Journal of Cross-Cultural Gerontology (2018) 33:229–245
https://doi.org/10.1007/s10823-018-9353-9

ORIGINAL ARTICLE

End of Life Care for Older Russian Immigrants - Perspectives of Russian Immigrants and Hospice Staff

Emily H. Eckemoff[1] · **S. Sudha**[2] · **Dan Wang**[2]

Abstract

This pilot study examined immigrant Russian seniors and adult children's views on end-of-life care, and hospice staff members' experiences providing care to diverse immigrant clients, in areas of North Carolina with a high proportion of immigrants. Data were collected through individual in-depth interviews with informants, including Russian immigrant seniors, Russian adult children, and hospice staff, and analyzed by qualitative techniques. Findings indicate that there is little awareness of end-of-life care options among the Russian immigrant community in North Carolina. End-of-life care is rarely discussed within the family of first generation Russian immigrants but second-generation families are more open to doing so. First generation immigrant Russian seniors in our study do not seem to want any specialized end-of-life care often due to lack of awareness, and prefer family care. Second generation seniors' attitudes are more accepting of this type of care. Hospice staff serve all those who seek care, receive training to serve diverse clients, and prioritize professional policies. There is sometimes potential for a gap between hospice policies regarding care and immigrant families' expectations for care. Results suggest a great need for community outreach to immigrant groups to raise awareness of end-of-life care, including advance directives and hospice care and the role of interpreters in health care settings.

Keywords Russian immigrants · End-of-life care attitudes in diverse populations · Hospice staff care for diverse patients

---

✉ S. Sudha
s_shreen@uncg.edu

Emily H. Eckemoff
Hensley.emily5@gmail.com

Dan Wang
wangdan.ivy@gmail.com

[1] School of Occupational Therapy, Brenau University, 500 Washington St SE, Gainesville, GA 30501, USA

[2] Department of Human Development and Family Studies, UNC Greensboro, 248 Stone Bldg, Greensboro, NC 27402-6170, USA

Introduction

Recent trends in immigration to the United States and decreased birth rates among native-born groups have led to an older American population that is increasingly diverse and foreign-born (Ortman et al. 2014). In 2010, almost 12% of seniors were foreign born, a proportion that is projected to increase (Scommegna 2013). Immigrant seniors will likely experience challenges because of unfamiliarity with the language, social norms, and health care system of the United States. These challenges may be especially likely when facing end-of-life care choices.

End-of-life care choices in the United States (US) include hospice care. Hospice care provides comfort care designed to alleviate pain and uncomfortable symptoms while acknowledging psychosocial and spiritual needs, in accordance with the patient's wishes (Bushfield 2010). Though hospice care use is increasing in the US, it is still not the predominant mode of care at the end of life. In 2016, fewer than half (about 48%) of deaths took place under hospice care (NHPCO 2018). Moreover, disparities persist in the use of hospice care, as race/ethnic minority groups are less likely to use hospice care or end-of-life care planning. Difficulties in cross-cultural communication play a role in this disparity (Carr 2012; Colón and Lyke 2015; Kwak and Haley 2005; NHPCO 2018). Fewer studies examine immigrants' use of end-of-life care in the US, and tend to focus on Hispanic or Asian immigrants (e.g. Pan et al. 2015; Rising et al. 2017), but those from other regions such as the Former Soviet Union (FSU) have been less examined. Hospice care does appear to benefit immigrants as enrolling in palliative care decreased immigrant patients' chances of hospitalization and increased their likelihood of discussing and documenting end-of-life care wishes (Carrion et al. 2012; Fernandes et al. 2010; Selsky et al. 2012). However, questions remain whether diverse immigrant groups are aware of such care, and whether they find it acceptable. To address this gap, this pilot study examines views on end-of-life care and hospice care among Russian immigrants in North Carolina, and hospice workers' training and policies regarding diverse immigrant patients.

Russian Immigrants' Use of Health Care

Since information on older Russian immigrants' use of hospice care is limited, insight can be gained by considering their use of health care overall. Immigrants and refugees from the FSU are one of the largest groups of 'émigrés' to enter the US in recent decades, due to the dissolution of the FSU and the outmigration of persecuted religious minorities (e.g. Jews and Protestant Christians) (Van Son and Gileff 2013). According to the American Community Survey 2009–2013, there are approximately 890,120 Russian speakers in the US who originating from the FSU (Schoua-Glusberg et al. 2016). Most research refers to them as 'Russians' (Newhouse 2013). They are mostly urban and middle class and 40% of them have college education. They are significantly older than the US population: 44% are aged 55 years and over (Ameredia 2012; Belusova 2011). Russian immigrants report higher levels of disability despite higher education and lower rates of smoking and alcohol consumption, than the general US population (Hofmann 2012; Mehta and Elo 2012). They are also higher consumers of health services, for reasons including loneliness and somaticized stress (Aroian et al. 2001).

Unfamiliarity with the language and medical systems in the US, and lack of money and health insurance, affect use of health services among older Russian immigrants (Ivanov et al. 2010). Understanding the role of insurance, fee-for-service, and other aspects of the US healthcare system is difficult for immigrants accustomed to universal socialized health care.

This results in feelings of ambivalence and lack of trust for Russian immigrants utilizing health services in the US (Aroian et al. 2001; Iowa Center on Health Disparities 2010; Yarova et al. 2013). Moreover, palliative or hospice care was not available under the Soviet health system and was introduced in 1990 in Russia. Though hospice coverage has grown in the FSU since then, Russia has no overall policy for palliative care, training for palliative care is limited among medical professionals, and strict controls on pain medications create a barrier to terminally ill patients accessing appropriate care (Goss et al. 2014). Lynch et al. (2013) describe Russia as being in the group of countries that provide 'isolated instances' of palliative care provision, which is patchy in scope, not well supported, restricted in provision of pain medication, and limited given the population to be covered. Thus, immigrants from the FSU are less likely to be familiar with hospice care or to seek it out when terminally ill.

Language differences and acculturation are also challenging. Jackson et al. (2011) found that in 31% of all medical encounters involving a patient with limited English the information communicated had been altered, significantly so in 5% of the cases. Phrases get lost in translation or appropriate terms may not exist in the patient's language, leading to substantial communication challenges for health providers discussing care with immigrant seniors. Older Russian-speaking immigrants who live alone are more likely to be depressed and to experience difficulties using the health care system (Tran et al. 2000, 2008). Immigrants more familiar with the new culture, who know the language, and make friends, suffer less from depression and culture shock (Tsytsarev and Krichmar 2000).

Hospice care in the US is paid for mainly through Medicare, Medicaid, private insurance, private pay, or charitable contributions. Medicare is the primary source of hospice payments. Patients receive hospice care regardless of ability to pay, but several factors may create perceived barriers to access for older immigrants. Older immigrants often lack a US work history that creates eligibility for Social Security or Medicare benefits (O'Neil and Tienda 2014). Low income naturalized citizens can receive Supplemental Security Income but may not apply for Medicaid during their first five years as citizens. Eligibility guidelines vary by state, are strict, confusing, and often the primary focus is on pregnant women and children, excluding many vulnerable seniors (Fortuny and Chaudry 2012). Some insurance options for immigrant seniors may be available under the Affordable Care Act (MedicareResources.Org 2015). The application process for US citizenship requires English capability, which may be challenging for older immigrants (Van Son and Gileff 2013). While no national level data appear to exist for older Russian immigrants' health insurance access, Current Population Survey data show that 23.2% of Russian immigrants overall are without health insurance (Camarota 2012). These factors may create a perception of barriers to accessing hospice care for Russian immigrants.

Therefore, families and health care providers will face challenges providing adequate end-of-life care to Russian immigrant seniors, aspects less studied for this population. The present pilot study aims to take a first step toward addressing these gaps. We examine the following research questions:

1. What are Russian immigrant older adults' awareness and views regarding end-of-life care?
2. What are the awareness and views of the adult children of older Russian immigrants on end-of-life care for their seniors?
3. What are the policies of hospice facility staff to care for older immigrants?

Materials

Participants

The pilot study was conducted in 2012–2013 in central North Carolina counties with a high concentration of immigrant populations. The research team comprised an undergraduate student having basic familiarity with spoken and written Russian and a personal connection with the Russian immigrant community, a faculty member with expertise in gerontology and immigrant health, and a graduate student, neither of whom know Russian. In addition, a Russian language native speaker was available for additional translation/interpretation support during interviews if needed. All team members have an academic focus on family studies. We used a qualitative approach to explore the research questions, with individual in-depth interviews as the method of data collection, to elicit greater detail on immigrants' and providers' perspectives (Strauss and Corbin 1998). This study was reviewed and approved by the Institutional Review Board of the University of North Carolina Greensboro.

We interviewed three groups of participants: a) Russian seniors aged 60 years and above, b) Russian adult children with an older parent, and c) local area hospice staff. The first author reached out to local employers and service and religious organizations with substantial numbers of Russian clients, and sought introductions to potential participants. We solicited additional introductions from the first set of interviewees. For hospice staff, the first author contacted the Directors of area hospice and palliative care organizations to solicit participants among the staff.

This selection strategy made purposeful contact with persons whose qualities and experiences highlighted end-of-life care for immigrants, allowing our pilot study to achieve meaningful information with fewer participants (Polit and Beck 2006). These participant subgroups shared aspects of homogeneity, such as demographic homogeneity and life history homogeneity, based on their ethnic background, life experiences, and work experiences. Moreover, the aim of our pilot study is idiographic in nature, to bring forth attitudes and experiences toward end of life care among this immigrant community and relevant professionals, so that a smaller number of participants gives the chance for each individual to have a voice within the study, in contrast to studies that aim to develop or test a general theory that need more participants (Robinson 2014).

The first author interviewed four Russian seniors and five Russian adult children (including one community leader). All these participants self-identified as members of the Russian immigrant community. The seniors' ages ranged from 60 to 70 years, and all were female. One had immigrated from the FSU as a young adult, and three were born in the US. The adult children's ages ranged from mid-thirties till 60 years. Four were female, and two were male. Only one (a man) was the child of one of the seniors. The others were unrelated. All were college educated with professional occupations. Three had immigrated from the FSU as young adults, and two were born in the US. Participants who were born in the FSU and had moved to the US are referred in our analyses to as 'first generation immigrants'. Those born in the US are referred to as 'second generation immigrants'. The first author also interviewed four hospice staff who were all US born and trained, all female, with work experience ranging from two to 30 years. One was a facility director, one was a nurse, and two were social workers. They worked at a free-standing hospice facility. The facility served all who sought care, irrespective of immigration status. They did not have information on whether Russian clients had been served.

Methods

Data Collection

The first author sought informed consent and interviewed participants at locations of their choice. The Russian immigrant participants were all fluent in Russian and had good conversational capacity in English. Due to participant preference, individual in-depth interviews were conducted in English, with occasional interspersed Russian words with some older adults. These words were within the linguistic capability of the first author. The additional Russian language interpreter support was not needed. Each initial interview, shaped by an interview guide, lasted about 45 min and was audiotaped, supplemented by handwritten notes, and briefer follow up interviews when needed. Interview recordings were transcribed mostly by the first author who translated where necessary, and some transcribed by the other two authors when no Russian words were used.

The individual in-depth interview guides included questions, follow up questions, and probes as needed (Strauss and Corbin 1998). Questions for Russian seniors and adult children included, for example, “What kind of care do you think older adults will need toward the end of life?” A follow up question was “What does your culture view as good care for older persons nearing the end of life?”, and a probe was “have you discussed this with your children/parent?” Additional questions investigated whether they had heard of hospice care or advance directives, whether the senior had health insurance, and how they accessed health care. We also solicited recommendations on what could be done to improve end-of-life care for Russian immigrants.

Hospice staff were also interviewed individually, in depth. Questions for hospice staff workers included, for example, “What are the hospice policies and procedures with regard to patients from diverse cultures, or unfamiliar with English, or with the U.S. healthcare system?” and follow up questions including “Have you received special training to care for older immigrant patients?” Probes included “What do you recommend to improve care for terminally ill seniors who are immigrants?” Questions for hospice staff focused on immigrants in general, and asked if they had experience with Russian immigrants in particular, which none reported.

Data Analyses

We followed a content analysis approach to analyze the interview data, using inductive approaches to identify emerging themes and patterns (Cho and Lee 2014). Data analyses were continuously carried out while data collection was ongoing, as emerging themes from transcripts were discussed during weekly research team meetings. First, each researcher individually read one or two transcripts and identified emerging themes, which were discussed during the meetings. Notes were kept of the meeting discussions and decisions. Follow-up interviews were conducted if questions arose that were not answered in the existing data. After all transcripts were analyzed, identified themes were discussed and organized. Questions and concerns were addressed and any disagreements resolved to consensus via discussion. These procedures facilitated close, ongoing engagement with the data; maintained an audit trail; and supported credibility, dependability, and confirmability of the data and analytic process; thus promoting rigor in this pilot qualitative study (Barusch et al. 2011; Knapik et al. 2010).

Results

Russian Immigrants

Themes emerging from data analyses are presented in Table 1.

We first present results from the interviews with Russian seniors and adult children. Five major themes emerged. The first was the preference for family care for aging parents. Second was the perceptions of care provided in institutions. One interesting sub-theme was that of assisted suicide as a preferred alternative to care. Third was differences in views based on acculturation of participants. Fourth was the lack of advance care planning by families, and fifth, the view that society had a responsibility to contribute to care of seniors.

Family Involvement in Care

There was a widespread preference for family care for elders. Some of the adult children had a parent living with them, or were in the process of having their parents immigrate to live with them. Seniors and adult children born in the FSU expected the family to act as primary caregivers. One participant said: "*as for our family traditions, we rely more on ourselves.*" This participant went on to explain her life in Russia and her feelings toward end-of-life care.

> *We were living together ... in Russia ... me and my brother, my mom, my dad, my grandmom ... and great-grandmom with her husband, ... in one small apartment. And ... I could not imagine that I will send my old grandparents somewhere to hospice.*

An older adult immigrant said: "*<sighs> I think it should be primarily the family, not the hospitals at all. I think a doctor who knows the family well and knows the older person well should be involved and be advising the family.*"

Table 1 Themes emerging from individual in-depth interviews

	Participants		
	Russian elders	Russian adult children	Hospice staff
Themes	Preference for family care for seniors	Preference for family care for seniors	Preference for family care among immigrants
	Negative perceptions of institutional care, lack of knowledge	Negative perceptions of institutional care, slightly more knowledge	Lack of knowledge of care institutions among immigrants
	Different views from younger generation	Different views from older generation	
	Lack of advance planning for end of life care	Lack of advance planning for end of life care, more open to it	Less knowledge of advance planning for end of life care among immigrants
	Societal responsibility for care	Societal responsibility for care	
			Receive training to work with diverse communities, challenges
			Patient self-determination can counter families' preferences

Perceptions of Institutional Care

Many participants did not distinguish between long term care facilities and end-of-life care, and expressed negative perceptions of facilities. An adult child first generation immigrant said:

> *In those senior places where people live doing nothing. They have no future ... They don't know what to do ... they're lost people there ... how those other Russians live here in this Golden Gate ... They have small rooms, they have everything there but they cannot go outside. They have no cars. They are locked there in this Golden Gate, even a cage or whatever.*

Thinking about himself, an adult child first generation immigrant spontaneously mentioned that he would prefer assisted suicide to hospice care or losing independence:

> *I would not want to end up in a hospice. I would rather have, what's the medical term for it, I don't know, to ending life before, like they have it in Oregon for example, so you ... don't have to wait till you are completely powerless about yourself.*

He indicated that his father also shared this attitude:

> *Well, my dad is pretty explicit about that, he said when he can't do stuff himself he'll just go 'off' himself, <chuckles> he was joking ... but that gives you the idea that he would not want ... just to extend another few months of his life -when it's time to go, it's time to go, that's his position.*

Another first-generation adult child explained how she took care of her mother who had suffered a stroke. Language unfamiliarity was a deciding factor in not utilizing a care facility: "*My mom lived with me after having one stroke and then a second one and she was in total care and that was fine. She didn't speak English well so she couldn't really go to a nursing home.*"

However, second generation adult children showed different attitudes toward care institutions including hospice, as exemplified by one woman:

> *I believe that older adults require careful attention. ... in order to relieve the children of primary responsibilities older adults should prepare themselves to go into ... graduated care, so their children don't have the primary responsibility for overseeing their care.*

A first-generation adult child acknowledged that family care could sometimes be difficult:

> *there could be different family situations, like you need to go to work ... and at the same time this older person will open the door and go somewhere on the street and be lost there forever ... so I am not sure what the approach is for each particular case could be.*

Acculturation

Differences appeared in expectations of end-of-life care between first- and second-generation immigrants, likely attributable to acculturation. Regarding preference for care, one first generation immigrant adult child said: "*we more rely on ourselves because ... I could not trust the first person from the street ... I could trust my own kids*". By contrast, one second-generation immigrant older adult expressed a preference not to be cared for by her children.

> *Interviewer- "So, you have no expectation whatsoever of your children being your primary caregiver?"*
> *Participant: "Not at all. I would not want it that way."*

She clarified that she was close to her children, but did not want them to be her primary caregivers, and was already on a waiting list for a retirement community. Regarding hospice care, she said:

> *When my dad became very sick … for his last six months he was visited by a hospice nurse every day, toward the end more than once a day, and it was a wonderful help both to him and my mother. I think it's an amazing institution.*

Another second-generation immigrant adult child said:

> *I don't want to be a burden to anybody. My mother and father both had chronic illnesses and that just drags it out ... for myself, I would just like to live close to one of my daughters, so they could stop in and … check in on me, not necessarily for me to live in their home.*

Such wishes reflected the preference found in US society for 'intimacy at a distance', where older adults prefer to live close to their family to facilitate contact and support, but not to live with them.

Advance Care Planning

Participants raised in the US appeared more familiar with American health and legal systems including advance care planning, advance directives, end-of-life care preferences, health care power of attorneys, etc. This information was lacking among the first-generation adult children, even in this more educated, professional group. One first generation participant said that he knew nothing about hospice care and living wills. He said: "*I hear about hospice care but I actually never have much closer [sic] experience.*" He also expressed concern about the cost of professional end-of-life care. Other participants also had not heard of the term 'advance directive', and confused 'living will' that documents preferences for life sustaining treatment and end-of-life care with the last will and testament that disposes of property.

In contrast, second generation immigrant adult children knew more about these systems, including potential difficulties. For example, regarding health care power of attorney, a second-generation woman, a nurse, said

> *I think it's a good thing. … The problem is that you need to carry it with you all the time. My mom would have these episodes where she would need to go to the ER, and I wouldn't have it with me (laughs).*

Regarding advance directives, she also said:

> *I think it's a good thing but with the same problem … my mom was hospitalized and they said 'remember to bring it in' and I kept forgetting … I think they are good things but not implementable and the whole idea is implementing them.*

There seemed to exist a ‘culture of silence’ surrounding discussion of end-of-life care among first generation immigrants. Some mentioned that in Russian culture, death is a taboo topic which people do not usually discuss until the very end. One adult child said:

> *I don't think Russians really discuss those matters, it's like ... something in the future and you don't really talk about this ... I don't see an easy way to start talking about that because if I say, ‘So, Mom what do you want to do when you have six months left?’ ... then she will be, ‘Are you already ready to bury me?’*

Another first-generation adult child also had no plan or legal paperwork for his parents. He said “*You know, I think they are living from another society. It may be ... [they think] we are kids and we will take care of them without signing any papers.*”

By contrast, second-generation adult children believed in the need for families to plan ahead of time. One second-generation daughter shared:

> *I think that within families it’s essential to discuss these things realistically ... we all die and that is an essential part of life and that is how I raised my children ... as difficult as it is ... it must be discussed. ... when people get older things do happen, like ... a person can fall down and then they have some injury ... then they need help, so ... they need to know what sort of things they want and discuss that with their family.*

Though first-generation adult children felt it would be almost impossible to discuss these issues with their parents, they did indicate a willingness to plan ahead for themselves. One first-generation adult child said: “*we do have a will right now (my wife and I), so even though we’re both mid-thirties, I think it’s good to have ... very few Russians have wills at all*”. This participant did not distinguish between a property will and a living will/advance directive, and had not heard of the latter.

Societal Responsibility for Care

Another theme evident among immigrant participants was that society should share the responsibility for end-of-life care. One participant said:

> *I strongly believe in socialized medicine ... a comprehensive coverage for everybody that is tax based, not insurance based ... the plan should include caring for people who are older ... but ... if the family wants to take care of this person, then they have absolutely the priority, ... only certain families can afford that and the predominant majority wouldn't be able to.*

Another participant, referring to terminally ill seniors, said: “*there should be family ... plus medical professional care. So, if this medical care could be ... paid for from government funds or some kind of health insurance funds ... then maybe family will be a little bit relieved*”. She felt that lack of health insurance prevented her elderly mother in Eastern Europe from joining her in the US:

> *my mom is getting sick right now and I’m here and ... I am trying to bring her here but ... because she will not have benefits for medical treatments, so she knows if something were to happen to her I would pay all the big amount of money for that, and maybe she don’t want to involve me with this trouble.*

Hospice Staff

We next present findings from interviews with hospice staff which also revealed five broad themes. First, though staff are trained to serve diverse populations, it is challenging to serve immigrant seniors. Second, immigrant seniors prefer family care. Third, the hospice philosophy that patients have the right to determine their own care can run counter to immigrant patients' and families' preference for families to have priority in determining care. A related theme was that non-family interpreters are sometimes not welcomed by immigrant families, because of the reluctance to involve outside persons in family matters; this runs counter to hospice guidelines about using non-family interpreters. Finally, hospice staff also noted that immigrant families were usually less familiar with health care systems in the US, especially end-of-life care. All staff had worked with diverse clients including immigrants, but none had worked with Russian immigrants.

Care for Diverse Immigrants at the End-of-Life

Hospice staff described receiving training on working with a diverse clientele. One staff worker said: "*We have policies and procedures that dictate every year that every clinical staff, that means anybody who walks into a home, takes a class on cultural competence ... that discusses diversity and respect, so we are extraordinarily mindful of that.*" However, staff also acknowledged that accommodating immigrant patients is more challenging, partly because some immigrants are not fluent in English, and partly due to the requirement to be culturally competent and to honor patients' preferences. A hospice staffer said:

> *It's definitely more difficult to have an interpreter ... at three o'clock in the morning to use the AT&T language line and have a relay conversation, rather than a direct conversation ... It takes another level of coordination ... It can also be difficult for staff to interact with people, families, patients who have customs and practices that are not familiar to them and it takes more time to learn ... so that you're respectful and mindful.*

Patients' immigration or insurance status was not considered by staff. A staff member stated:

> *Their status does not matter ... if they are uninsured with legal status or not, we will provide care ... we try to create a safe place that people can receive care ... at end of life, and are extraordinarily mindful of that responsibility because people are so vulnerable at that time.*

Preference to Stay at Home

Another theme mentioned by hospice workers paralleled Russian immigrants' reports that immigrant seniors strongly prefer to be cared for at home. A hospice worker with thirty years' experience said, "*The one thing that I have seen almost across the board in people from other countries who I've cared for at the end of life, is the desire to be in their own home, as opposed to being in a 'facility'.*" This participant expectation of family care contrasted to the time available to the younger generation to provide care:

> *I think that there is an expectation of older adults, especially those from other countries, that the family will provide … care at the end of their life. … I think some of the older adults may not be able to quite grasp that the younger people and their family maybe have to go to work every day, and that those care-giving responsibilities are more than what they are able to manage. And so a facility is something that is necessary.*

When families are unable to provide adequate care at home, hospice staff assist families to form a feasible plan. A hospice staffer said: "*It also often depends on the patient's physical needs, the reality of their situation. Many people hate the thought of being in a nursing home, but reality tells us if care needs are great that is sometimes the only option and sometimes we have to look at the best worst option.*"

Gap between Hospice Staff and Family's Views on Care

Hospice staff's philosophy on appropriate end-of-life care contrasted to immigrant seniors' and families' views. According to hospice policies, older persons have the right to determine their own care, even if the family disagrees. A hospice worker said:

> *Well I don't think that families … have the right to make any decisions if the patient is able to make decisions for themselves … as a professional, we need to advocate for that … even if takes longer to explain it to them … we … need to take the lead in seeing that that happens … in all cases we look to the patient first.*

Hospice staff felt that family members should consult patients' preferences and not make decisions without honoring the patients' opinion. Another hospice worker said: "*It's not really up to the daughters, and grandchildren, and the nephews. It's truly up to what that person wants and if they're capable of making decisions.*"

To address situations when a patient can no longer communicate, individuals are encouraged to document their wishes in an advance directive. A hospice staffer said: "*I think the idea of advance directives and helping people to define decision makers … is very important.*" Another said: "*If someone has an advance directive … if they're not able to answer a question at the moment but they identified somebody they wanted to speak on their behalf, we need to honor that.*"

However, this can be challenging. Different cultures may not share the idea that the patient should be told they are terminally ill, or that the patient should make the decisions, as one hospice staff member noted.

> *Sometimes the dynamics might seem different because we don't understand the cultural norms within a particular culture or family or religion. We might think it's inappropriate for the oldest man to be making the decisions when in fact that's really what happens.*

Another hospice worker said

> *But yeah, family dynamics, you have cultures where you don't tell people about their diagnosis … about the prognosis. You have to respect that, you know, maybe … let's just say, the mother, who is going through all of this … has cancer. But their culture dictates*

> *that you do not talk to the mother about that, you talk to the children. Children make the decisions for the mother.*

If the patient and the family don't agree on a care option, or if the patient can no longer communicate and family members disagree, an interdisciplinary team is brought in. Using open communication to express fears, concerns, and hopes, the team aims to bring everyone to an understanding of the situation and move at a pace which all are able to accept.

Use of Non-Family Interpreters

Another potential divergence between hospice policies vs. immigrant patients and families' views, is the use of non-family translation and interpretation services for patients with limited English. A hospice staff member said: "*Well, most agencies, government agencies especially, have to have an interpreter available, that's just a requirement.*" Another said:

> *Not only our licensure responsibility but our ethical responsibility is to provide care for a patient and their family in the language that they are most comfortable with. We also put a priority on family members not being the interpreters because that's just not ethically appropriate.*

This can create unintended friction when patients may prefer family members to interpret, and families might expect that they will interpret for their relative due to privacy concerns and being familiar with their language, needs, etc. Another hospice worker said,

> *With some populations ... they don't want a translator. They don't want to share their private information through anybody else. We recently had a patient that refused translation, and we had a signed consent that they did not want translation, to actually in some ways protect us. And that also was very, very hard because we knew they were not understanding what we were saying. And I think the translator also helps us identify what the patient's family really wants and needs. But if someone refused a translator, we had a translator come so that we could really determine that they didn't want a translator (laugh).*

Immigrants' Information on End-of-Life Care

Hospice staff also pointed out immigrants' information sources and gaps regarding end-of-life care. One hospice staffer said, "*we had a number of people who have experienced the health care system but maybe not understand exactly how it works.*" Another pointed out the importance of agencies and community organizations in connecting immigrant and refugee families with health care providers, and bridging the information gap. She said: "*A lot of needs are met when they initially get over ... they have the government actually moving them in, and getting them hooked up with whatever resources are here, and so that's usually how it all starts.*" Another staffer said:

> *Whatever agency might call us in ... we're working with that agency to help the family ... it's the people from their community that have been here longer and that know the resources that really ... provide the most help to them.*

Discussion

Russian Immigrants and Staff Views

This study examined Russian immigrants' views on end-of-life care and hospice care in the US, and hospice workers' training and policies regarding working with immigrant clients. Many prior studies showing that immigrants have less awareness and use of hospice care examined ethnic minority groups (Kwak and Haley 2005). However, immigrants from the FSU have been less studied. Our findings indicated similarities between the attitudes of immigrants from the FSU and other immigrant groups in the US. There was less awareness of end-of-life care among first generation immigrants, though adult children appeared more open to these options compared to seniors. Discussing end-of-life care with children seemed almost taboo among older Russians, as also noted by Newhouse (2013) who attributed this to factors such as poor health care in the FSU, beliefs about bad luck, and reluctance to talk about pain or to tell a family member about a terminal diagnosis. Such reticence is also noted among other immigrant communities such as Latinos (Kreling et al. 2010). Advance care planning and taking individual initiative on health care decision-making may be alien to seniors raised in the FSU, because individual planning was not a feature of a centrally planned Socialist society, and doctors were more authoritarian and complied less with patients' wishes (Kwak et al. 2014; Richter et al. 2001). We found a strong preference for families to care for aging parents. However, second generation participants were more likely to be aware of end-of-life care options, prefer non-family care, and discuss hospice care in families.

Practice Recommendations

Our findings suggest strategies for raising awareness and use of hospice care among Russian immigrant seniors, which parallel recommendations for other diverse groups. As also stated by Carrion et al. (2012), hospice staff should work more closely with immigrants' families to raise awareness of and allay concerns about hospice care. They should let families know hospice policies on interpreters, including that offering interpretation services is mandatory though the family can refuse them, and that family members cannot be interpreters due to ethical concerns. These policies are less known to immigrants. The policy of non-family interpreter / translator services can pose an unintended barrier for clients with limited English who do not want their private information to be shared with others. Hospice staff could consider honoring patients' preference for a trusted family interpreter when there are no circumstances that make this inappropriate. Patients could be offered a choice of interpreters (Van Son and Gileff 2013). However, professional recommendations endorse using a non-family interpreter trained in palliative care (Crawley and Koffman 2015; Newhouse 2013). Another challenge arises between families who want to direct seniors' care vs. hospice staff who focus on carrying out patients' wishes. Families and patients should be made aware early in the process that patients' wishes are paramount, and facilitated to discuss and document the patient's wishes, so that family members' 'subsidiary plans' (which might mask the patient's interests) are deflected (Michael et al. 2014). Having the physician initiate the dialogue, involving adult children, approaching the topic slowly, providing adequate information about choices, and showing personal warmth are also strategies recommended in the literature (Newhouse 2013).

Patients who received end-of-life care consultation had lower scores of pain and post-traumatic stress disorder; earlier transition to care provided more benefits (Casarett et al. 2008). Therefore, it is important to have immigrant families and communities educated about the U.S. health system, including options for end-of-life care.

There should be improved co-ordination between hospice staff, immigrant service agencies, and senior service organizations to develop and disseminate information to diverse immigrant communities on end-of-life care (Kwak et al. 2014). Fostering trust and open communication among the FSU immigrant community and those who can be seen as authority figures, is a delicate task which can be accomplished by sustained engagement between service providers and community leaders (Van Son and Gileff 2013). A variety of communication techniques and technologies should be used to overcome gaps in language, culture, education, reluctance to talk about death, etc. Agencies should fine-tune continuing education to their staff on end-of-life care to diverse cultures. To promote these goals, hospices and other agencies should actively recruit staff and volunteers with multi-cultural skills and multiple language competencies.

Current trends in demographic profiles of immigrant populations, coupled with trends in cause of death patterns, underscore pressing policy and outreach needs in end-of-life care including hospice care in the US. Increased variation in diagnoses, greater multimorbidity and disease complexity among people with terminal illnesses, accompanied by changing patterns and locations of end-of-life care, create greater ‘care intensity’ and associated need for high quality care at the end of life (Aldridge and Bradley 2017; Meier 2011). This creates growing need for hospice care and concomitant need for increased outreach to diverse populations including immigrants.

Study Limitations

This pilot study had some limitations. First, the research team could only interview a limited cross section of Russian participants, all whom were educated and middle class. Thus, the broader spectrum of Russian immigrants are less represented. Nonetheless, even among this segment of society, knowledge gaps regarding end-of-life care were revealed. A related major limitation is that all the participants of this study had sufficient English fluency to prefer to be interviewed in that language. This contrasts with a large proportion of immigrants from the FSU, about 42% of whom have limited English proficiency (Zong and Batalova 2015). Among older immigrants, the percent with limited English is likely greater. Thus, these results need additional verification from studies with a wider range of participants who were interviewed in the Russian language. However, since knowledge about end-of-life care was limited even in this group, it is likely that average Russian immigrants who are not fluent in English would know even less about these aspects of the US healthcare system. Therefore, our results represent a conservative estimate of the situation. Participant recruitment for this study was challenging, since the topic was viewed as sensitive. A community-engaged approach including ongoing partnership with community organizations and individuals is needed to reach more participants. It may also be that Russian immigrants raised under the Communist regime may feel apprehensive about being involved in a study of a sensitive topic, and wary of seemingly official inquiries. Notwithstanding these limitations, our pilot study adds to the evidence on views toward end-of-life care among immigrants from the FSU, and on potential gaps created by hospice policies versus immigrant patients’ preferences, and paves the way for further studies addressing end of life care needs among immigrants from the FSU.

Acknowledgements The authors are grateful to the Gerontology Program of UNC Greensboro for research support to the first author.

Funding This study received funding from the Gerontology Graduate Program, UNC Greensboro.

Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

References

Aldridge, M. D., & Bradley, E. H. (2017). Epidemiology and patterns of care at the end of life: Rising complexity, shifts in care patterns and sites of death. *Health Affairs, 36*(7), 1175–1183.

Ameredia (2012). Russian American demographics. *Integrated multicultural marketing*. Retrieved on May 13, 2014, from http://www.ameredia.com/resources/demographics/russian.html

Aroian, K. J., Khatutsky, G., Tran, T. V., & Balsam, A. L. (2001). Health and social service utilization among elderly immigrants from the former Soviet Union. *Journal of Nursing Scholarship, 33*(3), 265–271.

Barusch, A., Gringeri, C., & George, M. (2011). Rigor in qualitative social work research: A review of strategies used in published articles. *Social Work Research, 35*(1), 11–19.

Belusova M. (2011). The Russian diaspora in the US *Russian Analytical Digest No.* 107*,* 27 January 2011.

Bushfield, S. (2010). Use of spiritual life maps in a hospice setting. *Journal of Religion, Spirituality And Aging, 22*, 254–270.

Camarota, S. A. (2012). *Immigrants in the United States: A profile of America's foreign-born population*. Center for Immigration Studies. Retrieved from https://cis.org/Immigrants-United-States-2010. Accessed 2 Nov 2016.

Carr, D. (2012). Racial and ethnic differences in advance care planning: Identifying subgroup patterns and obstacles. *Journal of Aging Health, 24*, 923–947. https://doi.org/10.1177/0898264312449185.

Carrion, I. V., Park, N. S., & Lee, B. S. (2012). Hospice use among African Americans, Asians, Hispanics, and whites implications for practice. *Hospice and Palliative Care, 29*(2), 116–121. https://doi.org/10.1177/1049909111410559.

Casarett, D., Pickard, A., Bailey, F., Ritchie, C., Furman, C., Rosenfeld, K., & Shea, J. A. (2008). Do palliative consultations improve patient outcomes? *Journal of the American Geriatrics Society, 56*, 593–599. https://doi.org/10.1111/j.1532-5415.2007.01610.x.

Cho, J. Y., & Lee, E. (2014). Reducing confusion about grounded theory and qualitative content analysis: Similarities and differences. *The Qualitative Report, 19*(32), 1–20 Retrieved November 12, 2015 from http://nsuworks.nova.edu/tqr/vol19/iss32/2.

Colón, M., & Lyke, J. (2015). Comparison of hospice use by European Americans, African Americans, and Latinos: A follow-up study. *American Journal of Hospice and Palliative Medicine®, 32*(2), 205–209.

Crawley, L., & Koffman, J. (2015). Ethnic and cultural aspects of palliative care. In N. Cherny, M. Fallon, S. Kaasa, R. Portenoy, & D. C. Currow (Eds.), *Oxford textbook of palliative medicine* (5th ed.). Oxford: Oxford University Press.

Fernandes, R., Braun, K. L., Ozawa, J., Compton, M., Guzman, C., & Somogyi-Zalud, E. (2010). Home-based palliative care services for underserved populations. *Journal of Palliative Medicine, 13*, 413–419. https://doi.org/10.1089/jpm.2009.0216.

Fortuny K. & Chaudry A. (2012). Overview of immigrants' eligibility for SNAP, TANF, MEDICAID, and CHIP *ASPE Issue Brief March 2012*, Office of the Assistant Secretary for planning and evaluation, US Dept. of Health and Human Services. Retrieved May 26, 2015 from http://aspe.hhs.gov/hsp/11/ImmigrantAccess/#Publications

Goss, P. E., Strasser-Weippl, K., Lee-Bichkovsky, B., Fan, L., Li, J., Chavarri-Guerra, J., et al. (2014). Challenges to effective cancer control in China, India, and Russia. *The Lancet Oncology, 15*(5), 489–538, April 2014. https://doi.org/10.1016/S1470-2045(14)70029-4.

Hofmann, E. T. (2012). The burden of culture? Health outcomes among immigrants from the former Soviet Union in the United States. *Journal of Immigrant & Minority Health, 14*(2), 315–322. https://doi.org/10.1007/s10903-010-9436-3.

Iowa Center on Health Disparities. (2010). *Russians and Other Immigrants from the Former Soviet Union* retrieved on 8/5/15 from http://www.iowahealthdisparities.org/documents/russian.pdf

Ivanov, L. L., Hu, J., & Leak, A. (2010). Immigrant women's cancer screening behaviors. *Journal of Community Health Nursing, 27*, 32–45.

Jackson, J., Nguyen, D., Hu, N., Harris, R., & Terasaki, G. S. (2011). Alterations in medical interpretation during routine primary care. *Journal of General Internal Medicine, 26*(3), 259–264. https://doi.org/10.1007/s11606-010-1519.

Knapik, G. P., Martsolf, D. S., Draucker, C. B., & Strickland, K. D. (2010). Attributes of spirituality described by survivors of sexual violence. *Qualitative Report, 15*(3), 644–657.

Kreling, B., Selsky, C., Perret-Gentil, M., Huerta, E. E., & 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*(4), 427–434. https://doi.org/10.1177/0269216310366605.

Kwak, J., & Haley, W. E. (2005). Current research findings on end-of-life decision making among racially or ethnically diverse groups. *The Gerontologist, 45*(5), 634–641.

Kwak, J., Ko, E., & Kramer, B. J. (2014). Facilitating advance care planning with ethnically diverse groups of frail, low-income elders in the USA: Perspectives of care managers on challenges and recommendations. *Health and Social Care in the Community, 22*(2), 169–177. https://doi.org/10.1111/hsc.12073.

Lynch, T., Connor, S., & Clark, D. (2013). Mapping levels of palliative care development: A global update. *Journal of Pain and Symptom Management, 45*(6), 1094–1106. https://doi.org/10.1016/j.jpainsymman.2012.05.011.

MedicareResources.org (2015). Retrieved May 26, 2015 from http://www.medicareresources.org/faqs/can-recent-immigrants-to-the-united-states-get-health-coverage-if-theyre-over-65/

Mehta, N. K., & Elo, I. T. (2012). Migrant selection and the health of U.S. immigrants from the former Soviet Union. *Demography, 49*, 425–447. https://doi.org/10.1007/s13524-012-0099-7.

Meier, D. E. (2011). Increased access to palliative care and hospice services: Opportunities to improve value in health care. *Milbank Quarterly, 89*, 343–380. https://doi.org/10.1111/j.1468-0009.2011.00632.x.

Michael, N., O'Callaghan, C., Baird, A., Hiscock, N., & Clayton, J. (2014). Cancer caregivers advocate a patient- and family-centered approach to advance care planning. *Journal of Pain and Symptom Management, 47*(6), 1064–1077.

National Hospice and Palliative Care Organization. (2018). *NHPCO facts and figures: Hospice Care in America Rev Ed April 2018*. Alexandria: National Hospice and Palliative Care Organization.

Newhouse, L. (2013). Working with Russian-Jewish immigrants in end-of-life care settings. *Journal of Social Work in End-of-Life & Palliative Care, 9*(4), 331–342. https://doi.org/10.1080/15524256.2013.846884.

O'Neil, K., & Tienda, M. (2014). Age at immigration and the incomes of older immigrants, 1994–2010. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 70*(2), 291–302.

Ortman J. M., Velkoff V. A., & Hogan H. (2014). An aging nation: The older population in the United States. *Population Estimates and Projections Current Population Reports* Issued May 2014 P25-1140 U.S. Dept. of Commerce Economics and Statistics Administration U.S. Census Bureau.

Pan, C. X., Abraham, O., Giron, F., LeMarie, P., & Pollack, S. (2015). Just ask: Hospice familiarity in Asian and Hispanic adults. *Journal of Pain and Symptom Management, 49*(5), 928–933. https://doi.org/10.1016/j.jpainsymman.2014.09.016.

Polit, D. F., & Beck, C. T. (2006). *Essentials of nursing research: Methods, appraisal, and utilization* (6th ed.). Philadelphia: Lippincott Williams & Wilkins.

Richter, J., Eisemann, M., & Zgonnikova, E. (2001). Doctors' authoritarianism in end-of-life treatment decisions. A comparison between Russia, Sweden and Germany. *Journal of Medical Ethics, 27*(3), 186–191.

Rising, M. L., Hassouneh, D. S., Lutz, K. F., Lee, C. S., & Berry, P. (2017). Integrative review of the literature on Hispanics and hospice. *American Journal of Hospice and Palliative Medicine, 35*(3), 542–554. https://doi.org/10.1177/1049909117730555.

Robinson, O. C. (2014). Sampling in interview-based qualitative research: A theoretical and practical guide. *Qualitative Research in Psychology, 11*, 25–41. https://doi.org/10.1080/14780887.2013.801543.

Schoua-Glusberg A., Kenward K., & Morales G. (2016). Qualitative research with demographically diverse Russian speakers. - U.S. Census Bureau research support services *−2016 AAPOR Annual Conference–Austin, Texas–May 14, 2016*. Retrieved November 12, 2016 from https://www.census.gov/content/dam/Census/newsroom/press-kits/2016/Qualitative%20Research%20with%20Demographically%20Diverse%20Russian%20Speakers.pdf .

Scommegna, P. (2013). "Elderly immigrants in the United States," *Today's Research on Aging*, no. 29, Population Reference Bureau, October 2013.

Selsky, C., Kreling, B., Lhuta, G., Makgoeng, S. B., Gomez-Duarte, J., Barbo, A. G. A., Mandelblatt, J. S., & Latin American Cancer Research Coalition. (2012). Hospice knowledge and intentions among Latinos using safety-net clinics. *Journal of Palliative Medicine, September 15*(9), 984–990. https://doi.org/10.1089/jpm.2011.0517.

Strauss, A. C., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd ed.). Thousand Oaks: Sage.

Tran, T. V., Khatutsky, G. G., Aroian, K. K., Balsam, A. A., & Conway, K. K. (2000). Living arrangements, depression, and health status among elderly Russian-speaking immigrants. *Journal of Gerontological Social Work, 33*, 63–77.

Tran, T. V., Sung, T., & Huynh-Hohnbaum, A. T. (2008). Measure of English acculturation stress and its relationships with psychological and physical health status in a sample of elderly Russian immigrants. *Journal of Gerontological Social Work, 50*, 37–50.

Tsytsarev, S., & Krichmar, L. (2000). Relationship of perceived culture shock, length of stay in the U.S., depression, and self-esteem in elderly Russian-speaking immigrants. *Journal of Social Distress and the Homeless, 9*, 35–49.

Van Son, C. R., & Gileff, T. Y. (2013). Relying on what they know: Older Slavic Émigrés managing chronic health conditions. *Qualitative Health Research, 23*(12), 1660–1671. https://doi.org/10.1177/1049732313508842.

Yarova, L. A., Covan, E. K., & Fugate-Whitlock, E. (2013). Effect of acculturation and health beliefs on utilization of health care services by elderly women who immigrated to the USA from the former Soviet Union. *Health Care for Women International, 34*, 1097–1115. https://doi.org/10.1080/07399332.2013.807259.

Zong, J., & Batalova, J. (2015). European immigrants in the United States. *Migration Policy Institute Migration Information Source*, Dec 1 2015. Retrieved from: https://www.migrationpolicy.org/article/european-immigrants-united-states-2. Accessed 3 Oct 2016.