

Evaluation of MENA refugees' attitudes towards patient autonomy-based ethics of informed consent

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Research Article

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Abstract

Background

The objective of this study was to identify refugees' attitudes concerning the autonomy-based ethics of informed consent and to determine whether these attitudes varied by gender.

Methods

A quantitative methodology was adopted for this study. Questions were scored using a Likert-type scale and face-to-face interviews were conducted with 610 refugees who had migrated to Turkey from MENA (Middle East and North Africa) countries.

Results

Refugees from eleven countries participated in the survey, of whom the majority were men (62.5% male versus 37.5% female). Reasons for migration include war/security, poverty, and persecution (67.3%), and wanting to live in developed countries (81.1%). The decision to migrate was mainly decided upon either solely by males (as stated by 46.1% of participants) or by the family as a whole (39.0%). Regarding competence in spoken Turkish, most participants (58.5%) were judged to be at a moderate level. A plurality preferred to follow their doctor's advice for treatment (42.6%), while nearly one-third deferred to the male authority figure in the family (33.1%). A majority stated that they were unaware of the concept of informed consent (63.3%). There was a significant difference between the responses of men and women with respect to the eight questions concerning informed consent.

Conclusion

Autonomy is a fundamental principle of human rights and medical ethics. Refugees from MENA countries, where the concept of autonomy is contrary to deeply-held traditional religious views of much of the population, in general, have a poor grasp of informed consent as a patient right. Traditional religious/cultural values steeped in patriarchy constitute an obstacle to women making decisions regarding their own lives in MENA countries. Therefore, the practice of informed consent is of critical importance in helping to reduce gender differentials in health care.

Introduction

Migration is as ancient as the history of humanity itself; however, forced migration is another matter, and increases during wars, persecution, violence, and in situations involving human rights violations [1]. According to a report by the United Nations High Commissioner for Refugees (UNHCR), at present, 70.8 million people have been forcibly displaced worldwide [2]. Because current authoritarian regimes are

essentially a modern form of the feudal-authoritarian system, usually based on religious tradition and/or ethnic nationalism, socio-economic injustice and inequality, including gender discrimination and other human rights violations, tend to be inherent in their make-up. These issues, by no means unique to Middle East and North Africa (MENA) countries, triggered the so-called 'Arab Spring/Upheaval' in Tunisia in 2010, and subsequently spread throughout the region, resulting in what would become this century's largest migration of peoples from MENA to western countries [3]. However, the consequences of this rebellion have been dire: a refugee crisis triggered by the massive increase in migration; divided countries unable to establish institutions in support of democracy and human rights as a result of their long history of authoritarian rule [4, 5]; natural resource extraction primarily benefitting foreign multinational corporations [6], and; the involvement of foreign powers in countries affected by the "Arab Spring" [7], resulting in the former possibly being ensnared in civil wars that could last decades. Despite the collapse of dictatorial regimes in some MENA countries, nonetheless, democratic governments based on universal human rights have yet to be established. These refugees generally do not wish to return to their homelands. Refugees arriving in Turkey, the latter occupying both culturally and economically a kind of transitional space between MENA and Europe, express a desire not to remain in Turkey but prefer instead to settle in various developed western countries [8].

Although the refugees whom we interviewed expressed their support for peace and economic development in their homelands, they gave little attention to questions of gender equality, human rights, and democracy, all vital components of well-functioning western and secular countries. Traditional religious beliefs prevalent in MENA countries do not involve the principle of equality between women and men; moreover, gender discrimination itself is inherent in Islamic religious traditions that purport to protect the family, with the autonomy of women limited in nearly every aspect of life, including health care [9]. Traditional beliefs and sharia law justify the control of both women's attitudes and activities by men [10, 11]. Therefore, the concept of human rights in patient care [12] is not well developed in MENA countries compared to most western liberal democracies. The majority of the countries to which MENA refugees migrate, including Turkey, have instituted regulations concerning patient rights both legally and from the standpoint of acceptable ethical practices [13]. Autonomy, one of the fundamental parameters of patient rights and a basic principle of biomedical ethics, ensures respect for the patient by ensuring their right to accept or refuse treatment. The patient evaluates the medical information provided by the physician and makes an autonomous decision regarding their treatment accordingly; these decisions may be communicated orally and/or in writing. If this process is not managed appropriately, the patient has the right to complain to their doctor; the legal equivalent of this complaint is also enshrined in criminal law.

This study was conducted to evaluate how refugees in Turkey approach the concept of informed consent, which is based on the principle of autonomy in medical ethics and one of the basic values of human rights in patient care. Conflicts undeniably exist between the dominant values of the refugees' homelands versus those of their host countries, particularly with respect to democracy and human rights in patient care. In medical ethics, the concepts of autonomy and informed consent involve patients understanding medical concepts, diagnosis, medication, treatment options, and any accompanying risks, in order to

make a well-informed decision regarding their care. Since this topic has not previously been researched, the present study fills a gap in the literature concerning the attitudes of refugees concerning patient health policies.

The research questions How do the refugees participating in this study perceive informed consent? Do any differences exist between men and women regarding these perceptions? Is gender discrimination a factor in cases where women consider the principle of patient autonomy inherent in informed consent to be contrary to their own traditions and preferences?

Method

Study design

A quantitative methods design was employed to explore patterns of the participants' perspectives and expectations of healthcare providers/services based on informed consent (IC). Prior to the start of the study, refugees were questioned regarding their reason(s) for migrating, the main issues they faced, access to and satisfaction with healthcare services, and awareness of informed consent. Official permission from governors and ethics committee approval had to be obtained in order to initiate contact with the participants. Completion of these preliminary tasks lasted more than two months. The decision was made to distribute the questionnaires during face-to-face interviews instead of disseminating them via e-mail or phone. The reasons for choosing this method were to ensure that the participants correctly understood the questions and to answer any questions they may have had, as well as to help build trust between the refugees and the researchers.

Initially, socio-demographic data and informed consent questionnaires were distributed to assess the expectations of refugees receiving government assistance concerning healthcare services and medical ethics. A systematic random sampling method was employed, and the participants, who had migrated from eleven different countries, responded to a series of questions. The attitudes of the participants regarding informed consent were compared with their decision-making process involving their migration.

Participants: The objective of the present study was to gather descriptive information pertaining to issues of medical ethics as perceived by refugees receiving government assistance. However, as a study involving refugees requires official permission from numerous government agencies, including public universities, governorates, and the general directorate of immigration administration, the process was necessarily time-consuming, with a number of requests for permission rejected for various reasons by the authorities. This study, therefore, focused on the views regarding informed consent of randomly selected refugees residing in different cities in Turkey, including Istanbul, Adana, Konya, and Van. The participants had already received temporary residency status, housing, food, healthcare coverage, and financial support, all provided by the Turkish government. Permission was granted by the relevant authorities to meet with the selected refugees.

Preliminary preparation 1: Permission was obtained from official authorities to conduct this study. Subsequently, two multilingual interpreters (community workers) from among the voluntary refugees were chosen to assist in the study, thus overcoming the language barrier and helping to secure the trust of the refugees. The interpreters were recruited and trained for the study and assisted during the interviews of participants. Information was provided to the refugees regarding the purpose of the research and the participants gave their consent. The participants held positive attitudes toward the study because it was concerned with problems and issues that they themselves faced.

Preliminary preparation 2: A cross-sectional study using interviewer-administered questionnaires was conducted to assess refugees' expectations of doctors within the framework of autonomy-based informed consent. However, an individual's sense of autonomy is closely related to the concept of autonomy in his/her culture. For this reason, we prepared questions concerning autonomy and compared these questions with regard to the decision to migrate and choices involving treatment modality and informed consent.

Data collection tools

Data were collected using a questionnaire to determine the participants' socio-demographic characteristics and their expectations regarding medical ethics. The questionnaire, created by the researcher, was formulated in accordance with those used in previous studies reported in the literature.

A total of 735 refugees from Sudan, Syria, Afghanistan, Eritrea, Somalia, Iran, Iraq, Ghana, Nigeria, Yemen, Ivory Coast, Ethiopia, Libya, Kyrgyzstan, Uzbekistan, and the Democratic Republic of Congo participated in the study. Of these, 76 participants failed to complete the questionnaires, and 49 completed only a few questions; as a result, only the data from 610 questionnaires could be evaluated.

Demographic and professional background: Participants provided information regarding age, gender, marital status, number of children, job/profession, country of birth, reason for migrating, length of stay in Turkey, transfer country preference (where they hoped to settle), who made the decision to migrate, and proficiency in spoken Turkish.

Questionnaire: The questionnaire was prepared by the researcher following the pilot study to evaluate the initial responses provided by the participants concerning the suitability of the questions. Before starting, we had informal conversations with the participants to create a positive and relaxed atmosphere. Participants answered questions during face-to-face interviews. The questionnaire consisted of three parts, the first of which focused on demographic data and reasons for migration (Table 1). The second part concerned access to health care, patient rights, and satisfaction with health services, treatment decisions, and autonomy/informed consent (Table 2). Responses were scored using a 5-point Likert-type scale.

Statistics: Descriptive statistics were used to analyze the demographic characteristics of the participants, and categorical variables were compared using the Chi-squared test (χ^2) (Tables 1 - 4). A reliability test

was performed to assess the internal consistency of the scale, resulting in a Cronbach's alpha value of .72, which is considered acceptable (Table 4).

Ethical considerations

The study participants were vulnerable not only as a result of the language barrier but also due to their status as refugees. The interpreters provided information to the participants in their own languages and presented them with adequate opportunities to ask questions. The purpose, content, and methodology of the study were explained to the participants and their informed consent was obtained. The participants were able to communicate with the interpreters easily and seem quite pleased to talk about their experiences, answering demographic and other questions without hesitation. During the interviews, tea was also offered.

Results

A flow chart depicting in detail each step involved in the study is shown below (Figure 1). The responses of the 610 participants were analyzed using SPSS 16 (Tables 1 - 4).

1. Participants' demographics characteristics and preferences: The demographic data and responses to other questions were tabulated and categorical variables were compared using Chi-squared (χ^2) tests (Table1). The majority of the participants (62.5%) were male, with ages ranging from 18 to over 65 years old. The mean age of all participants was 32.35 ± 13.13 years. Among the participants, 32.0% were single, 66.4% were married, and the majority (59.0%) had one or more children.

The 610 participants had been in Turkey for an average of 3 years at the time of the study. The primary countries of origin of the participants were Syria (20.7%), Iraq (20.0%), and Afghanistan (19.0%), with lesser numbers from Somalia, Sudan, Yemen, Democratic Republic of Congo, Iran, Kirgizstan, Ivory Coast, Ethiopia, Eritrea, Nigeria, Libya, and Ghana.

A majority of the participants (67.3%) stated that the main reason for their migration was war/security in combination with poverty, a significant minority (28.8%) indicated political oppression/persecution, and only 3.9% cited solely economic reasons. More than half of the participants (55.6%) were unemployed prior to migrating to Turkey, (15.7%) were tradesmen, (11.35%) were students, and small numbers were farmers and faculty members (both 0.7%). When asked where they would like to reside, 96.0% replied that they would like to move to a developed western country as soon as possible. Only (8.1%) responded that they preferred to remain in Turkey, while another (8.1%) expressed a desire to return to their country of origin. The participants' Turkish speaking skills were significantly correlated with their length of stay in Turkey ($p < 0.05$). A small minority (13.3%) claimed to speak Turkish well, while the majority (58.5%) possessed moderate proficiency in spoken Turkish, and (28.2%) were unable to speak Turkish.

Decision-making regarding both migration and medical treatment: The question of who decides whether to migrate and who makes decisions concerning medical treatment allowed us to make a preliminary assessment of the relationship between decision-making and autonomy. When the participants were asked whose decision it was to migrate, nearly half (46.1%) of the participants said it was the male head of the household (husband, father, etc.), (39.0%) said other family members, and (14.9%) said the decision was made by women. Regarding medical treatment, (42.6%) of the participants stated that such decisions were made by doctors, nearly one-third (33.1%) said the patients themselves decided (33.1%), (22.0%) said a male authority figure (husband, father, etc.), and (2.3%) of the participants stated that medical decisions were made by joint agreement of the family (Table 1).

While 98.5% of the men who decided that their family should migrate stated that they made healthcare decisions, 67.2% of the women who stated that the male head of household made the decision to migrate also claimed that the same male made treatment decisions. Of all participants who jointly decided to migrate, an overwhelming majority (87.7%) indicated that they also made joint decisions regarding treatment. The χ^2 independence test indicates the presence of a statistically significant relationship between the categorical variables in terms of gender ($p < .01$).

Table 1. Demographic characteristics and country preferences

Characteristics	N %	Marital Status	N	%
Gender		Single	195	32.0
Male	381 62.5	Married	405	66.4
Female	229 37.5	Divorced	10	1.6
Mean age in years \pm SD:	32.35 \pm 13.1			
Country of birth	N %	Profession	N	%
Syria	126 20.7	Unemployed	339	55.6
Iraq	122 20.0	Tradesman	96	15.7
Afghanistan	116 19.0	Student	69	11.3
Somalia	96 15.7	Writer/Artist	22	3.6
Sudan	57 9.3	Athlete	20	3.3
Yemen	23 3.8	Interpreter	20	3.3
Dem. Rep. of Congo	16 2.6	Engineer	17	2.8
Iran	12 2.0	Office worker	11	1.8
Kirgizstan	8 1.3	Businessman	8	1.3
Ivory Coast	8 1.3	Farmer	4	0.7
Ethiopia	8 1.3	Academic	4	0.7
Number of children	N %	Reason for migrating	N	%
Single/divorced 0	221 36.3	Economy/unemployment	24	3.9
Married 1 - 2	33 5.4	War/security and poverty	410	67.3

Married 3 - 4	52 8.5	Political persecution	176	28.8
Married 5 - 6	183 30.0	Country Preferences	N	%
Married ≥ 7	121 19.8	Canada, USA, EU, Australia	594	97.4
(singles excluded) mean ± SD: 3.97 ± 1.809	mean ±	Turkey	8	1.3
Migration decision-making	N %	Country of birth	8	1.3
Men (single/married)	281 46.1	Turkish proficiency	N	%
Women (married)	91 14.9	High	81	13.3
Joint decision (married)	238 39.0	Medium	357	58.5
		None	172	28.2
		Language proficiency was significantly associated with length of stay	(p < .05)	

2. Refugees' access to information on healthcare

The data for this section are presented in Table 2. When asked to identify their main problems, a majority of participants stated that shelter was a major issue (80.3%), followed by nutrition (66.6%), choosing which country to settle in (56.2%), and health issues (50.7%). An overwhelming majority (92.5%) found it easy to access healthcare services during their stay in Turkey. Approximately half of the participants had received assistance from their Turkish neighbors in the form of transportation to the hospital (50.3%), and a lesser percentage had received help from their compatriots (32.5%). Over half of the participants also indicated that they were satisfied with the free healthcare services (52.0%).

Table 2. Refugees' problems and healthcare access

1. Main problems	N %	5. Satisfaction with healthcare services	N	%
Shelter	490 80.3	Yes: free of charge (care, transportation, medicine)	317	52.0
Nutrition	406 66.6	Sometimes: easy access but long waiting times	166	27.2
Which country to settle in	343 56.2	No: long waiting times, cultural and communication issues	127	20.8
Health	309 50.7	6. Patient rights	N	%
Education	160 26.2	Aware	107	17.5
Employment	160 26.2	Unsure	199	32.5
		Not aware	304	49.8
2. Access to health care	N %	7. Informed consent	N	%
Easy	565 92.5	Aware	78	12.8
Sometimes easy	39 6.4	Unsure	146	23.9
Difficult	6 1.0	Not aware	386	63.3
4. Information to access healthcare services	N %	8. Time in Turkey (years)		
		mean ± SD: 3.02±1.534	N	%
Turkish neighbors/people	307 50.3	0 - 2	85	13.9
Community friends	198 32.5	3 - 5	175	28.7
Immigration offices	105 17.2	≥ 6	350	57.4

To better understand their problems accessing the healthcare system, interviews were conducted with the relevant participants, with written records made of the discussions. In the interviews, the following themes emerged as the main reasons why they avoided going to the hospital or clinic:

1. Language barriers: Their lack of knowledge of Turkish presents serious communication problems and also explains why they were not aware of their right to free health care as refugees. One of the 45 refugees who complained about access to healthcare stated: *"If we do not speak Turkish or English we have to communicate through an interpreter. But it always seems as though something is missing from the translation. We feel that we cannot express ourselves very well, nor make ourselves understood."*

2. Concerns related to refugee status: As one refugee noted: *"We do not feel safe due to our refugee status, which is only granted temporarily. We would like the UNHCR to help us get to the EU, USA, or Canada, where we want to live as citizens."*

3. Fear of police investigation: One of the refugee families stated that they hid crimes involving weapons/knife injuries, underage pregnancy, rape, suicide attempts, domestic violence, and/or drug use. *"We fled from war, oppression, and poverty, but still could not achieve the conditions we desired. After escaping, new troubles appeared, and we are still worried about our future. This situation has also triggered some domestic problems in the family. For this reason, we have had health problems, but we do not want to lose our refugee status, so we feel as though we should hide our health problems, even various injuries, sexual assaults, or suicide attempts."*

4. Anxiety concerning future immigration to western countries: Almost all of the refugees inquired as to when they would be able to move to the EU, USA, or Canada. They discussed their own efforts to do so and the obstacles they faced and requested that the researchers help them in this regard, in particular, to contact UNHCR authorities. *"Turkey is good for a short time, but we want to go to the EU or Canada. In fact, we have relatives in these countries, we want to live together with them. Please convey this to the authorities."*

Despite our questions concerning democracy, women's rights, and human rights, most of the participants did not discuss these issues; only two of the refugee families broached these topics. One Afghan woman said, *"We escaped from the Taliban because the Taliban prevent women from working. I am a TV programmer, but the Taliban did not allow this and also forced us to wear burqas; covering our hair is not enough for them."* One Iranian family also stated that they fled for political reasons. However, the participants' major concerns all involved the four items above (language barriers, refugee status, fear of police, and future immigration prospects). This may be due to the urgency of these problems or because they have not yet thought about democracy, women's rights, patient rights, and/or human rights, even within the context of their own lives. A separate study to explore this in more detail could prove fruitful for understanding the apparent lack of interest in democracy and human rights on the part of MENA refugees.

Decision-making in terms of autonomy and informed consent: The study data concerning autonomous decision-making on the part of patients are presented in Table 2. In reviewing these responses, some common attitudes among the participants emerged. For example, large numbers stated that they were either not aware of or unsure of patient rights (49.8% and 32.5%, respectively), and a majority reported no knowledge of autonomy-based informed consent (63.3%). A plurality (42.6%) stated that their doctor should decide their treatment, with (33.1%) preferring to make such decisions themselves, and (22.0%) deferring to the male head of the family (Table 2).

3. Informed consent questionnaire:

The responses to the informed consent questionnaires provided further information regarding the views of both the male and female participants (Table 3). Overall, males were accepted as leaders and therefore as primary decision-makers. However, the feedback given in response to the below eight statements indicated that women also desired to be involved in the decision-making process as individuals.

The participants' statements contained in the informed consent questionnaire were as follows:

Table 3. Knowledge of and views on informed consent according to gender

1. "I appreciate the doctors' positive and friendly demeanor." While the male participants stated that positive behavior on the part of healthcare professionals was definitely important (35.6%), this rate was higher for women (42.4%); the difference was significant ($p < .05$).
2. "I would like my doctor to tell me all about my illness". Less than half (43.4%) of the male participants indicated that this was definitely important, while the rate for women was over half (54.2%) ($p < .01$).
3. "I would like to learn about all available treatments related to my condition." Less than half (46.6%) of the male participants declared this to be definitely important, while nearly three-quarters of the women did (74.2%) ($p < .05$).
4. "I would like to decide on my treatment myself." There was a significant difference between female (36.1%) and male (40.0%) participants with respect to this statement ($p < .05$). The majority of participants of both genders preferred to decide on treatment together with their doctors.
5. "I would like to know all the risks and benefits associated with the proposed treatment." Women (41.5%) stressed the importance of being aware of all the potential risks and benefits of treatment more than men (34.8%) ($p < .01$).
6. "I would like to know all about the treatment." There was a significant difference between men (36.1%) and women (40.0%) with respect to agreement with this statement, the latter being more curious than the former ($p < .05$).
7. "I would like the doctor to first inform me about my disease, before informing my family." There was no significant difference between the responses of male (44.9%) and female (44.7%) participants.
8. "The doctor should not inform my family about my condition without my permission." A lower percentage of men (28.2%) than women (34.8%) agreed with this statement. The χ^2 independence test determined that the difference between the genders was statistically significant ($p < .01$).

Table 4. Cronbach's alpha test results to determine the internal consistency of informed consent questions

Medical Ethics Questions	Definitely important		Very important		Moderately important		Somewhat important		Not at all important		Cronbach's Alpha
	N	%	N	%	N	%	N	%	N	%	
Q1	480	78.7	60 9.8		46	7.5	23	3.8	1	0.2	.698
Q2	518	84.9	39 6.4		30	4.9	17	2.8	5	0.8	.706
Q3	467	76.6	57 9.3		45	7.4	38	6.2	3	0.5	.658
Q4	382	62.6	48 7.9		65	10.7	114	18.7	1	0.2	.699
Q5	466	76.4	36 5.9		33	5.4	73	12.0	2	0.3	.684
Q6	479	78.5	35 5.7		28	4.6	67	11.0	1	0.2	.677
Q7	418	68.5	57 9.3		92	25.2	38	6.2	5	0.8	.679
Q8	383	62.8	53 8.7		143	23.4	25	4.1	6	1.0	.702

Cronbach's Alpha Based on Standardized Items: .72 N=610

Discussion

This study was conducted to investigate the differences with respect to informed consent between the attitudes of refugees and those of secular democratic countries where the principle of autonomy is central to medical ethics. Democratic ideals, based on individual liberty, hold that informed consent patient is a natural right, which in secular countries, including Turkey, is enshrined in law as well as in regulations concerning medical ethics; it is considered a basic human right that cannot be violated regardless of beliefs or traditions. However, MENA countries ruled by authoritarian regimes and steeped in patriarchal ideology value the rights of males, not human rights. In these countries, gender discrimination in practice often takes the form of a "collectivist" decision-making model, in which women are not granted the right to make decisions themselves regarding their own lives.

The most significant finding of the present study was the unfamiliarity of most of the participants with informed consent and the principle of autonomy in medical ethics. The refugees participating in this study expressed overall satisfaction with the health care and medical transport services provided free of charge to refugees in Turkey, although the language barrier was still an issue. However, they also communicated a concern related to their refugee status, namely that they would sometimes refuse to go to the hospital following injuries from fights, fearing that they might be deported as a result of police investigation into the incident.

Regarding the lack of awareness of informed consent on the part of the majority of the refugees participating in this study, the main reason for this most likely is the fact that their countries of origin have different approaches to the concept of human rights in patient care. Patriarchal-authoritarian societies often eschew the autonomy-based ethic of informed consent, instead relying on a “collectivist” model of decision-making that incorporates gender discrimination. According to the study participants, the question of whether to migrate was most often decided by the male head of the household (61.0%), versus decisions made jointly by family members (39.0%) (Table 2). This finding is consistent with the literature, where previous studies have reported significant gender gaps in MENA countries with respect to autonomy and decision-making [14, 15].

Although the traditional views held by most of the refugees participating in this study may conflict with those prevalent in the secular and democratic western countries that the overwhelming majority (97.4%; see Table 1) aspired to settle in, our findings indicated that the participants generally embrace democratic practices and human rights. For this reason, attending classes on human rights for patients would increase their awareness and understanding of the importance of autonomy in health care and its implementation in real-life situations. Policies concerning refugees should emphasize autonomy and informed consent in patient care, as part of the effort to strengthen democratic attitudes and practices in refugees from MENA countries where traditional patriarchal and authoritarian institutions have long been dominant.

Biomedical ethical principles may help to resolve certain contradictions between the host country’s approach to human rights and the current attitudes of refugees reflecting more traditional belief systems. Training should incorporate information on human rights in patient care and explain the concepts of discrimination, stigmatization, humiliation, and gender and racial biases as they pertain to health care. Because the practice of medicine includes not only diagnosis but interventions that may involve serious risks, the patient and doctor must agree on a treatment plan after having weighed all the potential negative consequences. A patient’s refusal or acceptance of treatment is a decision that carries risk but is nonetheless directly related to the individual’s fundamental right to life and health. Patient rights are encoded in law in western countries, and violations of those rights are penalized through the legal system. In Turkey, violations of patient rights are evaluated according to Articles 40 and 47 of the Constitution, Articles 129 and 13 of the Civil Servants Law (No. 657), and other legislation [13]. In addition, autonomy-based informed consent is supported by international ethical declarations such as the World Medical Association Declaration of Lisbon on the Rights of the Patient (1981), the European

Consultation on the Rights of Patients (Amsterdam 1994), Universal Declaration on Bioethics and Human Rights (2005), and the Declaration of Patient's Rights and Duty (2015).

In addition to the task of correctly diagnosing their patients' conditions, physicians should be aware of the social and cultural as well as biological factors that may affect their patients' health, especially those pertaining to gender [16, 17]. A plurality of the participants in this study stated a preference to follow their doctors' advice regarding treatment (42.6%), whereas 22.0% would accept the decision of the male head of the household, while 33.1% would prefer to decide themselves (Table 3). These results reflect their respect for traditional patriarchal authority dominant in their countries of origin and are also reflected in the data on the participants' awareness of informed consent. However, physicians do not possess the authority to make treatment decisions for their patients, either legally or with respect to medical ethics; therefore, the patient must take an active role in the decision-making process.

Based on the responses to the eight questions on informed consent, women were more supportive of and satisfied with the informed consent process than men and also wanted to make medical decisions for themselves (Table 3). This result indicates that even in the presence of a patriarchal family structure, women display a more positive attitude towards autonomous decision-making and informed consent.

The present study found that refugees still retain many of the restrictive traditional attitudes of their homelands even after years in their (less traditional, more democratic) host countries. However, the participants also expressed support for informed consent in both theory and practice. Both women and men tended to accept the doctor as a medical authority, consenting to their doctor's advice, rather than taking any initiative or responsibility for decision-making regarding their treatment. However, the number of men and women who hold such traditional attitudes appears to be declining, as the number who prefer to decide for themselves is not very low. For this reason, we suggest offering refugees courses on medical ethics and human rights in patient care, to foster the development of democratic attitudes in line with the principle of autonomy in health care. Such a program could be expanded to other countries with significant numbers of MENA refugees as well.

Limitations

Although the present study aimed for a representative sample of refugees from three major Turkish cities (Adana, Konya, and Istanbul), we faced a number of limitations, including time constraints, the number of refugees available/willing to participate, and recruitment challenges, such that their perspectives may not reflect those of all MENA refugees in Turkey. As the registration system for studies involving refugees entailed numerous procedures and permission from several government agencies, the entire process took a long time, and most requests for permission were rejected by the authorities. Therefore, a random sampling method was employed to maximize access to potential participants. Since we could not equalize the number of refugees according to country of birth, no comparisons were made in terms of their homelands. Nonetheless, we hope that this study constitutes a useful basis and reference for future research concerning refugees and issues of medical ethics.

Conclusion

The participants in this study, all refugees from MENA countries, were found to have limited awareness of fundamental human rights, an unsurprising result given their minimal exposure to democratic institutions. Most participants still expressed religious-based patriarchal views regarding women and were not familiar with the concepts of autonomy and informed consent in decision-making, which are vital components of human rights-based democracy. Therefore, the majority did not indicate a preference for autonomous decision-making concerning health care. The principles of autonomy and informed consent dictate that individuals of both genders make decisions affecting their own lives, thus taking responsibility for their own lives. Maintaining consistency on the issue of autonomy in health care, and not abandoning it temporarily to satisfy those adhering to traditional belief systems, ensures that national and international ethical codes and legal regulations will not be violated. Ideally, this recognition of individual rights will also strengthen democratic viewpoints among refugees from more traditional/patriarchal societies, as they eventually experience the benefits conferred by patient rights (specifically autonomy-based informed consent). Offering courses on human rights in health care to refugees should significantly contribute to their understanding of social justice and human rights in general.

Declarations

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Availability of data and materials: Data analyzed in this study were collected by the author who was identified with a numerical code to ensure their anonymity in the study. Therefore those checklists cannot be shared publicly, although they are in the main researcher's possession at the University. The datasets used and/or analyzed during the current study available from the corresponding author on reasonable request. All data generated or analyzed during this study are included in this published article.

Author contributions: The author had the initial ideas for the paper and prepared a plan and then collected data and finally written this article.

Consent for publication: Not applicable in this section.

Ethics approval and consent to participate: Research was conducted in compliance with the Helsinki Declaration and approved by the Ethics Committee of Clinical Research of the reference Van Yüzüncü Yıl University (institutional review board no. 14, dated 25/12/2020). All participants were adults and signed

an informed consent form with a confidentiality agreement. Also if the subjects are under 18, a parent and/or legal guardian signed an informed consent form for ethical approval.

Competing interests: The author declare that they have no competing interests.

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Figures

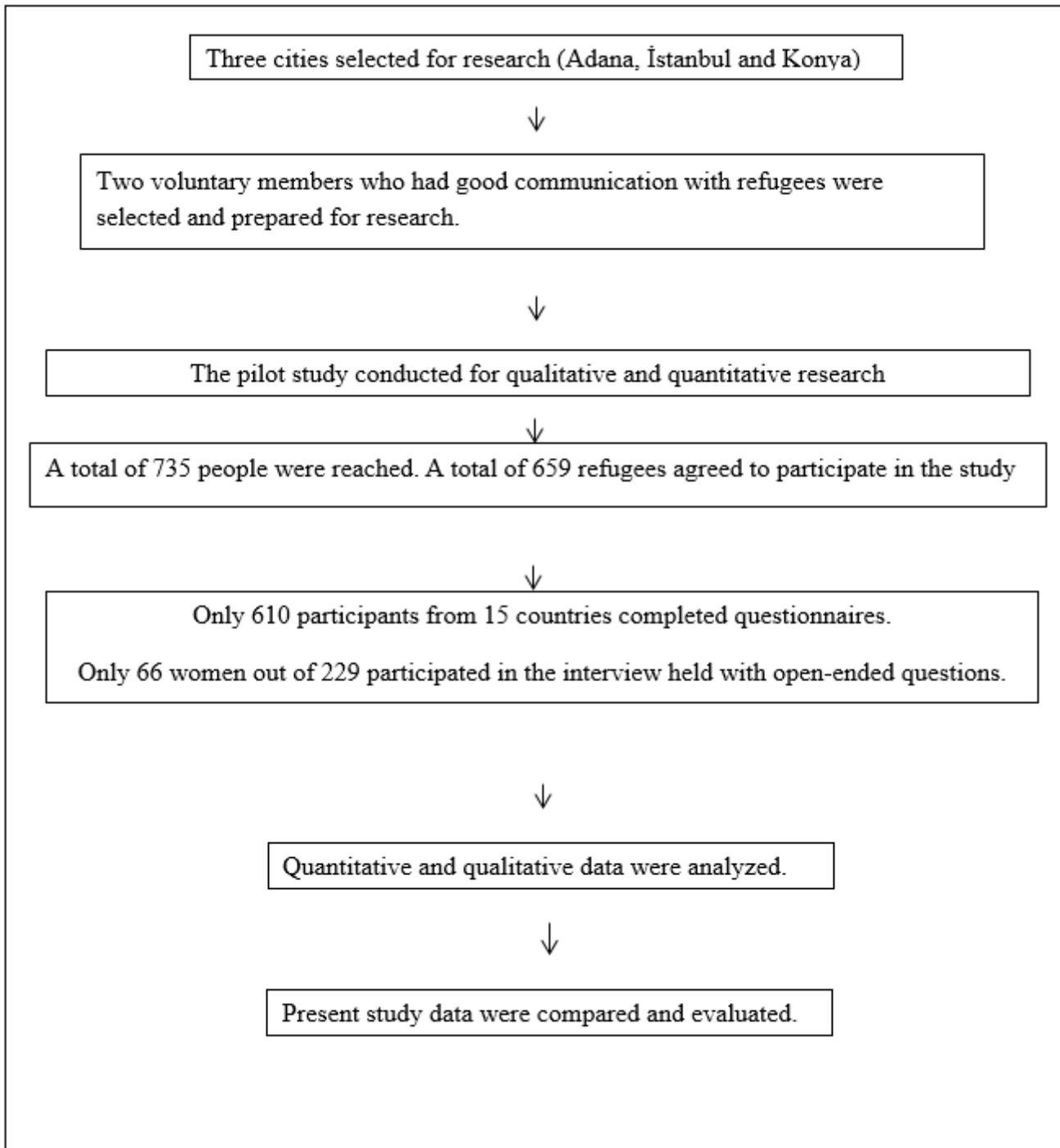


Figure 1

Study flow chart