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### **ARTICLE IN PRESS**



### 'I Prefer To Die at Home With Dignity': Perceptions of Death Rituals Among Religious Muslim Kidney and Liver Transplant Patients With COVID-19

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#### **ABSTRACT**

Background. Kidney and liver transplant recipients may be at a high risk of contracting acute COVID-19 due to chronic immunosuppression and comorbidities. These patients receive combinations of immunosuppressive drugs, altering their innate and adaptive immunity, thus, rendering them more susceptible to bacterial and viral infections and higher mortality. Kidney and liver transplant recipients frequently exhibit one or several risk factors, increasing the risk for unfavorable outcomes.

Methods. This qualitative study explores perceptions of religious rituals and practices relating to COVID-19 deaths among Muslim kidney and liver transplant recipients during the first, second, third, and fourth waves, focusing on their tendency to unlawfully refuse to be hospitalized due to their objection to certain guidelines that prevent or restrict religious practices and traditions. A qualitative study based on interviews with 35 older, religious Muslim liver and kidney transplant recipients was conducted face-to-face and on Zoom.

Results. Our findings indicated the absence of acceptable and respectful death rites for the deceased in the event of death from COVID-19, spurring the refusal of older, religious Muslim transplant recipients in Israel to be hospitalized after contracting COVID-19.

Conclusions. To address these concerns, health authorities and religious leaders must collaborate to find solutions that satisfy the requirements of both the health system and the religious Muslim community.

THE outbreak of the COVID-19 pandemic throughout the world posed a special threat to immunosuppressed patients. Although data has accumulated over the years regarding this virus, there is still much uncertainty, particularly regarding kidney and liver transplant recipients [1]. Due to the lack of knowledge of medical and nursing personnel during the first waves of the pandemic, COVID-19 took an especially high toll on older patients and patients suffering from chronic diseases and obesity [2]. Solid organ transplant patients, including kidney transplant recipients, were vulnerable to long-term complications from COVID-19 due to their chronic immunosuppressive medications and comorbidities (eg, diabetes, cardiovascular diseases, and hypertension) [3].

Kremer et al [4] conducted a systematic review and metaanalysis of 5559 kidney transplant patients ill with COVID-19 and found a 23% risk of death unrelated to sex, age, and comorbidities. Phanish et al [5] compared the health outcomes of kidney transplant recipients suffering from COVID-19 with dialysis and waitlisted patients. The authors found a much lower proportion of transplant recipients infected with COVID-19 than dialysis and waitlisted patients and a comparable mortality rate

COVID-19 presented health care providers with unprecedented dilemmas. New challenges arose with uncertainty and isolation, with patients dying unattended in hospitals, hospices, and other health facilities with family members unable to say

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1

Table 1. Official Recommendations for COVID-19 Treatment in Hospitals in Israel

Recommendation	Details
Isolation of patients	All confirmed or suspected patients with COVID-19 should be isolated in designated areas of the hospital to prevent spread of infection to other patients and staff
Use of PPE	Health care workers should wear appropriate PPE, including masks, gloves, and gowns, when in contact with COVID-19 patients
Supportive care	Patients should receive supportive care, such as oxygen therapy as needed, to manage symptoms and maintain vital organ function
Antiviral treatment	Antiviral treatment, such as remdesivir, may be considered for severe cases of COVID-19 requiring hospitalization
Corticosteroids	Corticosteroids, such as dexamethasone, may be used for hospitalized patients requiring supplemental oxygen or mechanical ventilation
Convalescent plasma	Convalescent plasma therapy may be considered for hospitalized patients with severe or life- threatening COVID-19
Prophylactic anticoagulation	Hospitalized patients should receive prophylactic anticoagulation to prevent blood clots, a common complication of COVID-19

These recommendations may vary based on the severity of the patient's illness, individual medical history, and other factors. Source: Director of Public Health Services, Israel Ministry of Health <a href="https://corona.health.gov.il">https://corona.health.gov.il</a> [55].

goodbye, which affected their experiences of death and bereavement [6–8]. Moreover, restrictions necessitating lockdowns and social distancing impeded the bereavement process. Table 1 summarizes the Israeli Health Ministry's recommendations for treating Covid 19 in hospitals in Israel.

These restrictions generated emotional and social disconnectedness, which led to unprocessed sorrow and regret, resulting in disenfranchised grief [6,9]. Disenfranchised grief is a process in which loss is experienced but not openly acknowledged, socially validated, or publicly mourned [9]. This creates problems in emotional processing and expressions of sorrow, with a loss of social support and compassion, challenging the ability to cope with the loss of life [10]. All persons who encounter restrictions to their traditional practices feel increased distress related to their loss and death in the context of COVID-19, both individual and societal [6].

The Islamic background illustrates this complication. In the Islamic religion, death is seen as a natural part of the ephemeral human experience with deep meaning and implications regarding how Muslim believers live their lives. When dealing with death, the Holy Qur'an states, "... do not call on any other God apart from God. There is no God but Him. All things will perish, save His magnificence. He is the judgment, and to Him will you be brought back in the end" (Holy Qur'an; 28:88) [11,12].

Although religious beliefs and rituals are personal, they entail societal and religious traditions and institutions [13]. When COVID-19 guidelines conflict with religious beliefs and the death rituals of believers, religious people may resist hospitalization in cases of severe COVID-19 [14,15]. Their responses to loss and death may be affected by the sociocultural environment in processing their loss [6,15]. Death is a profoundly social experience replete with cultural beliefs, language, norms, and worldviews involving interaction with others. Previous studies have explored the effects of death from COVID-19 on the grieving process of religious people of different faiths and cultures [16–18]. Preventing the collective rituals crucial to

process grief damages the deep human connection that offers support, comfort, and consolation during overwhelming sadness and vulnerability.

The current qualitative study examines the perceptions of death and bereavement rituals among older, religious Muslims who are kidney and liver transplant recipients living in Israel and who contracted COVID-19. The restrictions that prohibited family and friends from gathering for the burial rituals and funerals (*Janazah*), and the ensuing gatherings for mourning and collective prayer, including the closing of mosques, intensified the sense of loss experienced by the Muslim community [19].

The hospital experience was characterized by social isolation compounded by the unpredictable and often rapid decline in the patient's respiratory functioning, meaning many individuals died alone. Hospital chaplains and imams who usually provide spiritual support to dying patients and their families were limited in their access due to the virus. Muslim family members experienced great distress at being forced to stay away from the bedside of their loved ones during their last days of life and not allowed to perform the religious rites and rituals usually administered before death (ie, reciting from the Qur'an and offering encouraging final words) [20].

These dilemmas encouraged some families to initially keep patients afflicted with COVID-19 at home rather than seeking hospital care. Such a decision naturally created challenges because only a few families have had experience in caring for dying patients. There were accusations of being irresponsible or negligent for not seeking hospital-based treatment and fears about using pain-alleviating medication to relieve distress, including concerns of oversedation and a hastening of death [21]. Notwithstanding these and other considerations, Muslim ethnic minority communities tended to avail themselves less frequently of end-of-life care support from hospice facilities and expressed less satisfaction with the support provided [22,23].

PPE, personal protective equipment.

## PERCEPTIONS OF ILLNESS AND DEATH AMONG MUSLIMS

In Islam, the life of the individual and society is governed by the Qur'an and Islamic law precepts, directing every aspect of human life, decisions, and obligations, including how to respond to illnesses and diseases such as COVID-19 [24]. Islamic laws reflect 5 primary aims: to protect life, to safeguard freedom of thought, to preserve the intellect, to preserve human honor and integrity, and to protect property [25]. The Qur'an promotes well-being and governs conduct by laws forbidding a harmful way of life and behavior, with an emphasis on a lifestyle that promotes well-being (eg, moderate eating; abstention from liquor, tobacco, and other psychoactive substances; daily exercise; prayer; fasting; personal hygiene; breastfeeding, etc) [26,27]. Islam teaches that everything that occurs is from God; thus, serious illness, miscarriage, and death are seen as God's will. Death is regarded as a cleansing encounter rather than a sign of God's wrath [26]. Consequently, Muslims believe adherence to Islamic teachings and the Prophet Mohammed's recommendations are the only ways to survive the COVID-19 pandemic.

Islam implemented a series of health guidelines to prevent infection during an epidemic that included the following: 1) maintaining regular prayer; 2) obeying quarantine rules and avoiding crowded places; 3) maintaining body hygiene, clothes, and environment, including regular washing of hands with soap and water; and 4) avoiding contact with people who are ill or suspected of being ill [28]. Table 2 presents Sharia recommendations for COVID-19 prevention, treatment, and hygiene measures in Israel.

During the pandemic, unlike Islamic principles to accept health guidelines to reduce the risk of infection (ie, reciting individual prayers rather than praying collectively in mosques), no appropriate recommendations were made regarding religious death rituals [29]. The rituals accompanying the end of life remain the most profound and significant in the life cycle,

whereas death by COVID-19 deprives the living of saying goodbye or grieving in traditional ways [30].

According to Hasan et al [31], religious Muslims believe that the pandemic is God's will and, thus, do not accept responsibility for taking measures to contain it. Some believe COVID-19 is God's punishment for sinners and evildoers; thus, believers and pious worshipers will be protected. Others believe COVID-19 can be avoided by living healthy lifestyles, conscientiously reading the Qur'an, and praying together in mosques. If one contracts the disease, they must accept their fate as the will of God. Although the individual may consult with doctors and seek treatment, they are not convinced that medical efforts will cure them. Often, they blame themselves for what they see as punishment for the sins they have committed, whereas others perceive COVID-19 as a natural phenomenon and find no link between the pandemic and religion.

Since the outbreak of the COVID-19 pandemic in 2020, the Muslim community and other religious communities have been compelled by various government guidelines to modify certain religious rituals that appear to them as allowing leniency in worship. Some Muslim religious leaders encouraged believers to pray at home rather than in the mosque to comply with social distancing guidelines that could help contain the virus [32,33]. There are no definite answers in the Qur'an and the Sunnah for these issues that have emerged in modern times [27]. Extensive research has been conducted on physical distancing within religious minorities [34]; however, there is scarce literature dealing with one of the prominent issues discussed during the COVID-19 pandemic, namely, Muslim death rituals [13,15].

#### PATIENT-CENTERED CARE

Patient-centered care (PCC), a preferred approach in health care [35], is associated with a higher quality of care, patient safety, improved clinical outcomes, greater patient satisfaction, higher

Table 2. Sharia Recommendations for COVID-19 Prevention, Treatment, and Hygiene Measures in Israel

Recommendation	Prevention	Treatment	Hygiene Measures
Washing hands frequently	Recommended	-	Encouraged, especially before eating or touching one's face
Wearing a mask in public	Required	-	Encouraged
Social distancing	Recommended	-	Encouraged
Avoiding nonessential travel	Recommended	-	-
Quarantine for infected individuals	Required	-	-
Using honey and black seed oil	Encouraged	May have some benefits according to Islamic traditional medicine	-
Performing ablution (wudu) regularly	Encouraged	-	-
Avoiding close physical contact (hugging, shaking hands, etc)	Recommended	-	Encouraged
Avoiding large gatherings (such as prayer in mosques)	Required	-	Encouraged to pray at home
Seeking medical treatment when necessary	Encouraged	Encouraged	-

These recommendations may vary depending on the interpretation of Islamic scholars and the specific context of the community in question. Source: Director of Public Health Services, Israel Ministry of Health. https://corona.health.gov.il [55].

Table 3. Demographic Characteristics of Participants

No.	Age (y)	Sex	Marital Status	Kidney vs Liver Transplanted Organ	Level of Religiosity (Islam)	Years of Education	Number of Children
1	73	Male	Married	Liver	Religious	7	10
2	88	Male	Married	Liver	Religious	5	12
3	85	Male	Married	Liver	Religious	6	10
4	87	Male	Married	Liver	Religious	5	9
5	85	Male	Widow	Liver	Religious	6	11
6	80	Male	Remarried	Liver	Religious	5	18
7	88	Male	Remarried	Kidney	Religious	6	17
8	84	Male	Remarried	Kidney	Religious	3	16
9	80	Male	Married	Kidney	Religious	5	10
10	81	Male	Widower	Kidney	Religious	5	10
11	84	Male	Widower	Kidney	Religious	6	11
12	84	Male	Married	Kidney	Religious	5	12
13	83	Male	Married	Kidney	Religious	5	10
14	83	Male	Married	Kidney	Religious	7	13
15	80	Male	Married	Kidney	Religious	4	12
16	78	Male	Married	Kidney	Traditional/Religious	3	13
17	76	Male	Married	Kidney	Religious	5	14
18	79	Female	Remarried	Kidney	Religious	6	16
19	82	Male	Widower	Kidney	Religious	8	12
20	77	Female	Widow	Kidney	Religious	6	13
21	76	Male	Married	Kidney	Religious	6	11
22	80	Male	Married	Kidney	Religious	6	10
23	75	Male	Married	Kidney	Religious	3	10
24	77	Male	Married	Kidney	Religious	5	10
25	75	Male	Married	Kidney	Religious	6	13
26	73	Male	Married	Kidney	Religious	6	14
27	83	Male	Remarried	Kidney	Religious	8	18
28	83	Male	Remarried	Kidney	Religious	8	16
29	80	Female	Married	Kidney	Religious	5	14
30	80	Female	Married	Kidney	Religious	6	11
31	86	Female	Married	Kidney	Traditional/Religious	4	13
32	89	Male	Widower	Kidney	Religious	6	12
33	83	Male	Remarried	Kidney	Religious	7	19
34	84	Male	Remarried	Kidney	Religious	6	20
35	85	Male	Remarried	Kidney	Religious	6	20

quality of life and well-being, and less patient suffering [36,37]. Whereas the biomedical model focuses on the patient's physical COVID-19 symptoms, the PCC model concentrates on understanding the patient as an individual and their perceptions, expectations, feelings, and concerns [38]. Patient-centered care was developed out of a recognition of the limitations of the traditional "biomedical model" [39] and acknowledges the patient's psychological and social needs, and respects cultural values, beliefs, and choices [40]. Patient-centered care advocates flexible health care, emphasizing integrated, patient-tailored care aimed at meeting the needs of the patient rather than of the institution [41]. This approach is highly responsive to patient beliefs and preferences, using the patient's informed wishes to guide end-of-life activity [36,37].

Herein, we examine the following research questions: 1) What are the main factors causing the conflicts concerning medical care in elderly, religious liver and kidney transplant recipients who are Muslims living in Israel, in cases involving COVID-19?; and 2) What is the communal experience surrounding death from COVID-19 among older Muslim kidney and liver transplant recipients?

#### MATERIALS AND METHODS

To answer these questions, a qualitative paradigm was selected to holistically understand the phenomena by examining experiences, worldviews, and subjective meanings influenced by the participants' subjective interpretations [42].

#### **Participants**

The study participants were 35 older, religious Muslims aged 74 to 89 (average 81.3 years) who were kidney and liver transplant recipients. The participants were sampled from 7 Arab villages in Israel [1]; 32 men (6 liver transplant recipients and 26 kidney transplant recipients) and 3 women (kidney transplant recipients). The family sizes of the participants ranged from 10 to 20 people, with an average of 5.6 years of formal education and an average of 13.14 children (Table 3).

#### **Data Collection Instruments and Procedures**

Based on our experiences interviewing individuals residing in traditional Muslim communities, we considered the importance of approval from Islamic religious leaders. Moreover, we considered the unique aspects of the Islamic culture in creating the design, sampling, data collection, and the values of modesty, codes of speech, and the need for support from the Muslim religious leaders.

Initially, we asked for the imam's endorsement to facilitate the religious Muslims to agree to participate in the study. We explained the purpose of the study and asked for their help in circulating an invitation in their community to explore the community's willingness to participate in a study reporting on the refusal of religious Muslims who had contracted COVID-19 to be hospitalized due to religious reasons.

The imam contacted several moderators from the community who spoke to potential participants. Those interested in participating informed the moderators, who subsequently sent their contact information to the first author, a secular Muslim. The first author then telephoned each participant, explaining the purpose of the study, scheduled an in-depth interview via Zoom, and sent the participants an informed consent form using What-sApp. Participants were requested to sign the form with the help of a family member and email it back to the researcher, as well as to seek necessary help in activating the Zoom platform for the interview.

The interview opened with greetings and wishes for good health. The first author explained the study's goal, promised confidentiality and anonymity, asked for the participant's permission to record the interview, and asked whether the participants were still willing to participate. The interview on Zoom began with a few minutes of casual conversation to help break the ice and lasted approximately 60 minutes. The study participants were asked to describe their thoughts regarding the refusal of Muslims to be hospitalized in cases of serious illness (ie, a COVID-19 infection). The first author maintained a pleasant atmosphere, sought to avoid verbal or nonverbal judgment, and recorded the interviews, which were then transcribed. Each participant was assigned a code to preserve their anonymity.

#### Data Analysis

A thematic analysis was performed, namely, a qualitative method suitable to our epistemology, using the research questions to identify, analyze, organize, describe, and report the patterns that could be identified from the emerging data [43,44]. Thematic analysis is effective for exploring the participants' perspectives, highlighting their similarities, and generating unanticipated insights [43]. We aimed to crystallize the thoughts of participants as to the conflict with Muslim death rituals caused by hospital guidelines during COVID-19. We examined the data and generated an initial code [44]. Themes are units derived from patterns, such as recurring meanings, feelings, and perceptions [45]. We searched and reviewed the themes. The data analysis process, which is iterative, reflective, and developed over time, involves constantly moving back and forward between analysis phases.

We identified themes and patterns of perceptions from the data using 6 analytical steps: 1) reading and re-reading the interviews, listing patterns of perceptions of clashes between death from COVID-19 and traditional rituals underlying the refusal to be hospitalized; 2) identifying all data that related to the patterns already classified; 3) placing all data regarding a specific pattern with the corresponding pattern; 4) combining related patterns and categorizing them into subthemes to obtain a comprehensive view of the patterns that emerged regarding perceptions of death from COVID-19 vis-à-vis traditional rituals; 5) compiling themes to form a comprehensive picture representing the participants' viewpoints [44]; 6) by using the PCC theory and disenfranchised grief as a conceptual framework, gathering information that allowed us to extract inferences from the interviews as to how the deaths from COVID-19 caused conflicts with traditional death rituals and communal processes of grief as perceived by the interviewees.

We identified the links between the themes and produced a list of themes that captured the participants' main concerns. We marked elements and themes derived from patterns, such as recurring meanings and feelings [44], and created themes to form a comprehensive picture representing the participants' interpretation of death and grief from COVID-19. Certain unanticipated themes emerged, revealing a more in-depth understanding of the perceived reality among the participants during the pandemic.

The unstructured interviews were based on the interviewee's subjective, spontaneous responses to the questions without imposing any prior categorization that might restrict the field of inquiry [46]. Following data analysis, a translation was prepared from Arabic to Hebrew and English. To ensure reliability, each author separately conducted the data analysis of the interviews, and then they reviewed the themes and patterns together [47]. In cases of disagreement, the authors reviewed the data until a consensus was reached.

Three contexts were considered: broad, micro, and immediate. The broad context was the political tension between the Muslim minority and the government. The microcontext was the high infection and mortality rates among the Muslim minority. The immediate context was the "here and now," which may have also affected the interview content, particularly the neutral academic identity of the interviewer and his being Muslim. It should be noted that the participants' responses represented their lived experiences during the pandemic and reflected what they had seen and heard in their close environment and from reports in the media.

#### Ethical Approval

The ethics committee at the academic institution with which the first author is affiliated granted ethical approval for this study (IRB #1042). Participants signed an informed consent form to participate and for the publication of the manuscript. To protect anonymity and confidentiality, demographic data were presented only at the group level [48].

#### **RESULTS**

We present the point of view of older, religious Muslims afflicted with COVID-19 who were liver or kidney transplant recipients as to the practices of Islamic death rituals prevented by hospital guidelines during the first, second, third, and fourth waves of the pandemic. All participants were greatly saddened by the hospitalization of friends and relatives due to COVID-19 and their deaths. In these cases, their family members could neither visit due to the fear of infection nor perform religious rituals after death. Four central themes emerged from the qualitative analysis: the physical aspect of the purification ceremony, the spiritual aspects of the purification, the shrouding of the body, and a desire for a dignified funeral and burial.

#### Physical Aspect of the Purification Ceremony

Many research participants perceived the absence of the deceased's purification ceremony as a calamity that delayed their meeting with God. According to Islamic Sharia, purifying the dead is carried out after the body is released from the hospital and returned home. According to this process, the body must be washed by a Muslim who guides the process, with only men washing a man's body and only women washing a woman's

body. Some of the participants expressed concern about the purification process that was carried out in the hospital by people who did not comply with Sharia laws, as observed by an older kidney recipient (83 years old) who refused to be hospitalized due to his feelings of distress at the treatment of the deceased: "Due to the corona epidemic, the process of treating the deceased is carried out by people who are not qualified to purify the dead according to the Islamic Sharia. [...] Who knows who does the purification in the hospital, Muslim, Christian, Druze, or Jew? The purification should be done only by Muslims who pray and believe and are aware and recognize the Islamic Sharia, so we prefer to die at home." Another older kidney transplant recipient, aged 79, emphasized his preference to die at home with dignity and undergo a purification ceremony performed for him rather than in the COVID ward. He perceived this lack of knowledge on the part of the hospital as disrespect for the older patients due to age and background illnesses: "I prefer to die at home, to reach God as clean and pure from sins as the day I was born. The process of washing and drying the deceased should only be done by the imam and the family. Nothing assures me that the people caring for the deceased's body in the hospital are pure, religious, and say prayers."

An 85-year-old female kidney recipient feared hospitalization after contracting COVID-19, saying, "If I arrived at the hospital, they would not look at me at all because of my age and underlying illnesses." She described the disrespect shown toward the dead in the hospital and the blood-filled environment where the dead are kept. "In the hospital, there is no time for pure ritual; everything is performed under pressure because the staff needs the bed for another patient. There is no hot water to purify the body, and the whole process is not done properly. It is not performed as at home, in a clean area where incantations are recited over the dead from the Qur'an. In the hospital, nothing is done like this; it is desecrating the body."

#### Spiritual Aspects of Purification

In addition to the physical aspect of the purification ceremony, we found that the participants referred to the spiritual aspects. An 80-year-old transplant recipient said: "In Islam when the patient is dying, his family and the imam read verses from the Qur'an and remind him before he dies to raise the finger of his right hand to say the 'Shahada.' Anyone who says the 'Shahadah' correctly is guaranteed a place in heaven. These are the last words of any Muslim before his death." Another 83-year-old liver recipient explained the essence and importance of the "Shahadah" ceremony and his fear of dying without this last declaration of faith: "I don't want to go to a hospital because the patients are not reminded to say the Shahada ... When the patient is dying, it may be difficult for him and then the family or a religious cleric must remind him to say the Shahada."

#### The Shrouding of the Body

The research participants described the meaning of shrouding the body after death as part of the religious rituals on the dead body. An 81-year-old liver transplant recipient who had waited

10 years to receive a liver transplant stated: "In Islam, after death, men are wrapped in 3 sheets of cloth, identical to the Prophet Muhammad's wrapping after his death. Women are wrapped in 5 sheets of cloth for modesty. It is disgusting how in the hospital, they wrap the dead in black plastic garbage bags as if they were garbage or people murdered by the mafia, and the plastic bag may tear when the body is lowered into the grave. We are supposed to meet God and the angels naked and pure, with white clothes. I prefer to die in my home amongst my family members so that I can see them during my last moments. I can leave my instructions to them and die in peace."

Another older man, an 84-year-old kidney transplant recipient who refused to go to the hospital, described the treatment of transplant patients as poor and the treatment of the dead as truly shocking: "A deceased Muslim should be wrapped in a white shroud as a symbol of love or a new life in heaven. Man is supposed to return to God as on the day he was born, with his neck, hands, and feet bound as required, but those who die of COVID-19 are buried in a black plastic garbage bag." A 77year-old woman undergoing a kidney transplant with an immune system that makes it difficult for her to get to the hospital for check-ups tells of the poor monitoring of transplant recipients: "I am aware that I will die because of my age and poor immune system, so I prefer dying alongside my family and grandchildren." She described her preparations for death: "I sewed my own shroud with a green pad as a symbol of heaven and made myself a pillow from the hair I saved during combing since I was 12 years old to sleep on in the grave and also the nails I cut all my life to be buried with."

Another 79-year-old about to undergo a kidney transplant stated: "I am in greater danger of my life in the hospital because of the tendency to acquire more infections. I prefer to say goodbye to my family with dignity and be buried in the pure, modest clothes I wore on the pilgrimage to Mecca. If I receive treatment in a hospital, they will bury me in a black bag with bloodstained clothes. This is against the Islamic Sharia. I prefer to obey the laws of God than the laws of the state."

#### Desire for a Dignified Funeral and Burial

Thoughts about the funeral and burial ceremony, according to the Islamic Sharia, played a significant part in the interviews. The participants attached great importance to pay their last respects to the deceased, the prayer that will be said in their honor, and the participation of the family and the community at their funeral. An 84-year-old man stated his desire for a large and dignified funeral: "I want to die with a large funeral procession that gives respect to the deceased. Because of COVID, the entire funeral process is done in an alienated and strange way against the Islamic Sharia."

The participants spoke of funeral practices by relatives and acquaintances and respect for the dead, as reflected by a 79-year-old kidney transplant recipient: "At the funeral ceremony, acquaintances and relatives alternate carrying the coffin on their shoulders to the cemetery. This shows respect for the dead, which every deceased Muslim should have. But when the dead person is a coronavirus patient, the Ministry of Health requires

that he be brought on a stretcher in an ambulance; that is inappropriate and unacceptable for religious Muslims. Every Muslim wants to be prayed for after his death in his home and his mosque. This was not done during COVID-19 when the deceased went from the hospital straight to the cemetery."

Another 85-year-old kidney recipient spoke of the importance of conducting the burial ceremony according to Sharia law: "I am ready and want to die according to Sharia, where they lay me on my right side and direct my face south toward Mecca. Before the funeral, a grave is dug along the path, and on arrival at the cemetery, the coffin is placed on the ground, and confirming that there will be no outbursts of emotions because it is God's will, who forgives sins, especially if the Shahada is said before the soul departs."

The research participants expressed concern and fear over the possibility of a delay in the burial of the deceased due to their hospitalization. An 88-year-old male kidney transplant said: "After purifying the body, the eyes of the deceased should be closed, his body should be washed and perfumed, and his hands and feet should be straightened. Any delay in the treatment of the corpse may cause a bone fracture when the limbs are straightened. It is akin to breaking the bone of the living; this is forbidden and considered abuse of the corpse. Burying the dead quickly proves that he is given the respect he deserves and prevents unnecessary suffering until burial." One 83-year-old kidney transplant recipient described a custom after the burial: "After the deceased is buried, his sons remain by the grave for at least an hour because the angels descend from the sky to the grave and ask him the same questions and answers that the imam mentioned during the "Talqeen" (ie, indoctrination: the process of teaching a person to accept a set of beliefs uncriti-

When hospitalized patients are afflicted with COVID-19, there is no such possibility. Even the farewell kiss of loved ones is not possible.

The interviewees repeatedly emphasized the difficulty of dying without saying goodbye to their family, friends, and community and the importance of religious instruction (Talgeen) at the funeral. A 73-year-old liver recipient explained: "In Islam, the imam asks the funeralgoers to sit down and proceeds to deliver to the deceased the answers to the questions that the angels will ask of him: Who is your Lord? Who is your prophet? What is your religion? And what is your book? He will ask God to forgive the deceased and allow him into heaven. In the hospital, due to the virus, this process does not take place at all, and no last respect is paid to the dead." Another 86-yearold participant expressed his wish to have the Qur'an recited over his body after his death and said: "After my death, I want the imam of the mosque to recite a prayer for me and for my relatives to read the Qur'an during the 3 days of mourning. In the hospital, due to the virus, there will be no one to recite the Qur'an."

In contrast to the respectful ceremony at home, the participants described the distancing guidelines imposed by the Ministry of Health due to the virus. A 77-year-old male liver transplant recipient said: "A ceremony held according to the instructions of the Ministry of Health forbids approaching the

body, with the deceased being buried as soon as possible. The family of the deceased cannot remain near the grave as is customary."

#### DISCUSSION

The COVID-19 pandemic severely changed people's daily lives and social practices, including how people of all religions and nationalities died and grieved for their loved ones. Death and mourning during the COVID-19 pandemic emerged as a new challenge worldwide, altering the traditional ways of carrying out death rituals and practices. Our study findings suggest that the COVID-19 pandemic was devastating because it affected how we die, treat the dead, and grieve. COVID-19 restrictions and social distancing measures meant people died in isolation without allowing their families to say farewell. Religious death rituals and practices were denied to all families to contain the spread of the virus. The usual congregations of mourners were prohibited, thus denying them the traditional farewell, funeral, and solace of being together, forcing the bereaved to mourn alone.

This qualitative study explored death rituals, grief, and bereavement during the pandemic among Israeli, older, religious Muslim liver and lung transplant recipients who refused to seek hospital care during this time. The study links death with PCC, highlighting disenfranchised grief due to the clash of health authority guidelines with religious death practices. We recommend implementing PCC in cases of death from infectious diseases and the cultural perspective to enable a healthy bereavement process.

During the epidemic, a large percentage of older patients died as a result of difficulties in accessing timely quality care. Some kidney and liver transplant recipients were afraid to enter the hospital for fear of contracting COVID-19 and dying. Studies have shown that the percentage of older people who died in the COVID-19 wards was much higher because of overcrowding and staff with less experience treating COVID-19 patients and working during other epidemics [49,50]. The corona restrictions and social distancing guidelines resulted in older patients dying in isolation and not having the opportunity to meet their family members and die with dignity.

The coronavirus added burdens of loneliness and work to the deceased's family. Among Muslims, it is customary that after death, the family members all mourn together while relatives, friends, and neighbors maintain the house during mourning; however, due to the pandemic restrictions, this was prohibited.

## Clashes Between Institutional Regulations and Muslim Death Rituals

Muslim society has a unique culture with long-standing customs, traditions, and values and strong religious beliefs regarding bereavement and mourning [51]. Concern for the honor of the deceased soul, assistance to the bereaved family, community soul-searching and repentance, and rituals involving the active participation of the grieving family and friends help individuals cope with their loss. Moreover, the perception of older patients was that an older person's life is worth less because age shows

Table 4. Instructions for Treatment of a Deceased Person Suspected or Confirmed To Be Infected With COVID-19

Instruction	Details
Wrap the body	The body should be wrapped in a shroud or body bag to prevent exposure to bodily fluids and airborne particles.
Handle and transport by trained personnel wearing PPE	The body should be handled and transported by trained personnel wearing appropriate PPE, including gloves, gowns, masks, and eye protection.
Transport in dedicated vehicle	The body should be transported in a dedicated vehicle to a designated mortuary or cemetery.
Do not perform embalming or other invasive procedures	Embalming or other invasive procedures should not be performed on the body, as these procedures can generate aerosols that may increase the risk of infection.
Limit funerals and other religious rituals	Funerals and other religious rituals should be limited to immediate family members, and attendance should be limited to maintain social distancing and prevent the spread of infectio

It is important to note that these instructions may vary based on the specific context and may be updated as new information becomes available. Source: Israel Ministry of Health https://corona.health.gov.il/en/ [55].

PPE, personal protective equipment.

the cheapness of human life in the eyes of the coronavirus. They felt hospitals invest less effort in treating older people with underlying diseases such as kidney or liver transplantation. Thus, most religious, older Muslims preferred treatment and death at home with dignity.

In Muslim society, according to a 78-old kidney recipient, "the opinion of a cleric prevails over the opinion of the state, the laws of the state, or the Ministry of Health's instructions." Therefore, older patients who received a kidney or liver transplant will refuse to continue treatment in a hospital because they value the opinions of their clergyman, not the instructions of the Ministry of Health or the state, which change periodically. Consequently, older, religious Muslim transplant patients refused to go to a hospital because they believed they might not return home and would not experience a dignified death and funeral rites according to the Islamic Sharia (see Table 4).

Imber-Black reported that death from COVID-19 deprives the deceased of a chance to properly say goodbye and the living of mourning in their traditional ways, thus showing respect to the deceased, providing community support, and involving religious leaders. Family members and close friends were absent at the time of death, unable to embrace or kiss the deceased. Funerals were restricted, with only a few mourners allowed, with no time for recited prayers and no opportunity to position the body facing Mecca [30]. Couples married for decades were separated in death, and children could not say farewell to their parents. Alcorn claims that the traditional structure for mourning was missing, thus causing ambiguity and distress [51].

# The Communal Experience Surrounding Death from COVID-19

Due to reports in the media and social networks regarding the congestion in hospitals, the COVID-19 wards, and intensive care units, most religious Muslims believed that the percentage of older people who died in the COVID-19 wards was much higher due to overcrowding and staff with less experience in treating patients during an epidemic and patients with breathing difficulties if they were in a nonepidemic situation. We found that the COVID-19 transplant patients refused to be treated in a hospital, preferring treatment in the community, even though they were aware they might die without treatment. What was

important to them was to die with dignity in the company of their children and grandchildren and not to meet death humiliated in the COVID-19 wards.

It should be noted that in the early stages of the COVID-19 pandemic, some ultra-orthodox communities in Israel were resistant to cooperating with government guidelines and restrictions, including social distancing measures and quarantine guidelines. In some cases, members of these communities infected with COVID-19 refused to evacuate to hospitals for treatment due to fear of stigmatization or concerns about being unable to observe religious practices in a hospital setting. Instead, some ultra-orthodox communities set up underground hospitals or makeshift medical facilities within their own communities to care for those infected.

Our findings align with previous studies reporting on feelings of humiliation due to improper purification, lack of shrouding, and absence of burial rituals and prayers, leading to maladaptation, loneliness, and unhealthy mourning [16]. These findings also support previous studies on Muslims' death rituals and practices during COVID-19 in other countries [52]. Results suggest that the refusal of ill Muslims to go to the hospital stems not only from a preference to die at home but also from the fear of not being given the traditional death rituals.

The loss of traditional practices is perceived as infringing on communal structural duties and jeopardizing forgiveness and God's peaceful welcoming. Disenfranchised grief in bereaved families and the community may cause moral distress or secondary traumatic stress [17]. In addition, societal recognition of one's loss and grief may have also been absent during the pandemic when many people died. This feeling of being unsupported and unable to share and cope with grief publicly may intensify disenfranchisement [49,50,53]. When communal grief and loss are disenfranchised, effective bereavement is disrupted, alienating the community from general society.

# CONCLUSIONS Practical Recommendations

The COVID-19 pandemic damaged the PCC model and violated patients' rights to mourn in traditionally mandated ways. The PCC approach calls for the understanding of the refusal of the Muslim patient to be hospitalized from a socio-religious

#### 'I PREFER TO DIE AT HOME WITH DIGNITY'

perspective and actively supports respect for diversity through multicultural alternatives of death rituals [31]. Just as health care delivery to the living is culturally adapted, religious death rituals may also be culturally adapted through regulations that allow some cultural, religious death rituals to be performed within the health guidelines. Health authorities can assist in providing for the religious and cultural needs of religious Muslim patients and their loved ones [54].

Furthermore, we demonstrated the importance of traditional rituals of death and bereavement. Health authorities endeavor to foster a discourse among imams, undertakers, funeral directors, and family members to create safe alternatives to these rituals. Mourning practices in the community should be facilitated without violating physical distancing regulations. Technology should be engaged to allow for congregational prayers for the deceased, whereas modifying the purification, shrouding, burial, and funeral rites should be presented as having an important function in supporting PCC. Governmental agencies are also called on to adopt more flexible attitudes toward traditional rituals to support the bereaved [55].

Potential practical interventions, while maintaining precautions to prevent infection, include: 1) death rituals and traditions should be upheld to pay respect to the dead and offer emotional and instrumental support to the mourners; 2) lay people should be taught to perform purification and prayers and how to bury the dead; 3) guidelines should be formulated for performing the rituals of death, the funeral, and attending the house of mourning while observing social distancing; 4) prayers for the dead should be allowed on mosque grounds, and authorities should permit the deceased to be transported by ambulance and prayed over before burial; 5) clerics should be allowed into the hospital to perform purification in the presence of one of the family members instead of sending the body to facilities outside of the hospital and unfamiliar to the family. The deceased should be brought to burial as quickly as possible, and burial should not be delayed for hours or days; 6) Muslim health care professionals, in particular, should show high levels of compassion, patience, and emotional and spiritual support to help patients and their families meet the challenges brought on by the pandemic.

We must contemplate how to prepare ourselves by drawing conclusions and organizing for future epidemics. Preparations must be provided for more patients to be treated in the community rather than only in the hospital. Future studies should investigate the experiences of all religious leaders in epidemic-related deaths and examine how the proposed interventions affect the grieving process of Christians, Jews, and Muslim family members and communities.

#### **DECLARATION OF COMPETING INTEREST**

None.

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