Death, dying, and end-of-life experiences among refugees: a scoping review

Article (Accepted Version)

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<table>
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<th>Manuscript ID:  PAL-2018-0279</th>
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<tr>
<td>Manuscript Type:  Research Article</td>
<td>Manuscript Title:  Death, dying, and end of life experiences among refugees: A scoping review</td>
</tr>
<tr>
<td>Keywords:  War, death, Refugees, Displaced people, Dying</td>
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Abstract: Background: The objective of this scoping review is to identify and map the published evidence on death, dying and end of life experiences among refugees worldwide. This scoping review will also inform areas for potential future research in the field.

Methods: We included papers that satisfied the following inclusion criteria: 1) Population of interest: Refugees worldwide and populations/individuals who were internally or externally displaced due to wars, conflicts, non-natural disasters, or emergencies 2) Setting of interest: The phase of end of life, dying and death that takes place following the refuge or displacement reported after the year 1980 3) Study design: Any study design, including but not limited to: news, editorials, commentaries, opinion pieces, technical reports, primary studies, narrative reviews, systematic reviews, and policy briefs. We excluded papers that were not published in the English language; papers representing statistics of mortalities and papers focusing on the causes of death among refugees. We also excluded books and book reviews.

We searched the following electronic databases: Medline (1946 till July 17, 2017), Scopus (July 16,2017), CINAHL (July 17,2017), and JSTOR (July 24,2017). Additionally, we searched the UNHCR database Refworld (September 03, 2017).

Results: Seven papers answered our inclusion criteria and were included in the analysis. Regarding study design, one paper adopted a qualitative approach; one paper adopted a mixed methods approach; one was a narrative; and four papers were reviews of the literature. Three papers discuss the concept of access to medical/palliative care among older refugees. Three papers discuss the concept of dying and death in terms of bereavement and death arrangements. Moreover, one paper addresses the effect of transmigration and previous experiences of refugees from two cultural groups in their home countries on their anticipation of death.

Implications: This review creates a unique window for promoting research on death, dying and end of life care in the regions most affected by the refugee crisis. It also fills a gap by indicating the need to include end of life interventions in health policies for refugees by relevant agencies and hosting countries.
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Keywords
Refugees; Displaced people; War; Death; Dying.
Text

Background

The world is currently witnessing the largest refugee crisis since World War II. The United Nations High Commissioner for Refugees (UNHCR) has reported an increase in the number of forcibly displaced people from 33.9 million to 65.6 million between the years 1997 and 2016\(^1\). Refugees are exposed to high rates of violence in their home countries and face high rates of mortality\(^2\). This is especially the case during their displacement trajectory within their country or to another country, or during their resettlement to a third country. The experience of being forced to leave one’s own home is disturbing and implies the inability of accessing previously available resources for most refugees; especially among the elderly, widows, children and the handicapped. Most refugees are dependent on humanitarian aid and assistance and their quality of life and wellbeing are therefore dependent on the interventions and policies implemented by the hosting land\(^2\).

Scholars of migration view the earlier stages of the life-course as important determinants of migration processes. In contrast, dying and death are rarely a focus of research in migration studies\(^3\). During a humanitarian crisis, the focus of organizations’ health policies is directed towards youth’s wellbeing while leaving those with chronic medical conditions, especially the elderly, out of the scope of humanitarian response. For instance, 54% of older refugees in Lebanon suffer from chronic health conditions and risk of dying due to their inability to afford healthcare services\(^4,5\), and despite the limited existence of palliative care facilities in Lebanon, none exist in refugee settings\(^6\). The limited examples of end of life research on migrants show how transnational dying is undoubtedly a predicament of our time, and reveals how in death, as in life, the ‘diasporic condition’ involves contradictions and loss\(^7,8\). It is crucial therefore to understand all dimensions.
of the refugees’ life, including issues of end of life care and the associated cultural responses to dying, death and bereavement. Moreover, the availability and access to palliative and end of life care are acknowledged as fundamental human rights and as key determinants of universal health coverage.\textsuperscript{9,10}

Although refugee camps are intended to be temporary arrangements, several have existed in different parts of the world for decades, tied up with nation building, political struggle, and issues of human rights.\textsuperscript{11} The end of life consequences in these settings are completely lost to academic enquiry. For instance, very little is known about end of life care issues among Syrian refugees in settlements and camps, and the social and personal consequences of their experiences such as the logistics of caring for their loved ones during the process of dying and death; including mourning and burial.\textsuperscript{12,13}

In this context, the objective of this scoping review is to identify and map the published evidence on death, dying and end of life experiences among refugees worldwide. This study will identify areas where innovative, interdisciplinary research can contribute to addressing the policy and practice needs for death, dying and end of life experiences among refugees. This scoping review will also inform areas for future research.

**Methods**

A study protocol was developed and peer-reviewed by the co-authors before conducting the scoping review.

**Eligibility Criteria**

We included papers that satisfied the following inclusion criteria:
- **Population of interest:** Refugees worldwide and populations/individuals who were internally or externally displaced due to wars, conflicts, non-natural disasters, or emergencies.

- **Setting of interest:** The phase of end of life, dying and death that takes place following the refuge or displacement (within original country or to another hosting country) reported after the year 1980.

- **Study design:** Any study design, including but not limited to: news, editorials, commentaries, opinion pieces, technical reports, primary studies, narrative reviews, systematic reviews, and policy briefs.

  We excluded papers that are not published in the English language; papers representing statistics of mortalities and papers focusing on the causes of death among refugees. We also excluded books and book reviews.

**Information Sources**

We searched the following electronic databases: Medline (1946 till July 17, 2017), Scopus (July 16, 2017), CINAHL (July 17, 2017), and JSTOR (July 24, 2017). Additionally, we searched the UNHCR database Refworld (September 03, 2017).

We developed our search strategy (Appendix A) with the assistance of an information specialist.

We used both index terms and free text words for the two following concepts: refugees and death.

Some of the MeSH terms used were “refugees”, “death”, “palliative care”, “attitude to death” and key words were “displace* adj2 people”, “(life adj2 end)”, “death?”, “dying”, “terminal care”.

While conducting the search, we did not use any language restrictions.

**Study Selection**

Two teams of two reviewers screened titles and abstracts of identified citations in duplicate and independently for potential eligibility based on a standardized screening guide developed by the
team to answer the eligibility criteria, after completing a calibration exercise. We retrieved the full
texts of citations judged as potentially eligible by at least one of the two reviewers.

The team of two reviewers screened the full texts in duplicate and independently for eligibility
based on a standardized screening guide the team developed, after completing a calibration
exercise. The teams of two reviewers resolved disagreement by discussion and by seeking the help
of a third reviewer when needed.

Data abstraction

Two reviewers abstracted data from included papers using standardized and pilot tested forms that
they developed. The reviewers resolved disagreements by discussion and when needed by seeking
the help of a third reviewer. They conducted calibration exercises to ensure the validity of the data
abstraction process.

The variables we abstracted data for are: Last Name of First Author, Year of Publication,
Institution/Affiliation of first author, Country of affiliation of the first author, Last name of
corresponding author, Country of affiliation of the corresponding author, Collaboration between
academics/non-academics (NGOs), Name of the journal of publication, Type of Publication, Study
Design, Year study was conducted if different from publication year, Statements on conflict of
interest of authors and Ethical approvals of the study. Additionally, we abstracted the following
variables: Characteristics of the refugees/displaced, Characteristics of displacement, Timeframe
of the war, Type of residency location of refugees, Topic of the study and Quotes.

Data Analysis

We conducted descriptive analysis of the general characteristics of the included papers.
**Results**

We present the results of our search in the PRISMA flow chart (Figure 1). Our search on Medline, Scopus, CINAHL, and JSTOR resulted in 11153 records identified. After removing duplicates, the final number of records identified was 7909. After excluding 535 references published before the year 1980, the total number of records for which the titles and abstracts were screened was 7374. Out of these, 7022 did not answer our eligibility criteria; leaving 352 for full-text screening out of which, 20 records could not be retrieved. An additional 7510 records were identified through Refworld (UNHCR database), and we were only able to access the full reports of these. Thus, the total number of full-text references assessed for eligibility was 7842. Out of these, the majority were excluded because they focused on statistics of mortalities and causes of death among refugees while the rest did not satisfy the inclusion criteria in terms of the target population, outcome, timeframe and study design. Thus, only five papers answered our inclusion criteria. References cited in these five included papers were screened for eligibility and two papers satisfied the inclusion criteria and were thus included in the analysis. Therefore, in total, seven papers were included in the analysis.

The publication characteristics of included papers are presented in Table 1 (Appendix B). The data abstracted from the seven papers, showed that there was no academic-non-academic collaboration in any of these. Only one paper reported that the authors have no conflicts of interest while the other papers did not report on this variable. Regarding study design, one paper adopted a qualitative approach and was the only one to receive ethical approval; one paper adopted a mixed methods approach; one was a narrative; and four papers were reviews of the literature. The characteristics of included papers are presented in Table 2 (Appendix C). Only three papers mention the age group of the refugees/displaced people and mention that it was “late 50s”, “50 and
older” and “old”. Most of the included papers, six out of seven, report that the displacement of refugees was external to their home country while one does not report on it. The reported countries from which the refugees fled were Philippines and Cambodia, Mozambique and Palestine; in addition to continents including Africa (reported in two papers) and ‘14 countries from Europe, South-East Asia, Africa, Middle East’. The reported countries where the refugees resettled were Australia (reported in two papers), United States of America (reported in two papers), Malawi and Denmark; in addition to the continent Africa (details of countries in Appendix C). The reported timeframes of war (four out of seven) are “Cambodians: the late 1970s/Philippino-American veterans of World War II”, “the late 1970s until 1992”, “1990s” and “occupation-ongoing”.

**Older refugees access to medical/palliative care**

Three papers discuss the concept of access to medical/palliative care among older refugees\(^{14,15}\). The paper by Atwell et al. discusses the exposure of older refugees to health risks in addition to the challenges they face in accessing medical services. Having policies that address these specific challenges in order to ensure the access of elderly to appropriate and culturally sensitive health care services allows them to live a healthy old age. Hiruy & Mwanri discuss how the cultural and experiential differences displayed by Africans influence their experiences and access to end-of-life care in Australia and how integrating these differences into the system results in the development of an ethical framework that could be applied in different contexts. Kemp discusses the role of culture in influencing how patients, families and healthcare providers view the end of life experiences; including receiving palliative care, suffering and dying, grief, bereavement, and burial rituals\(^{16}\).

**Experiences of dying and death**
Three papers discuss the concept of dying and death in terms of bereavement and death arrangements\textsuperscript{17,18}. In his paper, Kristiansen et al. explores the role Islam plays in altering refugees’ experiences in relation to death and bereavement to conclude on the importance of accounting for the sociocultural context during the process of supporting someone who experienced loss. Englund discusses the importance of developing assistance strategies that can support refugees with a flexibility that endorses their death practices within their cultural environment. Harrell-Bond & Wilson demonstrate that mourning and burial are problematic to refugee populations\textsuperscript{19}. In order to overcome the challenges refugee populations face during end of life experiences, decisions need to be culturally sensitive and tailored to the needs of refugees.

Moreover, one paper addresses the effect of transmigration and previous experiences of refugees from two cultural groups in their home countries on their anticipation of death\textsuperscript{20}.

**Discussion**

Only seven articles were found eligible for inclusion following our methodology for this scoping review. This number may reflect an underestimation of the significance of dying, death and end-of-life experiences among refugees given the increasing number of refugees in the world today. The provision of palliative and end of life care has been highlighted as a fundamental human right\textsuperscript{9} and it becomes of higher significance when tailored to refugees whose access to health care is already challenged. The lack of evidence on refugees’ experiences in relation to the process of dying, death and after-death\textsuperscript{12,13}, which is also confirmed by the outcome of this scoping review, is problematic as it exacerbates the vulnerability of an already suffering population.

Most of the papers included in this review focused on the role of culture in shaping these experiences and the importance of integrating cultural aspects in the delivery of general medical and palliative care services to refugees. Our review did not capture any intervention or evaluation
of such integration and its influence on the wellbeing of refugees. Moreover, there were very few examples on the actual end-of-life experiences reported. Most of the papers comprised a review of existing literature on this topic rather than a more active in-depth methodology that aims to understand refugees’ experiences. A deeper insight of the experiences would have resulted in stronger evidence potentially used to inform policies and decisions which would have better implications for practice regarding the delivery of medical/palliative care in addition to bereavement and burial practices. All the papers included in this scoping review were conducted in universities/research institutes of high income countries; and in all except one paper, the country where the study was conducted is the country of settlement/resettlement of refugees. Thus, more papers need to be conducted on refugees in low and middle-income countries in order to reflect their status when settled/resettled in these countries. Moreover, it was shown that in the papers retrieved the majority of reported countries from which the refugees fled are low and low-middle income countries; whereas, the majority of reported countries in which the refugees settled are high-income countries. Thus, the experiences reported are mainly tailored to this inflow. Further studies that reflect more variation in the country of origin, settlement and/or resettlement are needed for a better understanding of each context.

Our review was only able to capture a small number of papers and this may have been due to our selection of databases. There may be related studies that we were not able to capture in our search in other sources however our methodology included databases recognized in this field.

Nevertheless, our findings have important research and policy implications. At the level of research, this review creates a unique window for promoting research on death, dying and end of life care in the regions most affected by the refugee crisis. It can be taken into consideration when setting research priorities for academic and research institutions working in crisis or post crisis...
areas. It also highlights the need for investing in more primary qualitative studies that address such experiences among refugees. As for policy implications, this review fills a gap by indicating the need to include end of life interventions in health policies for refugees by relevant agencies and hosting countries. Moreover, it is important to remember that not all refugees belong to the same category and the needs of refugees in terms of end of life interventions largely depend on the social, economic, political and cultural context of their country of origin, migration trajectory, and host country. It is therefore crucial to capture both universal and specific features of being a refugee, to retrieve general patterns for end of life interventions that can be implemented in refugee settings, while contextualizing these interventions and implementing them in a culturally sensitive manner.
Authors’ Contributions

FM was responsible for coordination of the project, literature review, search strategy, data screening, data extraction, and manuscript preparation. HI was responsible for data screening, data extraction and manuscript preparation. FF was responsible for the study conception, providing guidance during the search strategy and data extraction stages. HK was responsible for the study conception and manuscript preparation. SZ and JJ were responsible for the study conception. AS was responsible for providing guidance during the search strategy and data extraction stages, providing administrative/technical support and manuscript preparation All authors read and approved the final manuscript.

Competing Interests

The authors declare that they have no competing interests.
References


Figure 1

Records identified through database searching (Medline, Scopus, CINAHL & JSTOR) (n = 11153)

Additional records identified (Refworld) (n = 7510)

Records after duplicates removed (n = 7909)

Records excluded (n = 7022)

Records screened (n = 7374)

535 references excluded → published before 1980

20 could not be retrieved

Full-text articles assessed for eligibility (n = 7842)

Studies included in analysis (n = 5)

References cited screened

Total number of studies included in analysis (n = 7)

Studies included in analysis (n = 2)

Full-text articles excluded (n = 7837), with reasons:
- Language (n = 214)
- Population of interest (n = 960)
- Setting of interest (n = 6614)
- Study Design (n = 30)
- Year (n = 19)
Appendices

Appendix A

Search Strategy on Medline:
1. disaster victims/ or refugees/ (8465)
2. "emigrants and immigrants"/ or undocumented immigrants/ or "transients and migrants"/ (18855)
3. "warfare and armed conflicts"/ or armed conflicts/ or afghan campaign 2001-/ or american civil war/ or american revolution/ or crimean war/ or french revolution/ or gulf war/ or iraq war, 2003-2011/ or korean war/ or russian-japanese war/ or september 11 terrorist attacks/ or spanish-american war, 1898/ or vietnam conflict/ or world war i/ or world war ii/ or warfare/ or biological warfare/ or bioterrorism/ or chemical warfare/ or chemical terrorism/ or nuclear warfare/ or psychological warfare/ or war crimes/ or ethnic cleansing/ or genocide/ or holocaust/ or war exposure/ or war-related injuries/ or disasters/ or emergencies/ or emergency shelter/ (98160)
4. (refugee? or ((displace* or relocate* or re-locate*) adj2 (internal* or people or person? or individual? or population? or nation? or children or family or families)) or (border? adj2 cross*) or (disaster? adj2 (victim? or survivor*?))).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (15296)
5. ((migrant? or immigrant? or emigrant? or migration? or emigration? or immigration? or immigration? or outmigration? or transient?) and (war? or warfare? or disaster? or crisis or crises or conflict? or emergency or emergencies or (force? or forceful* or coerc*))).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (23393)
Annotation: Removing the concept of force could be accompanied with the concept of force with the concept of migrants and all
6. 2 and 3 (243)
7. 1 or 6 (8605)
8. 4 or 5 (37599)
9. 7 or 8 (37605)
10. death/ or palliative care/ or terminal care/ or death certificates/ or mortality/ or attitude to death/ or palliative medicine/ or mortuary practice/ or burial/ or cemeteries/ or thanatology/ (137960)
11. ((life adj2 end) or death? or dying or thanatolog* or mortality or mortalities or ((terminal or palliative or hospice) adj2 (care or caring or medication? or medicine)) or (funeral* or (mortuar* adj2 practice?) or burial? or cemetery*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary
concept word, rare disease supplementary concept word, unique identifier, synonyms] (1362171)
12 10 or 11 (1362171)
13 9 and 12 (3171)

Total number of records: 3171

Search Strategy on Scopus:
(TITLE-ABS-KEY ("end of life" OR death OR dying OR thanatolog* OR mortality OR mortalities OR funeral OR "mortuary practice" OR burial OR cemetery OR ((terminal OR palliative OR hospice) W/2 (care OR caring OR medication? OR medicine))) AND ((TITLE-ABS-KEY ("refugees" OR "disaster victims") OR ((displace* OR relocate* OR relocate*) W/2 (internal* OR people OR person OR individual OR population OR nation OR children OR family OR families)) OR (border W/2 cross*)) OR ((TITLE-ABS-KEY (migrant OR immigrant OR emigrant OR migration OR emigration OR immigration OR outmigration OR transient)) AND (TITLE-ABS-KEY (war OR warfare OR disaster OR crisis OR conflict OR emergency OR emergencies OR (force* OR coerc*)))))

Total number of records: 5666

Search Strategy on CINAHL:
# Query Results
S13 S11 AND S12 560
S12 S1 OR S8 250,885
S11 S2 OR S3 OR S4 OR S10 12,228
S10 S5 AND S9 272
S9 S6 OR S7 22,863

S8 (MH "Attitude to Death") OR (MH "Death") OR (MH "Death Certificates") OR (MH "Death Counseling") OR (MH "Dying-Death Measures (Saba CCC)") OR (MH "Bereavement Support (Saba CCC)"") OR (MH "Funeral Arrangements (Saba CCC)"") OR (MH "Terminal Care (Saba CCC)+") OR (MH "Palliative Care") OR (MH "Terminal Care") OR (MH "Burial Practices")

S7 (MH "Disasters") Display
S6  (MH "War+") OR (MH "Chemical Warfare") OR (MH "Military Deployment+") OR (MH "Overseas Deployment") OR (MH "Nuclear Warfare") OR (MH "War Crimes+") OR (MH "Holocaust") OR (MH "Terrorism+") OR (MH "Bioterrorism")
S5  (MH "Transients and Migrants") OR (MH "Relocation") OR (MH "Emigration and Display Immigration") OR (MH "Residential Mobility+") OR (MH "Immigrants+") OR (MH "Immigrants, Illegal")
S4  (MH "Refugees") OR (MH "Crime Victims")
S3  TI (refugee# OR ((displace* OR relocate* OR re-locate*) N2 (internal* OR people OR person OR individual OR population OR nation OR children OR family OR families)) OR (border* N2 cross*) OR (disaster* N2 (victim OR survivor#))) OR AB (refugee# OR (displace* N2 (internal* OR people OR person OR individual OR population OR nation OR children OR family OR families)) OR (border* N2 cross*) OR (disaster* N2 (victim OR survivor#)))
S2  TI ((migrant# OR immigrant# OR emigrant# OR migration# OR emigration# OR immigration# OR inmigration# OR outmigration# OR transient#) AND (war# OR warfare# OR disaster# OR crisis OR conflict OR emergency OR emergencies OR (force# OR forceful# OR coerc*))) OR AB ((migrant# OR immigrant# OR emigrant# OR migration# OR emigration# OR immigration# OR outmigration# OR transplant#) AND (war# OR warfare# OR disaster# OR crisis OR conflicts OR emergency OR emergencies OR (force# OR forceful# OR coerc*)))
S1  TI ((life N2 end) OR death# OR dying OR thanatolog* OR mortality OR mortalities OR (terminal OR palliative OR hospice) N2 (care OR caring OR medication OR medicine)) OR (funeral* OR (mortuar* N2 practice* OR burial OR cemeter*)) OR AB ((life N2 end) OR death# OR dying OR thanatolog* OR mortality OR mortalities OR ((terminal OR palliative OR hospice) N2 (care OR caring OR medication OR medicine)) OR (funeral* OR (mortuar* N2 practice*) OR burial OR cemeter*))

Total number of records: 560

Search Strategy on JSTOR:
(refugee* death*~25) OR (refugee* (palliative care)~25) OR (refugee* (terminal care)~25) OR (refugee* mortality~25) OR (refugee* mortalities~25) OR (refugee* (end of life)~25) OR (refugee* thanatolog*~25) OR (refugee* funeral*~25) OR (refugee* cemeter*~25) OR (refugee* (mortuary practice)~25) OR (refugee* burial*~25)

Total number of records: 1756

Search Strategy for Refworld:
Advanced search: "refugee* death* w/50"
Years: “1980” till “2017”

Total number of records: 7510
### Appendix B

Table 1: Publication characteristics of included papers

<table>
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<tr>
<th>Last Name of First Author, Year of Publication</th>
<th>Institution/Affiliation of first author</th>
<th>Country of affiliation of the first author</th>
<th>Last name of corresponding author</th>
<th>Country of affiliation of the corresponding author</th>
<th>Collaboration between academics/non-academics (NGOs)</th>
<th>Name of the journal of publication</th>
<th>Type of Publication</th>
<th>Study Design</th>
<th>Year study was conducted if different from publication year</th>
<th>Statements on conflict of interest of authors</th>
<th>Ethical approvals of the study</th>
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<td>Refugee Health Research Centre, La Trobe University</td>
<td>Not reported</td>
<td>Not reported</td>
<td>Not reported</td>
<td>No</td>
<td>International Journal of Migration, Health and Social Care</td>
<td>Article</td>
<td>Mixed Methods</td>
<td>Not reported</td>
<td>Not reported</td>
<td>Not reported</td>
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<td>Kemp, 2005</td>
<td>Louise Herrington School of Nursing, Baylor University, Dallas, TX</td>
<td>Not reported</td>
<td>Kemp</td>
<td>Not reported</td>
<td>No</td>
<td>Seminar(s) in Oncology Nursing</td>
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<td>Country</td>
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<td>Harrell-Bond, 1990</td>
<td>Refugee Studies Programme, Queen Elizabeth House, University of Oxford</td>
<td>USA</td>
<td>qualitative study</td>
<td>Journal of Refugee Studies</td>
<td>Article Review (Literature review)</td>
<td>Not reported</td>
<td>The study protocol and consent form were approved by the Institutional Review Board, Committee on Human Research, University of Oxford.</td>
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<td>Becker, 2002</td>
<td>Institute for Health and Aging, University of California, San Francisco.</td>
<td>USA</td>
<td>same as the first author</td>
<td>Journal of Gerontology: SOCIAL SCIENCES</td>
<td>Qualitative study</td>
<td>not reported</td>
<td></td>
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<td>ENGLUND, 1998</td>
<td>Nordic Africa Institute</td>
<td>Sweden</td>
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<td>Sweden</td>
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<tr>
<td>Hiruy, 2014</td>
<td>Institute for Regional Development, University of Tasmania</td>
<td>Australia</td>
<td>same as the first author</td>
<td>Australia</td>
<td>No</td>
<td>nursing ethics (SAGE)</td>
<td>article Review (Literature review)</td>
<td>The authors declare that there is no conflict of interest.</td>
<td>not reported</td>
<td>not reported</td>
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<tr>
<td>Kristiansen, 2015</td>
<td>Qatar University, University of Copenhagen</td>
<td>Qatar, Denmark</td>
<td>same as the first author</td>
<td>Qatar, Denmark</td>
<td>No</td>
<td>J Relig Health</td>
<td>article Narrative</td>
<td>2011</td>
<td>not reported</td>
<td>not reported</td>
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</tbody>
</table>
### Appendix C

Table 2: Characteristics of included papers

<table>
<thead>
<tr>
<th>Last Name of First Author, Year of Publication</th>
<th>Nationality</th>
<th>Age Group</th>
<th>Internal/External</th>
<th>Characteristics of the refugees/displaced</th>
<th>Characteristics of displacement</th>
<th>Timeframe of the war</th>
<th>Type of residency location of refugees (i.e. Camps, Households, Other)</th>
<th>Topic of the study (i.e. Death arrangement including burial, cultural/religious aspects, Access to medical/palliative care, Grief/Mourning, Other)</th>
<th>Quote about the experience of death/dying/end of life</th>
</tr>
</thead>
<tbody>
<tr>
<td>Atwell, 2007</td>
<td>More than one</td>
<td>Old</td>
<td>External</td>
<td>14 countries from Europe - South-East Asia - Africa - Middle East</td>
<td>Melbourne, Australia</td>
<td>Not Reported</td>
<td>Not Reported</td>
<td>Access to medical/palliative care</td>
<td></td>
</tr>
<tr>
<td>Kemp, 2005</td>
<td>More than one</td>
<td>Not Reported</td>
<td>External</td>
<td>Not Reported</td>
<td>United States</td>
<td>Not Reported</td>
<td>Not Reported</td>
<td>Influence of culture on end of life experiences of refugee patients, their families and healthcare providers (including medical/palliative care, pain/suffering, grief/mourning, dying/death and burial)</td>
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<tr>
<td>Africa (Uganda &amp; Mozambique)</td>
<td>Africa (Malawi, Sudan, Zimbabwe &amp; Zambia)</td>
<td>Not Reported</td>
<td>Not Reported</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Challenges of end of life experiences among refugees</td>
<td></td>
</tr>
<tr>
<td>Becker, 2002</td>
<td>Filipino American and Cambodian Americans</td>
<td>50 and older</td>
<td>External</td>
<td>Philippines, Cambodia</td>
<td>USA</td>
<td>lived in an innercity locale in a major urban area that also has large numbers of homeless people. Densely populated, this area has a high crime rate, and elders seldom venture out after dark. Cambodians lived with their extended families in small apartments, whereas Filipinos lived with their contextualize the anticipation of death by transmigrants: The purpose was to examine how Cambodian Americans and Filipino Americans view their homeland in old age and how those views affect the contemplation of death.</td>
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</table>

“My husband just died in May. I was able to bring him home. I went on vacation. He was sick for four years. I had such a hard time here because I was the one doing everything. He had cancer in the pancreas. The doctors spoke to me and told me that there was no hope for my husband so they will not try to treat him anymore. I said that I...
spouse and/or with other Filipinos in small apartmen
ts or single-
room-
occupanc
y hotels. 
A small proportion of Cambodias
ts and Filipinos lived in urban areas that have more spaci
ous housing, but those locations are geographi
cally isolated from transporta
tion and services.

was going to bring him home to the Philippines. I really needed to bring him home because my children called and wanted me to bring their father home. Because all of my children are in the Philippines. I only have one that is here. So I strengthen
d my insides.” “Sometimes I just remember him and I start to cry all of a sudden. But
you know, Jesus said that we shouldn’t cry because when his second coming comes, we will see our children and our husbands that have already died. And he said that he loves all those that have accepted him in his life. When I read that, my tears roll down my cheeks. I talked to my pastor here. Because some of them wanted to
do it in a Catholic church but you have to pay $200. But with the pastor you don’t pay. Anyway, I didn’t want a big to-do. In the Philippines it is also the same. So my pastor was there for 2 days, and it’s like that in the Philippines too.”
<table>
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<tr>
<th>ENGLUND, 1998</th>
<th>Mozambican</th>
<th>not reported</th>
<th>External</th>
<th>Mozambique</th>
<th>Malawi</th>
<th>The war between the Frelimo government and Renamo rebels, waged in Mozambique from the late 1970s until 1992 setllments or houses</th>
<th>Death arrangements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hiruy, 2014</td>
<td>African</td>
<td>not reported (in one case study it’s a man in his 40s)</td>
<td>External</td>
<td>Africa (with a focus on Ethiopia)</td>
<td>Australia</td>
<td>political conflict, in the 1990s not reported</td>
<td>Access to medical/palliative care</td>
</tr>
</tbody>
</table>

"The Ethiopian tradition demands that ‘a man shows courage and resilience no matter what the situation’. This is also strengtheneed by the religious belief that ‘death is..."
only a way to a better life – life with your God’. These customs and beliefs seem to have permeated Dagne’s contemplation as he dealt with dying on a daily basis.

"Dagne had an unflinching will to live and a radiant and positive attitude to what is considered a negative experience. His family was always beside him, and it was not easy for them to let
him be cared for by others at the palliative care ward. However, when the doctor advised that Dagne be transferred to palliative care, they had to agree mainly out of respect for authority rather than preference. Traditionally, such an arrangement would be less acceptable (at least in rural Ethiopia)."
Kristiansen et al., 2015
Palestine late 50s External Palestine Denmark occupation-ongoing house bereavement narrative

When they told [my husband]: you have cancer. It was a shock for me. […] Then when the doctor left, I cried, [and] I told my husband ‘Please don’t leave this life before me, pray for me that Allah will be with me, send me to Allah, send me to Allah, don’t go without sending me to Allah’. This is what happened, and I’m sure that he made dua for me because I
feel, Alhamdulillah [praise be to God], Allah is really taking care of me every day. "When people they ask me [about this last time with him], I say, I felt it was like honeymoon for me because before [his illness] we didn’t see each other so much. And, SubhanAllah, three days or two days [before he died] he had a mask [for
oxygen], he took it off and he said: ‘I love you’ and then he put it back, ‘I love you, do you hear. I am satisfied, may Allah be pleased with you’, he made du’a for me. So, until the last moment he was caring about me and [spoke] nice words to me.”
Figure 1

Records identified through database searching (Medline, Scopus, CINAHL & JSTOR) (n = 11153)

Additional records identified (Refworld) (n = 7510)

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535 references excluded published before 1980

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