Values and preferences for future end-of-life care among the indigenous Sámi

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Abstract
Introduction: Research with Indigenous peoples internationally indicates the importance of socio-cultural contexts for end-of-life (EoL) preferences. However, knowledge about values and preferences for future EoL care among the Indigenous Sámi is limited.

Aim: We investigated if and how a Swedish adaptation of the English-language GoWish cards, DöBra cards, supports reflection and discussion of values and preferences for future EoL care among the Sámi.

Methods: This qualitative study is based on interviews with 31 self-defined Sámi adults who used DöBra cards at four events targeting the Sámi population, between August 2019 and February 2020. Using directed content analysis, we examined aspects of interviews addressing Sámi-specific and Sámi-relevant motivations for choices. Data about individuals’ card rankings were collated and compiled on group level to examine variation in card choices.

Findings: All 37 pre-formulated card statements were ranked as a top 10 priority by at least one person. The cards most frequently ranked in the top 10 were a wild card used to formulate an individual preference and thus not representing the same statement, and the pre-formulated card ‘to have those I am close to around me’. Reactions to interviews varied, with some participants commenting on the taboo-laden nature of discussing EoL issues, although many commented positively about EoL conversations in general, and the benefit of using the DöBra cards in particular. We categorised reasoning about Sámi-specific and Sámi-relevant values and preferences under the themes: Attributes of contemporary Sámi culture, Spirituality, Setting for death, Maintaining identity, Preferences related to death, Dying and EoL care and After death.

Conclusions: The DöBra cards were found to be easy-to-use, understandable and a flexible tool for initiating and supporting conversations about EoL values and preferences. The open formulations of cards, with wild cards, enable discussions about individual values and preferences, with potential to reflect life as a Sámi in Sweden.
INTRODUCTION AND AIM

There is limited research about the Indigenous Sámi people in relation to end of life (EoL), in part due to assumptions of a culture of silence on the topic [1]. However, in our prior research, we found an openness among Sámi about sharing experiential knowledge about death, dying and bereavement. We have also shown how telling stories about Sámi-specific heritage included features that enabled clarification of last wishes, which can be seen as a form of advance care planning (ACP) [2]. Having conversations before death is imminent to clarify future EoL preferences, priorities, values and needs, internationally called ACP has been found to help people better deal with EoL issues when they arise [3], although formal ACP has been virtually non-existent in Sweden to date [4].

International research with Indigenous peoples indicates the importance of the socio-cultural context for EoL preferences [5]. Gott et al.’s research with both Indigenous New Zealand Maori and non-Maori elders [5] found similarities in EoL preferences by culture, gender and age. Kwak et al. [6] concluded that ACP is understudied among Native Americans while Dennis and Karla’s [7] study with tribal elders on a U.S. reservation suggests the importance of these issues, as talking about spirituality, death and dying, including ACP, was seen as a form of knowledge transfer.

A variety of tools [8] have been found to be beneficial in promoting ACP conversations, topics which may otherwise be difficult to approach and discuss. The DüBra cards, a Swedish adaptation of the English-language GoWish cards, aim to stimulate reflection and discussion of EoL values and preferences. The card deck, which has been made publicly available, contains 37 pre-formulated statements with items that research indicated are often important at the EoL, as well as wild cards for users to formulate other, more individual preferences not covered by those statements [9]. While most research on use of the cards derives from English-speaking populations in North America [10–13], they are available in nine other languages including Swedish (www.gowish.org), with research also conducted with elderly in Japan [14]. We are aware of only one study using the cards in an Indigenous population, i.e. an Australian study using the cards with Aboriginal peoples in a local remote community [15], where the cards were included as one of several ways to initiate EoL conversations.

Use of the DüBra cards has been investigated in different settings in Sweden and found to be well received among both the general public and staff in residential care homes [4, 9, 16–18]. The cards have been found to be feasible facilitators of conversations about values and preferences for EoL care, as well as useful for triggering general discussions about death and dying [9]. Eneslätt et al.’s research has pointed to the importance of considering how people reason about card statements, as this can vary by individual with regard to the same statement, and how wild cards are used to communicate individual values [4, 18].

Combining our previous experiences of conducting research with the DüBra cards [4, 9, 17, 18] and our research on EoL issues among the Sámi [2, 19], we focus here on investigating the use of the DüBra cards in Indigenous Sámi contexts. We were curious if both individual and culturally rooted preferences would be able to be clarified by the DüBra cards’ combination of pre-formulated card items and self-formulated wild cards. In this study, we therefore aim to investigate if and how the DüBra cards support reflection and discussion of values and preferences for future EoL care among the Sámi.

BACKGROUND

Context

The Sámi are Indigenous people who stem from northern Norway, Sweden, Finland and Russia. The number of Sámi in Sweden is controversial, with estimates ranging from ~17,000 to 40,000 [20, 21], with the lack of registry data on ethnicity in Sweden making estimations uncertain. There are several varieties of Sámi languages, with differences between that preclude mutual understanding. While it is approximated that 40%–45% of Sámi have some knowledge of their Indigenous language, there are no statistics on degree proficiency, although it is rarely used as a primary form of communication as virtually all Sámi are at least bilingual [22]. It appears that empirical research specifically about the EoL among Sámi in Sweden is limited to that by Kroik et al. [19], although Ness et al. [23] recently emphasised the importance of language and cultural adaptation when providing homecare for elderly South Sámi people. They point out that individual Sámi expectations may differ despite shared cultural background, as noted in their data from 56 older people in Sweden [23].
Research on Sámi elder care from Norway may also be relevant. Blix and Hamran [24] highlight cooperation with family networks, communication, spirituality and the understanding of illness as particularly important. They also point to a variety of EoL-related rituals and traditions taking place in local communities as important features to maintain.

METHODS

Research team

The research team had multicultural and transdisciplinary competencies to facilitate understanding of our findings from various perspectives (see also [25]) for discussion of benefits and risks in researching one’s own community. The team consisted of five researchers, two of whom were Sámi (LK and KS). Four (AEL, KS, LK and ME) have experience of living and working in rural areas in northern Sweden, and one researcher with a minority background emigrated to Sweden as a young adult and resides in an urban area in southern Sweden (CT). Four researchers are women (AEL, CT, LK and ME) of whom three are Registered Nurses with experiences of conducting research on EoL issues (CT, ME and LK). All but one in the team (ME) had previously researched EoL issues in the Sámi community, with KS and AEL having long research experience about Sámi cultural respective health issues.

Recruitment

Recruitment commenced following ethical approval (Umeå #2019-03488), with purposive sampling focused on self-defined Sámi adults attending four events targeting the Sámi population, between August 2019 and February 2020. Recruitment took place after initial contact with and invitations from the organisers of each event. Events were chosen for variation among attendees and were as follows: a repatriation event arranged by a group composed of Sámi, municipal, cultural and religious organisations; a political meeting; a celebration of Sámi culture and a social meeting for Sámi seniors. This recruitment strategy aimed at heterogeneity among participants regarding age, gender, Sámi language, inclusion of those with traditional Sámi occupations and other occupations, as well as participants from both rural and urban areas.

At the first two events, we arranged a data collection station in a central location. People who showed interest when passing by were invited to participate. The third and fourth events were smaller, with participants approached and informed about the project via a contact person arranging the event; not all present chose to participate. All data were collected by LK and ME individually, both doctoral students with experience of conducting qualitative research interviews.

Data collection

After receiving written informed consent, 32 audio-taped interviews were conducted in Swedish as none of the interviewers were fluent in any of the Sámi languages and the participants were all fluent in Swedish. Some participants were acquainted with LK due to her Sámi background, whereas ME was previously unknown to all participants. There were no dependent relationships between the researchers and participants.

Data were collected through individual in-person interviews, using the DöBra cards [9]. Participants were asked to first sort the card statements into three piles: ‘very important’, ‘somewhat important’ and ‘less important’, and continue by ranking their 10 most important cards. They were also asked to reflect on and motivate their choices throughout the exercise. At the end of the interview, participants were asked to describe how they experienced having a conversation about EoL issues using the DöBra cards as a tool. Participants were offered a card deck to keep if they so desired.

Interviews ranged from 10 to 60 min, median 28 min. Participants’ card rankings were photo documented. Field notes were taken by the interviewer, e.g. to document the setting and participants’ reactions. One interview with a couple was later excluded from analysis, as they did not define themselves as Sámi. The database underlying analysis thus consists of 31 individual interviews.

Data analysis

Analysis was led by LK and ME with input from the full team in repeated meetings throughout the analysis phase. Values and preferences were first explored by collating data about each individual participant’s DöBra card ranking in a matrix and compiling these data on group level. Data related to wild cards were explored to better understand both individual and Sámi-specific values and preferences. All interview data addressing aspects that could potentially be considered either Sámi specific or Sámi relevant were extracted from interviews as meaning units. These were transcribed, coded and categorised in line with directed content analysis [26]. Data about experiences of the interview conversations were also extracted separately and subject to content analysis [26].
Ethical considerations

As noted above, formal ethical approval was granted prior to initiating the study. Local ethical permission for data collection was obtained at all four Sámi events, i.e. the study was anchored within the appropriate Sámi community for the various arrangements (Church of Sweden, Sámi Parliament, two Sámi Associations and two municipalities in administrative areas for Sámi).

FINDINGS

Sample characteristics

Selected sample characteristics are shown in Table 1. All participants were born in Sweden and all but one lived in the north of Sweden. Twelve lived in cities and the others resided in more rural and remote areas. Fifteen participants described their geographical residence in relation to a Sámi Sïjte (Swedish: 'sameby'; i.e. a Sámi economic organisational unit/community devoted to reindeer herding) or Sámi Association. Six participants stated that they worked with the traditional Sámi occupation of reindeer herding, and another 13 worked in occupations closely tied to the Sámi community (e.g. translators, artists and journalists). All major Sámi languages were represented among the participants.

| TABLE 1 | Characteristics of participants in the study (n = 31) |
|-----------------------------------------------|
| Characteristics                          |          |          |
| Age, median (years)                        | 63       | Range:   |
|                                             |          | 26–84    |
| Sex                                          |           | %        |
| Female                                       | 18       | 58.1     |
| Male                                         | 13       | 41.9     |
| Education                                   |           |          |
| University                                  | 15       | 48.4     |
| High school                                 | 7        | 22.6     |
| Elementary school                           | 6        | 19.4     |
| Other                                        | 3        | 9.7      |
| Employment status                           |           |          |
| Employed, full-time                         | 15       | 48.4     |
| Retired                                     | 12       | 38.8     |
| Employed, part-time                         | 2        | 6.4      |
| Retired, working part-time                  | 1        | 3.2      |
| Student, part-time                          | 1        | 3.2      |
| Self-assessed health status                 |           |          |
| Good                                        | 25       | 80.7     |
| Neither good nor poor                       | 5        | 16.1     |
| Poor                                        | 1        | 3.2      |

Card choices

In Table 2, variation in ranking of the DöBra cards is presented in three forms; the first column shows how many times a card was prioritised among the 10 most important cards, and the second column presents the number of times a card was most highly prioritised (i.e. ranked in first place). The third column, which is the basis for presentation order, indicates a total score calculated by giving the highest ranked card 10 points, the second ranked 9 points, etc., with the last of the 10 most highly ranked cards given 1 point. If more than 10 cards were prioritised, only the top 10 cards received scores. It is important to note that as the DöBra cards are a tool for individual reflection on EoL values and preferences, this table is intended to indicate the broad variation in card statements selected by the individuals in this study, rather than provide a basis for conclusions on a group level.

As shown in Table 2, all 37 pre-formulated card statements were ranked in the top 10 by at least one person. The two cards most frequently ranked in the top 10 were a wild card, used to formulate an individual preference and thus not representing the same statement, and the pre-formulated card ‘to have those I am close to around me’. It should be noted that wild cards were ranked by 15, rather than 21 participants in their top 10 priorities (see Table 3), as four individuals used wild cards more than once among their top 10 priorities.

Wild cards

Table 3 presents the 27 different wild card formulations, as expressed verbatim by 18 individuals; these include 6 wild cards not among the top-10 priorities for that person. Twenty-one of the wild cards were ranked in the top 10 rankings with seven of these ranked in first place. Wild card formulations varied greatly, ranging from naming specific food preferences to expressing broader wishes, e.g. 'to be open about who I am'. Thematisation of wild cards is shown in Table 3 and elaborated below.

Themes in reasoning about Sámi-specific and relevant EoL values and preferences

Sámi-specific and Sámi-relevant reasoning is presented here, drawing on data from individuals’ explanations
about their wild card formulations and other card statements based on cases where preferences were explained in relation to Sámi background. All participants’ names are pseudonyms. This is presented under the themes in Table 3: Attributes of contemporary Sámi culture, Spirituality, Setting for death, Maintaining identity,
Attributes of contemporary Sámi culture

Preferences related to this theme occurred frequently and encompassed a wide range of cultural attributes, e.g. the Sámi language, reindeer, yoik (traditional á capella singing), use of traditional Sámi medicines and foods. Traditional food was associated with familiar tastes and smells, as well as a sense of security and awareness of how the food was obtained, e.g. the seasonal slaughter of reindeer. Stephan, a middle-aged man, talked about the importance of Sámi food to him, using a wild card to rank it as his highest priority:

<table>
<thead>
<tr>
<th># in rank</th>
<th>Participant Pseudonym</th>
<th>Wild card formulation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Stephan</td>
<td>Sámi flavors, since the sense of taste is among the most important a person has</td>
</tr>
<tr>
<td>7</td>
<td>Monica</td>
<td>Culture, yoik, the language of my ancestors</td>
</tr>
<tr>
<td>-</td>
<td>Christina</td>
<td>Yoik sometimes</td>
</tr>
<tr>
<td>-</td>
<td>Christina</td>
<td>Reindeer meat</td>
</tr>
</tbody>
</table>

Spirituality

6 Bert Spiritual health

Setting for death

1 Magda To die outdoors
1 Victoria To die in my environment, where I feel secure
5 Lars To hide myself under a stone to die without having to be found

Maintaining identity

1 Patrick To be independent as long as possible
1 Marie To be at peace with myself
1 Bert That I want to be myself
3 Bert To spend my life with people, want to participate
9 Monica To be open about who I am—not secretive
9 Victoria To express myself through that I believe in
9 Olov To be able to retain my temperament

Preferences related to death, dying and EoL care

1 Britta Active euthanasia when there isn’t more that can be done
2 Rut A Sámi hospice in Sápmi
2 Bert That it will be calm and peaceful
3 Britta To be cared for by staff who knows about my sickness/what’s wrong with me
5 Britta To not be connected to a respirator to extend my life, but to be connected to apparatus to decrease pain and anxiety
6 Lisa Minimal medication. Use nature as medicine
8 Josephina Making plans for the future end-of-my-life
- Christina Out on walks, out in the fresh air
- Christina Not sitting in my room all day

After death

10 Klara To make it simple and easy for those remaining and see the sun and not the darkness
- Curt Cremation or burial?
- Signe A church funeral where I want to be buried

Preferences related to death, dying and EoL care and After death.

Attributes of contemporary Sámi culture

Preferences related to this theme occurred frequently and encompassed a wide range of cultural attributes, e.g.
I want the flavor of my food. That’s a priority for me. Flavors—incr...and nature takes away and if it’s God or nature that takes...’ Bert, on the other hand, related spirituality to health in his wild card formulation. Monica, cited above, also connected traditional Sámi yoik and language to spirituality, as she reasoned about her second wild card formulation, saying: ‘And it’s a bit yoik, and language is also connected to that [...] To be able to pray, to be able to yoik [...] No, but the wild card should be: “to satisfy my need for spiritual health”’.

Another reindeer-herding man, Lars, formulated a wild card about his preference for place of death, saying jokingly, but with a serious undertone that he would most like to hide under a rock and saw no need for his body to be found. He related his preference to the Swedish majority religion and his own spiritual beliefs:

Oh, I don’t believe so much in the church and their God [...] I don’t believe in heaven and hell so I believe there’s probably just one end. So if the soul leaves the body, it doesn’t matter so much where the body is. Maybe I’ll eventually end up at that Saivo lake [referring to a holy, double-bottomed lake without inflow, where in Sámi tradition, one is united with one’s deceased family members] [laughs]

Setting for death

Wanting to die in a place that conveyed a sense of familiarity and security, sometimes naming specific places, was mentioned by some individuals. As can be noted above, several people said they preferred to die outdoors, e.g. in the mountains or forest. One younger woman, Magda, who had formulated a wild card reflecting this, said she also wished this for her older family members: ‘I’ve told my father that I hope I find them [her father and his male relatives, after they die] there [in the forest] because then I know they’re in a place they love’.

An older man, Jonas, shared this wish to die outdoors in a setting of his choice, but considered practical implications, as he said:

You’d most prefer to die in some good place in the woods or mountains. A place with memories [...] it might be of a stream or something like that where you have been happy and felt like here’s where you live your life. Then it’s most practical that you just disappear into the woods one summer...

There are a few pre-formulated DöBra statements implicitly and explicitly referring to the setting for death. In

Spirituality

Spirituality was described as connected to nature as well as religion, an interaction pointed to by Fredric, a reindeer-herding man: ‘That we get, we get from nature, nature gives...
this sample, the statement ‘to die at home’ was not highly ranked on a group level, while the card ‘To have those I am close to around me’ was one of those most often used and most highly prioritised. Signe, an older woman, reflected on the complexity of the concept of home, as she said: ‘Home is important, but those close to you are more important. I don’t know where I’ll be living then’.

Maintaining identity

In this category, preferences related to maintaining identity entailed both retaining independence and to maintaining one’s Sámi identity until death. A younger man, Patrick, reflected on his desire for independence, formulating his wild card ‘To be independent for as long as possible’. A woman in her 50s, Marie, said she used the pre-formulated card ‘To be at peace with my God’ to highlight the importance of being at peace with herself when approaching EoL, also formulating a wild card ‘To be at peace with myself’. Both Monica and Bert, an older man residing in an urban area, formulated wild cards about the importance of their cultural identity (see Table 3), with Bert explaining this by speaking of experiences of hate:

To be born a Lapplander [using a word for Sámi, now considered pejorative]. Lapp-hatred is still alive today. Now I don’t care so much about it. I’m not ashamed of being a Lapplander, I don’t want to call myself Sámi either, because I’m a Lapplander. That’s important to me. But otherwise, I can walk without support and now it’s the start of a nice time [of year, i.e. late winter] and your mood improves.

Olov, a reindeer herder in his 60s, formulated the wild card: ‘To be able to retain my temperament’, reflecting on its importance up until the time of death. Other participants emphasised the importance of maintaining one’s dignity, with some relating this to their Sámi identity, as Stephan said: ‘You base your sense of dignity on your identity’.

Preferences related to death, dying and EoL care

Preferences related to death, dying and EoL care were discussed quite specifically in relation to participants’ own dying, as well as in more general terms about health care services. Preferences included a quick death, and as Bert stated in a wild card: ‘That it will be calm and peaceful’.

One of the youngest women, Britta, who had experienced a life-threatening sickness, used her experiences to be very specific about her preferences for care provision, re-formulating two existing cards into wild card statements regarding staff and medical interventions; she also raised the issue of assisted suicide, formulating a third wild card: ‘Active euthanasia when there isn’t more that can be done’. Ruth, a retired woman, used a wild card for her wish to see a Sámi hospice, expressing a preference that benefits others beyond herself and relating it to dignified dying, saying: ‘It should be in Sápmi [the cultural region in Fenno-Scandinavia traditionally inhabited by Sámi] with staff educated in end-of-life care. It’s about making the end dignified’.

After death

Some individuals discussed preferences about the time after death, i.e. related to funeral arrangements and issues with continued implications for family members. Curt, a retiree, missed a pre-formulated card statement about an issue he considered, therefore formulating a wild card as a question, asking: ‘cremation or burial?’ Signe, who made her Christian beliefs clear throughout the interview, formulated a wild card about her final place of rest: ‘A church funeral where I want to be buried’. Another older woman, Klara, formulated the wild card ‘To make it simple and easy for those remaining...’ highlighting her concern for those who would live on after her demise. She had chosen music for her funeral, also explaining this in terms of consideration for her family: ‘I’m dead and not there, but would like to make it as easy as possible for those surviving [...] that my children and grandchildren will remember all the fun. We’ve spoken about this, we’ve discussed this [with her children]’. Monica, who had been interviewed at the repatriation event, commented on what she felt was the appropriateness of ACP interview at this time point, reflecting about ancestors and their wishes: ‘I mean how would they have wanted it to be for themselves?’.

Experiences of the ACP conversation

Participants were predominately positive about the ACP conversations in interviews, using terms such as ‘interesting’, ‘important’, ‘enjoyable’ and ‘simple’. While some commented that EoL issues had become more salient with age, others said they had not previously considered these questions. Individual variation can be illustrated as one person said the conversation brought her close to tears, while another commented she was not emotionally...
disturbed by it at all. Some referred to personal or professional experiences of dying and death or their own experiences of life-threatening illness; two people quickly ranked the cards before having a verbose conversation with the interviewer about their experiences of loss and severe illness.

The DöBra card items were commented on as ‘completely clear’, ‘concrete’, helping ‘put words to my thoughts’, and raising new issues of potential importance at the EoL, thus avoiding ‘starting from scratch’, as illustrated by Kenneth, a retiree:

I think it’s good […] you don’t think about it, that is before you are sitting here with the cards […] now you have a little guidance, what to think about. I think it was good! […] Good questions…that you’ve never thought about. Like keeping your sense of humor for example.

A few said the conversation and ranking of cards was difficult, and some related their reaction to general resistance about talking about EoL issues. Britta, who was very positive about discussing EoL issues, was the only participant who said she would like the DöBra cards translated to Sámi languages, and continued, based on her personal experience of illness, to elaborate on cultural taboos:

Talking about these kind of things…is very sensitive…And it’s a subject that you’re not so used to talking about. I’ve noticed this a lot in my Sámi culture, that it’s very hard to talk about all this about sickness, it’s almost taboo and embarrassing. I see it in my own family too […] [My father] is very rooted in a Sámi environment and a Sámi background and a Sámi upbringing. And then death is so big and problematic and taboo to talk about, so you don’t dare […] And the family in a Sámi… it is probably comparable to a Kurdish…or maybe an immigrant family in Sweden, much bigger than a nuclear family in Sweden […] you defend it all with your honor, you can be aware that someone feels bad or that that someone is sick, but you don’t talk about it. You don’t prepare for it maybe going badly […] I think it also has to do with the strict colonization that has affected us Sámi and our way of looking at things, and partly also religion [mentions a very strict form of Christianity in Northern Sweden]. It’s almost sinful to be sick, it’s almost sinful to feel bad, and it lives on in some way.

While other interviewees described more openness about EoL issues in the Sámi culture, several used the interviews to express a desire for further discussion about such issues. Britta related lack of openness to shame, whereas Olov described other hinders: ‘But you never have anyone to talk with about death, that’s the reality. You should do it and you should do it with the children. I’ve tried, but see they get so scared’.

DISCUSSION

In this article, we investigate if and how the DöBra cards were able to support reflection and discussion of values and preferences for future EoL care among a sample of Sámi individuals. Reactions varied on an individual basis among these participants who shared a Sámi background but otherwise constituted a heterogeneous sample. Some commented on the taboo-laden nature of discussing EoL issues in other contexts, while many commented positively about EoL conversations in general, and benefits of using the DöBra cards in particular. The cards were said to be relevant, highlighting several issues previously not considered by those interviewed. All 37 DöBra card statements were ranked among the top 10 priorities by at least one person, with the pre-formulated card item ‘to have those I am close to around me’ chosen by most people, and along with the wild card for individually formulated preferences, most frequently ranked as highest priority. Participants used wild cards for preferences categorised as relating to attributes of contemporary Sámi culture most frequently; maintaining one’s (Sámi) identity and dying in places with personal or cultural meaning were other prominent preferences in this sample.

The GoWish cards have been used in research studies with community-dwelling adults in several countries [10, 15, 27, 28] and as the DöBra cards with majority populations in Sweden [4, 9, 17, 18], however, we have seen no other studies that have reported an extensive use of wild cards as in the present study. This may be in part due to interviewers explicitly prompting interviewees about other potential preferences not covered by card items. However, in other Swedish studies, participants were also reminded about using wild cards, with about one-third of the Swedish sample using them [9], compared to over two-thirds in the Sámi sample. Use of wild cards may also be related to the Sámi-specific settings for data collection in the present study, which may have emphasised Sámi culture and thus influenced wild card formulations. It is notable that preferences to be able to speak or hear Sámi languages when nearing death were relatively frequent in this sample, although only one person expressed a wish to have the card deck translated to a Sámi language. This points to the
symbolic importance of Sámi languages, rather than being a favoured language for communication [19].

While Thompson et al. [15] do not report card frequencies in their study with Aboriginal Australians, it does offer other points for comparison, e.g. strong preferences related to final resting places and rituals in both studies. However, while Thompson et al. report preferences for hospital rather than home death, this study instead notes complexity in the concept of ‘home’ for reindeer-herding Sámi, with dying at home ranked among their top 10 priorities by only three people. Home death was not an important preference either in Gott et al.’s [5] NZ research, and Robinson et al. point out that hospital death in rural Canada may be a positive alternative to home death without adequate resources, especially if the hospital is in the community [29]. In contrast, McGrath [30] based on interviews with 72, predominately Indigenous, people in Australia, points to the close relationship between a desire to die at home and contact with the landscape and family, sometimes including ancestors. We also see this relationship between landscape and ancestors (see also 2), as described also from Australia, New Zealand and the USA [7, 31, 32]. This may be important to consider further as the emphasis in the literature is increasingly changing from home death to the importance of choice in place of death [33]. The desire to die outdoors, mentioned in our data by several participants, seems relatively unique in the literature and merits further research.

We also note a degree of discrepancy between interview data about the importance of maintaining independence as part of one’s identity and the ranking of the card preference ‘Not being a burden to those who are close to me’, chosen among the top 10 priorities by six people. With our insider perspectives on Sámi culture, we had expected this card to be highly prioritised more often. We also note how Christian values and traditional beliefs are able to be integrated in our data, which is in line with findings from a recent North American study [34].

It is important to remember that, as Blix points out [35], the Sámi, as with all other groups, are not homogenous, even though they may share culturally rooted perspectives. This presents an important implication for health care services, as it was notable in our findings that the Sámi did not expect to receive ‘culturally safe care’ [36]. While exploring EoL values, preferences and priorities may be important for facilitating high-quality EoL care when the time arises, Gott et al. [5] remind us that not everyone is comfortable in speaking about death. This is particularly important to remember as ACP becomes increasingly common; our sample was purely voluntary and should not be seen as representative. Also, the DöBra cards are intended to delve into individual preferences, and as noted above, presentation of group level data was only to demonstrate variation. We also see this variation in how participants experience the conversations, even though these individuals who actively chose to participate are generally positive.

In conclusion, we find that the DöBra cards are a relatively easy-to-use, understandable and flexible tool for initiating and supporting conversations about EoL values and preferences based on this sample of Sámi participants. The open formulations of the card statements enable discussions about individual values and preferences, with potential to reflect life as a Sámi in Sweden today. The flexibility allowed by the open formulations and use of wild cards may make the DöBra cards a potential tool with which to support ‘culturally safe care’ for Sámi.

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CONFLICT OF INTEREST
The authors have no conflicts of interest to report.

AUTHOR CONTRIBUTIONS
The entire research team has been involved in designing the study, discussing analysis and finalising the manuscript. LK and ME were responsible for carrying out data collection, analysis and drafting the manuscript.

ETHICAL APPROVAL
This study was approved by the regional ethical review board (Umeå #2019-03488) and written informed consent was granted by all participants.

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