

## **Exploring the lived experience of migrants dying away from their country of origin**

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to gain this knowledge.

## **Abstract**

**Purpose** Migrants experience challenges settling into a new society, while retaining their cultural and religious values. Concurrently facing an end-of-life illness can result in existential distress affecting quality of dying. This study aimed to explore the lived experience of migrants dying away from their country of birth or origin.

**Methods** The study design used a phenomenological approach using Heidegger's philosophy to gather and interpret dying migrants' stories. Participants were a purposive sample of New Zealand immigrants experiencing end-of-life illness and under hospice care. Participants were interviewed at home. Coherent stories were drawn from the transcribed interviews and analysed using iterative methods. Interpretive notions were formed through contemplation and writing.

**Results** The 10 participants, 7 male and 3 female, were of different ethnicities and countries of origin. Three notions emerged. The first was dual possession of a new hybrid identity developed in their adoptive country, and an inner ethnic and cultural identity, in varying degrees of harmony with each other. The second was being in life review – reliving homeland memories and letting go of dreams. The third notion showed how they sought resolution by enacting continuity through their children, hoping for a final homeland visit, or conveying their dying wishes.

**Conclusions** How life review was enacted for each migrant and resolution depended on finding some degree of belonging in their country of adoption. Implications for end-of-life care include education to increase practitioner awareness and use of formal and informal life review. Enhancing spiritual well-being can assist resolution of end-of-life adjustment.

**Key words** Migrants; End-of-life; Interpretive phenomenology; Identity; New Zealand; Belonging

## **Introduction**

There are growing numbers of migrants in New Zealand [1] who experience challenges settling into a new society and trying to reassemble their lives, while also retaining their cultural and religious values. Experiencing an end-of-life illness as a migrant can “call into question the fundamental sense of who we are and what we value” [2], and bring these different interests, orientations and lifestyles to the fore. Hallenbeck refers to dying as one of life’s major transition periods which is “heavily invested with culture” [3]. Experiencing a concurrent end-of-life illness, sometimes early in their socialisation as new immigrants, can result in existential distress affecting their quality of dying. Apart from their illness, some migrants face distress caused by “clashing interests, orientations and lifestyles” in their country of adoption [4].

Dying well depends on many variables that encompass the physical, emotional, social and spiritual domains of our existence. Migrants who are separated from family and their countries of origin may experience anxiety around practicing their cultural and religious expressions in their new host country, especially in a health care facility.

As the world of the migrants undergoes dramatic change from leaving their country of origin and integrating into a new society, the co-occurrence of life threatening and end-of-life illness has implications for their contemplation of life meaning and spiritual well-being. Puchalski states “Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred” [5].

Understanding the importance of spirituality helps minimise spiritual pain for dying people. End-of-life care aims to recognise and facilitate resolution of spiritual, social, emotional and physical issues to enable dying well in line with the vision of palliative care.

The object of this study was to explore the lived experiences and interpretations of migrants when dying away from their country of birth/origin, and how they were attempting to resolve the spiritual, social, emotional and physical issues they were facing at the end of their lives.

## **Methods**

### ***Study design***

The methodology was interpretive phenomenology, with Heidegger's philosophy used to guide the study design and methods used to evoke and interpret the dying migrants' stories. Heidegger's philosophy is centred on ontology and is concerned with how the phenomena of '*being*' (existence) reveals itself to us [6]. Heidegger's definition of phenomenon is "that which shows itself of itself" [6] p. 158. The ancient Greek expression phenomenon is derived from the verb "to show itself" which in ancient Greek, can also mean "bringing something to the light". The formal meaning of phenomena is something that for the most part remains hidden, in contrast to that which does show itself, which is the mere appearance of phenomena. Meaning is revealed as what is hidden becomes uncovered to achieve an understanding rather than just a physical perception. It also includes something that belongs to whatever shows itself, and belongs to it so essentially that constitutes its meaning and its ground [6]. This way of looking at phenomenon then also means that for the most part phenomenon is hidden or does not show itself or its meaning, or is shown in a distorted way [6]. The migrant's dying experience in an adoptive country in this research is a phenomenon that appears hidden and invites exploration. Seeking meaning from their narratives of experience and looking for the possible presence of dissonance could provide insights for practitioners working with people facing end-of-life.

### ***Setting and participants***

The participants were purposively recruited through four of the bigger hospices in Auckland, New Zealand. These hospices have catchment areas with populations of mixed ethnicity, and are where many migrants reside. Hospice workers identified potential participants who met the inclusion criteria: immigrants to New Zealand, aware that they were experiencing an end-of-life illness, able to participate in at least two interviews, and to coherently discuss the topics raised by the interview questions. Non-English speaking migrants were excluded. Participants were told that the study was about their experiences of being in a country different from their country of origin at their end of life. A diverse sample with respect to factors such as gender, ethnicity, reasons for migration, and country of origin was sought. Recruitment was challenging, as often by the time potential participants had been identified and communicated with, they were too unwell or had died before interviews could take place. After 10 participants had been recruited it was considered the sample was adequately diverse and a rich dataset had been collected.

### ***Ethical approval***

Ethics approval was obtained from the Northern Regional Ethics Committee, reference number NTX/11/11/101.

Informed consent was obtained from all individual participants included in the study.

### *Research processes*

The individual interviews took place in participants' homes. Using a semi-structured interview guide, participants' stories of particular events and moments were invited, as well as their understandings of meanings. They were invited to share memories from their life in their homeland, explain why they chose to move to New Zealand, their experiences of living here, and what it means to be ending their life in their adopted country. They were invited to share their desires, concerns or regrets, with questions based on the following semi-structured interview:

1. What was your life in [home country] like – relate snippets of life in [home country] that you can remember.
2. Tell me about why you decided to leave your country of birth and come to New Zealand to live. What were your hopes, wishes and fears of making the change?
3. Your story of making a new life in New Zealand interests me greatly. What was/is the experience like of being a migrant in a new society? What things stand out as being very different – values, traditions, rituals, attitudes, practices, preparation for dying?
4. What are things from your country of origin that you often think about/miss/wish to see again? Has your present situation triggered any particular thoughts, wishes regarding your birth country? What are they?
5. What is your experience of having an illness that means your life is coming to an end sooner than you expected? What does this mean for you? How is this affected by your life in a country different to your birth/mother country? Any regrets? Strong desires? Concerns about dying here? Is the experience the way you want it to be?
6. How have you been able to reconcile these concerns?
7. Are there any specific needs (culturally or traditionally) that you have that are not being met here in New Zealand? How do you envision that these might be met appropriately for you?
8. Are you confident that your carers will know your wishes near the end-of-life?

The interviews were audiotaped and subsequently transcribed verbatim by the lead researcher. Interviews were spaced one to two weeks apart to enable the verbatim transcripts to be checked by the participants for accuracy of meaning, and for further discussion if needed. A journal of visits was maintained to assist with analysis and recorded information about first impressions, expressions and context. To maintain confidentiality, participants' transcripts were given assigned names appropriate to their cultural backgrounds.

## *Analysis*

The transcribed interviews were checked and crafted to enable a flow of the stories, carefully maintaining each participant's expressions and meaning.

Crafting the stories provided a way to begin their interpretation. Interpretation continued with the twin processes of contemplation and writing as the stories emerged with each transcript, and insight was gained into what the experience was like for each participant. The emergent ideas from the data were categorised as notions - general concepts held by participants derived from their lived experience and interpreted in the research process.

As interpretation continued, the Heideggerian concepts of *Being* (the existence of self), *authenticity* (disclosing one's true self) and *clearing* (period of time when there is shared background and a state of interconnectedness with others) provided a way of interpreting the stories [7].

## **Results**

Ten participants were recruited into the study. They had range of ethnicities and countries of origin, there were three women and seven men, their ages ranged from 42 to 88 years, and they had lived in New Zealand for eight to 50 years (Table 1). All were diagnosed with a life-threatening illness, and were in end-of-life hospice care.

There were three main notions realised from the meaning of these migrants' stories as they reflected on their of end-of-life *clearing*.

### ***Living with two identities***

The first notion was the realisation of having two identities, which were in varying degrees of harmony with each other. These two identities consisted of a new hybrid identity developed in the adoptive country, and an

inner ethnic and cultural identity. Harmony between both identities engendered a sense of belonging in an adoptive country and a feeling of 'being settled'.

For two participants, their experience of living with two identities that were very divergent created feelings of dissonance in their end-of-life time. Both participants expressed their 'alone-ness' in end-of-life in New Zealand

*Yes, I miss my friends, my buddies and my colleagues and my relatives. All back in Malaysia. And here I have nobody except my sons and my wife. (Raymond)*

For two other participants, social connection had been rewarding and contributed to a sense of belonging in the adoptive country.

*You know here if we are mixing with the Indian community here we do the same things as we did back home. It's really no different apart from the external surroundings are different. We still practice some of the rituals. (Ernest)*

For three participants however, their two identities had merged and a sense of belonging early in the integration process in New Zealand came out prominently in their stories. These participants expressed their ease in assuming a new hybrid identity in New Zealand because their original lifestyle, religious and philosophical approach closely resembled those of the dominant population of western orientation in New Zealand.

*We expected that it would be a very easy place [New Zealand] to adapt to because so much seemed to be so similar to our lives in South Africa. We are Christian even though we don't practice it. The children are very much New Zealanders now. (Jenna)*

### ***Being in life review***

The second notion common to all participants was being in life review. The decisions associated with migrating to another country have effects that they are living through now as they look back on their experiences.

It was apparent from the stories presented by the participants that they had been engaged in constant experience of reminiscing and contemplation of their lives prior to sharing their stories with the researcher. In reading and contemplating the re-lived stories in the interviews, three particular areas stood out as salient of being in life review:

1. Pondering immigration decisions – a better life or a compromise.

2. Loss of dreams – their dreams that did not eventuate because of this illness;
3. Recapturing their memories of country of origin.

Their stories from country of origin have emotional impact on their present *being* in end-of-life. The central philosophical concept is '*disclosedness*' and how meaningfulness is uncovered as the participants engage in their life review. '*Disclosedness*' in Heidegger's philosophy describes the uncovering of phenomenological truth by the participants in their experience of facing end-of-life. Their understanding of what has been for their '*being*' is revealed. *Disclosedness* is how their *authentic* selves are becoming revealed as end-of-life approaches.

They considered the past and pondered past decisions especially around migration. Memories from homeland were relived.

*I miss my childhood friends. I don't have many old friends like family friends left. There is a place what we used to call the Watering Hole. Sometimes whether you just turn up or somebody calls you to that place.*

*We go all day and join in. A place to meet with friends. (Julius)*

There was the loss of dreams of visiting people and places and experiencing cultural expressions from the homeland.

*I planned you know when I get to 65, I really want to go back to Tonga do something there. I look after the land over there. (Maau)*

### ***Seeking resolution***

The third notion showed how they sought resolution. This might be from enacting continuity of mores through their children.

*And that's why I want to take the kids and we can go all over special temples and spiritual places and we can have our blessing then. That has spiritual meaning in our Indian culture, you know. (Hemani)*

It might be hoping for just one more visit to homeland. Wanting cultural continuity through their children did not diminish the hope three of the participants in their longing to experience being in their country of origin once again.

*I still would like to make a trip back to Malaysia if I can. (Raymond)*



Conveying their dying wishes was also evidence of acceptance of imminent end-of-life, as some of the participants expressed their wishes for the final resting place of their remains.

*I am happy about dying here. I would prefer to be buried here, where my family is, not in Ireland. (Sean)*

Being in transformation was observed in two participants as a position of ‘insightful equanimity’ that was named by Hinton,[8] as a place of transformation that follows full acceptance of dying. Both participants had sought resolution in contemplation and had arrived at a comfortable place of meaning for them in end-of-life. In the words of Ernest’s wife, Shelly

*He did it like he did his diagnosis and prognosis, stoically and within himself, then he let go of them and moved on positively with life. He was amazing, accepting and he was my strength.*

Maau displayed this transformation too and spoke about his feeling of fulfilment from leaving a legacy to his country of origin.

## **Discussion**

A systematic review of published research on the lived experience of migrants dying in a country different from their country of birth identified three main themes: a sense of dual identity, importance of traditions from their country of origin, and dying preferences [9]. Sense of identity featured strongly in this study. The dying participants in this study engaged in deep introspection as they examined their understandings of who they were, in relation to their countries of origin and adoption. Becker [10] confirms that people are likely to question their identity when they contemplate a disruption to life, or find themselves within the *clearing* of facing end-of-life. Part of the identity exploration for these migrants included their feeling of belonging in either country or both. Consequently how they approached dying in their adoptive country (such as their sense of completeness, whether they wished to be able to visit the homeland) was impacted by how they had lived here and their feelings of being settled. Gronseth observed that “migrants can be seen to live their everyday lives on the borderlands in between differently constituted, though mutually human, life worlds” [6, 11]. They experience two identities, the original that is retained quietly, and a new identity that envelopes their everydayness in a new society. This hybrid identity is the result of cultures coming into contact and the interchange of practices, values and beliefs that are borrowed or reconfigured [12].

For some, their two identities merged as they settled seamlessly and for others, their two identities coexisted amicably presenting no difficulties that they could not manage as they settled into New Zealand. However, for a few participants their two identities seem to oppose each other, as they kept the original identity a secret, while the other allowed them to live in their adoptive country, seemingly settled.

Identity and belonging are symbiotic concepts, and the migrants in this study discussed these in unison with experiencing belonging as dependent on feelings of inclusion or exclusion. For the migrants who had markedly different cultural and ethnic expressions in their religious and everyday lives, their feelings of exclusion were proclaimed as 'alone-ness' in country of adoption at this time of dying. Significantly for this group, after years of living in their adoptive country of New Zealand, they still voiced feeling like they were living in a 'foreign' land.

For these migrants, engaging in life review included pondering their migration decisions, contemplating dreams that will not eventuate, and re-living memories from homeland. The strong feelings of connection with their country of origin described by all the participants resembles the 'continuing bonds' model of loss and grief proposed by Klass [13] and also recalls Bowlby's 'Attachment Theory' [14]. Both these theories describe the lingering attachment, in the former to something that is lost and in the latter, a nurturing relationship as in a mother/child attachment. Stroebe and Schut concur that the impact of the bond may determine the transformation or not of the person [15].

The migrants sought resolution towards end-of-life in creating ways of enacting cultural continuity through children and ideas for memorialisation. They hoped for a possible last visit to motherland whilst also conveying their last wishes to their families. The essence of this research was the meaning-making in the everydayness of dying migrants, in their efforts to reach a place of equanimous acceptance and peace, as the most that can be at this end-of-life time. Reliving the stories of people, places, and occasions brought them closer with new understandings of relationships, and joy in meaning-making.

Respecting the human-ness and rights of different individuals ‘regardful’ of where they come from and their ethnic differences contributes to finding belonging, which is fundamental to settling in their adoptive country and achieving spiritual peace in end-of-life. However it must always be acknowledged that migrants, as do native residents, have a wide range of cultural histories, mores and religious practices. Considering all these as equally representing the cultural background of migrants at end of life risks having a single response that does not respect each individual’s life experience [16]. No death is the same, and differences in the setting in which someone dies, their age and cause of death and their socioeconomic status all lend heterogeneity to this issue [17]. What is considered a ‘good death’ might be considered differently by those dying, their relatives, and their carers [18].

Being able to review and make meaning out of one’s life promotes spiritual well-being and protects against end-of-life despair, regardless of individual religious beliefs [5].

Diversity in the sample that covered Eastern and Western ethnicities was a strength of this study and enabled a rich variety of stories to be interpreted. A limitation is the number of recruited participants, and more might have enabled further exploration of similarities and differences between ethnicities. However, the data gathered from the ten participants enabled robust interpretation and arrival at findings that could enable further expanded research in this field. Non-English speaking migrants are less able to access services easily and more at risk of experiencing social isolation. Their exclusion, which eliminated the need for third party translation, meant that the voice of this particularly vulnerable group was unheard.

The new knowledge from this research centred on how each migrant in end-of-life reviewed their life, and how resolution was found, which in turn, is dependent on finding belonging, or a degree of it, in their country of adoption. Reliving the stories of people, places, and occasions brought them closer, with new understandings of relationships and joy in meaning-making in their end-of-life. Through life review they sought meaning and purpose, and explored their connections with loved ones, with their homeland, and with their cultural values and practices, all of which contributed to their spiritual well-being [5].

The implications of this research for practice include education to increase practitioner awareness, and recommends the use of formal and informal life review with dignity therapy and meaning-making to benefit migrants grappling with dying away from their homeland. Spiritual well-being, a crucial part of end-of-life and palliative care, can offer assistance with resolution of end-of-life despair.

### **Author contributions**

This research was conducted as part of YB's PhD at the University of Auckland, New Zealand. FG-S was principal supervisor and VW-SC was co-supervisor. There was no additional funding source.

### **Author Disclosure Statement**

The authors declare that they have no conflict of interest.

**Table 1: Demographic characteristics of participants in the study**

<b>Participant*</b>	<b>Country of origin/place of birth</b>	<b>Age in years</b>	<b>Gender</b>	<b>Ethnicity</b>	<b>Years since migration to New Zealand</b>
1. Joh	South Africa	78	Male	European	18
2. Hemani	India	42	Female	Indian	20
3. Maau	Tonga	65	Male	Tongan	26
4. Raymond	Malaysia	52	Male	Chinese	8
5. Julius	Philippines	76	Male	Filipino	13
6. Sean	Ireland	88	Male	Irish	50
7. Ernest	India	59	Male	Indian	15
8. Susan	England	46	Female	English	18
9. Jenna	South Africa, born in Zimbabwe	51	Female	European	15
10. David	Fiji	50	Male	Fijian Indian	10

\* Assigned names

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