How Latino Community Leaders Talk About Death, Dying, and Cancer

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Abstract

Advanced cancer is the leading cause of death among Latino people in the U.S., but it has been shown that early integration of end-of-life (EOL) care can improve health outcomes and patient comfort measures. In order to integrate EOL care into rural Latino communities, where it is often lacking, it is imperative to understand traditional views towards death, dying, and cancer. The purpose of this study was to better understand the sociocultural factors related to talking about death, dying, and cancer from the perspectives of Latino community leaders. This qualitative descriptive research study was a part of a larger participatory action research study that aimed to learn traditional views of death and cancer. Three Focus groups were conducted with Latino community leaders from four counties in eastern North Carolina. Data was then transcribed and analyzed using thematic analysis techniques. Thematic analysis revealed two themes: Talk is (Sometimes) Taboo and Analogies Assist with Conversations. Findings reveal traditional sociocultural views about death, dying, and cancer. Findings also reveal the unique difficulties that accompany discussing death and the diagnosis of cancer for Latinos. This study signifies that understanding traditional views towards death and dying is an important step in bridging the gap to provide EOL care to underserved Latino communities.

Keywords

cancer, death, dying, Latino/Hispanic people, palliative care, conversations

Background/Significance

Latino persons are members of the fastest-growing ethnic minority group in the U.S. but continue to face numerous health disparities when accessing palliative care. For Latino people, the leading cause of death in the U.S. is cancer, accounting for 21% of deaths (American Cancer Society [ACS], 2018). Latino people have less access to quality care than non-Latino Whites and are less likely to be diagnosed with cancer in an early stage and receive follow-up care (ACS, 2018). Moreno et al. (2018) claim that Latino people experience lower overall satisfaction with quality of life related to their health, due to factors such as low income, lower formal education, and a lack of health insurance. Latino people are also less likely to participate in Advance Care Planning (ACP) and less likely to be knowledgeable about available EOL care options (Fischer et al., 2018). As the Latino community ages in place, patients with advanced cancer will need increased access to EOL and palliative care to improve quality of life. To expand palliative care access for Latino people, it is imperative to understand the preferences of Latino people in relation to conversations about death, dying, and advanced cancer.

Literature Review/Synthesis

A review of the literature was conducted using the following databases: Pubmed, ProQuest, CINAHL, and PsychINFO. Search terms were "Latinos, Hispanics, Cancer, Death, Dying, Culture, Beliefs, Communication, Discussion, Talk, and Community." The search was focused specifically on conversations and beliefs about advanced cancer, death, and dying. The literature was organized into two categories: Conversations about death and dying and Cultural views about death and dying.

Conversations about Death and Dying

Conversations about death and dying were identified within the family, between healthcare providers (HCP) and patients, and with community leaders. Conversations within the family were found in nine articles and focused on two cultural constructs: *familism and filial piety. Familism,* a cultural concept central to Latino families, is the attitude that family members have strong ties to each other and operate cohesively, valuing each other's opinions and values (Peterson et al., 2019). The concept of *familism* is very complex and manifests differently among participants from multiple studies. In some cases, having a strong family involvement increases EOL discussions, but in other cases, the concept of *familism* can inhibit open discussion about death by the patient and the family. In a qualitative study with nine participants, Logger et al. (2019) reported the willingness of Hispanic mothers to discuss advanced cancer diagnoses with their dependent children. Hispanic mothers believed in the importance of preparing their children for life after their death. Conversely, Kreling et al. (2010) discussed how *familism* inhibits EOL discussions by reporting that many Latino family members withheld the news of the cancer diagnosis from the patient to "protect" the patient from their diagnosis. In another study that emphasizes the importance of minimizing conversations about death, Boucher (2017) found that discussions about EOL and death were private matters, and if they were discussed it was only within the family unit. *Filial piety* is the respect of the parents in a family and duty to them. *Filial piety* is also complex because it can encompass a parental fear of being a burden to children and disbelief that all care and decisions should fall to family members (Boucher, 2017).

The family is often a significant source of support while coping with a cancer diagnosis. Being undocumented has many impacts on the ways that one can interact with family members. Bravo (2017) found that undocumented immigrants often can only communicate with dying

family members in the home through technology. The option of traveling back home to their birth country is impossible, which limits EOL interactions with dying loved ones. Traditionally, discussions about death are not easy but adding the challenge of being undocumented causes additional hardships and decisions that need to be discussed. Being undocumented also had many impacts on conversations in the hospital. Jaramillo and Hui (2016) presented a case study of an undocumented Latino patient in the U.S. and found that fear of paying for hospital services and fear of being deported were topics central to the patient's conversations with his family. This fear, coupled with inadequate translation services, confusing medical jargon, and lack of insurance are often barriers for undocumented Latino patients to receive EOL care.

Conversations between HCP and patients were identified in five articles and focused on respect for the authority. Peterson, et al. (2018) found that a majority of Latino patients welcomed the HCP to be present during family discussions of EOL care preferences. Other studies identified communication characteristics that improved the patient-provider relationship and made the patient feel in control of their treatment plan (Ko et al., 2018). Cervantes et al. (2016) conducted a systematic review that reported many patients experience frustration with lack of communication from healthcare staff. However, it was also found that patients felt better informed and in control of their medical decisions when there was a trusting patient-provider relationship and an optimistic HCP.

The role of community leaders is centered around patient navigators (PN) and death doulas. Rawlings et al. (2018) describe death doulas as patient companions who serve in a variety of roles to advocate for patients. In a study with 61 participants located in Colorado, Fischer et al. (2015) defined PNs as community leaders who "work with patients and families to address barriers to palliative care..." (p. 658). Home visits by PNs increased the likelihood of

EOL preference and pain management being documented. Hagwood and Larson (2019) detailed the benefits of Latino advocates in a case study where two Latino religious leaders discovered ways to initiate EOL communication.

Cultural Views about Death and Dying

A traditional view discussed in the literature was the notion of a "good" death, and how the good death can be influenced by place and time. Crist et al. (2019) found that many Latino people believed dying in the hospital can interfere with a "good" death, as the medical intervention often used disrupts the natural progression of death. These authors also found that an important part of death involves imparting life knowledge to those left behind. Additionally, many Latino people had a religious opposition to the practice of medically assisted euthanasia for terminal patients and some believed that euthanasia opposes a "natural" death (Cain & McCleskey, 2019). Another traditional cultural view about death focused around *Día de los Muertos* and presents traditional ways to celebrate and honor deceased loved ones in Latin America (Gutiérrez et al., 2015). Authors found that death should be openly discussed and that children were excited to honor the death of family members (Gutiérrez et al., 2015).

Conversations about death, dying, and cancer primarily occurred within the family, between the HCP and the patient, and with community leaders. There were several cultural concepts and beliefs that impacted these conversations, including *familism, filial piety,* the notion of a "good" death, and the celebration of *Día de los Muertos.* No known studies examined palliative care access for rural-dwelling Latino persons in eastern North Carolina. Thus, the purpose of this research is to better understand how Latino community leaders view death and dying in order to expand palliative and EOL care services to Latino patients with advanced

cancer. Specifically, our research question is how do Latino community leaders talk about death, dying, and advanced cancer?

Methodology

Study Design

This qualitative research study is a part of a larger participatory action study (Larson, et al. 2021). A participatory action research design (Israel et al., 2013) was used, guided by the Ethnocultural Gerontological Nursing (ECGN) model (Phillips et al., 2015), with an overall goal of understanding how Latino persons talk about death and dying. The 9-member research team consists of community members, university faculty (from nursing and anthropology), and undergraduate honors students. Three of the team members were of Latino heritage. The team used a focus group approach, as focus groups promote self-disclosure in a safe environment, encourage interaction, and expose multiple perspectives, while minimizing the researchers' position of power (Krueger & Casey, 2015).

Data Collection

Three focus groups were conducted with the participants from the target counties. Focus groups were facilitated by an experienced bilingual moderator and trained a co-moderator who took field notes and managed the recording devices. Focus groups followed a semi-structured format, which used open-ended questions that empowered participants to direct the discussion and share their understanding of the topics. The groups ranged in length from 50 to 60 minutes and were conducted in English; questions were translated into Spanish when necessary. Audiotapes were transcribed verbatim and verified by two research team members within 1 week.

Sample/Setting

The target sample of 15 Latino community leaders was established a priori. To recruit these leaders, team members traveled over 1,100 miles, distributing project information and meeting with staff at churches and advocacy groups (i.e., *Manos Unidas*, Catholic Charities), local health departments, community health centers, hospitals, and schools. Eligibility criteria included Latino men or women considered community leaders; over 18 years of age; able to read and write Spanish and English; willing to help Latino families with cancer; residing in the project's target counties; and having reliable transportation.

Analysis

After each focus group was transcribed and verified, all team members independently read the transcripts and conducted In Vivo descriptive codes (Saldaña, 2015). The research team met weekly to discuss coding and resolve discrepancies based on researcher reflexivity, which involved active engagement in identifying and correcting biases. The four team members who conducted the focus groups also conducted an in-depth key word in context (KWIC) analysis of each focus group transcript (Bernard, 2017). The KWIC analysis was used to find common words repeated by participants and discern the importance of these repeated words. One part of the analysis highlighted the importance of talk.

Findings

Talk is (Sometimes) Taboo

One major theme was Talk is (Sometimes) Taboo. Many participants had previous experiences with dying and cancer and were willing to share their personal experiences of approaching conversations about death and dying. Some participants often had similar views regarding discussions of death, however many had contradictory perspectives on this topic. Contradictory findings signify that sociocultural values can be used to understand attitudes of

Latino people towards death and dying, but cannot be generalized to all Latino persons, as there is deviance in every group and individuals have independent ideals.

Often participants would state that death was a difficult topic that people didn't discuss, that there was no easy way to discuss death, or that death was discussed privately within the family and between close friends. The reluctancy to discuss death or a cancer diagnosis was described by the statement,

>…but I guess uh in the um Hispanic community you really don't, don't talk, it's not something to talk about because most of the Hispanics don't even have a will, don't prepare anything. So it's more cultural than anything. (FG 2)

Many participants echoed this reluctance. It was often shared that death wasn't discussed in households with children, so when those children age and have families of their own, death is still an "unspoken" topic. It wasn't just death that people were reluctant to talk about. People also were very reluctant to discuss cancer diagnoses, "Well I think there's more people than I think around me that have cancer. I guess it's something that you don't talk about openly" (FG 1).

Even though there was often reluctance or hesitancy towards discussing death, many participants emphasized the importance of planning for the end of life. Many participants had informal discussions with loved ones about their EOL wishes but hadn't gone through the step of having legal ACP documents signed. This was described by participants throughout multiple focus groups,

>we have talk about this with my husband when he passed away, if he pass away, or I pass away, I mean, what do we want to happen but we haven't you know done a will or anything like that. (FG 2)

A few participants had taken the steps of having informal discussions with family members about EOL wishes and had formal conversations with healthcare workers about ACP. One participant stated "In my house, we are three, my daughter, me and my husband. We talk about death. We have everything in order" (FG 3). This participant highlighted the importance of having conversations and planning for death to prepare family members, which was a stark contrast to statements made by other participants.

Analogies Assist with Conversations

Another major theme was the use of analogies. Participants often used religious or cultural analogies as an avenue to have difficult conversations about death. One religious analogy was expressed by multiple participants and was used in conversations about getting into Heaven through the "Good Book". One participant described the "Good Book" in this excerpt:

> … you start putting pieces together of how your life will probably end up…You start preparing and that's when you grow up a little bit older, like my age or maybe younger, less younger, and you start being more closer to God because you're figuring that's where you want to end up, literally. That's where you really want to end up, in the Good Book. (FG 1)

Another religious analogy was expressed in the focus groups, however, it was used less universally among participants, as it related to a uniquely tragic event. This was an analogy used to discuss the death of a young child and was particularly important to the participant because it created an avenue to discuss such a hard and unspeakable topic. The death of a child was described by,

> …my younger sister died when she was like 6 months… So, the way my parents said, was that uh, she was a fallen angel and God wanted her back. She had been lent to us for

a little while so that we would know what being alive was and that we would see her

again when we would go back to Jesus, to God. And that whenever somebody passed

away angels came up and got them and took them up there and that we would see them

again. (FG 1)

Often, the most difficult conversations related to death were those that involved children.

Participants often found peace in their religion and culture during difficult times and religious

analogies gave them the words needed to have difficult conversations. Participants also used

analogies to facilitate conversations about death with children, who didn't comprehend death.

This analogy describes the EOL process in an easier way for children to comprehend,

…my grandson tells me, I don't want you to die grandma, and I say honey, we all that's

where we are all going to die, just like the flowers, and I try to explain to him at his age

that a flower is not born yet and the flower comes out the bud and I show him look that

flower is dead but then another one is going to come. So, I guess it's just a way of

looking at it, learning to look at it in a more positive way, which is hard but. (FG 1)

Discussion

This study found that Latino community members viewed conversations about death and

dying in a cultural context and that in some cases talk was taboo, yet analogies can assist with

conversations. This qualitative research study was a beginning step in filling the gap for

palliative care needs for Latino persons in Eastern NC. The larger participatory action pilot study

established a training program that can expand palliative care access with the help of Latino

community leaders (Larson et al., 2021). For the larger study to be effective, it was imperative to

conduct focus groups before the training program commenced. This subset of the larger study

was a critical step in disseminating the data and understanding how traditional cultural views towards death and dying impact EOL care.

A particular theme emphasized in the data was the importance of framing death conversations in a cultural or religious context. Many participants thought of death and dying as a cultural experience because of religion or because of their sociocultural and family beliefs. The importance of viewing these difficult discussions in a cultural context is imperative to understand EOL preferences. An important cultural aspect discussed by the participants was the importance of family, which correlates with the sociocultural value of *familism. Familism* is often so important in Latino culture that many Latino persons report they are more comfortable discussing EOL care options with HCPs when their family members are present for the conversations (Shen, et al., 2019). Understanding the importance of these sociocultural values in the EOL process is necessary to provide culturally responsive palliative care in the hospital setting. It is also important in the context of the larger study because it highlights that there is more comfort discussing EOL care with family members. Family member presence not only facilitates comfort while discussing EOL care, but it has also been found to improve rates of completing legal documentation, such as advanced directives (Maldonado et al., 2017). Even though these healthcare liaisons are not family members, they are able to understand sociocultural values and provide healthcare information in the comfort of the home, where traditional HCPs aren't.

Cancer, death, and dying are particularly difficult topics to discuss with family. Furthermore, the difficulty of discussing EOL becomes increasingly difficult when the sociocultural norm is to avoid the topic. Often, Latino community members view conversations about death as risky or abnormal and believe that discussing death suggests the presence of

impending illness (Peterson et al., 2018). Even when death conversations weren't viewed as "abnormal" they were often avoided because there didn't seem to be any correct words to properly discuss the brevity of the situation. Often when there were no right words to discuss death, analogies were used to facilitate the conversation. Another aspect that facilitated EOL conversations was when HCPs communicated in a culturally sensitive way with patients (Shen et al., 2019). This finding is particularly important as it emphasizes that providing education that is culturally congruent with the patient's beliefs will increase patient comfort and can be an avenue to facilitate difficult EOL discussions.

Conversely, while many participants had difficult times discussing death and EOL, many participants were adamant that having these hard conversations was the only way to prepare for death. A common finding throughout the Latino community was that some people discuss their wishes with family members, yet don't take the extra step of having these wishes legally documented in ACP paperwork. Many people also have discussions centered around funeral and burial arrangements but fail to have the discussions related to their wishes about EOL, dying, and what medical interventions they want (Peterson et al., 2018). Some participants took both steps of having the discussions with family members and filling out ACP paperwork. Those that completed both steps expressed the desire to be prepared in the event of an untimely death. Without ACP preferences documented, it is much easier for confusion and potentially medical interventions that go against the patient's wishes to occur.

One finding disseminated from the data that wasn't as prevalent as the other themes was the difficulty of being an undocumented immigrant. Being undocumented adds other difficulties to EOL conversations and places compounding stress on patients and families. Facing advanced cancer as an undocumented immigrant is a unique situation that cannot be generalized to other

groups and the difficulties of this situation cannot fully be conceptualized by anyone not in this position. Most death and cancer conversations discussed previously took place in the context of being sad about loved ones passing. These conversations shift for undocumented immigrants, as there is added uncertainty and fear. Many conversations for undocumented immigrants center around fear of being deported for seeking medical care, lack of insurance and transportation, and frustration surrounding inadequate translation services (Jaramillo et al., 2016). Because of these difficulties, many undocumented immigrants received minimal or no medical care for advanced cancer. When minimal medical care is received, it is extremely unlikely that adequate palliative care will be received, further exacerbating healthcare disparities for Latino persons.

Limitations

Limitations include a small, purposive sample. Although we attempted to recruit Latino community leaders from different walks of life, all were permanent legal residents.

Conclusion

The Latino community is the fastest-growing ethnic minority group in the U.S. and as community members age in place it is imperative to address health disparities regarding access to palliative care services. Understanding traditional Latino community views related to death and dying can help HCPs deliver culturally responsive services. Lay health advisors who serve as healthcare liaisons are community members who are uniquely equipped to fill this palliative care gap. Community-based care models can be adapted to many different populations to provide benefits to the communities in which they intend to serve. This research further suggests that community leaders can provide valuable direction for the development of palliative and EOL care services for underserved groups and can assist in the delivery and ongoing refinement of

such educational initiatives within the context of a continued commitment to participatory action research.

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Declaration of Conflicting Interests

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References

American Cancer Society. (2018). *Cancer Facts & Figures for Hispanics/Latinos 2018-2020.*

https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-

statistics/cancer-facts-and-figures-for-hispanics-and-latinos/cancer-facts-and-figures-for-

hispanics-and-latinos-2018-2020.pdf

Bernard, H. R. (2017). *Research methods in anthropology: Qualitative and quantitative*

approaches. (6th ed.). Roman and Littlefield Publishing Group.

Boucher, N. A. (2017). Faith, family, filiality, and fate: Dominican and Puerto Rican elders'

perspectives on end-of-life decisions. *Journal of Applied Gerontology, 36*(3), 351-372.

https://doi.org/10.1177/0733464815627958

Bravo, V. (2017). Coping with dying and deaths at home: how undocumented migrants in the

United States experience the process of transnational grieving. *Mortality: Promoting the*

Interdisciplinary Study of Death and Dying, 22(1), 33-44.

http://dx.doi.org/10.1080/13576275.2016.1192590

Cain, C. L., & McCleskey, S. (2019). Expanded definitions of the 'good death'? race, ethnicity

and medical aid in dying. *Sociology of Health & Illness, 41*(6), 1175-1191.

http://dx.doi.org/10.1111/1467-9566.12903

Cervantes, L., Zoucha, J., Jones, J., & Fischer, S. (2016). Experiences and values of Latinos with

end stage renal disease: A systematic review of qualitative studies. *Nephrology Nursing*

Journal, 43(6), 479-493

Crist, J. D., Ortiz-Dowling, E. M., Shea K. D., & Phillips, L. R. (2019). Knowledge gaps about

end-of-life decision making among Mexican American older adults and their family

caregivers: An integrative review. *Journal of Transcultural Nursing, 30*(4), 380-393. https://doi.org/10.1177/1043659618812949

Phillips, L. R., Salem, B. E., Jeffers, K. S., Kim, H., Ruiz, M., E., Salem, N., & Woods, D. L. (2015). Developing and proposing the ethno-cultural gerontological nursing model. *Journal of Transcultural Nursing, 26*(2), 118-128. https://doi.org/10.1177/1043659614563615

Fischer, S. M., Cervantes, L., Fink, R. M., & Kutner, J. S. (2015). Apoyo con cariño: A pilot randomized controlled trial of a patient navigator intervention to improve palliative care outcomes for Latinos with serious illness. *Journal of Pain and Symptom Management, 49*(4), 657-665. http://dx.doi.org/10.1016/j.jpainsymman.2014.08.011

Fischer, S. M., Min, S-J., Atherly, A., Kline, D. M., Gozansky, W. S., Himberger, J., Lopez, J., Lester, K., & Fink, R. M., (2018). Apoyo con cariño (support with caring): RCT protocol to improve palliative care outcomes for Latinos with advanced medical illness. *Research in Nursing &* [LK2] *Health, 41.* 501-510. https://doi.org/10.1002/nur.21915

Gutiérrez, I. T., Rosengren, K. S., & Miller, P. J. (2015) Día de los muertos: Learning about death through observing and pitching in. *Advances in Child Development and Behavior, 9,* 229-249. http://dx.doi.org/10.1016/bs.acdb.2015.08.004

Hagwood, D. N., & Larson, K. L. (2019). Planting the seeds: The role of Latinos lay health advisors in end-of-life care. *Journal of Hospice and Palliative Nursing, 21*(3), 223-228. 10.1097/NJH.0000000000000513

Israel, B. A., Eng, E., Schultz, A. J., & Parker, E. A. (2013). *Methods for community-based participatory research for health* (2nd ed.). Jossey-Bass.

Jaramillo, S., & Hui, D. (2016). End-of-life care for undocumented immigrants with advanced

cancer: Documenting the undocumented. *Journal of Pain and Symptom Management,*

51(4), 784-788. http://dx.doi.org10.1016/j.jpainsymman.2015.11.009

Kreling, B., Slesky, C., Perret-Gentil, M., Huerta, E. M., & Mandelblatt, J. S. (2010). 'The worst

thing about hospice is that they talk about death': Contrasting hospice decisions and

experience among immigrant Central and South American Latinos with US-born White,

non-Latino cancer caregivers. *Palliative Medicine, 24*(2), 427-434.

https://doi.org/10.1177/0269216310366605

Ko, E., Zuñiga, M. L., Peacher, D., Palomino, H., Watson, M. (2018). Efficacy of cancer care

communication between clinicians and Latino patients in a rural US-Mexico border

region: A qualitative study of barriers and facilitators to better communication. *American*

Association for Cancer Education, 33(1), 116-127. https://doi.org/10.1007/s13187-016-

1100-8

Krueger, R. A., & Casey, M. A. (2015) *Focus groups, A practical guide for applied research* (5th

ed.). SAGE.

Larson, K. L., Mathews, H. F., Moye, J. P., Congema, M. R., Hoffman, S. J., Murrieta, K., M.,

Johnson, L. A. (2021). Four kinds of hard: An understanding of cancer and death among

Latino community leaders. *Global Qualitative Nursing Research, 8*, 1-11.

10.1177/23333936211003557

Logger, E. T., Kirtane, K., Palacios, R., & Lewis, F. (2019). Leaving footprints, not scars: a

qualitative pilot study of Hispanic mothers' willingness to communicate with dependent

children about an advanced cancer diagnosis. *Supportive Care in Cancer, 27*(4), 1573-

1578. https://doi.org/10.1007/s00520-018-4576-4

Maldonado, L. Y., Goodson, R. B., Mulroy, M.C., Johnson, E. M., Reilly, J. M., & Homeier, D.

    C. (2017). Wellness in sickness and health (the W.I.S.H. project): Advance care planning

    preferences and experiences among elderly Latino patients. *Clinical Gerontologist 42*(3),

    259-266. https://doi.org/10.1080/07317115.2017.1389793

Moreno, P. I., Ramirez, A. G., San Miguel-Majors, S. L., Fox, R. S., Castillo, L., Gallion, K. J.,

    Munoz, E., Estabrook, R., Perez, A., Lad, T., Hollowell, C., & Penedo, F. J. (2018).

    Satisfaction with cancer care, self-efficacy, and health-related quality of life in Latino

    cancer survivors. *American Cancer Society, 124*(8), 1770-

    1779. http://dx.doi.org/10.1002/cncr.31263

Peterson, L. J., Dobbs, D. Meng, H., Gambaldo, A., O'Neil, K., Hyer, K. (2018). Sharing end-of-

    life care preferences with family members: Who has the discussion and who does not.

    Journal of Palliative Medicine, 21(4), 463-372. https://doi.org/10.1089/jpm.2017.0357

Peterson, L. J., Hyer, K., Meng, H., Dobbs, D., Gamaldo, A., & O'Neil, K. (2019). Discussing

    end-of-life care preferences with family: Role of race and ethnicity. *Research on Aging,*

    41(9), 823-844. https://doi.org/10.1177/0164027519858716

Rawlings, D., Tieman, J., Miller-Lewis, L., & Swetenham, K. (2018). What role do Death

    Doulas play in end-of-life care? A systematic review. *Health and Social Care in the*

    Community, 27(3), e82-e94. https://doi.org/10.1111/hsc.1266

Saldaña, J. (2015). *The coding manual for qualitative researcher.* Sage Publications.

Shen M.J., Gonzalez C., Leach B., Maciejewski P.K., Kozlov E., & Prigerson H.G. (2019). An

    examination of Latino-advanced cancer patients' and their informal caregivers'

    preferences for communication about advance care planning: A qualitative study.

    Palliative and Supportive Care, *17*(5), 1–8. https://doi.org/ 10.1017/S1478951519000890