noted to be very poor at 20% (Rennart, 2007), and researchers have noted that efforts to enhance knowledge and understanding in screening did not affect overall compliance, concluding that emotional barriers must first be targeted before any efforts are made to increase compliance via information delivery on CRC are justified (Ore, et al, 2001).

Culture and religion are known to influence medical and personal decision making (Bowen, 2003; Holt & McClure, 2006). Geertz (1973) stresses the importance of thinking in terms of "culture" when discussing religion, defining culture as the systems of meanings inherent in every action which create order, purpose and reason. As well, culture largely shapes what an individual or society deems disgusting (Olatunji & Sawchuk, 2005). Cross-culturally, bodily waste products are considered a core disgust elicitor (Rozin, et al, 2000), and the taboo against any mention of things related to excretion has been noted in the U.S. (Reynolds, 1974). Although preventive medicine is a centerpiece of the Jewish medical perspective (Rosner, 2002), bodily discharges are also specified as defiling in the sacred texts of which Judaism is built upon (Douglas, 1966). The CRC screening process involves discussions about elimination and physical contact with feces, both of which are taboo in the U.S. and in Judaism. Thus, it is



currently unclear how these compounded cultural and religious based concepts of pollution impact the health behaviors of U.S. Ashkenazi Jews, as well as what other socio-cultural factors influence AJ women's attitudes towards CRC risk and screening practices.

### **Rationale**

One of anthropology's great contributions has been to provide deeper understandings of meanings of cancer causality of various groups. This is crucial to any treatment, prevention or education initiative. Through ethnographic and other qualitative and mixed methods, anthropologists have been able to delve into depths of meaning and experience often lacking in other medical studies. This is particularly critical when diverse and complex groups are made to fit into a priori categories of race and ethnicity – often used interchangeably in medical literature - which may not explicate the underlying causal pathways that result in worse health (Lee, 2006). While culture and religion are known to influence medical and personal decision making (Bowen, et al, 2003; Holt & McClure, 2006), it is unclear what factors influence AJ adults' attitudes towards CRC risk and screening practices. This lack of understanding particularly applies to how the U.S. AJ Jews embody the concurrent religiously based Jewish concepts of pollution along with the U.S. culturally based taboo against anything related to excrement, nor how these compounded taboos impact health behaviors and risk. With the disparate rates of CRC in this group, a richer of understanding cultural and emotional beliefs as related to CRC is critical to the success of future cancer control initiatives in the AJ population. This dissertation is a descriptive,

qualitative study that incorporates the use of an ethnographic survey and a questionnaire which evaluates the experiences with and attitude toward colorectal cancer screening. This research will allow exploration of socio-cultural factors – including pollution concepts, religious perspectives, and risk perception - influencing the risks this population is willing to accept and avoid related to CRC.

As well, with CRC disparately affecting Ashkenazi Jews, a need exists to create solutions for the development of cancer communications regarding screening, and prevention. It is vital to understand the worldview of a group, and speak within that framework. The insights gained from this study can inform the design of relevant cancer communication initiatives for this population to reduce the disparate burden of CRC.

### **Research Questions**

The guiding research question for this study is: *how do the concurrent cultural and religious based concepts of pollution impact the health behaviors of U.S. Ashkenazi Jews, and what other socio-cultural factors influence AJ women's attitudes towards CRC risk and screening practices.*

This involves the following questions:

1. What are the cultural and religious influences on health behaviors in AJ women?
2. What are the social, cultural and religious contexts influencing individual perception of risk of CRC and autonomy to manage them?
3. What are the ways in which AJ women embody the concurrent U.S. and Judaic based taboos associated with the gastrointestinal tract as related to health and CRC health behaviors?

4. What are the sources and understanding of health information regarding CRC?

**Significance**

CRC remains a top health priority, particularly in the Ashkenazi Jewish population where it has been found to be as high as 2-3 times that of the general populations of developed countries, the most important worldwide cancer killer proven to disproportionately overburden AJ (Feldman, 2001). In the U.S., CRC screening rates are low in general (Mitka, 2008), suggesting that educational programs which convey uniform messages to an entire population have a limited effect (Pasick, Hiatt, & Paskett, 2004). It has been noted that research in the area of cancer screening and detection must be specifically designed for ethnic differences (Kagawa-Singer, 2000), thus educational programs should emerge from research –based programs. Previous studies have indicated that awareness and screening programs that have not addressed cultural and emotional issues or knowledge and acceptance barriers to screenings have had limited success in the AJ population (Ore, et al, 2001, Cappelli, et al, 2002). Thus, it is critical for cancer control initiatives to include formative research into the emotional and cultural beliefs of this population, which should then be to inform any cancer control program. As Pasick, Hiatt, & Paskett (2004) suggest, much can be learned from the formative research already being conducted in developing cancer screening interventions for specific ethnic groups, recommending “a shift from emphasizing outcomes to encouraging publications on the extensive qualitative work conducted as part of many intervention studies would provide a rich body of cross-cultural, comparative data.”

This research was designed to contribute knowledge to understanding the influence of religion and culture on the health behaviors and beliefs of Ashkenazi Jewish women, a high risk group disparately affected by colorectal cancer. This understanding is critical to the development of CRC prevention, education and promotion activities. Additionally, this research may offer insight into intra-cultural variation in the health behaviors and beliefs of the women under study. This is significant because known family history of disease often influences perceptions of personal risk; however within this group of subjects are several whose family medical history remains unknown due to their family perishing in the Holocaust. Finally, it has been noted that research dedicated to a better understanding of the relationships between health status and different ethnic and racial minority backgrounds will help acquire new insights into disparities (DOH, 2003). Thus, this research is important in providing better understandings of the worldview and perceptions of CRC risk from this population to help reduce the disparate CRC rates.

## **Chapter Two**

### **Review of literature and significance**

#### **Introduction**

This chapter reviews the relevant literature for this research. In this chapter I will describe the centrality of purity in Judaism, as well as anthropological concepts of purity and how this speaks to disease and stigma. Colorectal cancer screening, incidence, mortality within the general and U.S. population will be reviewed, and commonly identified barriers to colorectal cancer screening will be described. I will explain how Judaic concepts of purity as well as Western taboos against bodily waste could concurrently affect colorectal cancer screening in Ashkenazi Jews in the United States. I will examine Jewish culture specific to concepts of health beliefs, and how this could inhibit or promote preventive health behaviors. Additionally, I will review the categories used to monitor and track national health statistics in the United States, as well as the ways these categories may be ineffective in their task of monitoring health disparities and highlighting the varied disease risk of populations. Finally, I will discuss health disparities and the current focus on cultural competency within biomedicine; the pitfalls of confusion between race and ethnicity, and the reduction of culture to a trait- list. The danger of all this is that Jewish culture risks being the primary identified culprit in barriers to health behaviors, rather than examining the underlying culture of biomedicine, which bases health

research and the interpretation of the research findings on the "variables" of race and ethnicity from OMB Directive 15 categories, despite these categories being noted for their absence of "scientific or anthropological" foundations in its formulation, and without explanation of what was meant by "race" or "origin," or what distinguished these concepts. The review focuses on: 1) Jewish Religion and Culture; 2) U.S. Jewish Identity; 3) Judaism and Purity; 4) Bodily Margins; 5) Disgust; 6) Risk Perception; 7) Disease and Stigma; 8) Judaism and Medicine; 9) Stigma and Judaism; 10) Cancer and Culture; 11) Burden of Colorectal Cancer in the Ashkenazi Population; 12) Colorectal Cancer screening; and 13) Colorectal Cancer screening in the Ashkenazi Population. A summary finishes the chapter.

#### **Jewish Religion and Culture:**

Geertz (1973) stresses the importance of thinking in terms of "culture" when discussing religion, defining culture as the systems of meanings inherent in every action which create order, purpose and reason; it is these meanings which give rise to the social reality people accept as a given and these givens which form the tradition of a culture. He further defines religion as a system of symbols whose meanings both act upon and are acted upon by people's actions in a continuous dialogue, so that cultural systems both shape and are shaped by individual actions. Thus, ideas and meanings are embedded within our worldview, responsible for determining the mood and motivation of action (Brill, 2004). Berger (1967) characterizes culture as embracing all human activity, including worldview, lifestyle, eating habits and attitudes toward daily activities; similar to Geertz, religion is always embedded in culture, offering meaning in the

construction of cultural life. When applying this concept to Judaism, culture is not outside of Judaism, but is the very place which Judaism embodies. Herman (1989) notes that Judaism is the religious civilization of one particular nation, residing in the Jewish people, reflecting its history; in other words, the Jewish people are what they are because of this religious civilization, and because of this history, even the Jewishness of non-religious Jews cannot be completely divorced from its religious associations.

Geertz helped explain how the 'sacred canopy' of religious traditions provide a sense of human destiny, and an understanding that fuses normative notions of moral obligations and duties to others with descriptions of how the world is and came to be. In this way, particular moral norms are woven into the very fabric of the cosmos, understood to be self-evident. To live within the boundary of a sacred canopy is to possess a sacred narrative, recorded in a text which is understood to be more than just the product of the authors, involving divine involvement in their making and providing core moral insights. Sacred texts often are used as the basis for analysis of contemporary moral issues; in fact, some interpretations of these texts can be so central to the self-understanding of a community that they remain dominant for generations (Turner, 2003). Modern Judaism is Rabbinic Judaism, based on core texts which include both those of Biblical Jews as well as all the Rabbinic commentary and codification of biblical laws, including (Telushkin, 1991):

1. The *Tanakh* – the Hebrew Bible

- a. The *Torah* - the five books of Moses

b. 8 books of *Nvim* -Prophets

c. 11 books of *Ktuvim* - “Writings’ – Wisdom and Poetry books

2. The *Talmud* - record of rabbinic discussions pertaining to Jewish law, ethics, customs and history

a. The *Mishnah* (c. 200 CE) - the first written compendium of Judaism's Oral Law

b. The *Gemara* (c. 500 CE) - a discussion of the Mishnah and the basis for all codes of rabbinic law.

3. Halachic Literature – Jewish laws, including:

a. The *Mishneh Torah (Yad ha-Chazaka)* (C. 1170-1180 CE) - code of Jewish law by Maimonides

b. *Shulchan Aruch* (c. 1500 CE) - the codification of *halacha* (Jewish law) which, together with its commentaries, is considered by the vast majority of Orthodox Jews to be the most authoritative compilation *halacha* since the Talmud, with the exception of a minority who continue to hold by the *Mishneh Torah*.

4. *Midrash* - stories

a. *Aggadot* - folklore, historical anecdotes, moral discourse, and business and medical advice

b. *Halachic* stories to explain laws

### **U.S. Jewish Identity:**

The 2000-2001 National Jewish Population Survey (NJPS) estimates the



number of American Jews to be near 5.2 million, with 4.3 million American Jews reporting to have some sort of strong connection to the Jewish community, whether religious or cultural. Among those who belong to a synagogue, 38% are members of Reform synagogues, 33% Conservative, 22% Orthodox, 2% Reconstructionist, and 5% other types. Over 95% of the Jews in the U.S. are of Ashkenazi heritage (from eastern and central Europe) (Feldman, 2001). In socioeconomic terms, a recent survey found 46% of Jews in the U.S. to have incomes >\$100,000 and 59% to have a college and/or graduate degree (Pew Forum, 2008). Still, poverty is also an issue for many; in the New York metropolitan area, home to the largest Jewish population in the world outside Israel, 20% of the Jews are living in poverty, of whom 34% are over the age of 65 and 49% are Russian-speaking. Additionally, over 40% of adults in poor Jewish households report having a bachelor's degree (Ukeles & Grossman, 2004).

The fusion of religion, culture and ethnicity of Jews differentiates them from other European-origin groups (Kivisto & Nefzger, 1993). Religiosity, ethnicity and identity are interwoven, with Jewish identity embedded in everyday life. Amyot and Sigelman (1996) define Jewish identity as a *combination* of religious Judaism and cultural Jewishness. As previously mentioned, Jews currently have a strong socio-economic position in the U.S. society, and the strong economic and associational ties this position offers may reinforce ethnic identity among Jews (Goldscheider, 1995). Although high socioeconomic status usually indicates successful assimilation among minority groups into the

dominant culture, studies have indicated that assimilation has not meant giving up their Jewish identities (Kaufman, 1999). It has been argued that understanding of Jewish identity relies on biological discourse, such that Jews believe their Jewishness to be both hereditary and permanently fixed (Rothman, 1998; Kahn, 2005). Despite having a choice on *how* to express being Jewish – particularly for U.S. Jews who are free to choose among a variety of identities and practices - whether of not *to be* Jewish is often perceived as a given, a biological imperative, such that an essential Jewishness is part of their nature (Tenenbaum & Davidman, 2007).

### **Judaism and Purity**

Judaism is built upon doctrines which specify laws of purity, with reference to symbols of purity and impurity coming chiefly from the priestly writings, legal, prophetic or historical (Douglas, 1993). Jewish law indicates that sources of defilement include certain animals, the woman after childbirth, skin ailments, mildew in the house, bodily discharges, sexual misdeeds and the corpse (Neusner, 1973). Rabbinic commentary typically has two explanations of the purity laws: they are strictly hygienic, to avoid the spread of infection, or they are purely religious, to lead men to holiness. The Jewish concept of holiness is considered to be the very essence of God, His recoil from everything impure and unrighteous, and His freedom from that which makes men imperfect. In Judaism holiness is not an abstract idea; rather this concept shapes and regulates every sphere of human life and with the goal being for men to imitate these ethical qualities. Jewish laws take on the whole of human life as its province, controlling

all details of domestic, spiritual and physical existence; since none of these actions can be withdrawn from the unity of life, neither can Jewish law cannot be excluded from any aspect. Thus, not only is there a duty to avoid what is spiritually or physically defiling, but purity laws are a means to bring men toward cleanliness, and, ultimately, holiness (Hertz, 1993).

It has been argued that the laws were neither primitive health regulations nor randomly chosen as tests of Jew's' commitment to God; rather, the laws were related to symbolic boundary-maintenance (Douglas, 1966). Douglas (1966) notes that since each of the purity laws is prefaced by the command to be holy, so they must be explained by that command focused on the idea of the holiness of God which Jews must create in their own lives. "To be holy is to be whole, to be one; holiness is unity, integrity, perfection of the individual and of the kind" (Douglas, 1966, 67). Thus, everyone is liable to be defiled or to defile because impurity comes out of the body or from moral failure.

*One may think of it like a rift in existence: on the one side there is God and everything he establishes, on the other side, inevitably and necessarily, there is impurity. For the Bible, and in the whole region, the destructive effect of impurity is physical, like a lightning bolt or a disease. Nothing less than divinely instituted rites of purification will defend against it. (Douglas, 1993, 23)*

Initially the laws of defilement were used to protect the sanctuary; if you were impure you could not enter the *Mishkan* or Temple or participate in certain cultic acts, and if you were pure you could do so (Neusner, 1973). However, the purity doctrine eventually became part of the organization and rationalization of the philosophy of Judaism (Douglas, 1993). It is important to note, however, that aspects of ritual impurity and purity were fully consequential only within the

domain of the Temple; after the destruction of the second temple two thousand years ago, ritual impurity no longer was a relevant issue (Berkowitz, 2006). Still, ritual purity codes such as *niddah* persist in modern times (Hammer, 2007), albeit with great controversy to their interpretation.

### **Bodily Margins:**

Douglas (1966) found each culture to have its own special risk and problems, and to which particular bodily margins its beliefs attribute power depends on what situation the body is mirroring. When rituals express anxiety about the body's orifices, the sociological counterpart of this anxiety is a care to protect the political and cultural unity of a minority group. "[The] Israelites were always in their history a hard-pressed minority. In their beliefs, all the bodily issues were polluting. The threatened boundaries of the body politic would be well mirrored in their care for the integrity, unity and purity of the physical body" (Douglas, 1966; 124). Douglas (1966) explains that the power residing in the margins of the body is more often to be avoided than an instrument of desire, since any structure of ideas is vulnerable at its margins. Thus, we should not only expect the orifices of the body to symbolize particularly vulnerable points, but matter issuing from them to most marginal of all. "The possibility of imagining God with organs of digestion and excretion is out of the question for this divine. Indeed, it is not entertained at all for the Jewish religion" (Douglas, 1970, xxxiv).

It has been noted that with rabbinic Judaism, the sages understood that the body anchors discourses about religious practice and belief; *Midrashic* texts discuss at length the meanings of God's image and anchor them in the body of

*adam*, so rabbinic theology is inseparable from thinking about the body. Thus, the sages inherited the priestly doctrine of the *Torah* and greatly added to it; biblical law not only establishes the central difference between ritual purity and impurity to draw a connection between the body and the sacred, thus conferring all of subsequent Jewish culture with a corporeal conception of holiness, it is interested in the morphology of the body itself when it describes those with imperfections who may not approach the alter. Rabbinic commentary later elaborates and codifies these biblical laws, adding its own concerns, which include accounting for the body in aspects of religiosity (Fonrobert. 2005).

Jewish law (*Halacha*) is explicit regarding issues of impurity and bodily fluids. For example, the Torah has 'family purity laws' (*Taharat Hamishpacha*), which state that a menstruating woman is in a state of *niddah* for seven days from the beginning of her cycle; she is considered *tameh* (unfit/impure) and there are prohibitions for her husband from having intercourse with her. Talmudic scholars and customs extended the period of separation so that it lasts a minimum of 12 days, with separation beginning at the first sign of blood and ending in the evening of the woman's seventh "clean day." As well, rabbinic law later broadened the definition of separation, from avoiding intercourse to a man not sharing a bed or even touching his wife while she is in a state of *niddah*. Purification can be gained only by a ritual bath (*mikvah*) and until the woman has taken this she remains *tameh*. However, since the second Temple was destroyed two thousand years ago, the ritual purity aspect is non-functional, as all Jews are ritually impure; thus, it has been suggested to focus on the matrimonial aspect of

the laws, not on ritual purity (Berkowitz, 2006). Interestingly, the Prophets also used the term *niddah* to depict the People of Israel when they are involved in sin, such as immorality or idol-worship or violence, and consequent estrangement from God (Orthodox Union, 2007). As the language of defilement continues to be unnecessarily applied to women only (Ross, 2004), the subject of *niddah* and role of purity and gender in Jewish culture has been the topic of numerous studies and commentary (Fonrobert, 2007).

Jewish law and commentary is equally definitive regarding bodily waste. In ancient Judaism, just as purity codes were originally used to protect the Temple, with the ultimate goal to attain holiness, holiness was thought to be key in the winning any battles. Deuteronomy 23:10-15 thus explicate the need for function producing bodily waste to be performed outside a soldier's camp, in order to preserve it from defilement and remain holy. Laws specify that an area outside the camp must be designated as a privy, and a spade must be kept among soldiers' instruments in order dig and cover up excrement – laws still considered to be 2 of the 613 *mitzvot* (commandments) found in the Torah. This is because 'thy God walketh in the midst of thy camp to deliver thee and to give thine enemies before thee; therefore shall they camp be holy: that He sees no unseemly thing that one would be ashamed of and turn away from thee' (Deuteronomy 23:15). Further commentary by Maimonides explained that 'camp' actually designated any place of prayer or settlement, because wherever we live we are "to bear the stamp of a pure moral way of living, doing nothing to drive the divine presence away" (Fischer, 2002).

In fact the Talmud – the record of rabbinic discussions pertaining to Jewish law, ethics, customs, and history (circa 200-500 CE) - as well as later *halachic* literature, such as the *Shulchan Aruch*, explicated bathroom and bathhouse issues involving prayer and sacred objects. For example, *tefillin* (also called phylacteries; two boxes containing Biblical verses with leather straps attached to them which are used in Jewish prayer) may not be worn by a person with a digestive sickness, and they must be removed prior to going into a toilet, bathhouse or a place where there is excrement. In fact, one is even forbidden from passing flatus while wearing *tefillin*. Additionally, laws specify that one may not recite the *Shema* – the most crucial Jewish prayer – in the presence of a toilet (even if it is clean) or in an alley where there is excrement (Neusner, 2002). As Maimonides commented, “it is forbidden to see excrement at the time of prayer and when the heart cleaves to God, since repulsive things produce disgrace in the soul and will disturb the intention of the pure heart, but when it disappears from the Seeing Eye there is no evil” (Fischer, 2002).

Douglas (1966) notes how in Jewish texts “the idea of holiness was given an external, physical expression in the wholeness of the body seen as a perfect container” (Douglas, 1966, 65). Maimonides, the 12<sup>th</sup> century Jewish philosopher and doctor upon commenting how the term ‘bowels’ in the *Torah* is used in the sense of ‘heart’ or any other inner organ, noted “the organs of nutrition are never attributed to God; they are at once recognized as signs of imperfection.” While purity codes regarding bodily discharges are specified as being polluting *only* in relation to ritual purity, as Perin (1988) noted, in learning disgust toward

excrement, we also learn to be disgusted with this part of ourselves. Disgust acts to guard the ‘temple of the body’, violations of which form spiritual pollution and are *moral* violations, making us not only impure but stripped of the identity that is tied to the social order and spiritual universe associated with the concepts of purity (Looy, 2004). As Douglas (1970) suggests, social order shapes the perception of the body’s structure and function, and, in turn, shapes the understanding of disease. Thus, a polluting person is always in the wrong, as “he has developed some wrong condition or simply crossed some line which should not have been crossed and this displacement unleashes danger for someone” (Douglas, 1966; 140). Thus, just as the term *niddah* has been used both to describe the impure physical state of a menstruating woman as well as depict the People of Israel when they are involved in sin, such as immorality or idol-worship or violence, and consequent estrangement from God. (Orthodox Union, 2007), impurity and infractions against ritual purity codes may be perceived through a moral lens.

**Disgust:**

Disgust is deeply rooted in the body, and noted to be a ‘moral emotion’ – a function to facilitate evaluations of rightness and wrongness, and to motivate behavior away from the bad towards the good (Looy, 2004). Disgust has been defined as a specific reaction toward the waste products of human and animals (Rozin, Haidt & McCauley, 2000). Culture largely shapes what an individual or society deems disgusting (Olatunji & Sawchuk, 2005), and the triggers of disgust play a crucial role in cultural identity, revealing our embeddedness and



relationality (Looy, 2004). It is also core to pollution theory; Mary Douglas (1966) found that by defining what is polluted, people classify their social life into what is acceptable and what is unacceptable, a symbolic system which gives moral order to societies. Since it is difficult to think of our bodies except through cultural values and symbols, any understanding of the body reflects the symbolic classification system of the social context in which it occurs (Douglas, 1966). Disgust is also one of the emotions associated with moral behavior and judgments (Looy, 2004). Globally, disgust triggers fall into one of seven categories, all of which remind us of the animalness of our nature and thus our impurity: body envelope violations, sex taboos, food taboos, animals, body products, death, hygiene, interpersonal contamination, and social disgust (Rozin, Haidt & McCauley, 2000). In this way, disgust acts to guard the 'temple of the body', violations of which form spiritual pollution and are *moral* violations; thus, disgust allows one to maintain cultural identity and purity by avoiding anything that may threaten it (Looy, 2004).

Feces seem to be a universal disgust substance for adults (Rozin, Haidt & McCauley, 2000). Feces have also been considered a dangerous source of pollution in the medical world; while in the 19<sup>th</sup> century physicians focused on the odor of human waste as being among the most feared of all noxious emanations, with the development of a bacteriological framework in the 20<sup>th</sup> century the morbidity of stench was discounted in favor of the danger of germs, so that the dire consequences of feces derived more from direct physical contact than from any olfactory action (Anderson, 1995). The taboo against any mention of things

related to excretion has been noted to be Puritan in origin, principally found in Britain and the U.S. (Reynolds, 1974). Even in anthropology where pollution is a conventional topic, Jervis (2001) notes the field has directed little attention to elimination issues. As Perin (1988) notes, “the vital functions of the alimentary canal are pretty much banished in this culture to the domain of taboo and scatology, repugnance and shame, a moral province rarely to be visited objectively” (1988, 209). In Western beliefs, she explains, evil is embodied in excrement, with disease and sin shaping this conceptual system; feces bring the specter of death and decay into daily life, where they do not belong – matter out of place. However, while the biologically essential body functions of elimination are regarded as vulgar and unmentionable, sexual functions and aspects of the body are routinely discussed in modern conversation (Kira, 1966).

Concepts of disgust and shame are essential in humans learning to excrete in the socially appropriate place, and disgust remains “tethered concretely with everything the odor and appearance of excrement entails: losing control, feeling ashamed of oneself, and fearing social humiliation and ostracism” (Perin, 1988, 217). In learning disgust toward excrement, we also learn to be disgusted with this part of ourselves. In a study of U.S. colostomy patients, women particularly indicated they were much more threatened by the filth, odor and potential disease-bearing aspects of feces, considering feces as degrading, animal-like and poisonous (Orbach, Bard & Sutherland, 1957).

**Risk perception:**

*Risk* is a concept with dual meanings; it can refer to the possibility of loss

or injury, as well as to threatening or dangerous elements or factors (Sibthroe, 1992). *Risk perception* can be considered the beliefs, attitudes, judgments and feelings as well as socio-cultural disposition people adopt toward hazards and their benefits (Douglas & Wildavsky, 1980). Perceptions of risk are grounded in culture, and often entangled in the moral, gender and material contexts of one's life. While it has different meanings to different groups of people, all risks must be understood within the larger social, cultural and economic context, including those influencing individual perception of risks and autonomy to manage them. Because the perception of risk is a social process, people who live in different kinds of social organizations are inclined to accept and avoid different kinds of danger; social powers select dangers for public concern. However, Douglas and Wildavsky (1980) warn that one must look further to discover what forms of social organization are being defended or attacked.

### **Disease and Stigma**

Goffman (1963) described stigma as “an attribute that is deeply discrediting within a particular social interaction” (1963, 3). His explanation of stigma focuses on the public's attitude toward a person who possesses an attribute that falls short of societal expectations, who is reduced in one's mind from a whole and usual person to a tainted, discounted one. Diseases associated with the highest degree of stigma share common attributes that the person with the disease is seen as responsible for having the illness, the disease is progressive and incurable, the disease is not well understood among the public, and the symptoms cannot be concealed. Stigma – which can be felt or

enacted - can lead to feelings of guilt, shame and spoiled identity (Scambler, 1984), increasing stress associated with any illness. For example, Sontag (1978) explains how any diagnosis of cancer can be associated with fear and stigma, and felt to be obscene – ill-omened, abominable, and repugnant to the senses. Patients experience their bodies as vulnerable, out of control, and may feel they have to protect others from embarrassment, particularly with scars and body changes from treatment which may add to the stigma (Frank, 1991). Additionally, specific forms of cancer carry specific stigmas, including those that involve a personal area, such as colorectal cancer, which can make patients both self-conscious of their disease and uncomfortable, inhibiting them from seeking medical attention.

Stigma can also carry a moral edge, particularly when related to disease. Foucault (1975) proposed that with modern medicine, health replaces salvation as the manifestation of a virtuous existence. Thus, if good health represents a general orderliness of existence of moral righteousness, then illness conversely reflects moral flaw (Hunt, 1998). In this way, illness may be experienced as an essentially moral event, with the causality of illness going beyond physical boundaries to a moral context. In the case of cancer, scientific explanations of cancer often only offer limited insight into how cancer is understood, but only provides partial explanation. In order to meaningfully explain a person's illness, causal explanations must be framed in terms of a set of specific circumstances, often focusing on the broader context of moral life, in attempts to introduce order to disorder, producing a meaningful context for traumatic events (Hunt, 1998).

This is especially relevant if one considers Douglas' framework of pollution as matter out of place, or disorder.

### **Judaism and Medicine:**

Religion has been said to provide individuals and communities with interpretive horizons for understandings of healing, death, suffering, illness and moral reasoning; 'sacred canopies' or meaning and order (Turner, 2003). Michael Weingarten wrote that:

The immensity of the value of life in the Jewish tradition is forcefully expressed in a Talmudic source: "He who saves a single life is as if he saves the entire world, and he who destroys a single life is as if he destroyed the entire world". Three different reasons have been proposed for this special value. The first, an argument from ownership, is that since life is given by God it may only be taken by God; creation confers ownership rights on the creator... Maimonides (12<sup>th</sup> century, the most prominent of all post-Talmudic Jewish scholars and jurists) derives from this a positive duty to protect life as long as we possess it. The second argument, the argument from infinity, is that because life was created by God, who is by definition infinite, therefore every fraction of human life is of infinite value, every human life is equal in value, and no smallest part of life may be disposed of. Rabbi Jakobovits, the founder of modern studies of Jewish medical ethics, was the first contemporary Jewish authority to argue that life itself is of infinite value and therefore indivisible, each fraction of life possessing infinite sanctity... The third reason posited for the sanctity of human life in Jewish thought, is that every human being is created in God's own image.

Weingarten, 2004: 9

While in the U.S. there are a broad range of beliefs and practices that characterize the contemporary Jewish community, most Jews share a deep commitment, grounded in common textual tradition and historic memory, to the value of life (Astrow, 2005). There are a number of core Jewish values related to health, including the concept of *Pikuach nefesh* – the saving of a life, possibly the highest value in Judaism, a category which includes prevention; and *kol yisrael averim zeh bazeh* – that every Jew is responsible for every Jew, mutual responsibility, which includes informed awareness and behavior and

responsibility to family and community. To traditionally minded Jews, the Jewish medical perspective is a part of *Halacha*, which guides all of activities, while less religious Jews welcome traditional views to help with health decisions even if they may not live according to traditional religious practice. When considering the foundational tenets that ground much of Jewish bioethical tradition, including the infinite value of human life, and humans are to act as responsible stewards in preserving their bodies which belong to God, the treatment of illness or preservation of health is thus a duty, not personal choice (Goldsand, Rosenberg, & Gordon, 2001). Therefore, preventive medicine is a centerpiece of the Jewish medical perspective, such that prevention is emphasized over treatment, with biblical mandates regarding the avoidance of danger and the preservation of life and health (Rosner, 2002). No bodily function is too banal in Judaism; gratitude for a properly functioning body is declared daily, in the *Asher Yatzar*, a blessing recited as part of the morning blessings, as well as after elimination. This prayer expresses recognition that the body is complex and sophisticated, and thanks God for allowing it to function properly:

*Blessed are you, our God, Source of Life, who formed human beings with wisdom, creating openings, arteries, glands, and organs, marvelous in structure, intricate in design. Should but one of them, by being blocked or opened, fail to function, it would be impossible to endure and to stand before you. Wondrous Fashioner and Sustainer of Life, Source of our health and our strength, we give You thanks and praise*

Weintraub & Lever, 2001, 48

Historically, health screening programs geared to the Ashkenazi population have experienced successful participation, indicating the acceptance of this population of preventive screening. This was first seen with Tay - Sachs

disease (TSD), when screening programs based in Jewish communal institutions started in 1971 often with members of the Ashkenazi Jewish community collaborating with researchers who also tended to be members of the Jewish community (Edelson, 1997). By 1991, the impact of community screening resulted in a 90% reduction in TSD in AJ, and over one million Jews worldwide screened (Brandt-Rauf, et al, 2006). TSD screening programs served as a model for recruiting AJ for breast cancer researchers when the BRCA mutations were linked to the same population; researchers – often themselves Jewish – again allied with community leaders and institutions, organizing meetings in synagogues and advertising in Jewish newspapers (Edelson, 1997). Once more the Jewish community responded positively with participation in studies, even when research provided no direct benefits (Brandt-Rauf, et al, 2006). The wide participation of these screening programs may have further been facilitated by many of the researchers themselves being members of the Jewish community.

### **Stigma and Judaism**

Despite the strong Jewish bioethical tradition that human life has infinite value, (Goldsand, Rosenberg, & Gordon, 2001), stigma related to illness and disease is well known to exist in Jewish communities. This has been reported in families with children who have disabilities (Leyser & Dekel, 1991), HIV/AIDS (Schlesinger & Appell, 1997), mental illness (Goodman, 2001), and infertility (Remennick, 2000). Additionally, there is a tremendous angst in the Jewish community of being stigmatized, recalling the nightmare of the Nazi eugenic programs. As various genetic mutations are found in the Jewish population, there

is fear of a disease being known as a 'Jewish' disease, such as Tay-Sachs disease or breast cancer. Some rabbis and leaders of the Jewish community have tacitly advised Jews not to get a genetic test or participate in genetics research until legal protections against discrimination are established, contributing to a subtle tension between the Jewish tradition of encouraging the acquisition of knowledge, particularly medical knowledge and the fear of potential discrimination or stigmatization (Rothenberg & Rutkin, 1998).

## **Culture and Cancer**

### ***Explanatory Models***

Scientific medicine is a jealous discipline. It dictates, as a central article of faith, that the only valid road to health is paved with its own recommendations. Health behaviors and beliefs are beyond moral criticism only if they remain on this road. Otherwise, they are problematic, and are cast as abnormalities through the process of medicalization.

Balshem, 1991, 163

Noncompliance literature tends to problematize only the patient's perspective, while treating the health provider's perspective as an uncontroversial point of departure (Hunt & Arar, 2001). However, Kleinman, et al (1978), discussed the differences between *disease* and *illness*. Illness, the human experience of sickness, represents personal, interpersonal and cultural reactions to disease or discomfort, and is shaped by cultural factors governing perception, labeling, explanation and valuation of the discomforting experience. Illness is shaped in the sense that how we perceive, experience and cope with disease is based on our explanations of sickness, explanations specific to the social positions we occupy and systems of meaning we employ. The processes are embedded in a complex family, social and cultural nexus and the illness



behaviors we learn are governed by cultural rules; in other words, we learn 'approved' ways of being ill. Disease, on the other hand, in the Western medical paradigm is the malfunctioning or maladaptation of biologic and psychophysiologic process in the individual. Biomedicine is primarily interested in the treatment and curing of disease, paying little attention to illness or the family and community issues surrounding illness. Both illness and disease are explanatory models mirroring multilevel relations between separate aspects of the complex, fluid total phenomenon of sickness. However, modern medical practice tends to be discordant with lay expectations; whereas modern physicians want to diagnose and treat diseases, patients suffer from illness. This clash in expectations tends to be responsible for patient noncompliance, patient and family dissatisfaction with healthcare, and inadequate clinical care.

Culture and religion are known to influence medical and personal decision making (Bowen, 2003; Holt & McClure, 2006). There is a void in research related to the influence of Jewish culture and religion on CRC health behaviors and beliefs, which is what this research serves to fill. However, the influence of culture and health beliefs and behaviors has been studied extensively in other populations related to various cancers. For instance, Chavez, et al, (1995) studied the structure and meanings in beliefs about breast and cervical cancer risk factors among Chicanas, Mexicans and Salvadoran immigrants as well as Anglo women and physicians in California using ethnographic interviews. Chavez, et al (1995) found two general cultural models of cancer risk factors among the interviewees. Mexicans, Salvadorans, and some Chicanas discussed

breast and cervical cancer risk factors with a Latin immigrant model in mind. In the other model, Anglo women, some Chicanas, and physicians operated on the biomedical model, although Anglo women and Chicanas did less so consistently than the physicians. Chicanas and Anglo women also included beliefs about breast and cervical cancer risk factors that would not have been acceptable to physicians, such as environmental pollution and high stress. Latinas expressed similar themes when explaining possibly risk factors for both breast and cervical cancer, including physical trauma/stress and behavioral/lifestyle choices as influencing both cancers. Specific lifestyle factors influencing risk differed according to group; Anglo women emphasized proper nutrition and diet, whereas Latinas – especially Latina immigrants - emphasized the implications of behaviors perceived as non-normative and morally questionable. Chicanas consistently expressed integrated views reflective of both Mexican immigrants and Anglo women, reflecting their biculturalism. And, once more, speaking to Kleinman's explanatory models, the authors note that for effective communication between health practitioners and all of their patients – both Latina and Anglo- they need to understand the risk factors they derive from their cultural background – often entangled in the moral, gender and material contexts of their lives. Chavez, et al (2001) also researched the influence of cultural beliefs on behavior and beliefs about cervical cancer and Pap exams. Based on the original ethnographic interviews (1995), and then doing survey research with 1594 Chicanas, other U.S. born Latinas, Mexicans, Salvadoran and other Central and Latin American immigrants as well as Anglo women and physicians in California,

they found that individual Latinas' cultural consonance with Latinas in general did not significantly influence their use of Pap exams. For example, structural factors such as medical insurance, age, marital status, education and language acculturation explained Latinas' use of Pap exams – challenging the traditional notion that Latinas' lack of Pap exam use is strictly due to culture. However, when Latinas held beliefs similar to those of Anglo women – down playing sex-related risk factors- they were more likely to have Pap exams within past 2 years, even if the structural factors are held constant. Downplaying sex-related risk factors and elevating heredity for which no one is to 'blame' and a lack of medical care, as Anglo women do, did not raise the issue of morally questionable behavior, motivating the use of Pap exams. On the other hand, Latinas whose beliefs were closer to those of physicians – that sex-related behaviors were the most important risk factors- were less likely to have had the Pap exam recently. Beliefs that women who engage in 'immoral', sexually risky behavior increase her chances of cervical cancer, so that Pap exams are associated with morally questionable behavior, and thus may not be sought. His group (2001) stressed that it was important not to view structural and cultural explanations as competitive or mutually exclusive. Different orientations to disease and illness and resultant clinical reality can affect patient care, and clinical realities are culturally constituted and vary cross-culturally and across the domains of health care in the same society. Thus, in order to avoid the common mistake of blaming 'culture' for noncompliance, it is critical for researchers and practitioners to gain deeper understanding of the meanings of illness and symptoms of their patients.

Only in this way can they negotiate medical realities that can become the object of medical attention and treatment appropriate to treat both the disease and the illness, as well as better study and understand factors involved in compliance issues, uptake of services, and follow-up care (Kleinman, Eisenberg & Good, 1978).

### ***Health Disparities***

*Healthy People 2010* was initiated in 2000, with the overarching goal of eliminating health disparities (Satcher, 2006). The National Cancer Institute defines "cancer health disparities" as "differences in the incidence, prevalence, mortality, and burden of cancer and related adverse health conditions that exist among specific populations groups in the United States" (NCI, 2008). In 2000, United States Public Law 106-525, also known as the "Minority Health and Health Disparities Research and Education Act," provided a legal definition of health disparities:

“A population is a health disparity population if there is a significant disparity in the overall rate of disease incidence, prevalence, morbidity, mortality or survival rates in the population as compared to the health status of the general population.”

United States Public Law 106-525 (2000), p. 2498

Since the passage of this law, other agencies have incorporated this definition into their own materials. For example, on the U.S. Department of Health and Human Services' Office of Minority Health website:

“In general, health disparities are defined as significant differences between one population and another. The Minority Health and Health Disparities Research and Education Act of 2000, which authorizes several HHS programs, describe these disparities as differences in "the overall rate of disease incidence,

prevalence, morbidity, mortality or survival rates.”” OMH, 2008

And, in 2001, the Office of Minority Health mandated 14 culturally and linguistically appropriate services (CLAS) standards organized by themes: Culturally Competent Care (Standards 1-3), Language Access Services (Standards 4-7), and Organizational Supports for Cultural Competence (Standards 8-14) which are current Federal requirements for all recipients of Federal funds. The CLAS standards are primarily directed at health care organizations; however, individual providers are also encouraged to use the standards to make their practices more culturally and linguistically accessible (OMH, 2007). With these events and mandates has come the strong interest in ‘cultural competency’, including in the field of cancer. Indeed, there is a common concept that ‘cultural competency’ can be reduced to a technical skill for which clinicians can be trained and develop some expertise (Kleinman & Benson, 2006). In medicine, however, culture is often synonymous with ethnicity, nationality and language. As well, research has shown that physicians, including oncologists, do not consistently distinguish race from ethnicity, often considering race to be genetically-driven, while understanding ethnicity in relation to culture; culture, in turn, was often seen as a barrier to healthy behaviors. Furthermore, because no clear distinction was made between ethnicity and race, such that both race and ethnicity were genetically-driven, they did not see any need for cultural competency training (Baer, 2007). Clearly, there is a disconnect between well-meaning mandates and the intended audience. As well, cultural competency programs often a trait-list approach, reducing the complexities and nuances of

culture to a set of well-known factors, without any room for experience or personal sense of self. As discussed earlier, because structural and cultural explanations should not be seen as competitive or mutually exclusive (Chavez, et al, 2001), a trait list approach to cultural competency risks one's culture as being blamed as a barrier to healthcare, and not encouraging the physician to consider Kleinman's suggestion to practitioners of trying to gain deeper understanding of the meanings of illness and symptoms of their patients (Kleinman, Eisenberg & Good, 1978).

### ***Race and Ethnicity***

There seems to be consensus that 'race', whether imposed or self-identified, is a weak surrogate for various genetic and nongenetic factors in correlations with health status. We are at the beginning of a new era in molecular medicine. It remains to be determined how increasing knowledge of genetic variation in populations will change prevailing paradigms of human health and identity. Royal & Dunston, S7, 2004

Researchers measure and monitor national health statistics, including disparities as health consequences of systematic disadvantage using OMB Directive 15 categories. The categories of OMB 15 were developed to provide consistent data on race and ethnicity throughout the Federal Government, to monitor equal access in housing, education, employment, and other areas, for populations that historically had experienced discrimination and differential treatment because of their race or ethnicity (OMB, 1997). Directive 15 described four races (American Indian or Alaskan Native, Asian or Pacific Islander, Black, and White) and two ethnic backgrounds (of Hispanic origin and not of Hispanic origin). The American Anthropological Association 1997 Response to OMB 15 pointed out numerous problems with the directive, including that Directive 15

was not clear regarding whether the race or origins of persons was to be determined by self-identification or by others (interviewers) despite research which indicates substantial differences of racial/ethnic identification by these two methods. Also Directive 15 noted the absence of "scientific or anthropological" foundations in its formulation, and did not explain what was meant by "race" or "origin," or what distinguished these concepts. Still, the race and ethnicity categories of the Directive are used in scientific research and the interpretation of the research findings is based often on the "variables" of race and ethnicity (AAA, 1997). However, these categories however may not be appropriate for medical research because they create a priori frames into which diverse and complex groups are made to fit. They do not, however, elucidate the underlying causal pathways that result in worse health status for many despite assumptions made in much of the socio-behavioral research they do (Lee, 2006). Race and ethnicity are frequently used interchangeably in scientific and medical literature as factors in different causal frameworks, leaving out access to health services, medical outcomes, risk factors behaviors and ancestry. Lee (2006) has pointed out that much socio-cultural and behavioral research uses superficial categorical labels within race and ethnicity because alternative socio-cultural constructs lack validated metrics and can rarely be compared across studies. However, social position, poverty and systematic disenfranchisement known drivers that contributes to disparities in health status; migration, education, employment, social support, geography further modifies group identity and individual lived experience. Lack of distinction between mediating pathways, contributing factors

and biological mechanisms in the research can result is the obstruction of the development of theoretical frameworks which may lead to effective interventions in reducing health disparities (Lee, 2006).

It is critical to be aware of the specific, shifting cultural values regarding diseases prevention and control, and that there are a range of values within any population (Lee, 2006). For example, when Chavez, et al, (1995) studied the structure and meanings in beliefs about breast and cervical cancer risk factors among Chicanas, Mexicans and Salvadoran immigrants as well as Anglo women and physicians in California using ethnographic interviews, their results indicate the complexity and variations from biomedical perspectives, influenced by birth place (immigrant vs. U.S. born), ethnicity, and expertise. While Latinas in general shared beliefs about both cancer risk factors, U.S. born Chicanas also shared beliefs found among Anglos. These findings speak to the enormous caution that must be taken when referring to a generalizable *Latina* model.

### ***Ashkenazi Jews, Culture and Ethnicity***

Jews are said to be different from other European-origin groups due to their fusion of religion, culture and ethnicity (Kivisto & Nefzger, 1993). Religiosity, ethnicity and identity are interwoven, with Jewish identity embedded in everyday life. In America, Jews historically were considered Asian, called Mongoloid, and Asiatic. In the 19<sup>th</sup> and early 20<sup>th</sup> centuries, immigration laws were changed due to fear of an influx of undesirable Asiatic elements (Jews) who would either not assimilate or would intermarry and pollute the racial purity of America (Langman, 2000). Tobin, Tobin & Rubin (2003) wrote that:



Jews, as a group, were considered non-white by the American majority well into the 1950s and early 1960s. Jews were considered by others to be Black or Oriental. It is no coincidence that racially-restrictive covenants and housing laws in America, prior to the late 1940s, targeted African Americans, Asians, and Jews, all considered to be foreign, non-white racial groups.

Today, however, Jews are included in the 'white' OMB 15 category.

Langman (2000) writes that because they are considered a 'model minority' –due to their success of adapting to American culture – some feel they do not need the same attention as other groups do. There has been little, if any research about the influence of Jewish religion and culture on the CRC health behaviors and beliefs in the Ashkenazi Jews. In regards to colorectal cancer, Ashkenazi Jews have already been affected by their 'white' classification in health statistics, so that their increased risk of CRC is not tracked in national statistics or publicized. Additionally, there is no OMB 15 category of 'ethnicity' under which they would fall which would also highlight this risk. Therefore, the high CRC risk of Ashkenazi Jews remains buried in the statistics of the 'white' population within the U.S.

### **Burden of Colorectal Cancer in the Ashkenazi Jewish Population:**

Colorectal cancer (CRC) is the third most commonly occurring type of non-skin cancer in the United States, as well as the third leading cause of death by cancer (ACS, 2008). CRC incidence in Ashkenazi Jews, Jews of eastern or central European origin who account for 95% of the U.S. Jewish population, has been found to be as high as 15%, or 2-3 times that of the general populations of developed countries such that CRC has been found to be the most important worldwide cancer killer proven to disproportionately overburden Ashkenazi Jews

(Feldman, 2001). Specific CRC screening, incidence and mortality rates of Ashkenazi Jews in the United States are unknown because they are included in the 'white' category, and thus not tracked or monitored.

### **Colorectal Cancer Screening:**

It has been estimated that widespread application of screening technologies that address the whole colon could decrease CRC incidence by as much as 60-70%, and reduce CRC deaths by up to 80% (O'Dwyer, et al, 2007). CRC caught early has a 92% 5-year survival rate, however only 37% of these cancers are detected at a localized stage (Vogelaar, 2006), and, as of 2005, only half of people aged 50 or older has ever had a screening colonoscopy (Mitka, 2008). The goals of CRC screening are to detect premalignant polyps as well as presymptomatic carcinomas (Cooper & Payes, 2004). A number of screening options are widely accepted for use, including a fecal occult blood test (FOBT) or fecal immunochemical test (FIT) annually, a sigmoidoscopy or barium enema every 5 years and a colonoscopy every 10 years starting at age 50 (ACS, 2008). While colonoscopy is generally regarded as the most sensitive option, able to detect approximately 90% of large adenomas and cancers, it is also the most costly. Newer screening techniques are being designed to circumvent the invasiveness, cost and time of colonoscopy, including computed tomography (CT) colography (virtual colonoscopy), stool DNA mutational analysis and proteomic analysis of serum (O'Dwyer, et al, 2007).

### ***Barriers to CRC Screening:***

Worldwide, compliance with CRC screening recommendations is usually lower

than that recorded for breast or cervical cancer screening (Ore, et al, 2001).

Barriers to CRC screening have been well documented in the U.S. population.

Woolf (2000) categorized these barriers into 4 domains in the general population:

- *Attitude/Knowledge*: Awareness of screening guidelines, belief of risk posed by CRC and need for screening, misperceptions regarding cancer prevention and symptoms
- *Acceptance*: includes fear of pain, embarrassment or false-positive tests, concerns over harm from tests, problems with disagreeable nature/prep for tests cultural barriers, belief in preventive behaviors. Factors such as disgust, pollution concepts and taboo of the gastrointestinal tract are part of the acceptance domain
- *Reinforcement*: inconsistent recommendations from health provider
- *Ability*: includes lacking the time, money, transportation and resources for testing and treatment if test is positive; lacking regular health provider

Similarly, lack of access to healthcare has been found to be inversely related to CRC screening (Matthews, Anderson, & Nattinger, 2005, O'Malley, Forrest, Shibus, & Mandelblatt, 2005). Currently, only 25 states have laws mandating insurance providers to cover CRC screening tests – as compared with 50 states mandating breast cancer screening (EI Foundation, 2008). However, even for those with insurance coverage, screening remains suboptimal (O'Malley, et al 2005). Of those over the age of 65 years who are eligible for Medicare, less than half of women and men aged 65 and older have ever had a screening endoscopy or FOBT (Behavioral Risk Factor Surveillance System [BRFSS], 2004). As well,

CRC screening has been found to be suboptimal in areas with national healthcare; a Canadian study found only 21.2% of people in the screening-eligible age group (age 50-70) received any CRC investigation from 1997-2001 (Singh, et al, 2004).

### **CRC Screening in AJ**

While culture and religion are known to influence medical and personal decision making (Bowen, et al, 2003; Holt & McClure, 2006), it is unclear what factors influence AJ adults' attitudes towards CRC risk and screening practices. As well, in the United States national screening statistics use the U.S. Office of Management and Budget (OMB) directive 15 category federal standards for the reporting of *race* and *ethnicity* statistics, so that Jews are included in the 'white' category (CDC, 2007, OMB, 2007); therefore, the specific screening rates of U.S. AJ are not known. In Israel, an annual FOBT is free of charge for men and women ages 50-74 and there is an active invitation system (Ore, et al, 2001), however compliance rates with FOBT screening are about 20% (Rennert, 2007). Although barriers to colorectal cancer screening in the overall population are well documented (Woolf, 2000), there is a paucity of studies available in the literature that has examined the factors influencing behaviors related to CRC in the AJ population.

#### ***Inhibitors of CRC Screening in the AJ population:***

In considering the four domains of Woolf's barrier framework (2000) – knowledge, acceptance, ability, and reinforcement – ability and reinforcement do not seem to be primary inhibitors in this population. Studies have found that most

U.S. Jews tend to have access to high levels of medical care, and have higher socioeconomic status (Feldman, 2001). Additionally, a Canadian CRC risk study (Cappelli, et al 2002) offered CRC screening and genetic testing to virtually all of the adult Ashkenazi Jews in an urban community, with only 42% expressing interest in participation. Thus, ability does not stand out as a key barrier in this population. As well, Friedman, et al (1999) found AJ women to be vigilant with other types of cancer screening, and have sought medical knowledge not provided by their regular physician, so reinforcement may also not be a key barrier in this group. Knowledge and acceptance, however, do seem to drastically influence the CRC health behaviors of this population. In the AJ population, knowledge would include awareness and acknowledgement of not only the high CRC risk in the general U.S. population, but the disparate CRC risk in the AJ population, as well as the belief that screening is effective and prevention is possible. Previous studies indicate participants with family history of CRC who perceived themselves to be at high risk still not complying with screening guidelines (Friedman, et al 1999) and lack of screening related to the belief CRC screening itself is unnecessary (Cappelli, et al, 2002). Acceptance was also a barrier reported by this population; a primary reason 'refusers' cited for not participating in free CRC screening in the Cappelli study (2002) was fear that the screening would be physically uncomfortable.

### ***Knowledge***

As previously mentioned, in the AJ population, knowledge in the context of CRC screening would include awareness and acknowledgement of the disparate

CRC risk in the AJ population, as well as the understanding that screening is effective and prevention is possible. Friedman, Webb, Richards & Plons (1999) found overall compliance with CRC screening to be low in U.S. AJ women, despite being vigilant about screening for cancers other than CRC such as obtaining breast exams, mammograms, and pap smears; even those participants who perceived themselves as being at increased risk of CRC were no more likely to comply with screening guidelines. This paradoxical perception of risk may be related to lack of knowledge of screening effectiveness and screening needs of high risk individuals. In a study where genetic assessment and colonoscopy were offered to virtually all the Ashkenazi Jews in an urban Canadian community, only 42% of AJ expressed interest in participating. After following up with non-responders, researchers found predictors of refusal included the belief that participation was too much trouble, not necessary and would be physically uncomfortable, while participation was predicated by awareness that the Jewish community supported the study, past experience with genetic testing, belief that participation would be helpful to them and beneficial to their community, spousal influence, having a physician's recommendation and having children (Cappelli, et al, 2002).

As well, most research on CRC in AJ is predominately are based on genetic factors, although none of the mutations related to CRC in AJ found to date is sufficiently prevalent or penetrant to reason for the excess of large bowel malignancy in AJ population (Locker, et al, 2006). The intense focus of genetic research in AJ, linking Ashkenazi Jewish ethnicity to an increased risk for

hereditary cancer, such that gene mutations have become known as “Jewish ancestral mutations” has been found to limit the scope of research and risk perception (Brandt-Rauf, et al, 2006). This may be reflected in the general lack of acknowledgement of the disparate CRC incidence in AJ in both the healthcare and Jewish community. Also, as previously mentioned, since AJ CRC rates are counted in the OMB 15 category ‘white’, the disparate CRC burden of this group is not widely tracked or publicized. Before any cancer control initiative can begin, accurate baseline data in incidence, mortality, and screening in this high risk population needs to be collected and tracked.

### ***Acceptance***

Acceptance also seems to be a key barrier reported by this population, as seen when a primary reason ‘refusers’ cited for not participating in free CRC screening in the Cappelli study (2002) was fear that the screening would be physically uncomfortable. In Israel, an annual FOBT is free of charge for men and women ages 50-74 and there is an active invitation system, however baseline compliance with FOBT performance was very low, at .6%. Ore, et al, (2001) evaluated mailed FOBT test kits or order cards, with or without education leaflets as methods of increasing compliance to screening. Compliance was still low, with the mailed kits having the highest response rates at 19.9%, compared to 15.9% response of the kit request card; however the educational leaflet had no observable impact overall, nor did it show an impact by gender or age. Thus, while such leaflets may enhance knowledge and understanding, there is no guarantee they will affect compliance. This finding supports the notion that

compliance with cancer screening programs is not solely a rational behavior, rather emotional barriers must first be targeted before any efforts are made to increase compliance via information delivery on CRC are justified. (Ore, et al, 2001) As well, Azaiza & Cohen (2007) found high perception of severity and belief in the benefits of CRC screening in Israeli Jews; these variables also predicted test use, as receiving a physician's recommendation. However, the study did find low levels of cancer CRC worry, which they noted could be related to not being confronted with CRC in everyday life or being as familiar with as, for example, breast cancer. Thus, any future screening initiative for AJ should focus on knowledge and acceptance issues, including a better understanding of emotional issues surrounding screening, as well as providing accurate factual information to clarify CRC risk for this population and up-to date techniques for screening, stressing how they differ from previous, painful procedures.

### ***Other Barriers***

It has been noted that fundamental elements related to ethnicity and culture shape health perceptions, attitudes and behaviors, and it is important to acknowledge cultural diversity and study the specific cultural beliefs of each ethnic group as related to health and health behaviors (Leininger, 1995). Culture largely shapes what an individual or society deems unacceptable or disgusting (Olatunji & Sawchuk, 2005). Discussions regarding elimination and physical contact with feces are involved in the CRC screening process, however, both of these actions conflict not only with U.S. cultural taboos but also with specific Jewish purity codes. While disgust of feces and the taboo against any mention



of things related to excretion are ubiquitous in U.S. culture, for the U.S. Jewish population, factors such as pollution concepts and taboo of the gastrointestinal tract are religiously based, part of the priestly doctrine which are a key component in the organization and rationalization of the philosophy of Judaism (Douglas, 1993). Although Jewish pollution concepts are based on biblical purity codes, as Herman (1989) noted, the Jewishness of non-religious Jews cannot be completely divorced from its religious associations, and so these beliefs may be resilient in non-religious Jews. Thus, the concurrent taboos of U.S. culture and Jewish purity codes against bodily waste may override the Jewish bioethical tenet of preventive medicine as related to CRC screening. It is critical, therefore, to consider how the meeting of Western medicine and ethnic beliefs may confound perceptions and beliefs regarding health, illness and taking early detection screening (Angel & Williams, 2000).

**Summary:**

Anthropology is uniquely positioned to give voice to not only an explanation of cancer, but to explicate the articulation between provider and patient assumptions, expectations and perceptions. Assessing and understanding the cultural beliefs and customs surrounding issues and concepts of disease, illness, cancer and prevention, is critical for the development of successful initiatives aimed at CRC education, prevention, screening and treatment. Sontag (1978) wrote that diseases acquire meaning through the metaphors with which they are imbued, and these metaphors reveal the social, political, economic – and I would add cultural - issues of the context in which they

are developed. Thus, there is interplay between lay and scientific knowledge, particularly in areas where health promotion is a key component in disease prevention and management, propagating interest in accessing lay views with health-related issues, as well as understanding how meaning is attributed and practiced within the relevant cultural context (Macaden & Clarke, 2006). CRC incidence in Ashkenazim has been found to be the highest of any ethnic group in the world (Feldman, 2001). Preventive medicine is a centerpiece of the Jewish medical perspective (Rosner, 2002); however studies of AJ women have found overall compliance with CRC screening to be low, despite being vigilant about screening for cancers other than CRC. Specific rates of CRC screening, incidence, and mortality in the U.S. Ashkenazi Jewish population are not known because of the current system being used to track national health statistics. Culture and religion are known to influence medical and personal decision making (Bowen, 2003; Holt & McClure, 2006) and culture largely shapes what an individual or society deems disgusting (Olatunji & Sawchuk, 2005). Cross-culturally, bodily waste products are considered a core disgust elicitor (Rozin, et al, 2000), and feces in particular considered a dangerous source of pollution. The taboo against any mention of things related to excretion has been noted in the U.S. (Reynolds, 1974). The philosophy of Judaism is based on purity codes which consider bodily discharges taboo (Douglas, 1966). However, both discussions of elimination and physical contact with feces are involved in the CRC screening process. As well, the burden of CRC in the AJ population is poorly publicized, potentially affecting risk perception, which, again, may be due

to the OMB categories of race and ethnicity in which CRC statistics are tracked. It is thus critical to further explore how these compounded cultural and religious based concepts of pollution impact the health behaviors of U.S. Ashkenazi Jews, as well as what other socio-cultural factors influence AJ women's attitudes towards CRC risk and screening practices.

## **Chapter Three**

### **Methodology**

#### **Introduction**

In this chapter I will describe the objectives, setting and design of the descriptive study on the influence of culture and religion on the health beliefs and behaviors of Ashkenazi Jewish women as related to colorectal cancer. First I will explain the objectives and research questions the study is based on. Next, I will describe the research design, including the setting for the study, sampling, and recruitment processes. Data collection methods and tools will also be reviewed. Finally, I will explain data management and analysis.

#### **Research Question**

The inquiry of this study focused on the influence of culture and religion on the health beliefs and behaviors related to colorectal cancer screening in Ashkenazi Jewish women in the Tampa Bay area. The inquiry is guided by ethnographic interviews where the participants are able to describe their cultural and religious identity and how it they see it influencing their health behaviors and beliefs, and then triangulated by closed-end surveys related to CRC attitudes behaviors. The conceptual framework guiding this inquiry is based on notions of purity and pollution. Therefore, questions related to purity concepts in Judaism guided both data collection and data analysis of sorted and coded text. Because this is an area where there has been minimal previous research and published

results, this is designed to be a descriptive study, with the goal of describing the participants and exploring areas for further research.

The methods and analysis utilized present an avenue for exploring the cultural and religious identity and beliefs, health beliefs and behaviors related to colorectal cancer, knowledge of colorectal cancer and perceptions of how health is related to or influenced by Judaism of 36 Ashkenazi Jewish women. Also analyzed were the ethnographic interviews of 7 rabbis in the Tampa area, which were coded for health beliefs and behaviors, related to CRC, knowledge of CRC in the AJ population, and perception of health in relationship to Judaism.

The research for this study involved both quantitative and qualitative methods of data collection, in order to collect data on health beliefs and behaviors, CRC knowledge, Jewish identity and relationship of health to Judaism. A demographic survey (Appendix A) that included a question to gauge baseline CRC knowledge in the AJ population was first given to participants, after which the qualitative interviews were conducted, followed by a final quantitative survey on attitudes and behaviors related to CRC (Appendix B). The study utilized semi-structured, in-depth interviews, and 2 survey/questionnaires. Combining several such data collection strategies provided data triangulation, in that multiple sources of data serve as sources of confirmation or corroboration for each other (LeCompte & Schensul 1999:131). Prior to conducting the in-depth interviews, 2 focus groups of women in different denominations were conducted in order to pilot test the interview guide and surveys, and revise for any themes or issues which may have emerged during the sessions.

The methods selected provided the data to answer the research questions:

1. What are the cultural and religious influences on health behaviors in AJ women?
2. What are the social, cultural and religious contexts influencing individual perception of risk of CRC and autonomy to manage them?
3. What are the ways in which AJ women embody the concurrent U.S. and Judaic based taboos associated with the gastrointestinal tract as related to health and CRC health behaviors?
4. What are the sources and understanding of health information regarding CRC?

### **Research Design**

This study was designed as a qualitative inquiry into the influence of culture and religion on colorectal cancer beliefs and behaviors among Ashkenazi Jewish women. Because the Jewish population represents a wide variety of beliefs and practices, with only 40% reporting affiliation with a synagogue in the Tampa area, purposeful sampling techniques were employed to recruit participants from several populations, including those who were affiliated with synagogues of the major denominations (Reform, Conservative, Orthodox) as well as those who were not unaffiliated with any synagogue. The problem identified for this study was the disparate rate of colorectal cancer in this population; this is an area where there has been minimal previous research and published results. Therefore, this study was designed to describe the knowledge and influence of culture and religion on the participants' CRC health beliefs and behaviors. The women interviewed all lived in Florida, with the majority living in Hillsborough County, and three residing in Dade County. The present study focused on Jewish identity and relationship to health beliefs and behaviors as an

important aspect because, culture and religion are known to influence medical and personal decision making (Bowen, et al, 2003; Holt & McClure, 2006)

## **Sampling**

### **Key Informants**

Prior to the focus groups and in-depth interviews, I conducted semi-structured, in-depth interviews and with seven Rabbis of various denominations in the Tampa Bay area; three Reform, 2 Conservative, and 2 Orthodox. Non-probabilistic sampling was used to recruit for the key informants. In Tampa and Brandon there are two Reform synagogues, two Conservative synagogues, and one Orthodox synagogue as well as the Chabad (Orthodox) Tampa headquarters which also houses Tampa's only *mikvah*. Rabbis from all seven of these major synagogues representing the 3 major affiliations (Reform, Conservative, and Orthodox) in Tampa were contacted directly by phone or email and an appointment was made for the interview. All seven rabbis agreed to meet and be interviewed,

### **Focus Groups**

Two focus groups were conducted prior to the individual interviews, one with participants from a Reform synagogue and one with participants who were not affiliated with any synagogue. Non-probabilistic sampling was used to recruit for the focus groups. Participants were recruited through (1) advertisements placed in synagogue bulletins, emails and listserves (2) friends and family of Ashkenazi Jewish women, and (3) interviewee referrals. Reform affiliated focus group participants of which were recruited from advertisements in the synagogue

bulletin. Snowball sampling served as the primary and most effective strategy for recruiting unaffiliated focus group participant recruitment, through friends and family of Ashkenazi Jewish women who then gave me contact information for unaffiliated Ashkenazi Jewish women.

### **Individual Interviews**

Non-probabilistic sampling was used for recruiting participants for the individual interviews in this study. Participants were recruited through (1) advertisements placed in synagogue bulletins, emails and listserves (2) friends and family of Ashkenazi Jewish women, and (3) interviewee referrals. Similar to recruiting for the unaffiliated focus group, while the advertisements was successful in eliciting responses from some participants, snowball sampling served as the primary and most effective strategy for choosing participants for this study. Often, after interviewing a participant who may have responded to an advertisement in a synagogue bulletin, I was able to gain access to and interview other Ashkenazi Jewish women over the age of 50 when that original participant would either give me contact information for additional potential participants or give the potential participants themselves my contact information. By asking the first subjects for referrals of additional Ashkenazi Jewish women over the age of 50, the sample eventually snowballed on the basis of links to the initial cases (Neuman, 2004; 140). The referrals came across denominations, and not necessarily only from within the denomination or affiliation of the original participant.

The number of interviews for this study was based on theoretical saturation,



when no new themes are identified. Guest, et al, (2006) found that saturation occurred in ethnographic research within the first twelve interviews, with meta-themes present as early as six interviews, so I originally planned on interviewing 12 participants per denomination and unaffiliated. However, saturation was reached by 10 in each Reform, Conservative, and Unaffiliated. In the case of Orthodox, there are few Orthodox synagogues or central Orthodox Jewish community in the central and north Florida area; most Orthodox synagogues are in the form of Chabad, a specific branch of Orthodox Judaism dedicated to community outreach, so that many of its members may not necessarily identify as being of Orthodox Jewish denomination. I contacted eight Chabad branches from Sarasota to Pasco, all of whom consistently told me I would not find the number of participants in the age group I was looking for in this part of Florida; most of their communities were either not-observant or under the age of fifty. It was suggested that I look further down south of Palm Beach where there are a numerous organized Modern Orthodox communities and synagogues. I contacted 15 synagogues from Palm Beach south to Miami by phone, email and fax; of those only three responded and accepted the advertisements for their bulletins, but none ever contacted me with any participants. Finally snowball sampling served again to be a primary form of recruitment when I was put into contact with a Jewish professor in Miami who gave me twenty email contacts, of whom three responded to my emails; several others responded as well but were not eligible due to age. Those are in addition to the two Orthodox participants I recruited in the Tampa area, again by word of mouth. Therefore, due to lack of

participant availability in the central and north Florida and area, and lack of response in the South Florida area, recruitment was limited to five; however with the five interviews, the responses to the key questions were similar and no new themes emerged.

### **Research Participants**

The participants of this research for both individual interviews and focus groups were Ashkenazi Jewish women ages 50 and over. Originally the age for recruitment was set at ages 50-75; however several women in the focus pointed out that the upper age limit excluded many potential participants, so via a modification to IRB the upper age limit was eliminated. The lower age limit was chosen because 50 is the age at which it is recommended to have a colonoscopy for the first time.

Prior to participation in the study, the research was explained to all participants (individual interview and focus group participants, key informants) and written informed consent was obtained from all those who agreed to be in the study. For those women who participated by phone, the informed consent was faxed or emailed to them and participants then faxed or emailed a completed consent form back to me prior to starting the interview.

### **Data Collection**

#### **Key Informants**

Gatekeepers are considered those who control access to information, setting and individuals (Schensul, Schensul, & LeCompte, 1999). In synagogues, rabbis are considered the 'gatekeepers'; without their permission, the research would not be

able to be conducted in their congregations. Therefore, prior to the focus groups and in-depth interviews, this research also included semi-structured, in-depth interviews and with seven Rabbis of various denominations in the Tampa Bay area; three Reform, 2 Conservative, and 2 Orthodox. Of the Rabbis, only one was female, and the rest were male. All of the key informant interviews took place in the synagogues of the Rabbi's congregation where recruiting for participants would later take place. Interviews were conducted in a semi-structured, in-depth format, using an interview guide (Appendix C) similar to that which would be used later used with focus group and individual interview participants. Additionally, questions about the feasibility of having health related programs related to CRC in the synagogue were included. Data collection began in January 2008 and concluded in April 2008.

### **Focus Groups**

This study utilized a detailed set of questions, and plan of action for conducting the research (LeCompte & Schensul, 1999). It included an interview guide (Appendix D), as well as the 10 item self-administered survey on experiences with and attitude toward CRC Screening and the self-administered, 30-item demographic survey that included questions about baseline CRC knowledge in the Ashkenazi population, cancer screening habits and mikvah use. Data collection took place in February and April 2008.

### **Individual Interviews**

Similar to the focus groups, the individual interviews utilized an interview guide (Appendix E) as well as the self-administered, 30-item demographic survey

that included questions about baseline CRC knowledge in the Ashkenazi population, cancer screening habits and *mikvah* use administered prior to the interview and the 10 item self-administered survey on experiences with and attitude toward CRC Screening administered after the interview was complete. Triangulation involves confirming or cross-checking the accuracy of data collected by one source with data collected from other, different sources (LeCompte & Schensul, 1999) and this was achieved by via multiple methods, such as, semi-structured, in-depth interviews, and survey/questionnaire administration using repeated questions, and asking for the information on the same issues of Jewish identity, CRC health beliefs, and behavior in order to confirm and cross-check the accuracy of the data that was obtained from the participants. Data collection began in May 2008 and concluded in August 2008.

## **Data Collection Tools**

### **Demographic Survey (Quantitative)**

A 30-item demographic survey (Appendix A) was self-administered prior to each participant's interview for focus group and individual interview participants. The survey captured data on age, relationship status, ethnicity, employment status, personal/family history of cancer, health insurance status, level of education, occupation, migration status/family migration status, self-identification of denomination and denomination history, income, and screening history for several common cancers. Additionally, data was gathered on baseline knowledge of CRC incidence in the Ashkenazi Jewish population and history of *mikvah* (ritual bath) use. This last question was included because *mikvahs* are

commonly used by Jewish women monthly after menstruation when they are considered to be *tameh* (impure) during menstruation, and the *mikvah* is used to as part of a purification process. Use of *mikvah* could indicate that concepts of purity within Judaism resonate with the participant.

For the first focus group (Reform) the demographic survey was administered after the interview. However, because it includes questions about baseline CRC knowledge in Ashkenazi Jews, focus group participants suggested it be administered prior to the start of the interview; additionally, they found an error in the income categories on the demographic survey. The error was corrected and for the second focus group and all interviews thereafter, the demographic survey was administered prior to the start of the survey.

### **Semi-structured, In-depth Interviews**

Semi-structured, in-depth interviews were conducted from May 2008 through August 2008 with each woman. The interviews were conducted with the use of an interview guide (Appendix E), which was developed includes a list of questions, grouped according to topics and domains (Schensul, Schensul, & LeCompte, 1999). The interviews also took on an unstructured approach in that interviews were conducted with a preformulated interview guide, but allows the answers to those questions to be fully expanded at the discretion of the interviewer and interviewee, and can be enhanced by probes (Schensul, Schensul, & LeCompte, 1999).

Thirty-three of the interviews were conducted in person, and three were conducted by phone because of the location of those participants (Dade County).

Eighteen of the interviews were held in the homes of the women, five interviews were held at places of their employment, three were held at a library, two at a local café, and five were held at a synagogue.

### **Questionnaire on Experiences with and Attitude toward CRC Screening**

*The American Cancer Society's Questionnaire on Experiences with and Attitude toward CRC Screening* tool (Appendix B) was administered after each interview. The questionnaire has been validated in several studies (Straus, 2005; Straus, 2001), and currently is part of the ACS comprehensive toolkit for insurance providers to improve CRC screening for their members age 50 and over. The questionnaire consists of 10 questions, including current age, if primary care provider ever recommended CRC screening, age of first CRC screening, types of CRC screenings experienced, or if has never had screening check-off list or reasons why (all that apply – includes commonly documented barriers as well as open-ended option to answer), and 5 true or false questions about CRC risk, prevention, symptoms and screening guidelines. In many cases when the participant did not have time to fill this out in person, they were given a self-addressed, stamped envelope to mail back the survey. The total response rate for returning the surveys was 89%. Data from the ACS survey served to confirm the interview statements of the participants related to CRC health behaviors and beliefs (LeCompte & Schensul, 1999). The responses to the questions related to CRC risk, prevention, symptoms and screening guidelines provide quantifiable data on the interviewees' assessment of their own beliefs, and can be used to identify specific beliefs to target health education, promotions and interventions.

## **Questionnaire/Interview Guide Pilot Testing**

Before conducting the in-depth interviews, the interview guide and surveys were pilot tested with two focus groups. A total of 4 unaffiliated Ashkenazi Jewish women participated in the first focus groups, and 2 Ashkenazi Jewish women affiliated with a Reform temple participated in the second focus group; 2 other women were scheduled for the second group and cancelled at the last minute. The purpose of the focus groups was to solicit comments on the clarity of the questions, wording, and to obtain suggestions for question additions and/or deletions of both the interview guide questions and the surveys. Thus, the piloting was done to test the sequencing, flow and skip patterns, language use, comprehension and length, and the reliability of the questions (Schensul, Schensul & LeCompte, 1999). Based on comments and feedback, the timing of surveys was changed so that the demographic survey which assessed baseline knowledge about CRC rates in Ashkenazi Jews would be given prior to the interview rather than afterward. Also, some questions for the interview guide related to prayer and punishment/reward were added.

## **Recording and Transcription**

All interviews, including individual, focus groups and key informants, were digitally audio-recorded, except for 3 where the digital recorder failed to operate correctly. Detailed notes were also taken during interviews. All interviews, including individual, focus groups and key informants, were done in person except for 3 that were completed by telephone due to the interviewee's location. Permission to record the interview was explained and received during the

informed consent process, prior to the start of the interview session. The length of all interviews ranged in duration from one to two hours, with the content based upon Jewish identity and beliefs, perceptions of health related to Judaism, and CRC knowledge, beliefs, behaviors, and practices of the participants and the key informants. Length of the interview was based upon the scope of the information shared by each interviewee. I transcribed all of the recordings.

### **Validity and Reliability**

*Validity* refers to the extent to which measurements adequately measure what they are supposed to rather than measuring something else (Babbie, 1992), and is thus concerned with the credibility, authenticity, and quality of the research (LeCompte & Schensul, 1999) *Reliability*, on the other hand, is a matter of whether the same technique, applied repeatedly to the same objects, yields the same results; thus, its concern is with dependability (Babbie, 1992). *Triangulation* involves confirming or cross-checking the accuracy of data collected by one source with data collected from other, different sources (LeCompte & Schensul, 1999) and this was achieved using multiple methods, including semi-structured, in-depth interviews, and survey/questionnaire administration using repeated questions, and asking for the information on the same issues of Jewish identity, CRC health beliefs, and behavior in order to confirm and cross-check the accuracy of the data that was obtained from the participants, in order to create redundancy across the different denominations of participants. *Generalizability* refers to the degree to which specific research findings apply to people, places, and things not actually observed (Babbie, 1992). Because of the small sample



size, sampling method, and the use of the nonprobabilistic, snowball sampling strategy, this qualitative study did not presuppose generalizability to all Ashkenazi Jewish women; rather it was a cross-sectional, descriptive study in an area of research where there has been little examination and a paucity of published findings. Therefore, the aim of these analyses was to describe and understand a sample of this target population and to suggest areas of focus for future research.

### **Data Management**

Interview data were transcribed as recorded by the researcher. Data collected in this research (print and audio-taped) were secured in a locked file cabinet in the researcher's home. Audio-taped recordings were erased after data was transferred to computer files on password protected computer. Data transported during fieldwork was kept locked in the researcher's car until needed for use. After use, materials were transferred to the secured file cabinet where it was filed. Informed consent forms were kept in a locked file to protect the privacy of the study participants. Additionally, confidentiality was maintained by keeping interview data in a locked file when not in use. Computer files were maintained in a password protected computer. This data will be kept indefinitely after the study in a secure, locked cabinet (paper) or password protected computer file.

### **Data Analysis**

#### **Quantitative**

A statistical analysis of the quantitative data from this study (demographic survey and ACS questionnaire) was conducted on the pooled results of the semi-

structured interview participants and focus group participants (n= 42). All variables were coded categorically in order to describe the population sampled; analyses were conducted using the SAS 9.1 Software Package (Gary, NC) and included descriptives and frequencies of the focus group and individual interview participants. Univariate analysis (Cochran-Mantel-Haenszel) was used to examine any differences between select groups against demographic variables.

### **Qualitative**

Verbatim transcripts of thirty-six semi-structured in depth interviews, seven key informant interviews and two pilot focus group interviews were analyzed. 46 of those interviews were audio-recorded and then transcribed; three of the semi-structured interviews were analyzed by reviewing interview notes, since the audio recorder failed at those times. The data from the interviews was subjected to thematic analysis and coded, using NVivo 8 Software, seeking themes and identifying trends related to the influence of culture and religion on CRC health beliefs and behaviors, allowing the systematic identification of themes present in the participants' responses, and the specification of relationships among these themes and contextual factors.

### **Protection of Human Subjects**

This research adhered to the professional guidelines and codes of ethics for the protection of human subjects. These included informed consent, confidentiality and personal rights to privacy, and minimizing harm and maximizing benefits; beneficence, respect, and justice. As well, because anthropology research should never be clandestine (AAA Code of Ethics, 2008),

the purpose of the research was explained to all participants, and all were provided with an opportunity to ask questions, and to voluntarily participate in the research. The right to autonomy was respected for those individuals who did not wish to participate. Those who did agree were provided with the written informed consent form that explained the research and the right of the participant to withdraw at any point in the research. Each participant's signature was obtained for those agreeing to be included in the study.

Because informants have the right to remain anonymous (AAA Code of Ethics, 2008), pseudo identifiers were used to protect the privacy of the participants. The data will remain confidential with access only to me, the dissertation committee as needed, and as specified by IRB guidelines.

### **Summary**

This chapter described the qualitative and quantitative methods used in this study on the influence of religion and culture on the health beliefs and behaviors related to colorectal cancer in Ashkenazi Jewish women. The methods included semi-structured, in-depth interviews, questionnaire/survey administration, and focus group interviews. This study followed research ethics in its use of informed consent, confidentiality, autonomy, and security of participant data. Additionally, this chapter addressed the issues of data generalizability, validity and reliability as seen in the triangulation of data collection methods, and analysis. Results of the data are presented in Chapter Four.

## Chapter Four

### Data Analysis

#### Introduction

Analysis is meant to bring order to collected data, permitting the emergence of patterns and themes to be linked with other patterns and themes. In this way, raw data can be 'cooked' into results (LeCompte & Schensul, 1999). *Grounded theory* also referred to as *substantive theory* and *midrange theory* focuses specifically on explanations of local phenomena in the research site or that help to explain associations at the domain or structural level (LeCompte & Schensul, 1999). The literature and conceptual orientations, cited in Chapter two, the methods discussed in chapter three, and the four research questions were combined with a grounded theory approach for the data analysis of Jewish identity and influence on CRC beliefs and behaviors. The analysis was conducted with the goal of answering the research questions for this study:

1. What are the cultural and religious influences on health behaviors in AJ women?
2. What are the social, cultural and religious contexts influencing individual perception of risk of CRC and autonomy to manage them?
3. What are the ways in which AJ women embody the concurrent U.S. and Judaic based taboos associated with the gastrointestinal tract as related to health and CRC health behaviors?
4. What are the sources and understanding of health information regarding CRC?

The results presented here are delineated in four sections. Section I reports on the qualitative findings from the interviews with the key informants. Section II reports the findings of the qualitative data collected from the focus groups. Section III reports on the results of the in-depth, semi-structured individual interviews. And section IV reports on the quantitative data collected from the focus group and individual interview participants. Finally, a summary concludes the chapter.

### **Section I - Key Informants**

Rabbis are considered the 'gatekeepers' to synagogue congregations, in that; without their permission or enthusiasm, the research may not be able to be conducted with their congregants. As well, they know which members in their congregation are best contacts for helping in the recruitment process.

Additionally, the role that they play in their congregants' health, whether as advisor or support system, is important to elucidate, particularly in the planning of future, collaborative programs with synagogues for cancer prevention which may be informed by the outcome of this research. Therefore semi-structured, in-depth interviews with seven Rabbis of various denominations in the Tampa Bay area were conducted, including three Reform, two Conservative, and two Orthodox. Of the Rabbis, only one was female, and the rest were male. Congregations varied from well established, large synagogues with 2500 members to much newer, smaller synagogues with 150 families.

### **Qualitative Interviews**

All of the key informant interviews took place in the synagogues of the

Rabbi's congregation where recruiting for participants would later take place. The semi-structured, in-depth interviews was similar to the interview guide that would be used in individual and focus group interviews, and also included questions about the feasibility of having health related programs related to CRC in the synagogue. Key informants are coded by denomination (R = reform, C= conservative, O= Orthodox) and number.

### **Judaism and Health**

The first part of the interviews with the key informants related to concepts of health, disease, and perceptions of the role Judaism plays in health behaviors and beliefs. The first question asked was for the key informants to give their definitions of health. Analysis revealed a common thread among Rabbis, whereby a healthy body is interconnected with a healthy spirit. Examples of the homogeneity across denominations in the Rabbis' cultural construction of health are reflected the following comments:

Well, I would say wholeness of body and spirit; that's the way to describe it. When we, the prayer that we say for healing talks specifically about – the Hebrew word is *rafuah* - it talks specifically about healing of the body and healing of the spirit. I think you can be sick in body and whole in spirit, or vice versa, and to be healthy, ideally, you have both. (KI-R1)

Health is a combination of body and soul. There is the body which is the vessel, and it is affected by what is inside the vessel which is the soul. The soul is effected by the body, just like you would be effected by the garments that you wear, if they're too tight your body will feel uncomfortable, restricted, the same is true of the body and soul vis a vis health. In order to have a healthy, whole person, you have to have a healthy body and a healthy soul. The two are intertwined – the body and soul and health are intertwined. (KI-O1)

Rabbis were then asked to define illness and asked how this may differ in their minds from disease. Answers to this question revealed variation based on

denomination; Reform and Conservative gave answers based on physical functioning of the body and duration/severity of affliction.

There's illness which is, which temporally comes upon somebody. Versus, disease, compromised health in perpetuity (KI-C1)

On the other hand, the Orthodox rabbis' answers were couched in the context of spirituality and God, as reflected in the following comments:

To some degree disease means part of your physical body is lacking some form of spirituality, some form of completeness. Whatever reason, that part of the physical body is missing the holy ingredient that would make it function. The physical body is a vessel, the vessel functions when the spiritual light, God, comes into it, and when a person passes away the physical person is there, the soul has departed, the spiritual, the Godliness has departed. Now in order for the spirituality to function, the body has to be in its proper way. At this particular person, there's something wrong with the physical body that the spirituality, God force is not penetrating to make it function properly. (KI-O2)

Key informants were then asked about the roles they had in their congregants' health. Analysis indicates the roles they had overall in the area of spiritual and emotional support, occasionally offering guidance of *Halacha* (Jewish medical law). This is reflected in the comments below:

My experience is that, people are, people view these as autonomous issues, and with anything, when congregants come to talk about medical issues, it's usually just to get some type of an affirmation, and validation of whatever choices they've already made. (KI-C1)

In Lubatavicher its tradition to give your opinion and have a friend who is a doctor, maybe give you some input. There's a tendency in the medical profession in general, people are overwhelmed you're just another file and that isn't good, because when a person is concerned than there's more of an interest, alertness to find a solution, rather than just going through another file. (KI-O2)

Key informants were then asked how much control they believed a person had over their health. All key informants referred to the biblical mandate to safeguard one's health and the sanctity of life in their replies.

Clearly we have some; it's based on how much we exercise, what we eat, what we drink, what we smoke... So I mean clearly there is inherent control that we have over everything. The *Torah* also commands us not only to preserve our health, but if somebody is ill to be actively involved in helping them get well, it's a *mitzvah*, a commandment. And obviously there's stuff that we don't have control over. (KI-C1)

God has given us control. God created us in a way that we should be responsible people and make decisions in taking care of our lives, so a decision to eat well is something that God wants us to do, like any other thing we're going to do in life. God gave us that ability and God wants us to do it, or else He would have created us in the spiritual world without lusts and material matters. (KI-O1)

The concept of the belief in God is that if you believe in God that's true, but God has also said "you're in charge in this physical world and you have freedom of choice" That's not the case, you're not supposed to put yourself in danger, you can't rely on miracles, you have to do everything in your power to safeguard yourself within the parameters in the normal, after that its up to God. So it's a partnership. (KI-O2)

The mandate to safeguard one's body and the centrality of the infinite value of life was a running theme throughout the Rabbis' interviews as related to Judaism and health, regardless of denomination. This is based on the biblical commandment that life is valued above all else, including trumping any other prohibitions such as fasting. The infinite of life involves not just the obligation to safeguard one's own life, but also to save another's (Telushkin, 1991).

In Judaism health is of paramount significance. There's a *mitzvah* in the torah which is "that you should protect your soul, protect your body, take care of your health." It's not something that during the course of the year that in some way isn't addressed from the pulpit weaved into a sermon. We have this idea of *Pikuach nefesh* – saving a life takes precedence over anything else... There are these two parts of the tradition, one which says 'take care of yourself' and the other, which is in essence, is 'take care of others (KI-C1)

The role of health is very important in Judaism, I mean the Torah decrees that one should guard their lives, for that reason, the life of a person has a priority over the rest of the commandments of the Torah, for instance, Shabbos, if you're talking about the saving of a life and so on and so forth, the life of a person is the most important thing. Now when you save the life of a person, to save a life that also means the person is responsible to eat healthy things, that's part of it. (KI-O1)



One of the commandments is “And you shall guard your health” why are you supposed to guard your health? Very simple. You’re a healthy person, you can do the job, you can serve God, you can be a good example, you can teach, you can do a variety of things you’re supposed to do, be an active role model. So therefore, life takes precedence over all other commandments, in order you should live and fulfill more commandments. (KI-O2)

Key informants went on to explain that because the Jewish concept of the infinite value of life is based on a biblical commandment, it is thus an obligation and duty for health, not a choice. They referred to the Talmud, Sanhedrin 4:5: “He who saves one life, it is as if he saves an entire universe. He who destroys a life, it is as if he destroys an entire universe” as well as Leviticus 19:16: “neither shalt thou stand idly by the blood of thy neighbor” - the source of the Jewish value *Pikuach nefesh* (Jewish Virtual Library, 2008) - as some of the many Jewish sources which pertain to the infinite value of life, and the obligation to not only save your own, but your neighbor’s as well. All of the rabbis described the body as a gift from God, to be cared for accordingly. They explained how this concept forms the basis for a view of health through the prism of Judaism – a Jewish way of looking at health - which focuses on the idea of moderation.

I think American culture is individualistic and the notion that “I am center of my universe” is a very American idea, “I’m an autonomous creature, and I should take care of my health” but ultimately I think its hard to justify simply based on American cultural norms why a person should, necessarily, right, whereas - because if you choose not to, that’s its your choice, you’re an individual, right? Judaism isn’t like that, Judaism doesn’t put the individual at center, Judaism suggests the fact that your body isn’t actually really yours, right your body is lent to you by God, you’re not the highest value in terms of deciding, you have an obligation, not just to yourself or your kids, lets say to care for your body but an obligation to God to do so, and I think that just shapes it in a completely different kind of way. (KI-R1)

Obviously I would try to look at this through the prism of our tradition, which obviously views life and the body as a gift from God, something which is holy, something which should be maintained through the best of one’s potentiality.

(KI-C1)

Jewish way of life teaches that we should follow the middle path, moderation which I believe is very good for the body, extremes are not good for the body, the purging the body and the spirit; and the surroundings; it all comes from the source, that there one unifying force or source which is God, its not dismembered, separated. (KI-O2)

Despite the centrality of the obligation to safeguard one's body and health in Judaism, most of the rabbis questioned how much this Jewish view of health informed the actions of their congregants, highlighting the intractability of Jewish and American cultures.

I don't how many of my congregants would say that their bodies and their lives are gifts from God, that is a classical Jewish approach, I think Jews believe that they must take care of themselves, not – well they think it, how much they must act on it – I think they think that way - if they don't hear God's voice in it, then they think 'you gotta do it for your family or for your kids.' (KI-C2)

We've reached levels; I would say unfortunately, that many Jewish people have assimilated into Western culture. I mean if you will interview the average Jewish person and the average Western person as to how many times they went to McDonalds and Burger King, a great sector of Jews don't keep kosher, and on that level they're equal; if you're talking about more religious people, obviously who only keep kosher, I'm sure that many people keep kosher but never the less they so to speak eat everything they want and they're not careful. (KI-O1)

I don't think your average American Jew is thinking about health as a Jewish topic, and my guess is you'd get a lot of blank stares if you asked this. (KI-R2)

*“Does God ever punish with disease – or reward with health?”* This question was intended to elicit the Rabbis' belief system –and as spiritual leaders, what they taught – as to whether following commandments and obligations of Judaism would be met with rewards such as health, whereas disregard for commandments and *Halacha* may lead to punishment by God. Most key informants rejected this notion outright, across denominations. While they agreed there was a place in Jewish theology for this type of thinking, they

themselves not only did not believe in it, they discouraged their congregants from believing it as well. This is reflected in comments below:

If you look into the bible, the five books of Moses, it talks about a lot of disease if you don't listen, if you don't harken to God's commandments, and this will happen and that will happen, if that would've been true than we would have been much more ill than we are, so I don't look at it that way, I look at it as part of society, its definitely God's will that it should to happen to you, you deal with it, you go to a doctor, taking medicine, and praying to God that God should help you out, and at the same time saying that well if this is kind of an awakening call for me, I should search within myself to see if I can become a better person, that's also okay. But I'm not here to say that this happened because this person behaved improperly, I'm not here to say that because I'm not God. God is the ultimate judge, not me, so I discourage people from even thinking that way. (KI-O1)

The problem, I think is theologically is that we all want to believe that God can heal us if we pray enough, and if we believe that God can heal us, it goes hand in hand a little bit with the theological notion that God can make us sick...its hard to grasp on to one without the other. And I don't have a great answer to that dilemma, except to say that I don't see why anyone would want to pray to a God who would strike a person down ill for their – give them cancer or cause a child to die, what kind of God is that? (KI-R1)

One Orthodox rabbi, however, did agree with the notion that God indeed does punish with disease. In this reasoning, because God is all powerful, all things that happen can only be attributed to God, including disease and health.

If we believe that God is in control of everything, God is omnipotent, so though he has hidden himself and given us free choice within our conscious domain, he still is in charge. Are there illnesses that are part of a punishment from God? Yes. One could conjecture which ones they are; but everything that happens to a person is in the hands of God. (KI-O2)

### **Judaism and Purity**

Interview questions at this point were related to the concept of purity in Judaism. Purity is central to Judaism and illustrated in numerous issues including laws of *kashrut* (dietary) and *niddah* (separation during menstruation); typically purity laws relate to bodily discharges and fluids. Because my third

research question pertained to Judaic taboos concerning the gastrointestinal tract, these questions served to establish the key informants' interpretation of Judaic purity laws and establish a baseline as to what to possibly expect in the interviews.

When asked to explain the concept of purity in Judaism, key informants all related it to holiness, not necessarily cleanliness or being dirty. Holiness, in Judaism, again refers back to the infinite value of life, so anything that relates to death is considered unholy.

You know with impurity, it doesn't mean you need a shower, if pure means you're in a state of perfection with regard to certain matters, than impurity means you can't, for instance when you say a woman is impure so she can't have relations with her husband; relations with her husband is perfection, the possibility of a child being born, so to use the terminology where she cannot have relations at that moment is because the perfect opportunity does not exist at that moment, so she's rendered impure, but not impure like she's, in the physical sense...You are lacking a certain thing, a certain perfection of holiness. (KI-O1)

Impurity is a very, it's a difficult concept I think to translate into notions that make sense to us. When we hear pure and impure, we tend to translate to clean and dirty, but it's the opposite of something that's sacred or holy, it's like life and death being opposites. And I understand it in that sense, it's connected to death and loss and those kinds of things. (KI-R1)

Several of the Rabbis did relate Judaic purity to concepts of liminality, and those things that were on the border of life and death were considered powerful and impure.

I think the issue with *taharat hamishpacha* [family purity laws] it's simply the issue of blood, at least it started that way. A woman was losing blood – blood is the stuff of life. Through how the priestly sources saw blood is the stuff of life, if you're losing blood, then to use the Yiddish expression you're *nishdhigh*, *nishdahair*, you're walking on the borderline between life and death. The bible hates everything that smacks of death. The Hebrew God is a God of life, and everything that is reminiscent of death is considered *tameh* – to be impure. A woman losing blood was walking the border between life and death and that's

what made her *tameh*. (KI-C2)

When we speak about various types of impurities, blood's a very easy one. Why does blood render one impure according to the Torah? Obviously the Torah doesn't tell us, it just tells us that that's what it does. But there's – for us, the reason we have a prohibition – blood isn't death, blood is life. And it's about this whole sense of whether you're talking about fecal material, seminal fluid, discharges, all of these things, they're like right on the cusp, and somehow they didn't realize the potential in some fashion. And, if you will, there's a sense that that's powerful stuff and we have to have this appreciation, and again reflects this Jewish [concept] toward sanctity of life itself. (KI-C1)

To further explore concepts of purity in Judaism, I asked key informants for their explanations of the family purity laws (*taharat hamishpacha*). These are still followed by many and have been the subject of much debate within the Judaism today, depending on how the laws are understood and the terms are translated. Based in Leviticus (18:19 and 20:18), the family purity laws state that a man and woman cannot have sexual relations during the time of her menstruation. Talmudic scholars and customs have extended the period of separation so that it lasts a minimum of 12 days, with separation beginning at the first sign of blood and ending in the evening of the woman's seventh "clean day." Later rabbinic law broadened the definition of separation, from avoiding intercourse to a man not sharing a bed or even touching his wife while she is in a state of *niddah*. Purification can be gained only by a ritual bath (*mikvah*) and until the woman has taken this she remains *tameh*. The word *tameh* generally is translated to mean impure or unfit. Most of the rabbis explained the differences between original meanings of *tameh* (ritually unfit) and its current negative connotations (unclean).

You know, originally there was no 'ick' factor in all of this, it wasn't about 'unclean', the word unclean is a terrible translation of the Hebrew [*tameh*] it was

about the flow of life and death and women had to go to the *mikvah* after the menstrual cycle just like men did after seminal emissions because it was a missed opportunity of life. That was all about the cycle of life and death; it was a very powerful connection which turned over time into a taboo, yucky issue... Somewhere in the last 2000 years, the last 3000 years, this went from a topic that was mainly about the effect of contact with death on your spiritual readiness to something about women's taboo. (KI-R2)

You are lacking a certain thing, a certain perfection of holiness. It's the fact of, the nature of the body, it didn't have a child, you have your period, and the expectation is next time there might be the opportunity. But it's not moral, absolutely not. (KI-O1)

Reform and Conservative rabbis also expressed doubt that the family purity laws themselves resonated with their congregants at all. This is reflected in the comments below:

This whole thing about blood, and impurity and this – granted this is what *Vahichrah* [Leviticus] is all about, the third of five books of the Torah, its completely about this, its all over the place, its ubiquitous, that you're engrossed in the tradition, it becomes this whole practice, but for my people that is just the most furthest thing from their minds. (KI-C1)

I think the reason they've rejected the *niddah* is because for the most part the community ethos isn't such that menstruation is impure. I mean, but that's in fact why a lot of Jews have walked away from *niddah* because they're in fact rejecting that notion. (KI-R1)

Continuing with the theme of purity, I next asked about how excrement is considered in Judaism, giving examples of Levitical purity laws. For instance, bodily discharges are considered defiling, which Douglas (1970) interprets to include excrement; as well as there is a chapter of Deuteronomy (23:15) in which laws are specified that an area outside the camp must be designated as a privy, and a spade must be kept among soldiers' instruments in order dig and cover up excrement because 'thy God walketh in the midst of thy camp to deliver thee and to give thine enemies before thee; therefore shall they camp be holy: that He sees no unseemly thing that one would be ashamed of and turn away from thee.'

These laws still considered to be 2 of the 613 *mitzvot* (commandments) found in the Torah.

Answers to this question varied. The Orthodox key informants discussed excrement in terms of holiness and ability to serve God.

Excrement is something – you should keep a clean body. You cannot pray to God if you have an unclean body, your stool or you're running [to the bathroom] So therefore, that again helps enhance the wellbeing of the individual following the biblical commandments...it is spoken about in the code of Jewish law; when you approach God you approach with a clean body; a person happens to have diarrhea you shouldn't put on the *tefillan*, a variety of things he shouldn't do until they overcome that.... if you're in a room and there's a terrible smell, sure you can serve God but its distracting, its not the right feel. (KI-O2)

Holiness and cleanliness are intertwined, it says so, so if you are filthy, and dirty and smelly, there's a lack of holiness so to say. (KI-O2)

Reform and Conservative key informants, however, focused on the interpretation of the chapter of Deuteronomy to be understood in the context of the times during which it was written – as a means of enforcing sanitation and guarding the health of the community.

In ancient times, disease was always punishment from God on some level. And, if you think about it, if you didn't have proper sanitation in your army, then you're going to wind up with disease just wiping out your army... which was punishment from God, right? So it was almost an observation it wasn't so much a judgment on excrement as an observation that people who don't do these things get punished. (KI-R2)

I understand that the laws about the latrines with the armies was exactly the way they had to look at the world, it was honest religious law for them because of their understanding of all diseases...For me to then ignore that context and say whatever they had that law, that was a law, and therefore it's my law, doesn't make any sense, which is exactly why I'm a Reform Jew. Right, my need to look at it and say that law evolved under specific circumstances for them, those circumstances don't exist here, they're not for me. These laws about excrement being inherently wrong would lead you to essentially stigmatize someone with a colostomy bag. (KI-R2)

Building further on how digestive functions are treated within Judaism, the

Rabbis were asked to explain the *Asher Yatzer*, a prayer typically recited every morning as well as after each visit to the bathroom. While excrement itself was previously referred to as 'less than holy', the Rabbis responded to this in the context of how all bodily functions – including those of elimination - are God given and to be praised, once more referring to the sanctity of life and the connection between the physical and the spiritual.

Its interesting that after you go to the bathroom you say this prayer that talks about all the different parts of your body, holes, the revealed ones the concealed ones, that only God knows exists on a person's body; that shows every part of your body was worked upon by God, so even the food that absorbed and the waste is removed. (KI-O1)

I think it's an incredibly powerful prayer. I think it's a great example of a side of Judaism we don't talk about in lots of different ways. It's, it's very much talking about this connection of the physical and the spiritual. (KI-R2)

### **Colorectal Cancer Beliefs and Behaviors**

Having established a worldview of health and illness via the lens of Judaism, including purity concepts, the role of excrement, and the centrality of the sanctity of life, the interview next turned to cancer beliefs, starting with the following question:

*Are there any cancers which you believe may occur more frequently in the Ashkenazi Jewish population?*

Two of the Rabbis believed breast cancer to occur more often in the Ashkenazi Jewish population. None, however, cited colorectal cancer (CRC) as being more prevalent. At this point in the interview, I informed the interviewees of the rates of colorectal cancer in the U.S. population in general and the Ashkenazi Jewish population specifically. All were very surprised at hearing these rates; none had heard about this before. When asked for their guesses as



to why CRC is more prevalent in Ashkenazi Jews, most guessed diet (“too much chopped liver, too much kugel”) and genetics from intermarriage. One key informant (KI-O1) informed me that his father died of colorectal cancer, and that is why he got screened early at age 40. Another (KI-O2) recounted how his mother, who was over 80 years old at the time, was convinced by her doctor to have a routine colonoscopy and died a short time later from complications. Because of *halacha* [Jewish law] which requires maintenance of the integrity of the body, an autopsy was not performed; however this has tainted his perception of how safe the procedure is to have done, and has never been screened. A third key informant (KI-C1) said that he also has never been screened because he just does not like doctors and does not get any type of preventive screenings done. He explained it as “that’s just my own *mishegas* [craziness], it’s not like it’s informed by anything intelligent...It’s just my own idiosyncratic behavior.” He did, however, say he would encourage someone else to get a screening “without question.” All the other key informants who were over the age of fifty (KI-R3, KI-C2, KI-O1) had been screened.

When asked why thought others would avoid getting CRC screening, the reasons ranged from within the typical barrier domains cited by Woolf (2000) of attitude/knowledge, acceptance, reinforcement, and ability:

I think the screening is not very pleasant, and I suspect that’s why people avoid it . . . To do the full screening, you still have to drink the stuff; I think that’s a big dis-incentive to people. (KI-R1)

People don’t want to, it costs money, they’re worried about a perforation. It costs a few hundred dollars, people therefore hold back.” (KI-O2)

Laziness, absolutely laziness, they figure “the doctor is going to do this to me”; its

unpleasant, nothing else to it (KI-O1)

However, most of the key informants agreed that, in keeping with a 'Jewish way of looking at health', Jews are very proactive about their health. One Rabbi explained it in this way:

What I do hear, is it seems to me that my congregants are very, very aggressive about getting colonoscopies...I think, there again the concept in Judaism of taking care of your body comes into play. If there's anything a Jew can do to minimize the possibility of getting this disease, Jews will be very quickly line up to do it. (KI-R3)

On the other hand, key informants did provide some explanations why Jews may not get CRC screenings. Most of this focused on risk perception and lack of knowledge, bringing up the responsibility for media and research to publicize the results and reach out to the Jewish community.

People aren't aware that they're more at risk Jewishly; I don't recall ever hearing that. And I'm better than average informed about the world in general... so maybe the other question would be also is, has whoever's working on colorectal cancer, whatever part of the American Cancer Society, have there been specific programs of outreach in the Jewish community? Has there been any of that? (KI-R1)

No one has probably pushed it or publicized figures – a lack of knowledge. I mean if someone were to come up and say "we know a study that 20-30% will have this and so many will die and if you catch it early so many less will die" and if you provide the financial structure to test so it doesn't cost people than people will be more prone to taking it. (KI-O2)

One rabbi did cite lack of control during the procedure as an inhibiting factor specifically for Jews, that Jews have a need to be in control, and so being under anesthesia inhibits Jews from getting the test done. He explained it this way:

I think one of the big factors is that you're put to sleep for the colonoscopy, and Jews like to be in control; I think that in Christianity, there's a greater sense of the greater feeling of comfort and ease about putting your life in God's hands, I don't think most Jews including Orthodox particularly like to put their fate in God's

hands, I think Jews like to feel that they're in control. And that being the case, I don't think they like to go under the anesthesia. I think if they could find a way to do this, either less invasively or so that the anesthesia could be different, I think Jews would be readily willing to do it. (KI-R3)

Finally, relating CRC screening to Judaic concepts of purity elicited responses across denominations that there is nothing inherent to Judaic law prohibiting or discouraging screening, and in fact referring back to the sanctity of life, it is part of the obligation to safeguard one's life.

its laziness, lack of knowledge, I mean I wouldn't have done – I take a test, but if my father wouldn't have had it I don't know if I would have done it, but it has nothing to do with purity or impurity I would like to meet somebody who would state that to me, I've never heard of it. (KI-O1)

Excrement itself is a level of holiness that when you pray you move from it, that's the residuals from what you ate, its not the positive things you ate, so therefore you don't pray in front of that, but its not that as a result that if a doctor has to insert tools into that area that that its impure. The thing itself [is unholy] yes, absolutely, because its waste. Maybe a person has such feeling, but to shape that in a sense of what one should do, should not do, or *halachally* or not, absolutely not. Categorically not. And I'm not talking about feelings, just talking about accepting this as a rule, no. (KI-O2)

I mean *halachally*, you gotta believe that, *koaf nefesh*, the commandment to save a life, is gonna trump any stigma, any stigma against handling feces. If colorectal cancer really is the number two killer, and this is going to help prevent it, that's got to trump it in any reasonable version of Orthodoxy. (KI-R2)

Referring back to the *Asher Yatzar*, the prayer recited in the morning and after using the bathroom, I was reminded by one key informant that Judaism views everything as God given and to be appreciated, including elimination and excrement:

We take these parts of us that we think are so vile, and so unholy, right, its not - can you think of an act that seems less holy than going to the bathroom? But if you can't do that, you can't do anything else in the world, up to and including the ultimate acts, such as standing before God. So instantly these acts we think of as vile become supporters of sacred acts, and therefore are sacred themselves. (KI-R2)

And one Rabbi pointed to the stigma of excrement in non-Jewish American culture.

Its an American way of thinking for sure, I mean I think that, you know, we like to, in America we like to pretend that people didn't really go to the bathroom somehow, you know, "can you show me the ladies room?", you know, we have all these sort of euphemisms for going to the toilet... So I think in general, I think it's a more an American thing than a Jewish thing. (KI-R1)

## **Section II: Focus Groups**

Before conducting the in-depth interviews, the interview guide and surveys was pilot tested with two focus groups. A total of two Ashkenazi Jewish women affiliated with a Reform temple participated in the first focus group; two other women were scheduled for the second group and cancelled at the last minute to due to work obligations. This focus group took place in a meeting room of the synagogue the women were affiliated with. Four unaffiliated (UA) Ashkenazi Jewish women participated in the second focus group, which took place in a meeting room of a local public library. The purpose of the focus groups was to solicit comments on the clarity of the questions, wording, and to obtain suggestions for question additions and/or deletions of both the interview guide questions and the surveys. Thus, the piloting was done to test the sequencing, flow and skip patterns, language use, comprehension and length, and the reliability of the questions (Schensul, Schensul & LeCompte, 1999). One of the major points of feedback provided from the focus groups was the need to administer the demographic survey prior to the interview instead of afterward, because it contains a question which asks baseline knowledge about cancer in Ashkenazi Jewish population. Because this is covered in the content of the

interview, answers given to the question given after the interview would not be valid. Additionally, there were suggestions for making clarifications of choices for the household income question on the demographic survey. Based on comments and feedback, the timing of surveys was changed so that the demographic survey which assessed baseline knowledge about CRC rates in Ashkenazi Jews would be given prior to the interview rather than afterward, and the income choices were clarified. Because the focus group participants filled their surveys out after the interviews, and due to the ultimate need to change timing of distribution of surveys to increase validity, data collected on income and baseline knowledge about cancer in Ashkenazi Jews is not used from the first focus group. Also, some themes for the interview guide related to prayer and punishment/reward were added. The changed timing of survey administration and addition of questions was added to the second focus group and received positive feedback. The focus groups were conducted in February 2008 and April 2008. Question guides were used in the focus groups, and each session lasted about 90 minutes. Like key informants, focus group participants are coded by affiliation (UA, R) and number.

### **Focus Group Participant Description**

A description of the focus group participants is summarized in Table 1. The average age of the focus group participant was 65, with ages ranging from 51-78; the average age was 54.4 in the Reform group and 71 in the UA group. All six participants were born in the United States, and in the UA group, three reported one or more parent born in Eastern Europe. Five of the participants

were married, and one was widowed. Education levels ranged from high school graduate to post-graduate education; in the Reform group one participant was a high school graduate and one had postgraduate education. In the UA group, one was high school graduate, one had some college, one graduate college and one had postgraduate education. Four participants reported having ever smoked in their lives (three in UA group, one in Reform group), however none reported currently smoking. Income was not collected due to an error on the survey forms in the Reform group; in the UA group, one participant declined to answer, one reported income of \$20,000-\$29,999 and two reported incomes of \$80,000 or more a year. All six focus group participants reported having health insurance coverage; the types included private, Medicare and Tricare. In the Reform group, one participant self-identified as Reform, one as Conservative. In the UA group, three participants self-identified as Reform and one as Conservative. Additionally, in the UA group, two reported being raised as Modern Orthodox Jews, one as Reform and one as Conservative. In the Reform group, participants' reports being raised the same as they currently self-identify one as Reform, one Conservative.

One of the UA focus group participants reported a personal history of cancer (Clear Cell Lymphoma), while one in the UA and one in the Reform group report family history of colorectal cancer. All six focus group participants reported having had a mammogram in the last two years and five report having had a Pap smear in the last two years (one UA participant did not). Five reported having had a CRC screening in the last ten years; the one participant (Reform group) who

did not have the CRC screening was scheduled in the next month for her first colonoscopy. The average age of first CRC screening was 56, and methods included flexible sigmoidoscopy, fecal occult blood test and colonoscopy.

**Table 1-Focus Group Participant Description**

Focus Group	Mean Age	Smoke hx	Smoke Now	Health Insurance	Education	Personal Cancer HX	Family Hx CRC	Ever Screened for CRC	Mean Age first CRC Screen
Reform n=2	54.4	1 (50%)	0	2 (100%)	1- HS 1-Postgrad	0	1 (50%)	1 (50%)*	48
UA n=4	71	3 (75%)	0	4 (100%)	1- HS 1- Some College 1- College Grad 1-Postgrad	1 (25%) CLL	1 (25%)	4 (100%)	58
Both n=6	65 (51-78)	4 (67%)	0	6 (100%)	n/a	1 (17%)	2 (33%)	5 (83%)	56

\* One Reform focus group participant scheduled for first CRC screening the following month

## Judaism and Health

The first part of the focus group data analysis revealed participants' construction of health and illness, their perceptions of control over health and the role of Judaism in health behaviors and beliefs. The first question asked was for the focus group participants to give their definitions of health. Analysis revealed both focus groups perceived health mostly in terms of physical functioning, with one member of the UA group bringing up mental health. Spiritual health – a common theme with the key informants – was not mentioned.

UA-11 - Being without major disease process and not hurting – health as good health, bad health is what disease.

UA-12: Health is either way, just your medical status, whether it be good or bad

UA -13: You think about health when you think of longevity, and you want to be healthy, so that you can enjoy your life, and as we get older it gets a little more difficult to stay healthy

UA-11: She's right, mentally, you know, that's the most important thing is mental.

Participants were then asked to define illness. The Reform focus group participants both commented that they didn't actually think about illness, that was

something that affected their parents, not them. The UA group, on the other hand, defined illness in physical terms once more, as related to limitation of bodily functions. Both groups were also asked how they perceived illness to be different from disease. For the most part, participants from both groups considered illness to be the same as disease. Several in the UA group did differentiate illness from disease based on the duration and severity of the affliction, as reflected in the comment below:

UA-14: Illness seems milder, like a simple thing that's temporary whereas the disease process is something – heavier.

During the first focus group (Reform) I began to ask questions about the influence of Judaism on the participants' perceptions of health. During their answers, however, degrees of belief and types of Judaism (i.e. secular vs. religious) were brought up, which could be relevant to informing how Judaism would inform their views on health. Therefore, in the second focus group and every interview thereafter, I asked the participants to define what their Judaism was to them, how they saw it in their lives. The UA focus group participants described their Judaism by denomination, with three participants identifying themselves as Reform, one as Conservative. Two of the participants who currently identify as being Reform, described growing up Modern Orthodox in kosher homes, with one or both parents coming from Eastern Europe. One of these women went to Orthodox day school growing up, but now describes herself as "liberal reform" The other participant who grew up Modern Orthodox – now is Reform – recollected wanting to go to the Orthodox synagogue near her home, and how she was able to go to religious school for free.



When asking about how Judaism influenced their way of thinking about health, the Reform focus group participants did not see any connection between their culture or religion and their views on health.

R-12: I think its separate, I don't see any connection. I hate to say that. The reason I think I'm so health conscience I started, my mother was when it was very unpopular, back in the day, she nursed me, she was into natural health foods, and we didn't fry and all that stuff, she was totally not religious; I don't see a connection

Answers from the UA focus group focused on specific Jewish rituals and rules, including circumcision, *kashrut*, and *niddah*. However, while they were able to come up with many examples within the religion itself, they did not necessarily relate these back to their own experience.

UA-14: Well like circumcision, the kind of circumcision that does have certain health aspects associated with it, supposed to prevent penile cancer supposedly ... I think the original *kashrut* laws have a lot to do with health.

UA-12: We do not eat pork because of trichinosis and don't eat shellfish because hepatitis and the fish without scales they were the scavengers of the sea, the bottom feeders, so that was maybe not as healthy. So I think we're aware of it, but didn't make a big issue about it but it's somewhere in the back of your brain you knew if I am to eat pork it should be cooked be really good.

UA-14: Some of the laws around menstruation and women not being approached at certain times, that may have also been to protect the woman from harm that might come to her if she were approached at a time when she was really at risk of being injured

UA-11: The whole cleanliness issue, like Hassids, if you ever go into a Hassid community you cannot believe the stink, but I think it came through the generations, the house had to be clean, no messing around, as clean as when you took a chicken and did all this stuff to it – food and the house.

UA-14: And salting the chicken to get the blood out

UA-11: So all that extreme cleanliness was – to make it a health issue

UA focus group participants were also asked to discuss how Judaism may

have influenced the way they think about their body. Discussion on this point was focused on dressing modestly in temple, and the modest dress of Orthodox women who cover their arms, legs and hair.

The question then was asked whether participants thought there was a 'Jewish way' of looking at health. The Reform focus group participants brought up what would be a common theme in the individual interviews, the role of education in Jewish culture which impacts the way Jews tend to take care of themselves. Economic status was also discussed, and how the Jewish cultural push for education results in better economic status which also influences healthcare utilization in Jews.

R-11: I think if you follow religious rules and if you're not a secular Jew, I think if you're more of a religious Jew, health is very much connected with the religion, just in what you should and should not eat, the dietary laws, really pretty much fit what the doctors are currently saying are healthy for you. The kind of meats, those kinds of things. Is there a Jewish way of thinking? The chicken soup thing.

R-12: I think, to me it appears that not so much the Jewish, but people have more money, but I was thinking about our cleaning lady and she doesn't have any health insurance and it looks like she's aging much too fast.

R-11: Well that also goes into a religious thing. We are in a synagogue, which is called a *shul*, and *shul* means school, that's what the word literally means. It means school, and Jews have typically pushed themselves academically, we're driven academically, so that goes to what you're saying, if you're driven academically in jobs

R-12: You have more money

R-11: And better jobs, and comes health insurance and health.

UA focus groups had similar responses to the question, bringing up a Jewish cultural drive for education, which results in better awareness about health.

UA-11: We – being Jews – are more obsessed with making sure you go to the doctor, you know you have a hangnail you have to make sure you go to a

specialist, at least most of the Jewish people I know, they're quicker to take care of what needs to be taken care of. My husband has patients that – they have diseases that have gotten so far beyond what the disease should be –

UA-14: That's socioeconomic –

UA-11: It's not just that, not all of them are living in the woods, some of them are just ignorant – they don't have a clue.

UA-13: They don't ask questions

UA-11: I think we as a population are more into education, I don't want to say more intelligent, but I will say more education and more aware, and that leads to being more careful with yourself

A participant in the UA focus group also related the idea of guilt and obligation as being tied to a Jewish way of looking at health; this speaks to one of the key informant's comments about the Jewish concept of health relating to obligation to family, community and God. However in speaking with the Reform focus group participants about obligation and duty as components of a Jewish way of looking at health, they stressed that it was hard to differentiate because "As a Jewish woman, I think maybe because I didn't grow up religious I feel my responsibilities as a woman, as a person, and being Jewish is part of my persona." In terms of duty to community, both again discussed how it is hard to differentiate between being a religious duty or for other reasons of community:

R-11: Unfortunately in this congregation there have been a number of women who have had breast cancer. And I think this congregation has rallied behind them. While they were going through the chemo, we have prepared meals, cleaned home, things like that. And so we do it because of lots of things, the next one could be any one of us I think, most of us living here in Tampa don't have a family, and the congregation is our extended family, so the God Forbid factors. It could happen to me and I need the outside support. I don't know we do this because of religious reasons, though it's definitely all there, or because its humanitarian reasons, or even selfish reasons, that it could be us.

Focus group participants were then asked how much control they believed

a person had over their health. Both participants in the Reform focus group couched their answers in the context of God and free will; in fact their answers were in line with those of the key informants, in that God has given us knowledge and free will, and it is our responsibility to make the right choices.

R-12: I think God helps us to help ourselves, in that respect, and that does not cover everything, there are things that are out of our control, and diseases but we can make a big difference that's under our control generally speaking

R-11: Going back to what your eating, and exercising and things like that, So its laid out for you but you do have to choose, its like the comment people have, with having children, having another child, the comment "Well God will provide, and God did provide" God provided you with a brain to know when you can or not afford another child, whether you can take care of it, not only financially, but emotionally, God provided that, if you choose not to follow those advices, well that is your choice, so in health as well. Do you eat the processed food? Do you eat the healthy stuff? Do you exercise? God provided us with the knowledge to know which path we should take, the healthier path, whether we follow it or not.

On the other hand, God did not inform the answers of the UA focus group.

Rather, their responses focused on diet, lifestyle choices, genes and luck. When asked where they thought God fit into the picture, several voiced skepticism about belief in an all-powerful, personal God.

UA-11: I think that people's image of God and being very connected to each individual person is very egocentric; if God is, then he rules universe, the universe is a very big place, and I think having faith and prayer can help people, and spiritually it – when someone's ill, having tremendous faith and believing in prayer circles and all that helps them, I really do believe that, but I don't think there is the big white bearded guy up there pointing his finger saying "I'm going to get you" or "I'm not going to get you" or "I'm going to help you"; my image of God is not somebody who is not directly connected to me.

UA-12: I think its individual. I'm very proud to have been born a Jew, but I don't know if I believe in a lot of the things that they preach as far as the Supreme Being.

As well, when asked they believed whether God ever punishes with disease or rewards with health, similar to most of the key informants, participants

in both groups agreed that this was not the case. One of the participants related a story about losing her father when she was a baby and that's one of the reasons [her] mother isn't religious, because she couldn't believe in God after that happened to her" but she chose to believe it was a plan, not a punishment; that everything happens for a reason. Participants in the UA focus group as well did not buy into this framework; there is too much inconsistency with good people being afflicted with bad things, and bad people remaining healthy. As one participant explained:

UA-12: There are so many instances where wonderful people are afflicted in some way and it's hard to believe that God would want it to be like that. Is he allowing all these things to happen in Darfur?

### **Judaism and Purity**

Questions at this point were pertained to the concept of purity in Judaism, starting with asking about how they perceived the concept of *niddah* and their experiences with a *mikvah*. In the Reform focus group, the participants were familiar with *mikvahs*, although neither they nor their parents had used one. For one of the participants, the concept of *niddah* related to being physically unclean, not to a missed opportunity at life as the key informants defined, and therefore it resonated in a negative way with her:

R-11: It bothers me that women are considered unclean when they're having their period and that's just a natural part of life, I don't understand why that would be considered, why you'd be considered unclean.

This was a similar experience to the UA focus group; the participants had not grown up using the *mikvah*, and the concept of *niddah* resonated in a way which they perceived denigrated women.

UA-12: I always thought it was a way of making women second class citizens, I don't believe in it, we know of it, we grew up with it, but my family never practiced it.

UA-14: I was appalled the first time I was introduced to it. I wouldn't go – when I got married I was supposed to go and I refused. I challenged all these things that had to do with women and putting them in a inferior role, I was very offended by it, I was so offended and I spoke up and I guess I should have kept my mouth shut. I was really hurt by it. It strikes me as stupid...degrading.

Participants from neither focus group were familiar with the *Asher Yatzar*, the prayer recited after using the bathroom, thanking God for the body functioning properly. Still, no one was surprised that there existed a prayer for this function; “we have a prayer for everything!” was exclaimed by both groups. And a participant in the UA focus group related the prayer back to the concept of *niddah*:

UA-14: That to me is a nicer thing than making women into some impure object that need to cleanse themselves for normal bodily functions.

### **Colon Cancer Beliefs and Behaviors**

Having established a worldview of health and illness via the lens of Judaism, including purity concepts, the focus group questions next turned to cancer beliefs, asking focus group participants which cancers, if any, they thought affected the Ashkenazi Jewish population disproportionately. Both groups mentioned breast cancer. Ovarian cancer was also cited by one member in the UA focus group. One participant in the Reform focus group also mentioned colon cancer, as her step sister and grandmother both died of colorectal cancer. When I informed both groups of the disparate rates of colorectal cancer in Ashkenazi Jews, both groups were surprised. The UA focus group was asked what their guesses were for why the rates were so high; they

first guessed genetic mutations, and then diet. The discussion also turned to the possibility of longevity in Ashkenazi Jews factoring into higher rates.

At this point in the focus groups the questions moved to experiences and perceptions about colorectal screenings. In the Reform focus group, one of the participants was scheduled for her baseline colorectal screening the following month. The other participant, who had two members of her family die of colorectal cancer, has been screened twice already; she mentioned that her husband (Ashkenazi) also had a family history of colorectal cancer. Participants from both focus groups agreed that the preparation for the screening was the worst part, the test itself not being so bad because of being medicated – contrary to the one key informant who thought that the anesthesia was an inhibitor for Jews to get CRC screening - as reflected in the comments below:

R-12: The rest of it is a piece of cake for everyone I know. I mean you're sleeping, its like taking a nap, and for anybody I know , including myself, there's no pain, nothing, absolutely nothing, you don't even feel sore, Its to drink that stuff, after the first couple mouthfuls it starts to taste bad and its just torture for me and most people I know to get it all down.

I asked participants in the Reform focus group if they knew people who avoided getting screened because of the preparation. The participant with the family history of colorectal cancer explained that the preparation never would stop her because of knowing the cancer is in her family, and watching her step sister die at a young age (56) and “its one of those things that, with me sometimes I hear about things but I don't really believe them until I come into full contact.” The other Reform focus group participant referred back to the Jewish culture of education and health in that Jews are educated and aware enough to

do what they have to do for their health, even if they do not like it.

R-11: I don't think I've ever heard, a Jewish person, say "I'm not going to the doctor to get X done, whatever X might be, because it's going to hurt; they do it. They may not like it, but...And maybe this does fit, I think for the most part, most of the Jews, maybe it's because the ones I know are educated and have insurance, and even if they don't have the insurance somehow they find the money for it. It's very rare that you find Jewish people without teeth in their mouth, be it real or fake. Especially down here, I see many people with missing teeth and we're not talking about people in poverty, we're talking about people in the same economic level as I'm at, same education level, they don't have teeth in their mouth, for whatever. So maybe we've just answered one of your other questions. I don't know anybody that wouldn't have a colonoscopy because it's uncomfortable; you might put it off a little because oooh, the whole thought, but you do it anyway. Generally, we [Jews] complain about it but we go. As a rule we go the other way, we're always going to the doctor, we're worriers from way back."

Like the key informants, participants in the UA focus group believed people did not get their colorectal screenings due to the nature of the test, and fear and ignorance of what actually happens during the exam. They also believed there was a lack of publicity of the risks in the Jewish population.

UA-11: I do think that's why a lot of people don't do it – they're not going to have anything put where they don't want it put. Women have gone to the GYN getting that kind of exam is difficult enough, but the other end is 10 times worse in people's minds, and once you've had the test you realize its nothing; so what you get diarrhea for a night, but I don't think its such a terrible thing, and what not being able to eat for a day, I could use that. But, I think it's the fear of having something placed where most people don't place things

At this point due to time constraints, the UA focus group ended. In the Reform focus group I went on to ask about the relationship of Jews not getting colorectal cancer screenings to purity concerns. However, both participants adamantly agreed there was no 'ick' factor, religiously related or not, that was inhibiting the screenings, rather there was a lack of publicity so people were not aware of the increased risks.



## Section III: In-Depth Interview Participants

**Table 2 – Individual Interview Description**

Affiliation	Age	Smoke Hx	Smoke Now	Health Insurance	Income	Education	Personal Cancer HX	Family Hx CRC	Ever Screen for CRC	Mean Age first CRC Screen
UA n=10	62.8	6 (60%)	1 (10%)	10 (100%)	2- \$20K+ 1- \$40K+ 1- \$60K+ 5- \$80K+ 1- decline	3 – HS 2- some college 2-graduated college 3-Post grad	1 (10%) breast	2 (20%)	9 (90%)	54
R n=10	57.7	5 (50%)	0	10 (100%)	1- \$40K+ 1- \$60K+ 8- \$80K+	6-graduated college 4-Post grad	2 (20%) Breast, bladder	2 (20%)	10 (100%)	45.4
C n=11	60.7	6 (60%)	0	11 (100%)	1- \$20K+ 1- \$40K+ 6- \$80K+ 3- decline	2- some college 8-graduated college 1-Post grad	2 (18%) Breast, brain	3 (27%)	10 (91%)	56.6
O n=5	56.4	4 (80%)	0	4 (80%)	1- \$20K+ 3- \$80K+ 1- decline	1- some college 1-graduated college 3-Post grad	2 (40%) Ovarian, skin	0	5 (100%)	49.6

### In-depth Interview Participant Description

A description of the individual interview participants is summarized in Table 2. Thirty-six Ashkenazi Jewish women ages fifty to eighty participated in the individual interviews; the average age was sixty years old. Ten participants were not affiliated with any synagogue at all, ten were affiliated with a Reform synagogue, eleven were affiliated with a conservative synagogue and five were affiliated with an Orthodox synagogue. Twenty-nine women were married, one was cohabiting with a partner, five were divorced and one was widowed. Educational levels ranged from high school graduate to doctoral degree.

All but one woman reported having some form of health insurance; health insurance types included Medicare, Tricare and private insurance. Five women declined to report household income data; of the thirty one women who did report income, it ranged from \$20,000-\$39,999 to \$80,000 and above. Twenty-two women reported household income above \$80,000, two women reported household income of \$60,000-\$79,999, three women reported household income of \$40,000-\$59,999 and four women reported household income of \$20,000-

\$39,999. Seven of the women have ever been to the *mikvah*; of those, only two have gone more than once. Aside from current affiliation status and denomination, 19 participants self-identify as being Reform, 12 as Conservative, and 5 as Orthodox/Hasidic/Modern Orthodox; however 15 participants report being brought up Reform, 12 Conservative, 5 Modern Orthodox, and 4 as 'cultural/secular'. While 21 women reported ever having smoked in the past, only one now reports smoking 'occasionally'.

Seven of the women had a personal history of cancer; one with a history of ovarian, one with skin, one bladder, three with breast and one with both breast and brain. Additionally, eight of the women had family histories of colon cancer, and in at least 2 of the cases this is involved multiple members of the same family. All but two of the women have had screening for CRC, and three screening methods were cited including fecal occult blood test (FOBT), colonoscopy and flexible sigmoidoscopy. The average age of first time colon cancer screening was age 51.8. Two of the 36 women reported not having a mammogram in the last two years, five reported not having a Pap smear in the last two years, and three report not having had a colorectal cancer screening in the last 10 years (two have never had one in their lifetime, one is not up to date).

### **In-Depth Interviews**

Semi-structured, in-depth interviews were conducted from April 2008 through August 2008. The interviews were conducted with the use of an interview guide, which included a list of questions, grouped according to topics and domains (Schensul, Schensul, & LeCompte, 1999). The approach to the

interviews was that they were conducted with a preformulated interview guide, but answers to those questions were allowed to be fully expanded at the discretion of the interviewer and interviewee, and could be enhanced by probes (Schensul, Schensul, & LeCompte, 1999).

Thirty-three of the interviews were conducted in person, and three were conducted by phone because of the location of those participants (Dade County). Eighteen of the interviews were held in the homes of the women, five interviews were held at places of their employment, three were held at a library, two at a local café, and five were held at a synagogue; each interview lasted about 60-90 minutes. Like key informants and focus group participants, interview participants are coded by number and affiliation (UA, R, C, O).

### **Judaism and Health**

The first part of the interview focused on the participants' construction of health and illness, their perceptions of control over health and the role of Judaism in health behaviors and beliefs. In answer to the first question, "What is your definition of health?" most participants, regardless of affiliation or denomination, answered in the context of physical and mental well being and functioning, highlighting the importance for good function is both of those areas. Examples of comments are below:

Health is when you are able to have a lifestyle that allows you to participate to at least a maximum degree of activity, disease free or least symptom free so that you are able to function –feeling also not just physically but mentally healthy, that's a big part of health. (10-R)

Two of the participants included spirituality in their definitions of health.

Being able to do everything you would normally would like to do during a day, all of your organs are working, and are in good health, if you do have something its

under control. If you're spiritual there's something in your genetic makeup that kicks in your brain that helps heal, I don't know what it is, but people who give up and don't have a faith sometimes are less likely to survive than somebody who has a stronger faith I know it has nothing to do with what faith it is, it just seems to be something in your brain's wiring that does it. (1-C)

Absence of medical issues, being disease free. Healthy mind, healthy body, I think of health, I think of physical health first. I think there is also a deep connection between health and spirituality. (10-C)

When going on to give their definitions of illness, many participants simply said "the opposite of health"; as in definitions of health, illness was frequently defined not only in a loss of physical function, but of mental function as well. Emotional health was brought up at times; however, spirituality did not get linked to constructions of illness.

The opposite [of health], your body is not functioning at its optimum, whether it's some organ in your body, or mental ability. (2-R)

When asked about their perceptions of the differences between illness and disease, participants had a variety of explanations. For many, the two were synonymous; they could see no difference between illness and disease. Others found differences based on severity and duration of the affliction; a commonly used example was that a cold would be considered an illness, while cancer is considered a disease. Both of these perceptions – illness and disease being synonymous or differing based on duration and severity – are similar to answers from the focus groups. Several participants affiliated with a Conservative synagogue, however, saw illness and disease in a framework of control, with illness related to lifestyle choice and being able to be controlled, and disease as uncontrollable:

I think disease is something that you often have no control over getting. An

illness are often things that lifestyle choices can affect, you choose are you going to exercise, what are you going to eat, obesity is an illness, high blood pressure is an illness, but what are you doing to help deter those things from becoming part of your life, how much responsibility – I don't think you can have any responsibility for a cancer cell lodging in your brain, its just bad luck. A self responsibility with illness. In disease you can do so much, you don't have as much control over how pervasive that disease becomes. (8-C)

In order to start addressing the influence of culture and religion on the participants' health behaviors, they were first asked to explain they see their cultural or religious Jewish identity. How the participants described their Jewish identity ranged greatly within affiliations and denominations as well as between. For example, in the unaffiliated participants, Jewish self-identity varied from not knowing much about Judaism or having it as part of their life, to having Judaism as their core identifying factor. This is reflected in the comments below:

Judaism is a religion that my parents I don't believe really knew that much about even though my father went to college and was a pharmacist; I really wasn't taught much about it I'm realizing on my own that it's an ancient religion that Muslims and Christians are taking the basic tenets of, and I also realized that I don't know much about it, (9-UA)

It's so much a part of me; it's the same identity as saying how you describe being a woman, a wife, a child. That's how I was raised – you're Jewish, no less than I'm an American. It's my approach to life, my outlook, it's more than a belief system, it's cultural. (3 – UA)

Several participants described having a solid Jewish identity, despite their belief in God being uncertain or non-existent. Still, they explained a deep connection through community, traditions, culture, rituals and shared history.

For me it's my core identity, it's a very important part of who I am. I wouldn't say I'm particularly religious but I identify strongly with everything that's Jewish – in the cultural sense, in the religious sense to some extent, I'm not even sure I believe in God, but its important to me for my grandchildren to understand Jewish customs and even though I may not – I'm uncertain about God, I still think its important for me to have a historical and cultural connection with my grandparents, great grandparents in doing some of the rituals... I guess I'm a

closet atheist, but I still want to be Jewish. That's why I think there are a lot of Jews like me, and if Time magazine comes and asks what I am, I'm going to absolutely say Jewish. (5-C)

It's a way of life; its religion, but to me it's more of a way of life, following traditions. I have my doubts if God exists; I say my prayers, and the rabbi and I discuss this why I say my prayers. But to me, religion is and was crowd control; you can control the masses with religion. For me it's a thing I can identify with, traditions I can follow. (3-O)

For other participants, their Jewish identity relates to community and cultural and historical links of their families, with very little religious component.

What I identify as Jewish is tied with my grandparents, so it's more the people, more cultural, not spiritual. I never had a strong literal belief. (BM-C)

To me Judaism is a culture, it surrounds an ethnic group, involves family identity, much more so than the concept of religion, religion to me is not really Judaism. A cultural identity. Family traditions. (4-UA)

Several participants from across denominations described how their Jewish identity included both spiritual and cultural aspects of Judaism. They explained how Judaism shaped and grounded many aspects of their lives.

For me it's religious and cultural and organizational and everything – in other words, it's like an apple, you cut it up into sections but it's still the whole apple. In other ways, I couldn't do without the social part of it, or the organizational part because you volunteer and do things for the community, its part of your life, the religious part it's a given, teaching your children, Sunday school and Hebrew school that's part of it. Your ethics come from it. I like the rituals and the holidays and the kids participating and being a part of it, I've always done that all my life. My children send their kids – its part of the way we are. (9-C)

It very much shapes how we live. A lot of my friends are also observant, so a lot of our social events are religious. I dress modestly – we're modern Orthodox. It's very much a spiritual connection and historical, my mother was a holocaust survivor, she escaped on the kinder-transport, and it's a very much spiritual connection for me...Spiritually I get a lot of energy from this. I feel there is a force in the universe that backs me up. (5-O)

I asked next for participants to describe how they think Judaism has influenced the way they think about health. A number of UA, Reform and Conservative

participants replied they never thought of Judaism in the context of health at all; they did not see any relationship. Others related to Jewish laws of *kashrut* to be an influence in the way they think about health. For some of the participants, the *kashrut* laws were ancient health and hygiene rules which predated modern medical knowledge about risks of trichinosis and hepatitis from eating foods such as pork and shellfish.

Well, food. And again, I was told these may have been sources that wanted to justify but I had been told along the way that the restrictions for eating pork may have had their origins in trichinosis, making pork a more difficult meat to consume without consequence, so it again it may have had a practical origin, 'lets just not eat it.' (7-R)

However, more often, when participants cited *kashrut* rules as an example of how Judaism influences their thinking about health, they use it in the context of mindfulness. They describe how following strict rules about what you eat forces you have to always consider what you are putting into your body rather than just mindlessly consuming whatever you feel like, and that can lead to a healthier way of eating. In this way the rules of *kashrut* themselves are not necessarily inherently healthier, but the mindfulness they require in what you eat can lead to a healthier lifestyle. The rules and resulting mindfulness serve to connect with elevating food to something holy, a way to sanctify your body and honor God.

*Kashrut* is being mindful and also being responsible. I think there is a relationship between you and the food that becomes almost sacred. It has to be a very personal thing. I do what I do to the level that I do, and I think what it does it mandates you to have a relationship with the food that's bigger than just immediate gratification. And I think there's something about that, it says to you, it's not just about you, it's about something bigger than you. (8-C)

The whole idea that there would be laws about what you eat is a reflection on the fact that if you pay attention to what you eat there's a conscience thought and effort that goes into it, and you don't live to eat, you eat to live – moderation,

which is a lifestyle, and *kashrut* which is a lifestyle with an elevated purpose of holiness which embraces the fact that food is a gift to be enjoyed but also part of the creation of the world, and you're honoring God by not abusing something that is really magnificent. It's mindful as well as holy, and to make certain things holy is to – it's a Jewish thing to honor God, but in that you elevate your whole spiritual being by honoring God by honoring yourself. (2-UA)

Other aspects of being mindful about one's body were also described as a concept of health related to Judaism, including many of the issues brought up by key informants. These include the centrality of the sanctity of life in Judaism, moderation, and treating the body as a gift from God.

In a sense everything your doing is in partnership with God. Being religious reminds you it's not just about you. You're really in a partnership with *Hashem* [God], so I would say that extends to your health as well, Its something you're getting help with, you're thanking God in the morning, I think of everything I do in partnership with *Hashem*. Everything is a test, and the fact that I was sick, I'm healthy and I have been for a long time, its gift, life is a gift and I thank *Hashem* every morning for that and before bed. (1-O)

I think if you have a belief in God, and you embrace the values of Judaism, it's awfully hard to mistreat your body in good conscious. If you really believe that you evolve from God, I what you're doing is taking something given by God and you're really destroying it, so being healthy is a way to honor Judaism and honor your beliefs. (10-C)

Similarly, when asked to describe the influence of Judaism on their bodies, the theme of body as a temple or gift from God and that we are responsible for taking care of it was commonly brought up. This was related once more in terms of Jewish laws of *kashrut* and how one treats the body in terms of tattoos and piercings (Jewish law prohibits desecration of the body such as tattoos or piercings, and that in burial a body must be whole).

[Judaism] teaches me to respect my body. Not to mutilate it, no tattoos, we are a vessel for a soul given to us by God according to Judaism, so I respect my body; I consider it a temporary gift that I have to take care of. It impacts on the spiritual, so that it gives me a moral code of not to abuse my body. (4-O)

The question then was asked whether participants thought there was a



'Jewish way' of looking at health. Similar to the focus group participants, interview participants described Jews as being very educated and about health.

The Jews that I have known tend to try to find as much – they're information oriented, they want as much information as possible about how to stay healthy if they have an illness how to deal with it. I don't – that orientation toward knowledge is power is probably fairly uniquely Jewish. I'm sure other people do it too, I just know a lot of people like that and they all happen to be Jewish. I think Jews pride themselves on being aware of health information like that. (8-UA)

I think Jews really value life very much, everything is '*l'chaim*' ['to life'] and 'you should be healthy' and 'may you live to be 120', we really value life. I think people do it to different degrees and in different ways, but we all Jews really put a big emphasis on health. The average Jew that I know, if they are told they have a life threatening illness would go to as many specialists as possible to double, triple, quadruple check. (4-O)

Jews are very intelligent and have a higher level of understanding to get through a medical system. It's the worry component that drives you to take care of yourself. (7-C)

And, similar to focus group participants, several participants related health awareness to the strong push for education in Jewish culture, acknowledging that this also impacts economic access to healthcare.

I do believe that Jewish people as a whole do [act proactively] in that they tend to believe very strongly in education, and education is a definite proactive way of making your life better, so I guess I believe in it as 'educate yourself so you know how to handle situations, health or other. (4-UA)

I think that over the years when I was growing up, education seemed to be much more important to Jews. And I think part of the education was about health and because there were so many doctors in families, if it wasn't your father or your uncle, it was a cousin or someone, so I think the closer the tie that you have to a medical profession, the more you're going to be aware of a preventive healthcare. Access – from a financial point of view and from knowledge. (1-UA)

Interview participants were then asked about whether they believed God ever punished with disease or rewarded with health. Participants adamantly disagreed with this framework; although their concepts of God's hand in health

varied. Several participants described not believing this because they don't afford God such power in their lives; rather they believe that God created us and gave us free will.

I don't empower a Spiritual entity with that kind of control, if I believe in God at all, I believe that there may have been a force that created everything, that allowed everything to happen that's happening, but doesn't control like a puppeteer, no master plan in that sense, just make some potentials happen and now we get to play it out, whatever that is. (7-R)

Since I don't believe that prayer and reason are 100% responsible for our health good, bad or indifferent, I can't say that God is either. God is not a punishing God. As equally random as shit is, good stuff happens too. (2-UA)

I think God is involved only in so far as that breath of life. I know we read about how God will punish up until what generation, I think that in the end its free will; I gave you a brain, use it. (6-C)

Others explain disease as a part of God's plan that we do not understand – but still not a punishment or reward. This explanation was primarily given by Orthodox participants.

People get sick and die. God has a reason and a plan and we'll never understand them. I don't think it's a punishment because horrible people live. We'll never understand why things happen. I can't believe that God is a punishing God. If people are not punished here, I do believe it will happen later, in the afterlife. (2-O)

There's always that – why do bad things happen to good people. I don't know if any of us really understand that, whether its illness or some tragedy in history. I can't believe that God punishes with disease. I know there are teachings that we read about, like Miriam punished with *tzoris* for talking badly about Moshe, but I also believe there are certain things we may not understand or fully interpret. I can't believe we have a punishing God in that regard, not with disease. I think that ultimately to me it goes back to free choice and free will. As much as we try to take care of ourselves, it's never a guarantee. Clearly I think I will be rewarded with good health by treating my body healthfully, as opposed to trashing our body; we all have free will, and to a certain extent and clearly we will bear the consequences of. I guess in that regard I have been rewarded because God has instilled my will and determination to live well. But I also know there will be times I'm going to be susceptible to things. Real illness, I don't know, I can't believe that God punishes or rewards with big things like that, I don't know. (4-O)

As well, the inconsistency of illness in good and pious people was cited as a reason not to believe in the punishment/reward framework.

Look at the 6 million who died in World War 2, a lot of them were religious. So I don't think He does. Its like in the morning prayers, you're thanking God for the rain and all this, and some of the prayers talk about 'I will give you rain; but there isn't, there's still droughts, and floods – so I don't think so. I don't think He rewards with health or punishes with disease. (3-O)

I don't believe God is personal God. Not to me, if he was a personal God you would say why was this righteous Jew killed in a car accident, and this terrible Jew who rapes and robs stores allowed to go free? (3-UA)

I proceeded on with this topic of punishment and reward by asking how the liturgy of Yom Kippur resonated with the participants. Yom Kippur is the Jewish Day of Atonement, with central themes of repentance and atonement for sins against God and fellow man. It is considered the most solemn and holiest holiday in Judaism with intense liturgy that includes the following *Unetaneh Tokef* prayer:

*All mankind will pass before You like members of the flock. Like a shepherd pasturing his flock, making sheep pass under his staff, so shall You cause to pass, count, calculate, and consider the soul of all the living; and You shall apportion the fixed needs of all Your creatures and inscribe their verdict. On Rosh Hashanah will be inscribed and on Yom Kippur will be sealed how many will pass from the earth and how many will be created; who will live and who will die; who will die at his predestined time and who before his time; who by water and who by fire, who by sword, who by beast, who by famine, who by thirst, who by storm, who by plague, who by strangulation, and who by stoning. Who will rest and who will wander, who will live in harmony and who will be harried, who will enjoy tranquility and who will suffer, who will be impoverished and who will be enriched, who will be degraded and who will be exalted.*

One of the key informants (1-R) recalled the power of this imagery for some congregants, particularly those who are ill. This could reflect a literal belief in a

punishing God, so I asked participants how this holiday, and in particular this prayer, resonated with them. Most participants described taking the liturgy symbolically and metaphorically as opposed to literally. For these women, the day was a reminder that life is fragile, and how important it is to be kind to those around you, ask for forgiveness and forgive those who have wronged you and be a better person. Examples of this are written below.

I find it enormously powerful. I think when I was first getting into it, it was a Cecil B Demille dimension to it, 'I hope I'm not struck down on the spot herein front of all my friends!' Basically it's still very powerful stuff to me, and I take it very much to heart, I don't take it literally. It's very much a spiritual wake up call to me. It's meant to get your house in order in every level that you can and should do better. (1-O)

Well it gets me to think about mortality, because obviously there will be those praying among us who will not be there next year, and that's a reality, and that's a reality for all of us. Whether its this year, or 10 years from now, or 40 years, we will all have an eternal life, and it's a reminder for me of that, not to put off and put off the things that are important to me, because I've got to make happen whatever's going to happen in the lifetime that I have, whatever that is...For me, its not literal, I don't see that I have to jump through certain hoops or recite certain prayers to be rewarded another 12 months of assistance, I don't tend to focus on that, but more on for me would be important to do this year, how do I want to use, assuming I have this next year, to grow, impact my community and the things that are important to me. (7-R)

I guess I think of it in generalities, than in individuals. I don't think 2023 people will be stoned, and another 9286 will be burned; I think that in the world today people will die of various means, and because we never know where we're going to die, we should repent the bad things we've done and try to live a more righteous life. It's not a literal thing; I don't think the worlds created in 7 days either. (3-UA)

Two participants describe Yom Kippur as having no effect on them one way or another. And one Orthodox participant did describe taking the liturgy literally:

That knocks me out. I started to take it very seriously around the time of Hurricane Andrew. Every night I thank God for another day of life, I really do try to make resolutions. To me that is a literal statement, I really do believe in it. (2-

O)

This same participant, however, adamantly did not believe in the idea of God punishing with disease or rewarding with health.

The next question in the line of reward and punishment framework related to the praying for the sick. In Judaism, the prayer is the *mishaberach*, a prayer to invoke divine blessing on someone, typically for healing the sick. Often this is done by congregants submitting names to the Rabbi to include in the prayer, and then names are also called out for inclusion during the prayer. In some synagogues, congregants go onto the *bimah* [pulpit] under a healing canopy. I asked participants if they participated in the *mishaberach*, and, if they did, how they thought it worked. Many participants were not sure if they believed the prayer worked or not to heal but participated in it anyway, based on the idea that “it can’t hurt”.

I always participate. I don’t know if works or doesn’t work. But what’s the harm in saying someone’s name? (8-R)

It sure doesn’t hurt; I pretty much don’t think it helps either, except for you. I think it’s just a nice tradition that we remember sick, think of the sick and maybe it reminds us to do more than that like call them, see what they need. Like I can’t have said a person’s name and not come home and call them. (6-C)

Several participants described the *mishaberach* working as a function of community, in that announcing the name in service alerts others that the ill person needs attention and care, and also by announcing a person’s name in a caring community validates your own caring feelings for that person. It also could be that the ill person feels better knowing others are thinking about him or her.

I don’t know [how it works] it’d be nice, it nice to think if there’s a chance that would help. Maybe just saying it out loud makes it official, makes it okay other

people are thinking too, so maybe the more positive thoughts you have coming from people, not necessarily God, but someone else positive is thinking and sending some positive thoughts. (10-R)

I think it's more the community helping the person, than God actually. When I think of that prayer, I think of it going directly to the person, not to God. (6-R)

I think they provide comfort to those people who have sick relatives. But I don't really think we're intervening with God, I don't individualize it. There's a sense of comfort that everyone's pulling for you, to get better, thinking good thoughts. I have no ego to think that my prayers are going to provide a healthy surgery for someone, but it may make someone feel good to know that someone is hoping that they do well; it helps someone who is struggling with their illness, themselves, their loved ones. (3-UA)

A few participants felt there was something about the 'good vibes' or 'universal force' that came from the prayer and intervened with the ill person. This was a direct intervention, not through God.

I think that, like a lot of things in Judaism, you can see prayers at different levels; I don't think I'm writing a note to a big guy in the sky; I do think that prayers are meditative and put you in contact with the universal spirit and force, that tap into millions of pieces of energy, and this operates in ways we don't understand. The universal force is part of God, but not the same thing. God cannot be defined or explainable. But God created a universal force. (5-O)

I believe that prayer has an energy power than can affect others, just like our own energy has an energy that can affect others. It's the prayer itself. (5-R)  
One Orthodox participant did feel that God listened to her prayers and intervened for the ill person based on the prayers.

I like to think that God hears our prayers. I've heard too many instances of someone getting better after a lot of prayer. I've been part of groups – there's something very powerful and spiritually charged in the room – I don't know, I suppose on some level it sounds like a lot of hooey, if you're looking at it from an objective standpoint, it sounds like superstition. Part of me too, I was raised very Darwinian in terms of my approach to science and health, it still is very much there in my psyche, but I can't argue with what I sometimes see or hear or experience, and there's so much in the world is unexplained, and science is not always scientific. Its an art too, and with art comes variation, I don't anyone has the one answer, and I'm not ready for the medicine as we know it to be tossed aside for only faith healing, I like to think of a combination of medical science along with a spiritual approach. Both can do a tremendous amount of good. I do think an awful lot of illness we have in this world could be spiritually or

emotionally driven, and applying that approach as well, the spiritual dimension, has tremendous merit too. (1-O)

But others adamantly felt that God did not intervene in one's health.

I don't believe that, since I don't believe that prayer and reason are 100% responsible for our health good, bad or indifferent, I can't say that God is either. (2-UA)

I think that spirituality comes from God, and I think that is a healing power, but I don't think I can pray to God and ask: "heal me from my disease" and be healed; it's not a bargain. (5-R)

I don't believe that you can throw it all up at the man upstairs and he's going to take care of it all, I believe in science. I think that it depends on the circumstance, God will do what he can for you, if he can, but he cannot do the impossible. (6-UA)

The final question in this domain of health, illness and the role of Judaism is how much control the participants believed they had over their health. Answers to this delineated along the lines of how personal the participants' belief in God is; whether God gives us free will and our genes and then the responsibility for our health is up to our choices and luck after that, or whether your health is part of God's master plan, even if you do not understand it. Either way, participants reiterated that they did not believe that any illness or disease was a punishment from God. The comments below describe the participants' description of their health being primarily under their own control which is similar to responses from both focus groups:

Up to a point I think I do [have control] - you eat well, you sleep, you go to the dentist, the doctor, get checkups, do all the things that you can do, within that realm of activity you have some control. Genetic control, you have no control. God doesn't come into the picture. You're born - perhaps God has something to do with your parents, their health how they got together - and then that's it. Then your body goes the way it's going its going to go, [and] you can't blame God for everything (laughs). I've heard people say [my health is in Gods hands] but I don't believe it, because you can't believe that God is going to be responsible for

everything that happens to everyone; you can't believe we're all that important. (1-C)

I think we have a lot; it's what we choose to do with it. Positively; we're our masters there; we're going to do the right thing or not. Not taking care of ourselves, taking the consequences. It's up to the individual. I don't think God fits in; I think we're in charge of ourselves. I don't understand why some people get afflicted by some diseases and some don't, but I don't think it has to do with God, I think it's in our makeup. I don't buy into the fact that someone gets cancer as a punishment from God for something they did 50 years ago. (5-UA)

I do know a lot of people who are Christian who are always thanking God for their good health. I don't know if God has anything to do with it, if God has something to do with my health then God has something to do with my getting sick, and I don't see God as being that personal. I'm responsible for my own health to an extent, and if something really bad comes I don't think God is punishing me with my health for something that I've done. (3-UA)

Four participants described believing both in free will and health being part of God's master plan; however, they did not believe in a punitive God who would 'strike me [down] because I should have known better.' These participants describe how we have the free will to make choices which harm or help our health; however in the end our health is part of God's master plan that we may not understand, but it exists nonetheless. This viewpoint was prominent amongst the Orthodox participants.

I think we have control in making reasonable decisions. I think there's a long term plan, and we have the free will, but the long term plan is going to happen no matter what. So we have the free will to make our health better, to make the world better, but I think there's also a predetermination of where this world is going to. And it's hard for us as human beings to see the limited amount of time whether it's even one or several lifetimes as opposed to millennia of where we fit into the overall cosmic purpose and the overall accountability and the connection between what we do and the results. (4-O)

I think we have a lot of control, there are a lot of things we can do preventatively, and medicine - where it's come in the last 10 years - there's so much in terms of testing and preventative care that we have a lot of control over it, and I think it is a lot about early detection. I think that everything happens to us for a reason, and God is at the center of that, there's a greater plan, And a lot of times if we get



sick, and we think 'oh this is the worst thing that can happen' there's a reason, its how we deal with this, and how much we can handle, I think there's a greater plan. God doesn't give you more than you can bear. There's free will – it is in Gods hands, but there is free will in terms of behaviors. (1-UA)

I think we have a lot of control over our health, but not 100% - things happen and I think we can deal in our modern day, we know a lot of things we can do to control our health, get a checkup, take vitamins, wash pesticides off fruits, get exercise, there are a lot of things we can do. Does it give us control? Not necessarily. Does this mean we can get to the hospital bed – I did my share, now God do your share? –I think that some of the other parts lie with God, but not in a quid pro quo way, there are challenges there for a reason. And I think some of it –there is an element of randomness. The really Orthodox will say God controls everything, and that is doctrine. I think as a child of a holocaust survivor that may be the most difficult question for me because if there's randomness, if there no element of stuff happens, then you're dealing with a very different God. So to me it's the same question why do bad things happen to good people, but what helped with me is the willingness to live with that question. I can live with knowing there is stuff I'm not going to understand. (5-O)

### **Judaism and Purity**

At this time, interview questions related to concepts of purity in Judaism.

The first question asked participants to describe their perception of the concept of *niddah* and their experiences with a *mikvah*. Only seven of the participants had ever attended a *mikvah* – one of the unaffiliated, one of the Conservative and all five of the Orthodox participants. Of those seven, one reported attending monthly, the others attended once or a few times. Opinions about use of the *mikvah* and rules of *niddah* seemed to focus on three viewpoints. The first was of those who did not follow or know extensively about the rituals, but what they did know of them they found them beautiful and appreciated from a historical perspective, often relating them to hygiene. This is reflected in the comments below:

I think its probably a healthy thing to do – there's something about the traditions that come from, that are lovely and they come from, long ago, and they had more

meaning then, because we're taking showers everyday. (5-R)  
Cleanliness is important, its part of taking care of your body. The *mikvah* goes back so long ago. People didn't have bath or shower in their house, you prepare for Shabbat, or clean up after sex or your period, it doesn't work for me that way anymore, we do it in the home. (6-C)

The second viewpoint was of participants who adamantly found the rituals and rules of *niddah* to be distasteful and degrading to women, perceiving them to insinuate that women are less clean than men for their normal bodily functions.

Why would I want to go, I'm clean, in and out! My mother put it in my mind. My mother never went to the *mikvah*, we were modern orthodox. It's not necessary. I think it's unfair that women have to go, why? We had to go once a month to cleanse ourselves, but I don't really think we're dirty! I was always taught that you went to *mikvah* to cleanse yourself for being unclean. I'm giving my husband babies; do they not think I'm clean enough? No, I personally think it's an insult! (1-C)

I never took well, that whole women are unclean thing that Orthodox Jews do, I always took offense at that. I don't consider menstruation unclean, it's a bodily function. I'm not sure what else would have come from that. I was hearing the Orthodox stand on menstruation and women and I also was very influenced growing up during the women's liberation movement. We were taking back our bodies, we were normalizing and validating our bodily functions, and this very much ran contrary to that, that the perception that there are things that our bodies do when they're healthy that are bad, or are unclean. That was difficult not to reject all of that. (7-R)

Finally, there were those who appreciated the rules and rituals in the context of the family purity laws, for elevating the act of sex to a level of holiness and also for providing a time to mourn the loss of a missed opportunity at fertility. For these participants – all of whom included the women who had actually been to a *mikvah* in their lifetime – there was nothing inherently impure or 'dirty' about the woman or her bodily functions, rather the unfitness was referring to the missed opportunity at life, the shedding of the uterine lining. This definition recalls that of the key informants describing the original intent of *tameh* and the

*mikvah*, and the 'dirty' meaning it has taken on through the years. Again, these explanations were by women who actually attended in their lifetime.

The whole idea of *tameh* and what have you, I don't see it as I once did, a woman is unclean, and old kind of rhetoric that you've heard before, so much as the death of a potential life. It's like a bad translation that just perpetuates itself and takes on a life of itself. When I learned more about it, you're basically in mourning for a potential life that's lost, because I know when I longed to become pregnant, it was devastating when I got my period. When you have your period and you don't get pregnant, the opportunity for life has passed and that there's a period of seeing that as mourning, as something that you recognize for a miraculous possibility that is missed. (5-O)

I think it is a wonderful way to live because it is an opportunity to look at the sexual act as purposeful, prepared – you prepare for it – it can be a holy thing; and you also get time off. So the separation and the time off is an opportunity to – there is some anticipation, a couple has an opportunity to develop a lifestyle that respects each others' bodies and the sex act as a purposeful, holy participation. The part about it that is also misconstrued is that a woman is dirty if she's menstruating, and that is not the purpose, nor is it reality, nor is it the way an informed and modern woman would think if she participates in it, because that's not what it is. It has more to do with procreation and sanctification. (2-UA)

I asked the participants if they could describe the place of purity in Judaism. This concept did not resonate for many of the participants; for those for whom it did, purity was in the context of spirituality and morality, as opposed to a physical sense. In this way, purity is related to holiness, even in the physical acts which sanctify the body in a spiritual way. Most of the participants for whom the concept of purity in Judaism did resonate were Orthodox.

To me purity goes back to free will, and also we all have a *yatzer hara* [bad inclination] and a *yatzer tov* [good inclination]. The constant tension we all live every waking moment, it's that *dever* present tension, and God is always trying and hoping that we choose the *yatzer tov*. Our challenge is to overcome the *yatzer hara*. In that sense any kind of purity is tainted. We do the best we can, and the ultimate challenge is to rise above it. (1-O)

I think impurity is a less than perfect translation, I think the concept of sanctity is essential to Judaism. Sanctity in marriage, exclusivity in marriage. There is a

point in your life that you hold yourself and are governed by what you think is right in the world, it may be coming from your religion. I think the keeping a kosher home has an element of sanctity or purity because I think that we're going to eat in a special way, more spiritual more fulfilling, it's a level of thoughtfulness and sanctity to how we eat that makes it special, were not randomly taking handfuls of grub and shoving it down. We are deciding that even though we may not understand the teaching entirely because some are arbitrary if we can see it's a spiritual way of living, then it's sanctified in that way and it's an extra level (5-O)

It's a moral purity. To me physical purity is more than about spirituality, about drinking, smoking taking drugs, how you take care of yourself. It's taking care of yourself, and I do think that's a Jewish value. (3-O)

I next asked participants about the *Asher Yatzar*, and provided a translation for those who were not familiar with it – which included most of the participants.

Some participants remarked how it promoted awareness of body functions and not taking them for granted. While no one was swayed to start saying the prayer, several participants described how they thank God in their own way on a regular basis for their bodies and their health.

That's a nice prayer; it's like thanks for creating who I am. God knows if one of two body parts shut down, we're in deep trouble! I think this is a wonderful prayer. It sort of reminds us that this wasn't by accident; we needed all these body parts. (3-UA)

There's probably no other religion that would come out of the bathroom and say a prayer. In that way it's uniquely Jewish. There you're focusing on the everyday gifts that life brings us. (6-C)

Two Orthodox participants continued in this theme of gratitude and awareness, but also described the idea that God is in charge of everything, including our function of elimination, and this Jewish concept of being aware of such a mundane thing is healthy and good. These comments speak to the descriptions of the *Asher Yatzar* given by the key informants.

I know of course there's a very fundamental blessing – there's blessings for

everything you do, from when you get up in the morning, from seeing a rainbow, to your bodily functions after you go to the bathroom. It's constantly reminding you of God miracles. When you think about the human body functioning even when exiting the bathroom and saying the *bracha* (blessing) it does remind you that God is in charge and all these myriad of things we take for granted are all things that God has taken for granted, and how miraculous it really is, and they're all functioning. (1-O)

I thank God for my bodily functions working as part of my daily life. The whole idea certain things about your body being nasty is a childish idea. The more you see these functions as natural and the more you're grateful for them, the healthier you are. I see a Jewish concept to be grateful and to step away from childish attitude; this is natural and I'm glad I have been given this mechanism to process my food, and we have modern sanitation; I'm not going to be ashamed that it happens. (5-O)

A few, however, found the prayer to be bordering on neurotic, although with after some time they were not surprised it existed because "there are prayers in Judaism for everything."

I've never even heard of anything like that. That's *mishegas* after the bathroom! I'm shocked! I'm shocked that it would extend to the bathroom, to me that is *mishegas*! (10-UA)

### **Colon Cancer Beliefs and Behaviors**

Having established a worldview of health and illness via the lens of Judaism, including purity concepts, the interview next turned to cancer beliefs, asking participants which cancers, if any, they thought affected the Ashkenazi Jewish population disproportionately. Fifteen participants (42%) believed breast cancer occurred more frequently, six (17%) believed ovarian cancer occurred more frequently, and three (8%) believed that colon cancer occurred more frequently in the Ashkenazi Jewish population. Most of the women who knew about breast cancer being more prevalent had read about the BRCA mutations and also known a number of other Jewish women with breast cancer. Of the

participants who cited colon cancer, one participant had breast cancer and was told by her oncologist that her children could also have a risk of prostate and colon due to the Ashkenazi heritage and her breast cancer history. One of the other participants who cited colon cancer had three family members who had colon cancer in her immediate and extended family and had already had genetic testing for the APC 1307K mutation (she was negative). For the other participants, when I asked whether they thought colon cancer may be higher or lower in Ashkenazi Jews, most did not think it was any higher in the Jewish population. However one participant thought it may be a higher risk due to problems with constipation that she thought were typical in the Ashkenazi Jews. After informing participants of the high rates of colon cancer in Ashkenazi Jews, constipation and diet were cited again as possible reasons for why the rates may be higher. Specific factors participants named included consumption of traditional foods such as chopped liver and chicken fat, and lack of physical activity, both of which may contribute to constipation.

Well I know Ashkenazi are at higher risk because of eating style, because they used to eat a lot of chicken fat and stuff like that, and that may have caused a higher risk for certain colon and stomach cancer, eating a diet rich in certain things. (4-C)

I'm telling you it runs in the Eastern European Ashkenazi tradition, that people are constipated! It's in the genes or somewhere, and there is a constipation and colon cancer, there must be if so many AJ are constipated and so many are getting colon cancer, there must be something. When I look at what the Jewish people I know from Eastern Europe eat, it's the starchy food, the chicken soup, kneidlach. (1-C)

Physical activity helps the colon move more, and helps any impurities in the food move along, and Jews are not very good with physical activity. (7-R)

Genetic mutations were also thought to play a role due to the traditional rate of

intermarriage amongst Jews. And one participant, the daughter of two Holocaust survivors, described her theory that the illnesses that Jews have a higher propensity for are due to all the trauma and stress they have survived through the years, up to and including the Holocaust.

This is the story I always heard from my parents. The suffering – a large part of the Ashkenazi Jewish population lived in inclement conditions, they ate rancid food, and lived in terrible conditions, in filth, exposed to illnesses, I believe that the generation that lived [through the Holocaust], somehow their bodies were never cured of some of the things they had, like typhus, and they passed them on to the next generation. So it makes sense that Ashkenazi are more susceptible because that gene followed them through and in a few generations it will be gone because of the assimilation going on here. (2-C)

Another participant related a similar line of thinking as to why Ashkenazi Jews may have a propensity to colon cancer, in that they have endured so much strife and persecution that their outlook is negative and pessimistic and this has affected this physical well-being and susceptibility for disease.

The Jews moved around so much and were persecuted so much, to me that's why there is such a history [of disease]– I see the Jewish people as being very stressed out, they take things so seriously. I think if you change your lifestyle and try not to be so pessimistic, it will help your situation. (3-O)

At this point in the interview, the questions moved to experiences and perceptions about colorectal screenings. All but two participants have had colon cancer screenings in their lifetime. The two participants who did not have screening done relate different reasons for not doing it. The first participant explained that she did not have the screening done because it is an invasion of privacy:

With a colonoscopy – everybody is angry, but I just can't bring myself to do it, it is an invasion of privacy. It's the concept; everyone says it's not painful, but an invasion of privacy. I think it's a little disgusting, but I don't think of it as unclean. (3-C)

She went onto say how she has a daughter with Crohn's Disease who has undergone many invasive tests and is still not stable, and this may 'colored my lack of desire to have the test.' As well, she does not perceive much risk because most people have normal results.

I do pap smears, but even they are difficult; screening takes away my dignity. Paps were expected of women, but colonoscopies are new in the public domain, like mammograms. Most people are normal, so there is no urgency to get it done. (3-C)

The second participant who has never had a screening had reasoning similar to one of the key informants who did not have screening – not liking doctors.

I like to stay away from doctors, I guess I'm afraid they'll find something, I don't want them to find something, I don't want to hear anything negative, and if I feel okay, if something is really wrong with me, usually, which isn't too often, I will go to a doctor, I guess I just don't want to hear something is wrong. (9-UA)

She also did not perceive much risk, as she assumed she knows her body well enough that if something is wrong she can tell. Additionally, she mentioned that her mother went for routine cancer screening yet still got cancer (non-Hodgkin's lymphoma) so she does not necessarily believe that preventive screening will work.

I know my mother went every year for screenings and when she finally got that cancer, she got it anyway. But I'm not letting that be a guide for myself. When something is wrong, I will know it. My physician just talked to me about screening the first time, and I didn't do it; after that, they threw their hands up and said 'that's it.' Something about it is very unappealing to me, especially unappealing. If I got symptoms I would consider it, bad symptoms. But I'm not interested in getting information, I'm hardcore. (9-UA)

Another participant said she refused a colonoscopy when she was in her late seventies; prior to that, however, she got colon cancer screenings done periodically in the form of a fecal occult blood test. This participant described similar reasoning to the last participant as to why she refused; why go looking for



trouble if you feel good?

When you feel okay and something's not bothering you, and you go look for something, you're going to find something. It was recommended by our internist, and I refused. Probably it was when I was in my 70's it was recommended, not before then. And if it was it wouldn't have made a difference. At this point they don't even suggest it anymore. I have done a fecal occult test; I used to do those in my home – probably up until 10 years ago. (6-UA)

As she continued talking about why she stopped getting screened, however, she brought up another issue of girlfriends who had colostomies and how bad she remembered them smelling, which impacted her thinking about screening and fear of colon cancer.

Its just one of those things, if that's what I have, I don't want to know about it. Maybe because if it's something you have and it's bad, I don't want a colostomy. I had a young friend who had one; she lived to be very old. She had it when she was in her late 20's. I knew what she went through and I don't want any part because I remember another friend having it, and thinking 'she smells so bad; and I knew she had a colostomy. Maybe those things are in the back of my mind. If something was wrong with me, and I was bleeding, I would be first in line to get one done, although I realize it could be long gone by the time you have a symptom. It's just the one thing, because I get everything else done. It's just a crazy *mishegas*, because we're really good with doctors with everything else. (6-UA)

Several of the participants described delaying the test after it was recommended.

It was suggested a few years before that when I was in my late '50's. I started to make an appointment and I cancelled. I have a friend who was recovering from colon cancer who was trying to get me to do it then. Fear of the prep made me put it off; not of the findings, of the prep. (5-UA)

I had my first 2003, I was 55 or 56. I didn't put it off, just didn't do it; I had heard so many terrible things about it in terms of the preparation. I had a sigmoidoscopy at age 53, and then the colonoscopy 2 years later. I heard the prep was a pain in the butt. So I put if off, it was stupid, but I did. (3-R)

My father in law died of colon cancer. My husband and I just had colonoscopies, so it's not like we're not aware of it; I probably should have had one at 50. It was both of our first ones, we both came out clean, a few polyps, nothing malignant. Our general physician wanted us to do testing a few years ago, and we didn't move as quickly as he wanted us to, and he mentioned it every time we saw him,

so eventually we got our act together and got the tests done, but its not like they said it was an emergency. Our doctor before him never suggested it.  
(5-O –age 59)

Most participants who were screened describe being told to get colonoscopies, and not being given options for other methods. Several report being screened before the age of fifty because of symptoms such as low blood count and rectal bleeding, and several also were screened at a younger age because of a personal history of cancer. Two participants voiced a preference for a colonoscopy over a fecal occult blood test.

I don't want to do a fecal occult, and when the doctor tells me to I don't do it. I'm uncomfortable with it, I don't know if it embarrasses me, I don't know but I don't do it. I would much rather get a colonoscopy than that, something about. I'm asleep, it doesn't bother me. (5-R)

When I asked why they thought someone would avoid having a screening for colon cancer, the unpleasantness of the colonoscopy preparation was a common reason cited by most participants. Fear of pain and of the procedure was also mentioned as a possible reason. The fact that a colonoscopy required so much time between preparation and the test itself which involves the risk of anesthesia and requires someone to drive you to and from the test was a hindrance for many. Another commonly cited reason was that cited by the participants who were never screened -fear of finding out there is a problem.

I do believe even of the people who don't get it done, they know that this is something that they probably should do. It's not a pleasant experience, certainly not something someone would look forward to, not as easy to go and get and go out as say a pap smear. You have to clean your gut out, and that's a yucky experience, and go under general anesthetic, and come out of general anesthetic, and find out your results, and it's a commitment. And a lot of people don't want to make the commitment but they know they should. I think the yuck aspect for those of us who have been through it is more related to cleaning out the gut and the horrific – I get abdominal cramps when I take what they give me

to clean the gut, I have to take the day off work because I have to run to the bathroom every 5 minutes. (7-R)

I do know people who don't go because of the prep. They're ignorant because, they're afraid of the procedure, afraid the doctor will puncture their colon, or afraid the procedure will hurt, or afraid to find out bad news. (2-O)

Other factors described as inhibiting screening for colon cancer screening included the cost, lack of risk awareness, not enough media attention and lack of physician recommendation or discussion related to screening itself. Most of these reasons were also cited by the key informants.

I think it's a perception of the discomfort why people won't get colonoscopy. And if your doctor is not detailed in description, then they would not know. I think people don't see a doctor regularly, and don't stay on top of it. People get busy and just put it off; unless there's an immediate threat or perception of threat you're more likely. And also cost; it's expensive if insurance doesn't cover it. An immediate threat or perception of a possible one is a great modifier. (1-UA)

Most of my friends, they've had to ask, their doctor didn't suggest it. Even this one I have scheduled, I had to bring it up to my internist. I don't think they're as aggressive as they should be about telling people to get screenings. (6-C)

And the issue of embarrassment was described as an inhibitor.

You see everything on TV about sex but something going up their rectum they're embarrassed about. They're embarrassed they aren't going to get cleaned out properly. I've had women tell me that they're terrified not of labor and how much that would hurt, but about have a bowel movement during labor and that would be the most horrible thing they could think of. (5-C)

To determine sources of health information, I asked participants where they got their health information. Most responded that they read in popular magazines, or watched the news, looked up questions on the internet, a surprising amount cited the "Oprah" show as a good source of medical information. When I asked if they would ever go to their rabbi for questions about health, most replied unless it was regarding a crisis – acute illness and needing

spiritual support or existential questions – they would not think about it. One Orthodox participant did comment that it is customary to consult the rabbi for health matters in Orthodox Judaism, although she herself does not.

I know Orthodox people who will go to their Rabbi and ask about doctor's advice. I've spoken with Chabad Rabbis; it's very customary for the Rebbe [Rabbi] to tell people to get 3 opinions and decide on 2 that agreed. So they do consult each other. They consult their Rabbis for everything, for health certainly. (4-O)

I then asked participants if they could think of any Jewish religious issues that would influence someone to not get a colon cancer screening done. A number of participants disagreed with the notion, considering the tendency to want to delay the screening more of a general 'human' tendency than one informed by religion.

I would hope it has nothing [to do with religion], I think its naïveté, its stupidity, when one's religious belief causes you not to do what are healthy, then you have to ask yourself "Why are you doing this?" I don't know people who have not done it because of religion; most of my friends are not that traditional. Probably they are just putting it off, just normal human behavior of why people don't do things. (4-C)

I don't know if [getting CRC screening] has to do with your religion as with your healthcare plan, and your mix of friends, and who your doctor is – your support system. I wouldn't think there is anything biblical. (9-R)

Would a Jew avoid [CRC screening] more than a non-Jew? No because a Jew is educated or tries to be the emphasis on education, to know things. The grossness of the test is universal. (4-R)

As the key informants has mentioned, several participants referred back to the concept of the infinite value of life, and how Judaism actually obligates a person to get this screening done.

It goes back to your obligation for taking care of yourself. If you're not well not only can you not take care of yourself, you can't take care of your family, and that's such a critical part of who and what you are, and what you do in this life. (1-O)

I don't think the tenets of my religion are going to stop me from doing this [CRC screening] because the tenets – what's behind Judaism is that *Pikuach nefesh* –

that trumps everything. (2-UA)

Similar to key informants and focus group participants, individual interview participants felt that more information and education would increase understanding of the risk of colorectal cancer in Ashkenazi Jews. In other words, not understanding the increased risk inhibits screening, however once the information is available to the Jewish community about the disproportionate CRC risks, participants felt that, in keeping with the “Jewish way” of looking at health, Jews would educate themselves, understand what needs to be done and be proactive enough to get screened even if it is unpleasant.

I think if anything more was made of it, more people would jump on it, especially in the Jewish community. Because I think we tend to be much more proactive. I think it can be done in a lot of different ways. I think in general synagogue people are very highly educated when it comes to medical issues. (10-C)

A number of participants brought up the responsibility of the media – both secular and Jewish – to bring greater awareness of the high rates of colorectal cancer in Ashkenazi Jews. When I asked participants where they thought the role of Jewish organizations was in terms of Jews’ health, opinions were divided. Many thought that there was not enough focus on the health of congregants in the synagogue, and health programs would be welcomed there.

You never hear about a connection in terms of Jews and colon cancer and I think that falls to the synagogues to do. Apparently they’re not doing it, and they should do it. It needs to be in the synagogue, and with public service announcements. (1-UA)

A health forum does have a place in the synagogue; I definitely think the synagogue is the right place. Absolutely it is an appropriate place. You’re talking about a target population, where else are you going to reach Jews? Absolutely health and Judaism belong together. (8-C)

Others did not think that health issues belonged in the synagogue at all, but did

agree that Jewish cultural organizations and media, like the “Jewish Press” and the Jewish Community Center (JCC) would be appropriate sources of information for awareness campaigns related to health issues prevalent in the Jewish population, such as colorectal cancer. These participants describe the responsibility as being of the Jewish culture, not the Jewish religion.

I think we need to have a community campaign; I don't see it coming from the synagogues, I think the JCC and the Jewish Press. It's not a religious matter. The way we treat it - it's our responsibility as a Jewish community, not necessarily as a religion. (2-UA)

I could see it more at the JCC rather than the religious institution. I don't think it should be a religious issue unless someone seeks religious support for a condition that they have. I think the Jewish Press as an avenue within the Jewish community has a responsibility to print risks and also to – and maybe even people with the JCC and Jewish Federation need to take responsibility and have some screenings there. (10-UA)

Other participants described health issues as belonging solely between an individual and their doctors, and that the Jewish cultural or religious community should not be involved.

Everyone should be aware of physical health, but I don't think in the synagogue it should necessarily be, like pushing to go for your pap smears and mammograms and blood tests. No, I don't think that's for the synagogue to say. They can, but it's certainly not a priority. I'm more into talking politics than I am talking about health. People are just supposed to know. (6-R)

It belongs where it belongs; it belongs to the doctors, not the synagogue. (6-UA)

## **Section IV. Quantitative Surveys**

The quantitative portion of this study included a demographic survey which included several questions about baseline knowledge of colorectal cancer in the Ashkenazi Jewish population and overall cancer screening behaviors, and *The American Cancer Society's Questionnaire on Experiences with and Attitude toward CRC Screening*.

### **Demographic Survey**

Forty-two participants (100%) completed the demographic survey. Characteristics of the participants can be seen in Table 3. 74% of the participants reported having college degrees or postgraduate education, and 57% having annual household incomes >\$80,000. As well, 81% reported being married, 93% were born in the United States, and 57% reported both parents born in the United States. 83% have never attended a *mikvah*. In terms of current denomination, 52% self-identify as Reform Jews, 36% as Conservative Jews and 12% as Orthodox Jews; growing up, however, 17% of participants reported being raised as Orthodox Jews, 33% as Conservative Jews, 17% as Reform Jews and 10% reported being raised as "Cultural" Jews, with little if any religious practice.

**Table 3 - Characteristics of Participants – Focus group and Interview (n=42)**

		Total N	%
		<i>Mean age: 60.7 years</i>	
Age	50-60	21	50%
	61-70	17	40%
	71-80	4	10%
Self-Identified Denomination			
	Reform	22	52%
	Conservative	15	36%
	Orthodox	5	12%
Denomination as Child			
	Cultural	4	10%
	Reform	17	40%
	Conservative	14	33%
	Orthodox	7	17%
Affiliation with synagogue			
	None	14	33%
	Reform	12	29%
	Conservative	11	26%
	Orthodox	5	12%
Place of Birth			
	U.S.	39	93%
	Outside U.S.	3	7%
Parents Place of Birth			
	One parent born outside U.S.	11	26%
	Both parents born outside U.S.	7	17%
	Both parents born in U.S.	24	57%
Education			
	High School Grad	5	12%
	Some College	6	14%
	College Grad/PostGrad	31	74%
Income			
	Decline to answer/no answer	8	19%
	\$20K-39K	5	12%
	\$40K-79K	5	12%
	\$80K+	24	57%
Partner Status			
	Married	34	81%
	Divorced	5	12%
	Widowed	2	5%
	Cohabiting	1	2%
Employment			
	Fulltime	15	36%
	Part-time	10	24%
	Retired/homemaker	14	33%
	Disabled/other	3	7%
Mikvah Attendance			
	Never	35	83%
	Yes	7	17%



**Table 4 - Health and Lifestyle Characteristics of Participants – Focus group and Interview (n=42)**

	Total N	%
Health Insurance		
Yes	41	98%
No	1	2%
Smoking Status		
Ever Smoked – Yes	25	60%
No	17	40%
Currently Smoke – Yes	1	2%
- No	41	98%
Drinks/Day/Month		
None	8	19%
1-9	19	45%
10-20	11	26%
21-30	4	10%
Primary Care Provider		
Yes	42	100%
Personal Cancer Diagnosis		
Yes	10	24%
No	32	76%
Types:		
Breast	3	7%
Ovarian	1	2.4%
Brain + Breast	1	2.4%
Other	5	12%
Family History Colorectal Cancer		
Primary relative	3	7%
Extended family	3	7%
Primary + extended family	2	5%
Mammogram last 2 years		
Yes	40	95%
No	2	5%
Pap smear last 2 years		
Yes	36	86%
No	6	14%
Skin Cancer Screening last 2 years		
Yes	28	67%
No	13	31%
No answer	1	2%
Oral Cavity cancer screening last 2 years		
Yes	37	88%
No	4	10%
No Answer	1	2%
Colorectal Cancer Screening last 10 years		
Yes	37	88%
No	4	10%
No Answer	1	2%

Lifestyle and health characteristics of the participants can be seen in Table 4. Forty-one participants reported having health insurance and all participants report having a primary care provider. While 60% of participants report having a primary care provider. While 60% of participants report smoking at one time in their lives, only one participant (2%) reports currently smoking. 64% of participants report having <10 alcoholic drinks/month. Ten participants (24%) report having a personal history of cancer, four of which involved the breast. Eight participants (19%) report a family history of colorectal cancer. In terms of cancer screenings, 95% of participants (40) had a mammogram in the last two years, 86% of participants (36) had a pap smear in the last two years, and 88% of participants (37) had an oral cavity cancer screening in the last two years and a colorectal cancer screening in the last ten years. Only 67% of participants (28) have had a skin cancer screening in the last two years.

Table 5 shows participants responses on the demographic survey about which cancer, if any, may be more prevalent in the Ashkenazi Jewish population. Forty participants answered this question which served to gauge baseline knowledge about elevated CRC risk in Ashkenazi Jews; replies from the two Reform focus group participants were not counted due to needing to change to timing of providing the survey in order to reduce bias. Only two participants (5%) indicated that they thought colorectal cancer may be more prevalent in the Ashkenazi Jewish population. However, most participants (35%) either did not know if any cancers were more prevalent or they were aware of ovarian and/or breast cancer being occurring more frequently (40%). Eight participants (20%)

did not think any cancers were more prevalent in the Ashkenazi population, while three participants (8%) named cancers other than colon, breast or ovarian as being higher. Participants were able to identify more than one type of cancer, so for those who did think there was a higher prevalence of cancer may be represented in more than one of first three categories in Table 5.

**Table 5 – Participant Replies –Cancer Prevalent in AJ**

<b>Cancer Type</b>	<b># responses</b>	<b>Percent</b>
Ovarian and/or Breast	16	40%
Colorectal	2	5%
Other cancer	3	8%
No-no increased risk	8	20%
Don't know	14	35%

### **American Cancer Society Questionnaire**

Thirty-eight participants (90%) completed *The American Cancer Society's Questionnaire on Experiences with and Attitude toward CRC Screening* tool.

Four women did not return the ACS questionnaire, despite reminder phone calls and emails being sent. Those women who responded addressed beliefs and attitudes about colorectal cancer risk, prevention, symptoms and screening guidelines. As a researcher preference, the survey was administered after the interviews to all participants.

Two participants (5%) report never having been told by their doctors to have a colorectal cancer screening. Thirty-five respondents (92%) have had a colorectal screening, while three participants (8%) report never having had a screening. One participant did report having a colonoscopy scheduled for the next month and two never had colorectal screening before. Average age of colorectal cancer screening for the thirty-eight participants was 52.4 years, ranging from 43-68 years. Screening methods included flexible sigmoidoscopy,

fecal occult blood test, and colonoscopy – colonoscopy being the most common method. Participant CRC screening information is summarized in Table 6.

**Table 6 – CRC Practices of Participants**

<b>Primary Care Provider Ever recommended CRC screening</b>	Yes: 36 (95%) No: 2 (5%)
<b>Have you ever been screened for Colorectal cancer?</b>	Yes: 35 (92%) No: 3 (8%)
<b>Average age at first screen</b>	52.3 years (43-68 year range)
<b>Type of methods used for screening</b>	Colonoscopy, FOBT, flex sigmoidoscopy

Of the two participants who never have had colorectal screenings, one checked off the reasons as her primary care provider not recommending it and not being sure if she wants to know if she has cancer; the other chose the reason that she didn't need the screening because there was no colorectal cancer in her family. Additionally, both participants chose the reason that they didn't need a screening because they felt fine. Information on these participants from their demographic survey indicates that neither has been screened for cervical, skin or oral cancers in the last two years, and one also has not had a mammogram.

The second part of the ACS Questionnaire consisted of five true/false questions related to beliefs and knowledge about colorectal cancer. Participant results are summarized in Table 7. 100% (n=38) believed that "colorectal cancer screening is not a one-time event; average risk people individuals should begin at age 50 and be screened on a regular basis." Thirty-five participants (92%) believed that "colorectal cancer can almost always be detected early or detected early with screening tests." Of the three participants who thought this statement

was false, one had never had a colorectal screening test. Thirty-seven participants (97%) did not believe that “people cannot get colorectal cancer unless it runs in their families. Thirty-six participants (95%) believed that “people can have colorectal cancer with having any symptoms”. The final question on the survey elicited the most variation in response. “Simple lifestyle changes such as improving diet and increasing physical activity cannot reduce your risk of getting colorectal cancer”: Twenty-eight participants (74%) marked this statement false. However, comments later from participants discussing the question were they were not always sure how to answer the question to indicate they did not agree with it – that, in fact they believed that lifestyle changes could reduce colorectal cancer risk. Thus, responses may not be valid or reliable.

**Table 7 – CRC Screening Knowledge and Belief Answers**

<b>Question</b>	<b>True</b>	<b>False</b>
A colorectal cancer screening test is not a one-time event. Beginning at time 50, average-risk individuals should be screened on a regular basis.	42 (100%)	0
Colorectal cancer can almost always be prevented or detected with early screening tests.	35 (92%)	3 (8%)
People cannot get colorectal cancer unless it runs in their family.	1 (3%)	37 (97%)
People can have colorectal cancer without having any symptoms.	36 (95%)	2 (5%)
Simple lifestyle changes, such as improving your diet and increasing physical activity, cannot reduce your risk of getting colorectal cancer	10 (26%)	28 (74%)

### **Differences between the Groups**

This was a cross-sectional, descriptive study in an area of research where there has been little examination and a paucity of published findings. Therefore,

the aim of these analyses was to describe and understand a sample of this target population and to suggest areas of focus for future research. All variables were coded categorically in order to describe the population sampled; analyses were conducted using the SAS 9.1 Software Package (Gary, NC). Cochran-Mantel-Haenszel ( $p < .05$ ) was used to examine any differences between select groups against demographic variables. Variables included in the univariate analyses were current denomination, denomination as a child, income, education, mikvah use and history of colorectal cancer screening.

Table 8 looks at differences in participants according to self-identified denomination. This variable was used to describe any differences in terms of income, education, smoking practices, partner status, screening practices and mikvah use among different denominations reported by study participants. Of these variables, only mikvah use was found to be significantly different between groups; this is in accordance with religious practice and would be expected as mikvah use is generally adhered to in the more observant circles. 100% of the Orthodox participants reported visiting at least once, while 100% of the Reform participants reported never visiting the mikvah. Screening practices for colorectal, breast, and cervical cancer were not significantly different among denominations. Income levels ( $p = 0.07023$ ) also did not appear to be significantly different according to the participant's self-identified denomination, with 18-20% of participants of all denominations reporting annual household income  $< \$59,999$ , and 54-69% reporting annual household incomes  $> \$60,000$ . Similarly, there was no significant differences in education levels ( $p = 0.2006$ )

between denominations, with 68-80% of participants from all denominations reporting having graduated from college or having postgraduate education.

**Table 8 – Differences by current self-identified denomination**

	<b>Reform n=22 n (%)</b>	<b>Conservative n=15 n (%)</b>	<b>Orthodox n=5 n (%)</b>	<b>p value</b>
Education				0.2006
High School Graduate	4 (18%)	1 (7%)	0	
Some College	3 (14%)	2 (13%)	1 (20%)	
Graduated College	8 (36%)	9 (60%)	1 (20%)	
Postgraduate	7 (32%)	3 (20%)	3 (60%)	
Income				0.7023
\$20,000-\$39,999	2 (9%)	2 (13%)	1(20%)	
\$40,000-\$59,999	2 (9%)	1 (6.7%)	0	
\$60,000-\$79,999	1 (5%)	1 (6.7%)	0	
\$80,000+	14 (64%)	7 (47%)	3 (60%)	
Refused/No Answer	3 (13%)	4 (26%)	1(20%)	
Partner Status				0.4321
Married	17 (77%)	12 (80%)	5 (100%)	
Cohabiting	1 (4.5%)	0	0	
Divorced	3 (13.5%)	2 (13.3%)	0	
Widowed	1 (5%)	1 (6.7%)	0	
Current Smoker				0.5587
Yes	0	1 (6.7%)	0	
No	22 (100%)	14 (93.3%)	5 (100%)	
Ever Had CRC Screening				0.8546
Yes	21(95%)	13 (87%)	5 (100%)	
No	1 (5%)	2 (13%)	0	
Current CRC screening				0.4570
Yes	19(86%)	13 (87%)	5 (100%)	
No	2 (9%)	2 (13%)	0	
N/A	1 (2%)	0	0	
Current Mammogram				0.2182
Yes	20 (91%)	15 (100%)	5 (100%)	
No	2 (9%)	0	0	
Current Pap Smear				0.3226
Yes	18 (82%)	13 (87%)	5 (100%)	
No	4 (18%)	2 (13%)	0	
Ever visit Mikvah				<.0001
Yes	0	2 (13%)	5 (100%)	
No	22 (100%)	13 (87%)	0	

**Table 9 – Differences by Ever CRC Screened and Never CRC Screened**

	<b>CRC Screening</b> n= 39 n (%)	<b>No CRC screening</b> n=3 n (%)	<b>p value</b>
Current Denomination			0.8546
Reform	21 (54%)	1 (33%)	
Conservative	13 (33%)	2(67%)	
Orthodox	5 (13%)	0	
Denomination as Child			0.4876
Cultural	3 (8%)	1 (33%)	
Reform	16 (41%)	1 (33%)	
Conservative	13 (33%)	1 (33%)	
Orthodox	7 (18%)	0	
Education			0.2266
High School Graduate	4 (10%)	1 (33%)	
Some College	5 (13%)	1 (33%)	
Graduated College	18 (46%)	0	
Postgraduate	12 (31%)	1 (33%)	
Income			0.4561
\$20,000-\$39,999	3 (7.5%)	2 (66%)	
\$40,000-\$59,999	3 (7.5%)	0	
\$60,000-\$79,999	2 (5%)	0	
\$80,000+	24 (62%)	0	
Refused/No Answer	7 (18%)	1 (33%)	
Partner Status			0.8847
Married	32 (82%)	2 (66%)	
Cohabiting	0	1 (33%)	
Divorced	5 (13%)	0	
Widowed	2 (5%)	0	
Current Smoker			0.7815
Yes	1 (2.5%)	0	
No	38 (97.5%)	3 (100%)	
Current Mammogram			0.0172
Yes	38 (97%)	2 (66%)	
No	1 (3%)	1 (33%)	
Current Pap Smear			0.0079
Yes	35 (90%)	1 (33%)	
No	4 (10%)	2 (67%)	
Current Skin Screening			0.4407
Yes	27 (69%)	1 (33%)	
No	11 (28%)	2 (66%)	
No Answer	1 (3%)	0	
Ever visit Mikvah			0.4271
Yes	7 (18%)	0	
No	32 (82%)	3 (100%)	
Insurance Status			0.7815
Has Insurance	38 (97.5%)	3 (100%)	
No Insurance	1 (2.5%)	0	
Place Born			0.0332
New York	12 (31%)	3 (100%)	
Florida	6 (15%)	0	
Other – U.S.	18 (46%)	0	
International	3 (8%)	0	



Table 9 describes the differences between those participants who have ever had a colorectal cancer screening and those who have not among select demographic variables including; income, insurance status, screening and smoking practices, place of birth, current denomination and denomination as a child and mikvah use. Screening practices reported for cervical cancer ( $p=0.0172$ ) and breast cancer ( $p=0.0079$ ) were significantly different between those participants who had ever had a colorectal cancer screening and those who had not. Of the three participants who had never had a CRC screening, one (33%) also had not had a mammogram for breast cancer screening in the last two years and two (66%) had not had a pap smear for cervical cancer screening in the last two years. This compares with the thirty-nine participants who have had a CRC screening; one (2.5%) reported not having a mammogram in the last two years, and three (8%) report not having a pap smear in the last two years. As well, place of birth ( $p=0.0332$ ) was significantly different between those participants who had ever had a colorectal cancer screening and those who had not. All three (100%) of those participants who have never had a CRC screening reported being born in New York. Of those thirty-nine participants who have had a CRC screening, twelve (31%) reported being born in New York, six (15%) reported being born in Florida, eighteen (46%) in states other than New York or Florida, and three (8%) were born outside the United States in Canada, South Africa and Israel. As is reported in Table 9, other variables of interest did not appear to differ between CRC screening groups.

Finally, Table 10 describe differences between participants who have ever had a colorectal cancer screening and those who have not in their responses to colorectal knowledge and attitude questions on the ACS survey. No significant differences appeared between groups.

**Table 10 – Difference between CRC screen and non-CRC screen on education and belief questions**

	<b>CRC Screening n= 39 n (%)</b>	<b>No CRC screening n=3 n (%)</b>	<b>p value</b>
A colorectal cancer screening test is not a one-time event. Beginning at time 50, average-risk individuals should be screened on a regular basis			0.3320
True	35 (90%)	3 (100%)	
False	0	0	
No Answer/missing	4 (10%)	0	
Colorectal cancer can almost always be prevented or detected with early screening tests			0.6203
True	33 (85%)	2 (66%)	
False	2 (5%)	1 (33%)	
No Answer/missing	4 (10%)	0	
People cannot get colorectal cancer unless it runs in their family.			0.3539
True	1 (3%)	0	
False	34 (87%)	3 (100%)	
No Answer/missing	4 (10%)	0	
People can have colorectal cancer without having any symptoms			0.2791
True	33 (85%)	3 (100%)	
False	2 (5%)	0	
No Answer/missing	4 (10%)	0	
Simple lifestyle changes, such as improving your diet and increasing physical activity, cannot reduce your risk of getting colorectal cancer			0.5913
True	10 (26%)	0	
False	25 (64%)	3 (100%)	
No Answer/missing	4 (10%)	0	

## Summary

This was a descriptive study exploring a topic for which little research has been done in this population. Key informant interviews, focus groups and individual interviews, which were conducted to elicit descriptions and perceptions related to the influence of culture and religion on the colorectal cancer belief and behaviors amongst Ashkenazi Jewish women. This chapter provided analysis of

the data obtained from key informant interviews, focus groups and individual interviews, as well as the surveys that were administered to obtain demographic data and measure screening behaviors and colorectal cancer knowledge and beliefs. Analysis of the data conducted with the goal of answering the research questions for this study, the first of which was to describe the cultural and religious influences on health behaviors in Ashkenazi Jewish women. In this study, qualitative methods were employed to elicit descriptions and opinions of Jewish identity, influence of Judaism on concepts of health and body, understandings and subscriptions to Jewish laws related to health, including purity laws. The second goal of the research questions was to describe the social, cultural and religious contexts influencing individual perception of risk of colorectal cancer and the autonomy to manage them; qualitative methods were again used to elicit descriptions and perceptions of personal control over health, personal responsibility and obligations for health maintenance, and subscription to a belief framework related to a punishing/rewarding God. Quantitative surveys were also used to collect data related to family and personal history of cancer, colorectal (and other cancer) screening behaviors, and knowledge related to colorectal cancer symptoms, prevention, screening as well as incidence in the Ashkenazi population. The third goal of the research questions was to describe the resources and understanding of health information regarding colorectal cancer; descriptions of health sources were provided in the qualitative interviews, as well opinions about the role of the rabbi as an information source. Additionally, the ACS survey gauged knowledge related to colorectal cancer

symptoms, prevention, screening. Finally, the fourth goal of the research questions was to describe the way in which Ashkenazi Jewish women embody the concurrent U.S. and Judaic based taboos associated with the gastrointestinal tract, related to colorectal health behaviors. Once more, perceptions and descriptions were elicited from qualitative interview questions related to issues of Judaic purity issues, U.S. and Judaic taboos associated with feces, and the relationship with colorectal screening practices.

## **Chapter Five**

### **Discussion and Conclusions**

#### **Introduction**

This chapter discusses the responses of the key informants and participants in focus groups and individuals to the semi-structured interviews, as well, the results from the quantitative surveys as related to the research question pertaining to the cultural religious factors that influence health beliefs and behaviors related to colorectal cancer in this population. Contributions of this research to theory, applied anthropology as well as biomedicine will be described. The limitations of the study will also be delineated. Finally, implications of the research and recommendations for future research directions will be explicated.

#### **Research Question 1 - What are the cultural and religious influences on health behaviors in AJ women?**

The first research question attempted to describe the cultural and religious influences on the health behaviors in Ashkenazi Jewish women. An important component to answering this question was understanding both the participants' cultural construction of health and their perception of their Jewish identity. In regards to their construction of health, most participants related health to physical and mental or emotional well-being. For only a few did spirituality enter into their definitions of health, and more in the sense of an important component of

maintaining health. Participants' often perceived both illness and disease as the same thing, or differing only in terms of duration and severity, with disease 'worse' than illness. Overall, participants' explanatory models of illness included a sense of responsibility and potential to control their health through their actions and lifestyle, but were not inclusive of a punitive God who punished with sickness. Disease and illness were explained as related to mental and physical functioning, with no spiritual component. In terms of Jewish identity, while belief in God and degrees of adherence and practice of Jewish laws varied widely, nearly all cited a strong Jewish identity; some describing it as their core identity. Even for those who did not practice Judaism identified themselves categorically as being Jewish, which is similar to findings in previous studies (Tenenbaum & Davidman, 2007). Participants described their Jewish identity as being based on Jewish community, spirituality, historical connections, culture or a combination thereof. As key informants suspected, many of the UA, Reform and Conservative participants could not think of ways Judaism influenced their thinking about health and their body – aside from laws of *kashrut* - which most did not follow - and which they described as an ancient hygiene system. However, several participants who identified as being Orthodox as well as other denominations did refer to Judaism teaching them to consider life and their body as a gift from God, and learning to respect and sanctify it through the Jewish laws such as *kashrut* and against harming the body. Overall, however, participants readily agreed that there was indeed a 'Jewish way' of looking at health, either in terms of a Jewish cultural push for education that improved economic access and understanding

and awareness of health issues, and/or through a core value for the infinite value of life that underlies Jewish culture. The latter health value was focused on by key informants as well, and encompassed factors such as living life in moderation, being mindful of what you ate and put into the body, maintaining the body's integrity (no piercings, tattoos, cremation, not intentionally harming the body), and the obligation to take care of your health and body in every way possible. This speaks to what Michael Weingarten has written on the Jewish value of the sanctity of life: "There is no intrinsic sanctity of life; rather life is given by God to man in order to sanctify it" (Weingarten, 2007).

Having control of and responsibility for taking care of your health clearly informed the personal views on health of participants. Participants typically related this view to sanctity of the body and/or the Jewish culture of education. None of the participants thought that God ever punished with disease or rewarded with health. This was further explicated when participants discussed prayers related to Yom Kippur, and being written back into the Book of Life; all but one participant found those prayers to be metaphorical as opposed to literal. Even the participant who took the prayer literally explained that she did not believe in disease as punishment. While most participants do take part in prayers for healing, often it is from the view of 'it can't hurt'; overall there is little belief that prayers for healing work by God's direct intervention. In fact, all participants said that since we have a degree of control over one's health, we have an obligation to take care of it and should not simply put all our health in God's hands. Participants described a view of God giving us free will to make

decisions, leaving our health up to our choices and luck. Even when for those participants who believed in God having a master plan for all of us which we may not always understand, they still spoke to an obligation to take care of your health, referring back again to the body and life being a gift from God.

**Research Question 2 - What are the social, cultural and religious contexts influencing individual perception of risk of CRC and autonomy to manage them?**

Both the idea of Jews being educated and more aware of health and the Jewish concept of the sanctity of life strongly informed participants' views on health, and both are issues which they clearly connect to Judaism, either through Jewish culture (push for education) or through Jewish practice and teachings (infinite value of life). This is summed up in the comments of one of the UA focus group participants:

We have the Jewish guilt factor; God forbid you get colon cancer because you didn't get you colonoscopy, or you didn't get your mammogram and you end up with breast cancer, I don't know if the rest of the population would feel this way, but I think a Jewish person might feel very guilty if they didn't do what they were supposed to take care of themselves. (11-UA)

This personal view of taking control of one's health could inform the high rates of colorectal cancer screening despite lack of knowledge of the increased risk. On the demographic survey, most participants indicated that they either did not think or did not know whether there was an increased rate of any cancer in the Ashkenazi Jewish population. Of those who did think there may have been increased cancer prevalence, many were aware of the increased rate of ovarian and/or breast cancer. However, only two participants (5%) named colorectal cancer as being increased in the Ashkenazi Jewish population. Ten (24%) of



participants reported a personal history of cancer, 40% of which were breast cancer. While no participants reported a personal history of colorectal cancer, eight participants (19%) reported a family history of colorectal cancer. Despite the lack of knowledge of increased risk and lack of personal or family colorectal cancer incidence, participant rates for ever having a colon cancer screening are 92%, and being up to date on colorectal cancer screening are 88%, which is higher than the screening rates reported for over the age of 50 (Mitka, 2008).

Of the participants who had never screened for colorectal cancer, risk perception clearly played a role for two participants; the third participant actually had her colonoscopy scheduled for the following month. For the first two participants, they both commented that most people have normal tests and are fine, and they know their bodies well, so if something is wrong, they could tell. One of the participants also did not believe cancer screening held value, since her mother was vigilant with screenings and ended up dying of cancer anyway. It should be noted that screening practices reported for cervical cancer ( $p=0.0172$ ) and breast cancer ( $p=0.0079$ ) were significantly different between those participants who had ever had a colorectal cancer screening and those who had not. This speaks to the idea of acceptance and knowledge (of risk) being the main barriers in this group – as opposed to reinforcement and ability-similar to previous findings in this population (Cappelli, et al 2002, Azaiza & Cohen, 2007).

Most participants and key informants related the increased risk of colorectal cancer in Ashkenazi Jews to diet and genetic factors related to the

tradition of intermarriage in Jews. The Jewish culture of education also came up in that because study was so encouraged, physical activity was discouraged which could increase constipation and risk of cancer; constipation was also related to the traditional Ashkenazi diet and related to colorectal cancer risk. Finally, two participants described the history of trauma and persecution as related to the prevalence of disease in the Ashkenazi Jews from an emotional and physical etiology.

**Research Question 3 - What are the ways in which AJ women embody the concurrent U.S. and Judaic based taboos associated with the gastrointestinal tract as related to health and CRC health behaviors?**

Biblical purity laws form the foundation of Judaism. However, as the key informants surmised, these notions of purity do not resonate with many of their congregants; and, in fact, a number of participants either do not practice or outright reject common Judaic purity laws including *niddah* and *kashrut*. Those participants who did not follow the laws of *kashrut* tended to see it as an ancient hygiene system; however those who do follow the laws of *kashrut* see them as a way of sanctifying food and the act of eating to something holy, connecting them spiritually with God. Similarly, most participants (82%) reported never visiting a *mikvah*, and while some participants related the rules of *niddah* as beautiful, historical connections to an ancient hygiene system, many more women found the rules to infer that women were dirty, unclean and somehow inferior because of a normal body function. At this, they rejected the laws as degrading to women. However, those participants (18%) who have attended the *mikvah* tended not to focus on impure aspects of the laws; rather they stressed how the

rules allow for a time of mourning at a missed opportunity for life. This is the same as the way key informants explained the rules of niddah in addition to also relating that most women, especially those that do not practice the rules, translate *tameh* to mean 'dirty' and 'unclean' as opposed to 'unfit'. Additionally, those participants who have visited the mikvah focused on the *taharat hamishpacha* (family purity laws), commenting on how the rules lift the act of sex to something holy and spiritual, thus sanctifying the body and connecting it and the act of sex with God. No significant differences were seen in mikvah use, current self-identified denomination or denomination as a child between those who had ever had a colorectal screening and those who had not.

Many of the participants saw purity within Judaism in terms of moral and spiritual purity; physical purity did not enter their construction. Across denominations, all participants adamantly denied that anything related to Jewish purity inhibited colorectal cancer screening. Similarly, key informants categorically insisted that not only does Judaism not contain prohibitions which may deter a person from getting a colorectal cancer screening; in fact Judaism explicating obligates you to get a screening as part of your responsibility to take care of your body. Many participants spoke to this way of thinking as well, referring back to the infinite value of life in Judaism. As well, the Jewish push for education related to getting preventive screening for colorectal cancer, since Jews are educated and know how to handle their health and what they need to do. This was not to say that the participants and key informants did not recognize the unpleasantness of the test, only that "the grossness is universal." Disgust

related to excrement was viewed more in terms of a U.S. or at least non-Jewish issue, which participants thought affected everyone, Jewish or not. Participants and key informants named a number of barriers which inhibit people from getting the tests, including the time required to get the colonoscopy, the preparation, costs, anesthesia and fear of finding out bad news. However, they felt Jews would be more likely than non-Jews to get the screening done due to higher education and focus on the infinite value of life.

Jewish purity laws resonated for only a minority of participants. For those that it did resonate for, the focus was not on cleanliness or impurity, or fear of a punitive God, but in sanctifying the body, which is part of the concept of the obligation to take care of one's health, including preventive screening.

#### **Research Question 4 - What are the sources and understanding of health information regarding CRC?**

The last research question explored the participants' health information sources and understanding of colorectal cancer information. Participants did cite sources including popular magazines, the medical websites (i.e. WebMD), newspapers and even the "Oprah" show as being sources of health information. However, they also confirmed what key informants described, that congregants do not go to rabbis for health information. On the other hand, both key informants and most participants were open to having health information programs, including colorectal cancer information based in synagogues and other Jewish organizations and media. Lack of media attention related to colon cancer incidence in Ashkenazi Jews was cited by both key informants and participants as potentially contributing to Jews not getting screened, again speaking to the

knowledge barrier this population. Additionally, many participants cited it as the responsibility of the Jewish media and organizations to have such programs and raise awareness.

In terms of understanding health information related to CRC, based on the ACS surveys, most participants had a clear understanding of screening and prevention of colon cancer, with >90% scoring correct answers on all knowledge questions with the exception of the last question about lifestyle, which a number of participants were confused about the wording and how to answer the question in a way that reflected their disagreement with the statement. Even those participants who themselves never have had a colon cancer screenings done did not score significantly different in the knowledge and belief questions on the ACS questionnaire (Table 10). In fact, as Table 9 summarizes, there were no significant differences found between those participants who have ever had a colorectal cancer screening and those who have not, in terms of education, income, insurance status, screening and smoking practices, place of birth, current denomination and denomination as a child and mikvah use. While knowledge and attitudes were not significantly different between groups, screening practices for cervical and breast cancer appears to be significantly different between those participants who had ever had a colorectal cancer screening and those who did not. This may speak to the risk perception of those who have not had screening; two of the participants who did not have CRC screening cited on the ACS Questionnaire that one of the reasons was because they felt fine. One of those participants also frequently said in her interview that

she was in touch with her body and would know if something was not right with it. Thus, behavior related to getting screened may be more related to emotional issues and perceptions of risk, despite having accurate knowledge related to CRC screening and prevention, referring again to knowledge and acceptance barriers in this population as found in other studies (Cappelli, et al 2002, Azaiza & Cohen 2007).

### **Contributions to Theory**

This research's contribution to anthropological theory includes describing new ways in which to consider purity and risk frameworks within this population. Concepts of purity and pollution were the basis for part of this study, and the findings were initially surprising that inquiries related to pollution theory did not resonate with subjects, including those that practiced Jewish purity laws such as *niddah* and *kashrut*. Mary Douglas went into tremendous detail breaking down pollution theory and why things or people are considered dangerous and polluted. She spent a great deal of effort applying this to Biblical Judaism, where she explained (1966) that the Judaic biblical purity laws were not either primitive health regulations or randomly chosen as tests of Jew's' commitment to God; rather, the laws were related to symbolic boundary-maintenance. Douglas (1966) notes that since each of the purity laws is prefaced by the command to be holy, so they must be explained by that command focused on the idea of the holiness of God which Jews must create in their own lives. "To be holy is to be whole, to be one; holiness is unity, integrity, perfection of the individual and of the kind" (Douglas, 1966, 67). This explanation is echoed by key informants and

participants who observe purity laws such as *niddah* and *kashrut*; rather than see them as ancient hygiene systems, these are ways in which the body can be sanctified and made holy. Those who do not observe the laws tend to see them more in a hygiene framework; as well, they also tend to reject the rules, particularly *niddah*. Douglas (1970) suggests that social order shapes the perception of the body's structure and function, and, in turn, shapes the understanding of disease. Thus, a polluting person is always in the wrong, as "he has developed some wrong condition or simply crossed some line which should not have been crossed and this displacement unleashes danger for someone" (Douglas, 1966; 140). Based on responses from this study, however rather than the traditional bodily substances as being considered impure as per biblical purity laws, the lack of taking care of one's health – thus not honoring the obligation to the infinite value of life - may be seen in the stigma framework. This recalls Foucault's notion (1975) that with modern medicine, health replaces salvation as the manifestation of a virtuous existence. Therefore, if good health represents a general orderliness of existence of moral righteousness, then illness conversely reflects moral flaw (Hunt, 1998). Along these lines, not taking care of your health – failing your obligation to God or your educational potential - could be experienced as an essentially moral event. In this way, compliance with Jewish health values may reflect a different way of studying concepts of purity in modern Judaism, as opposed to contact with bodily discharges.

Similarly, purity issues within Judaism are related to risk perception. Risk perception can be considered the beliefs, attitudes, judgments and feelings as

well as socio-cultural disposition people adopt toward hazards and their benefits (Douglas & Wildavsky, 1980). Perceptions of risk are grounded in culture, and often entangled in the moral, gender and material contexts of one's life. While it has different meanings to different groups of people, all risks must be understood within the larger social, cultural and economic context, including those influencing individual perception of risks and autonomy to manage them. Several of the Reform and Conservative key informants noted that bodily substances that were subject to biblical purity laws, such as blood, were considered dangerous because of their liminal status; both a symbol of life and death, blood was considered to be powerful and thus dangerous and needed laws to control it.

The real challenge for us is having the humility to look at these laws through a prism that is different from our own, and trying to understand a different worldview. A lot of this stuff that has to do with purity and impurity, is focused upon those things which sort of straddle between life and death. The reason we have a prohibition – blood isn't death, blood is life. And its about this whole sense of whether you're talking about fecal material, seminal fluid, discharges, all of these things, they're like right on the cusp. And there's a sense that that's powerful stuff and we have to have this appreciation, and again reflects this Jewish attitude toward sanctity of life itself. (KI-C1)

Key informants also described laws and commentary related to excrement (Deuteronomy 23:15) as needing to be understood within the context during which it was written. Because sanitation was crucial for survival of any group, strict laws were written to enforce that hygiene was followed, with threats of punishments from God if they were not complied with. However purity laws do not necessarily resonate with Jews in the same way or for the same reasons today. This may speak to the incredible adaptability which has been necessary for the Jewish people to survive over so much time. Thus, it may be that risk and



purity may need to be explored in different terms in Judaism. One example of this may be to explore those contemporary issues seen today as threatening and dangerous to existence and survival of the Jewish people, such as out of faith marriages, lack of affiliation with the Jewish community, or lack of traditional religious education for children. All of these may be seen as being as dangerous to the survival of the Jews today as bodily fluids may have been perceived to have been in biblical times, and thus may be the focus of modern Judaic purity laws.

### **Contributions to Applied Anthropology**

This research addressed the influence of culture and religion on the colorectal cancer health beliefs and behaviors. Geertz (1973) stresses the importance of thinking in terms of “culture” when discussing religion, defining culture as the systems of meanings inherent in every action which create order, purpose and reason, ideas and meanings are embedded within our worldview, responsible for determining the mood and motivation of action (Brill, 2004). Culture and religion are known to influence medical and personal decision making (Bowen, et al, 2003; Holt & McClure, 2006). Although the colorectal cancer incidence in Ashkenazi Jews has been found to be highest of any ethnic group in the world (Feldman, 2001), studies of AJ have found overall compliance with CRC screening to be low, despite being vigilant about screening for other cancers (Friedman, et al, 1999). There is a paucity of research related to how culture and religion impact the health behaviors of U.S. Ashkenazi Jews, as well as what other socio-cultural factors influence AJ women’s attitudes towards CRC

risk and screening practices. Thus, a first contribution of this research is to the applied anthropology literature on Ashkenazi Jewish women related to colorectal cancer health beliefs behaviors. For example, this research has generated knowledge on the role Judaism plays in the views of health of some Ashkenazi women, indicating some see may see health maintenance as a religious obligation while others relate health care and awareness to a Jewish cultural value of education. It has also contributed an understanding that health is viewed as controllable by these women, rather than a punishment or reward meted out by God. Additionally, this research has contributed to the applied anthropology literature the knowledge that Judaic concepts of purity do not resonate for many, and for those that it does resonate, it is related to a method of sanctifying the body as opposed to a dirty/clean framework with a negative view of bodily functions. Additionally, emotional barriers inhibited CRC screening, despite accurate knowledge of colorectal cancer; these barriers included fear of bad news from a doctor, and fear of embarrassment. Perception of risk was also related to not getting screened, whether from lack of knowledge due to inadequate media attention and national screening or assumption that most people have normal tests and therefore screening is unnecessary. Such knowledge is beneficial for designing and implementation of interventions.

A second contribution is to the value of using qualitative, anthropological methods such as in-depth interviewing, and thematic analysis as research tools. The use of these anthropological methods provided for a richer contextualization and understanding of the experiences of the participants in this study.

## **Contributions to Biomedicine**

Ore, Hoegel, Lavi & Rennert (2001) found that enhancing knowledge and understanding of colorectal cancer did not impact overall response to screening compliance. This supports the notion that compliance with cancer screening programs is not solely a rational behavior, rather emotional barriers must first be targeted before any efforts are made to increase compliance via information delivery on CRC are justified (Ore, et al, 2001). Results of this study indicate similar issues; knowledge and understanding of colorectal cancer was high based on the ACS questionnaire, with no significant differences between those participants who have ever had a colorectal cancer screening and those who have not. As well, Azaiza & Cohen (2007) found low levels of cancer CRC worry in Israeli Jews, which they noted could be related to not being confronted with CRC in everyday life or being as familiar with as, for example, breast cancer. Similarly, only two participants (5%) were aware of the higher prevalence of colorectal cancer in Ashkenazi Jews while sixteen (40%) were aware of the increased prevalence of breast cancer. As well, two of the participants who have never had a colorectal cancer screening cite reasons including not being worried about abnormal results since “most people are fine.” Several participants who have had colorectal cancer screening also said they did not think there was any urgency to get it done and delayed it by years in some cases. Other issues inhibiting screening included perceived unpleasantness of the procedure, time commitment required for having the test done, preparation required to drink, embarrassment, and fear of finding out bad news; one participant also did not

think having the screening would make any difference in whether she ended up with cancer or not. Importantly, most participants also said they would endure the embarrassment and unpleasantness if they knew they were at a higher risk. Cost for this group generally was not a problem, as most had insurance that covered the procedure, and for those that did not, they were willing and able to self-pay. Thus, any future screening initiative for AJ should focus on acceptance issues, including a better understanding of emotional issues surrounding screening, as well as providing accurate factual information to clarify CRC risk for this population and up-to date techniques for screening, stressing how they differ from previous, painful procedures.

Equally important, this research speaks to potential problems with assumptions of *culture* as the culprit for lack of CRC screening. Often, medical practitioners and researchers mark differences in health behavior as ‘cultural’, denying individual agency. Doing so both ignores the reality that many people do make poor choices – not just those of a particular culture – as well as masks the structural inequalities constraining those behaviors (Lee, 2006). For instance, poor uptake of Pap exams has typically been asserted to be a Latina ‘cultural’ issue, although Chavez, et al (2001) challenged that notion with their detailed, mixed method research. Assertions of difference in health behaviors and beliefs often stand in for unexamined ideas that reflect assumptions about blame and responsibility for noncompliance with medical recommendations and treatment. In the case of the three participants who had never been screened for CRC in this sample, Jewish culture had nothing to do with inhibiting screening; in fact,

according to analysis, Jewish culture seems to work quite the opposite, as a promoter and emphasizes of preventive health practices. Most participants described clearly that they not only did not believe in a God that punished with disease, but that they had quite a bit of control over their health, as well as an obligation to take care of it. Of the three non-screeners, one woman was scheduled for a screening the following month. For the other two participants, risk perception and emotional barriers served as the primary inhibitors. As Lee (2006) has commented:

Culture cannot be treated as a binary variable reduced to the normal or the pathological, just as the complexity of the interactions between genes and environments rarely reduces simply to nature versus nurture. (Lee, 2006: 7)

Thus, it is important to look at all underlying variables which may impact health behaviors, including income, education, insurance, migration, and emotional issues. In this case, non-screeners' reasons were similar to those found in the Cappelli (2002) study of refusers including the belief that CRC screening was too much trouble, not necessary and would be physically uncomfortable. All of these reasons fit into the framework Woolf (2000) outlined for barriers of CRC screening, which included knowledge, acceptance, reinforcement and ability.

In addition, risk perception also was cited as a reason for not being screened, which could speak to the categories used to track and analyze health in the United States. Media campaigns for high risk groups are often based on national statistics, which utilize OMB 15 categories. As well, CRC initiatives based in the Jewish community often are related to breast and ovarian cancer, with few, if any, focusing on CRC. This may reflect the general lack of

acknowledgement of the disparate CRC incidence in AJ in both the healthcare and Jewish community. Lack of CRC recognition as well may relate to the AJ CRC rates being counted in the OMB 15 category 'white', so that the disparate CRC burden is not widely tracked or publicized. The categories of OMB 15 were developed to provide consistent data on race and ethnicity throughout the Federal Government, to monitor equal access in housing, education, employment, and other areas, for populations that historically had experienced discrimination and differential treatment because of their race or ethnicity. (OMB, 1997) However, these may not be suitable for purposes of medical care and research, as diverse and complex groups are made to fit into a priori frames, with 'race' and 'ethnicity' used interchangeably as factors in different causal frameworks in terms of risk factors, medical outcomes, healthcare access, behaviors and ancestry (Lee, 2006). A better system of collecting data for medical research and healthcare purposes may include all of the known drivers of healthcare – behaviors, ancestry, risk factors, healthcare access such as income, insurance, education and transportation, medical history and ethnicity – in an open ended format, rather than forcing the patient to choose from an inappropriate list. As well, operational definitions and standards of usage of terms such as 'race' and 'ethnicity' for medical research and literature may be developed so that causal frameworks for disease and disparities can be accurately and efficiently explored and resolved.

Before any cancer control initiative can begin, accurate baseline data in incidence, mortality, and screening in this high risk population needs to be

collected and tracked. In other words, it is doubtful that Jewish culture is the culprit behind noncompliance with screening; rather, it is biomedical and government culture and insistence on maintaining the use of a system to track health statistics which is clearly ineffective in delineating disparate rates of disease in specific populations and thus not servicing those who need it most. If the CRC incidence, mortality and screening rates of Ashkenazi Jews had been tracked, it would have afforded direct statistics, media attention and national campaigns, thus improving risk awareness.

Finally, although 46% of U.S. Jews have been found to have incomes >\$100,000 (Pew Forum, 2008) – and, indeed, 57% of this study's sample reported annual household income >\$80,000 – for many Jews, poverty is an issue. In the New York metropolitan area, which is home to the largest Jewish population in the world outside Israel, studies have found that 20% of the Jews are living in poverty, of whom 34% are over the age of 65 and 49% are Russian-speaking (Ukeles & Grossman, 2004). Thus, it is crucial for cancer control efforts to focus outreach efforts to these groups who, in addition to being at high risk for CRC which they may be unaware of due to inadequate national tracking categories, also face additional barriers related to language, medical care access, transportation, income and insurance.

## **Implications and Recommendations for Future research**

### ***Medical Anthropology***

While the prevalence of colorectal cancer has been found to be high in the Ashkenazi Jewish population, little research has been done on the cultural and

religious influences on CRC health behaviors and beliefs. A very interesting finding of the study was that while many of the participants did not relate Judaism as an influence on their concepts of health (except, perhaps, in some very abstract ways such as dietary restrictions which they did not follow), the concept of a “Jewish way of looking at health’ which was cited by nearly all of the participants across denominations. This “Jewish way of looking at health’ was described as being grounded either in the Jewish culture of education which increases health awareness and socioeconomic access, as well as the Judaic concept of the infinite value of life, and the sanctity of the body, along with the duty to take care of it. While this obligation to take care of one’s body was recognized by some as being a duty to God, more often it was seen as a duty to family and self, not only so that one could be productive and be able to take care of others, but not be a burden on the family. Either way, health was seen as something which we had both an obligation to take care of and over which we had control. These explanatory models of health should be further explored, particularly the perceived differences between the cultural and religious influences on health, to whom one is obligated to in taking care of the body, and how this could translate into health behaviors and messages. This study described women of various denominations and affiliations who not only recognized a “Jewish way” of looking at health, but who also had a desire for cancer awareness and education programs to be tailored to them, and presented by both the Jewish and secular media. Many were surprised to have not known about this increased prevalence of CRC in the Ashkenazi Jewish population,



despite priding themselves on being very health conscious and aware. While this study did not find significant differences between the denominations in terms of screening practices, the sample size was small, and this may be a valuable avenue to explore in a larger sample. Additionally, place of birth was significant between those who have ever had a colorectal cancer screening and those who have not; all three participants who have never had CRC screening were born in the state of New York, to parents who were born in the U.S. The significance of this is unclear; however, the influence of place of birth on screening practices could be explored in future studies. As well, further exploration into ancestry, migration context, socioeconomic backgrounds, childhood religious practices and effects of acculturation on the families of participants should be explored for the effects of health care beliefs and practices related to CRC. For example, a number of the participants were first generation, their parents being Eastern European Jews – German, Polish, Rumanian – who survived the Holocaust, and migrated to the U.S., either directly or via South Africa, Cuba, and Canada. Many other participants were second, third or even later generation U.S. Jews, with families coming from Russia and Poland. In general, Jews in Russia, Prussia, Austria and Poland were oppressed by their governments through military conscription, taxation, and expulsion, and tended to be relatively impoverished (Kamp, 2008). They maintained their Jewish traditions through close community life. The pogroms (massacres) directed against the Russian Jews in the late nineteenth and early twentieth centuries led an infusion of young Eastern European Jews who were religiously traditional and spoke Yiddish; by 1924, over

two million Eastern European Jews had immigrated (Sarna & Golden, 2000). During this time in Germany was the rise of the Reform movement, a reaction against Orthodox rigidity and a way to be less 'other', dropping rituals that isolated Jews from their German neighbors (Telushkin, 1991). Jews in Western Europe did better economically and socially, gaining acceptance, with some Jews attaining significant wealth and status. Thus, the refugees from Nazi Germany were primarily middle-class, middle-aged professionals and businessmen, representing a different type of immigrant from the young, working class, traditional Jews from Eastern Europe in the earlier wave of immigration. Thus, exploring the context of migration of participants' families to the U.S. may have significant bearing on the health beliefs and behaviors related to CRC. Additionally, exploring religious upbringing and any turning points may clarify influences on health beliefs and attitudes. For example, one participant described growing up strictly kosher until they moved to Miami Beach into the back of their store, and not only was the kitchen too small to be a kosher kitchen, but the parents were too busy running the business to participate in guiding their children in their religious studies. Finally, this research points to the need for further exploration of health beliefs and behaviors related to CRC based on religion and gender. The subjects who I interviewed grew up in a time when Bat Mitzvahs and religious educations for women were voluntary at best, and a waste of time at worst. A number of subjects expressed that even though they grew up in observant homes, they knew little about Judaism because they were girls, and had no formal education, although they knew prayers, holidays and

rituals through staying home and learning with their mothers and grandmothers. This echoes Debra Kaufman's findings (1999) of the formal and informal Jewish education based on gender in U.S. Jews. As well, several women discussed how growing up at the time when the feminist movement was taking off made them rethink some of the more stringent Jewish laws, such as *niddah*.

### ***Biomedicine -Community Outreach***

Educational initiatives to raise awareness can use these research findings as a basis for developing communications tailored in to both the cultural duty – the 'Jewish way of thinking' cited so often throughout the interviews, as well as based on the Judaic concept of the infinite value of life and the sanctity of the body. Which message resonates depends on the audience and formative research would be required prior to conducting the actual initiative. However, this research indicates that it may be effective to tailor two separate messages, as well as include factual information related to actual risk and better descriptions of testing in order to allay fears. Partnering with the Jewish community in developing awareness and lifestyle modification programs, possibly via community based participatory research would definitely be another area of research that this community is receptive to. Historically, health screening programs geared to the Ashkenazi population have experienced successful participation, indicating the acceptance of this population of preventive screening. This was first seen with Tay-Sachs disease (TSD), when screening programs based in Jewish communal institutions started in 1971 often with members of the Ashkenazi Jewish community collaborating with researchers who also tended to

be members of the Jewish community (Edelson, 1997). Finally, it is important to further develop this research topic to contribute a clear understanding to barriers in CRC screening. Often culture is blamed as the barrier itself; however, this study showed that Jewish values were strongly focused on health maintenance and preventive care, from both a cultural and religious standpoint. In this sample, lack of screening related to risk perception and emotional barriers. Once more this speaks to the need for to clarify risk perception in this population, which could be aided not only by broader media coverage but also by improvements in the way individuals are categorized for health statistics. Use of OMB Directive 15 categories for collection and analysis of health issues clearly has been a disservice for this population, where their higher rates were neither recognized nor tracked, and thus not brought to the forefront of media attention.

### ***Biomedical Research***

Results of this research may be used to focus CRC intervention in the AJ population directly in several specific ways. First of all, while this small sample was very compliant with CRC screenings, with 92% (n=35) having ever been screened, only 5% (n=2) report knowing that colorectal cancer incidence was higher in the Ashkenazi Jewish population. The women who were aware of the increased incidence of CRC in the AJ population tended to have a family history; unfortunately, a number of the subjects do not know their family medical history due to families perishing in the Holocaust. As well, the mean age of first CRC screening was 52.3 (range: 43-68), and several of the participants were screened exceptionally early due to medical issues such as rectal bleeding or suspected

diverticulitis, not purely a preventive measure for CRC. Participants did note that if they knew they were at a higher risk for something, they were more likely to get screened earlier and be more regular with screenings for it – in fact this was a common response from when who had delayed getting their first CRC screenings because they did not feel an urgency to do so, once more related to risk perception. Furthermore, while the recommended age of first CRC screening is 50, it has been suggested that based on ethnicity alone, AJ should have their first CRC screenings at age 40 (Locker & Lynch, 2004). Therefore, increasing awareness of disparate rates of CRC in AJ may serve to encourage AJ to not just continue getting their screenings, but get them at the recommended age, despite lack of personal or family history or symptoms, without delay. Additionally, as previously stated, this research can raise awareness to direct efforts to those segments of the AJ population who face not only the disparate risk of CRC, but financial, language and access barriers as well. These programs may be grounded in the Jewish concept of *pikuach nefesh* – help yourself and help others – by enlisting Jewish organizations and researchers in this effort – similar to the TSD efforts – such that awareness would be heightened on both the levels of the members of the Jewish helper organizations and the targeted segments. Finally, this research may directly be used to initiate further research on lifestyle and cancer, the type which has been conducted broadly in other groups, but not in U.S. Jews. Cancer research in the AJ population in the U.S. has been limited primarily to genetics, despite the understanding in biomedicine of environmental factors which influence cancer development (including genetic mutations) and, as

this research indicated, that AJ feel that they have tremendous control over their health as well as a responsibility to make good choices.

### **Limitations**

1) This study included forty-two Ashkenazi Jewish women as the primary research population. Though sufficient for this study, the small sample size is not meant to generalize to all Ashkenazi Jewish women, rather it is only meant to describe this sample and provide implications and recommendations for future research.

2) Due to lack of availability and poor response, the sample size for the Orthodox was limited. Still, their qualitative interviews provided remarkably similar responses to questions related to health and Judaism, purity and colorectal cancer beliefs and behaviors.

3) Non-random sampling in the form of snowball and convenience sampling was a primary means to recruit participants. The potential for bias in participant response is a possibility where one friend recruited another to participate in this study and may have shared information with each regarding the interview and questionnaire process. Therefore, information may have a response bias due to the influence of friends and/or family.

4) Forty women (90%) returned the self-administered ACS survey after the interview and focus group. This was despite reminder phone calls and emails.

### **Reflections as a Native Anthropologist**

I chose this project as an opportunity to work within my own community, to heed that from where the second part of pikuach nefesh (help others) comes –

“You shall not stand idly by the blood of your neighbor” (Lev. 19:16) – and contribute an awareness of a problem that I was fairly certain was not very known. The rewards of working as a native were immeasurable. Overall, recruitment was easy, because of the trust of participants and key informants, who either knew me, my family or friends from the community or simply trusted me because I was Jewish – an insider. Buy-in to the research idea was never a problem either, again I think because I was Jewish, which echoes the successful TSD research based in Jewish organizations by primarily Jewish researchers (Brandt-Rauf, et al, 2001). And finally, as an insider, I was able to speak the language, understand the background story and worldview - the ‘sacred canopy’ (Geertz, 1973) that we share, even if they are understood and practiced differently. However, there were several challenges as well; the setting for my study was the community where I live, and where I continue to live, and so will continue to see many of the people who have been interviewed, including key informants. Several of the participants and key informants were quite opinionated on issues pertaining to interfaith marriages, politics and theology, and some wanted to discuss these which put me in a delicate situation as I am in a mixed marriage, with a Muslim, and have quite different theological and political views. So it could be challenging, because lying was not an option, however transparency was not either because I did not want to alienate anyone for future studies nor myself since, again, this is my community. Therefore, a more neutral, calm stance tended to be the one I took most often.

Still, this experience has been more rewarding and enriching than I

imagined, bringing me closer to appreciating and understanding the historical and cultural connections I share with all the subjects. It also brought to the forefront an realization and appreciation for the sheer adaptability of the Jewish people, because even though we all may be under the rather narrow umbrella of 'Ashkenazi Jews', this is far from a homogenous group. The variety of countries our families' immigrated from, the reasons for leaving, context of coming to the U.S., community settled into and current lifestyle and family all have lead down the resultant generations down many paths, as related to acculturation. Some subjects related stories of their families wanting nothing more than to blend into U.S. society, so that they found their own way back to Judaism, while others describe their families bringing 'the old country' with them to the U.S. and how they struggled to break from those bonds, still identifying as a cultural Jew, but with little use for the rituals and religion of their ancestors. And still, there are so many stories yet to tell, woven with similarities but each with its unique angle, and all offering a better understanding of not only my own story, but my family's journey and my people's history.

## **Conclusion**

Utilizing an applied anthropology perspective I explored the influence of culture and religion on health behaviors and beliefs as related to colorectal cancer in Ashkenazi Jewish women. Forty-two women as well as seven key informants participated in the study. The study explored the influence of Judaism on perceptions of health and illness in participants of different denominations and affiliations. This study also described the role of Jewish purity laws in the lives of



the participants and how it relates to their health beliefs and behaviors. While rates of colorectal cancer screening were high in this group, most were not aware of the higher prevalence of colorectal cancer in Ashkenazi Jews and think it is the responsibility of secular and Jewish media to bring it to the forefront. Of those that did not have colorectal cancer screening, risk perception played a role, in that they reported thinking most people do not actually get it. While biblical Jewish purity roles did not impact health behaviors and beliefs related to colorectal cancer screening, the Jewish value of the infinite value of life and the Jewish cultural value of education did seem to strongly play a role, as did the belief that you have control as well as the responsibility for taking care of your health.

This research provides valuable insights and information related to the influence of culture and religion on the health beliefs and behaviors related to colorectal cancer in the Ashkenazi Jewish community. This dissertation fills a void pertaining to the Ashkenazi Jewish view of health beliefs and behaviors and the influence of culture and religion.

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## Appendices





Appendix A (Continued)

10. What is/was your occupation? If retired please state prior occupation

11. During your entire life, have you smoked at least 100 cigarettes, which is about 5 packs of cigarettes?

- Yes
- No
- Don't know / not sure

Do you now smoke cigarettes?

- Everyday
- Some days
- Not at all

12. During the last 12 months how many times **per month** did you have at least one drink of alcoholic beverage? A drink of alcohol is 1 can or bottle of beer, 1 glass of wine, 1 can or bottle of wine cooler, 1 cocktail or 1 shot of liquor.

\_\_\_ days per month

- No drinks in past year

On the days when you drank, **what** did you drink and about **how much** did you drink on average? (Mark all that apply for an average day and amount)

- |  | <u>How<br/>Much?</u> |   | <u>How<br/>Much<br/>?</u> |
|--|----------------------|---|---------------------------|
| <input type="checkbox"/> Bottles of beer     | _____                | <input type="checkbox"/> Glasses of wine        | _____                     |
| <input type="checkbox"/> Number of cocktails | _____                | <input type="checkbox"/> Bottles of wine cooler | _____                     |
| <input type="checkbox"/> Shots of liquor     | _____                | <input type="checkbox"/> Other types of alcohol | _____                     |

13. Do you have any children?

- Yes
- No

14. What are their ages?

Appendix A (Continued)

15. What is your household income?

- Less than \$20,000
- \$20,000-\$39,999
- \$40,000-\$59,999
- \$60,000-\$79,999
- \$80,000 or above
- Decline to answer

16. Do you have any type of health care coverage?

- Yes
- No

17. What type of health care coverage or insurance do you have?

(Check all that apply)

- Medicare
- Medicaid
- TRICARE/Military
- Private
- Self-pay insurance
- Other \_\_\_\_\_

18. Do you have a general care physician/primary care physician?

- Yes
- No

19. Have you ever been told by your doctor that you have cancer?

- Yes
- No

20. What type of cancer were you diagnosed with?

21. Have any of your relatives had cancer?

22. What type of cancer has your relatives had?

Appendix A (Continued)

23. What types of screening tests have you had in the last 2 years? (Check all that apply)

- Mammography – breast cancer screening
- Pap smear – Cervical Cancer screening
- Skin Exam – Skin cancer/melanoma screening
- Tongue exam – Oral cancer screening
- Fecal Occult Blood Test (last two years) or Colonoscopy (in the last ten years) – Colon Cancer Screening

24. Are there any cancers you think the Ashkenazi Jewish population is at a higher risk for than the average U.S. population?

- Yes
- No

If so, which ones?

25. Are there any cancers that you think the Ashkenazi Jewish population is at a lower risk for than the average U.S. population?

- Yes
- No

If so, which ones?

26. How would you identify your Jewish denomination?

- Reform
- Conservative
- Orthodox
- Other \_\_\_\_\_

27. What Jewish denomination were you brought up in during childhood?

- Reform
- Conservative
- Orthodox
- Other \_\_\_\_\_

Appendix A (Continued)

28. Have you ever or do you currently attend a Mikvah?

29. How often?

Once

Monthly

Other \_\_\_\_\_

30. What is the main reason you attend a Mikvah?

Thank you for taking time from your busy day to complete this survey.

**Appendix B: ACS Questionnaire on experiences with and attitude toward colorectal cancer screening**

1. How old are you? \_\_\_\_\_
2. Has your primary care provider (the doctor or nurse that cares for you regularly) ever recommended that you have a colorectal cancer screening test? (Circle one ) \_\_\_\_\_ Yes or No
3. How old were you when you had your **first** colorectal cancer screening test? \_\_\_\_\_

If you have never had a colorectal cancer screening test, please skip to question 5.

Otherwise, please continue to question 4.

4. Which of these tests for colorectal cancer have you had?  
(Please check all that apply and then skip to question 6).

*Flexible Sigmoidoscopy* \_\_\_\_\_

A slender tube is inserted through the rectum into the lower part of the colon. Patients prepare for this test with an enema and are usually awake during the procedure.

*Fecal Occult Blood Test (FOBT)* \_\_\_\_\_

Patients receive a test kit and instructions on how to take stool samples at home.

The samples are then sent to a lab for testing.

*Colonoscopy* \_\_\_\_\_

A slender tube is inserted through the rectum into the entire colon. Patients prepare

for this test with an enema and laxatives. They receive medication through a vein

to make them relaxed and sleepy during the procedure.

*Double-Contrast Barium Enema (DCBE)* \_\_\_\_\_

A chalky substance is inserted into the colon through a tube placed in the anus. Air

is then pumped into the colon to make it expand. Patients prepare with laxatives and

an enema.

Appendix B (Continued)

5. If you have never had a colorectal cancer screening test, what are the reasons?

(Please check all that apply).

- My primary care provider didn't recommend it. \_\_\_\_\_
- I haven't seen my primary care provider recently. \_\_\_\_\_
- I don't know much about it. \_\_\_\_\_
- I know about the different tests, but it's very confusing. \_\_\_\_\_
- I don't need one because I feel fine. \_\_\_\_\_
- I don't need one because there is no colorectal cancer in my family. \_\_\_\_\_
- The exam would be painful. \_\_\_\_\_
- I might be injured by the test. \_\_\_\_\_
- I don't want to handle my stool. \_\_\_\_\_
- I don't want to use an enema. \_\_\_\_\_
- The test is too embarrassing. \_\_\_\_\_
- The tests are too time-consuming. \_\_\_\_\_
- I am not sure I want to know if I have cancer. \_\_\_\_\_
- Some other reason \_\_\_\_\_

Please indicate whether you think each of the following statements is true or false.

(Circle one)

6. A colorectal cancer screening test is not a one-time event. Beginning at age 50, average-risk individuals should be screened on a regular basis. \_\_\_\_\_ True or False
7. Colorectal cancer can almost always be prevented or detected early with screening tests. \_\_\_\_\_ True or False
8. People cannot get colorectal cancer unless it runs in their family. \_\_\_\_\_ True or False

Appendix B (Continued)

9. People can have colorectal cancer without having any symptoms. .... True or False

..... Symptoms of colorectal cancer include:

- A change in bowel habits that lasts for more than a few days.
- A feeling that you need to have a bowel movement that is not relieved by doing so.
- Blood in the stool.
- Cramping or steady pain in your stomach area.
- Weakness and fatigue.

10. Simple lifestyle changes, such as improving your diet and increasing physical activity, cannot reduce your risk of getting colorectal cancer. .... True or False

Thank you for taking time from your busy day to complete this survey.

## Appendix C - Key Informant Interview Guide

Research Objective O-1 Determine the cultural and religious influences on health behaviors in key informants

Questions:

- What is your definition of health?
- What is your definition of illness?
- Is this different from disease?
  - *Probe -How?*
- In what ways can you think Judaism has influenced you to think about health?
- What about how it influenced you to think about the body?
  - Probe – how would you say you learned this, from specific texts or from an overall way you were brought up, or some other way?

Research Objective O-2: Determine the social, cultural and religious contexts influencing individual perception of risk and autonomy to manage them

Questions:

- Do people in your congregation use the Mikvah regularly?
- What do you think about the concept of niddah?
- How do you think niddah resonates with your congregants?
- Does anyone recite the Asher Yatzar – or familiar with it?
- Do you teach it?
- What do you think about it?
- How much control do you think you have over health and disease?
  - *Probe – for example do you feel this is up to doctors to take care of, of in God's hands, or up to you to take care of things?*
- Do people ever get diseases because of something they did that was immoral? Does God punish with disease?
- If you had to come up with a typical 'American' way of thinking about one's health, what would that be?
- What about a Jewish way of thinking?
- When you think about the word cancer, what types come to mind as being the most threatening to the average U.S. population?
- What types of cancer do you think of effecting the Jewish population
  - Probe: where does colon cancer fit in?
- How does excrement operate within the Jewish rules of purity?
  - *Probe: for example, how do you interpret Deuteronomy 23:15, and rules about prayer and sacred objects in bathrooms?*



## Appendix C (Continued)

Research Objective O-3: Identify the ways in which key informants embody the concurrent U.S. and Judaic based taboos associated with gastrointestinal tract as related to health and other CRC behaviors

### Questions:

- Have you ever had a screening for colorectal cancer?
- Can you tell me who made the suggestion and which test it was for?
  - *Probe – what other choices were you given?*
- What was your reaction to the test?
- What had you heard or expected about the testing procedure?
- What comes to mind when you think of screening?
- What made you think about getting a screening?
- What made you NOT want to get a screening?
- Are there any Jewish health issues that make you more or less inclined to get screened?

Research Objective O-4: Identify sources of understanding of health information regarding CRC:

### Questions:

- What is your role in terms of your congregants' health? Do they ever come to you for advice?
- How do you think most Americans think about colorectal cancer or getting screened?
  - *Probe – do you think most people get their screenings?*
- *What do you think holds them back?*
- Do you think this may be different in the Jewish population?
  - *Last ditch probe – bodily waste is classified as impure in Jewish law, how do you think this plays into thinking about colorectal cancer?*

Research Objective O-4: Identify sources of understanding of health information regarding CRC

### Questions:

- Where do you get most of your health information from?
  - *Probe – do you ever look to your Rabbi for guidance?*
- What do you think about colorectal screening campaigns in the U.S.?
  - *Probe – like colorectal cancer awareness month (March)*
- How do you think most Americans think about colorectal cancer or getting screened?
  - *Probe – do you think most people get their screenings?*
  - *What do you think holds them back?*

## Appendix C (Continued)

- Do you think this may be different in the Jewish population?
  - *probe – bodily waste is classified as impure in Jewish law, how do you think this plays into thinking about colorectal cancer?*

Solutions:

Questions:

- If your doctor did not recommend a colorectal screening exam, how do you think you would have approached this subject with him or her?
- What type of information or procedure would make the screening easier?
- Why do you think so many people don't get colorectal screenings done?
- What types of places do you think might be appropriate for Jews to learn about colorectal cancer?
- How supportive do you think synagogues would be of awareness campaigns? Would you attend a program there?
- Do you think religion plays a role in Jews not getting CRC screening?

## Appendix D- Focus Group Guide

Research Objective O-1 Determine the cultural and religious influences on health behaviors in AJ women

Questions:

- How would you describe your cultural or religious identity?
- How does your Judaism affect your life?
- What is your definition of health?
- What is your definition of illness?
- Is this different from disease?
  - *Probe -How?*
- In what ways can you think Judaism has influenced you to think about health?
- What about how it influenced you to think about the body?
  - Probe – how would you say you learned this, from specific texts or from an overall way you were brought up, or some other way?

Research Objective O-2: Determine the social, cultural and religious contexts influencing individual perception of risk and autonomy to manage them

Questions:

- Do you or anyone you know use the Mikvah?
- What do you think about the concept of niddah?
- Does anyone recite the Asher Yatzar – or familiar with it?
- What do you think about it?
- Do you think God ever punishes with disease or rewards with health?
- What do you think about during Yom Kippur, with the Book of Life, and the liturgy about “Those who will perish by fire, and those who will perish by water”... - how does that resonate for you?
  - *Probe – is that more metaphorical or literal?*
- Do you ever participate in the Mishaberach prayer? How do you think those work?
- If you had to come up with a typical ‘American’ way of thinking about one’s health, what would that be?
- What about a Jewish way of thinking?
  - *Probe – what kind of difference is there?*
- How much control do you think you have over health and disease?
  - *Probe – for example do you feel this is up to doctors to take care of, of in God’s hands, or up to you to take care of things?*
- When you think about the word cancer, what types come to mind as being the most threatening to the average U.S. population?
- What types of cancer do you think of effecting the Jewish population
  - Probe: where does colon cancer fit in?

## Appendix D (Continued)

Research Objective O-3: O-3 Identify the ways in which AJ women embody the concurrent U.S. and Judaic based taboos associated with gastrointestinal tract as related to health and other CRC behaviors.

### Questions:

- Thinking back, can you talk about the first time when it was suggested to get a colorectal cancer screening test?
- Can you tell me who made the suggestion and which test it was for?
- *Probe – what other choices were you given?*
- What was your reaction to the test?
- What had you heard or expected about the testing procedure?
- What comes to mind when you think of screening?
- What made you think about getting a screening?
- What made you NOT want to get a screening?

Research Objective O-4: Identify sources of understanding of health information regarding CRC

### Questions:

- Where do you get most of your health information from?
  - *Probe – do you ever look to your Rabbi for guidance?*
- What do you think about colorectal screening campaigns in the U.S.?
  - *Probe – like colorectal cancer awareness month (March)*
- How do you think most Americans think about colorectal cancer or getting screened?
  - *Probe – do you think most people get their screenings?*
  - *What do you think holds them back?*
- Do you think this may be different in the Jewish population?
  - *Probe – bodily waste is classified as impure in Jewish law, how do you think this plays into thinking about colorectal cancer?*

### Solutions:

### Questions:

- If your doctor did not recommend a colorectal screening exam, how do you think you would have approached this subject with him or her?
- What type of information or procedure would make the screening easier?
- Why do you think so many people don't get colorectal screenings done?
- What types of places do you think might be appropriate for Jews to learn about colorectal cancer?
- How supportive do you think synagogues would be of awareness campaigns? Would you attend a program there?
- Do you think religion plays a role in Jews not getting CRC screening?

## Appendix E- Individual Participant Interview Guide

Research Objective O-1 Determine the cultural and religious influences on health behaviors in AJ women

Questions:

- How would you describe your cultural or religious identity?
- How does your Judaism affect your life?
- What is your definition of health?
- What is your definition of illness?
- Is this different from disease?
  - *Probe -How?*
- In what ways can you think Judaism has influenced you to think about health?
- What about how it influenced you to think about the body?
  - *Probe – how would you say you learned this, from specific texts or from an overall way you were brought up, or some other way?*

Research Objective O-2: Determine the social, cultural and religious contexts influencing individual perception of risk and autonomy to manage them

Questions:

- Do you or anyone you know use the Mikvah?
- What do you think about the concept of niddah?
- Does anyone recite the Asher Yatzar – or familiar with it?
- What do you think about it?
- Where do you think purity plays a role within Judaism?
- Do you think God ever punishes with disease or rewards with health?
- What do you think about during Yom Kippur, with the Book of Life, and the liturgy about “Those who will perish by fire, and those who will perish by water”... - how does that resonate for you?
  - *Probe – is that more metaphorical or literal?*
- Do you ever participate in the Mishaberach prayer? How do you think those work?
- If you had to come up with a typical ‘American’ way of thinking about one’s health, what would that be?
- What about a Jewish way of thinking?
  - *Probe – what kind of difference is there?*
- How much control do you think you have over health and disease?
  - *Probe – for example do you feel this is up to doctors to take care of, of in God’s hands, or up to you to take care of things?*
- When you think about the word cancer, what types come to mind as being the most threatening to the average U.S. population?
- What types of cancer do you think of effecting the Jewish population
  - *Probe: where does colon cancer fit in?*

## Appendix E (Continued)

Research Objective O-3: O-3 Identify the ways in which AJ women embody the concurrent U.S. and Judaic based taboos associated with gastrointestinal tract as related to health and other CRC behaviors.

### Questions:

- Thinking back, can you talk about the first time when it was suggested to get a colorectal cancer screening test?
- Can you tell me who made the suggestion and which test it was for?
- *Probe – what other choices were you given?*
- What was your reaction to the test?
- What had you heard or expected about the testing procedure?
- What comes to mind when you think of screening?
- What made you think about getting a screening?
- What made you NOT want to get a screening?

Research Objective O-4: Identify sources of understanding of health information regarding CRC

### Questions:

- Where do you get most of your health information from?
  - *Probe – do you ever look to your Rabbi for guidance?*
- What do you think about colorectal screening campaigns in the U.S.?
  - *Probe – like colorectal cancer awareness month (March)*
- How do you think most Americans think about colorectal cancer or getting screened?
  - *Probe – do you think most people get their screenings?*
  - *What do you think holds them back?*
- Do you think this may be different in the Jewish population?
  - *probe – bodily waste is classified as impure in Jewish law, how do you think this plays into thinking about colorectal cancer?*

### Solutions:

### Questions:

- If your doctor did not recommend a colorectal screening exam, how do you think you would have approached this subject with him or her?
- What type of information or procedure would make the screening easier?
- Why do you think so many people don't get colorectal screenings done?
- What types of places do you think might be appropriate for Jews to learn about colorectal cancer?
- How supportive do you think synagogues would be of awareness campaigns? Would you attend a program there?
- Do you think religion plays a role in Jews not getting CRC screening?

### **About the Author**

Karen Besterman-Dahan received her Bachelor of Science in Dietetics and Nutrition from Florida International University in Miami, Florida, and a Master of Arts in Adult Education from University of South Florida in Tampa, Florida. She has been a clinical research dietitian since 1989. Since 1992 she has been at the H. Lee Moffitt Cancer Center and Research Institute, first as a clinical research dietitian, and then as a research associate on chemopreventive trials, working with individuals and diverse communities. She is an experienced clinician, educator and researcher. Her research interests include issues related to health disparities, cancer and prevention.