Primary Health Care is a scenario capable of producing care at all stages of life, from birth to death. However, the health care of severely ill people requires a complex and holistic approach to these subjects and families, often being provided at home. One of the duties related to end-of-life care is the issuance of a death certificate when death occurs at home. From the perspective of a Family and Community doctor a narrative and reflective experience is reported by a home care service for issuing a death certificate. From this narrative we discussed how the visit for the issuance of the death certificate invites us into a territory full of subjectivities, which evokes many reflections on the process of death and dying, causing changes in our lives both personally and professionally.

**Keywords:** Primary Health Care. Death certificate. Narrative medicine.
It is the ephemerality of life that strengthens love. The bigger the risk, the stronger the bond. For most of us, the fact that some day we will lose the ones we love, and they shall lose us, bonds us all and constitutes a silent chime that wakes us in the middle of the night1. (p. 11)

Introduction

Primary Health Care (PHC) is guided by the pivotal duties of first access, longitudinality, integrality and coordination of care and, also, other secondary duties such as family approach, community emphasis and cultural competence2. “Welcoming” is a term related to both the users’ access environment and to several care attitudes taken up by healthcare professionals. Over the past decades, we have observed the accelerated aging of the Brazilian population linked to a huge load of morbidities and greater social inequality3. Palliative care (PC) is aimed at providing integral care to people who hold chronic degenerative diseases and it has no healing purpose, thus it solely seeks to offer an improvement in patients’ quality of life during this natural development process of the disease and terminality4. Therefore, in this ever-growing and complex context, PHC faces a plethora of challenges in order to offer accessible health care, joining both quality and equity, from birth to death.

Life and death are natural processes inherent not only in humans but in all living beings. However, although death and dying are natural phenomena, talking and reflecting upon the finiteness of human existence is, often, challenging for many people5. Healthcare professionals are very much exposed to such issues for they deal with life and death on a daily basis, and therefore, need to face death and the finiteness process of other people and their own. In the PHC scenario, these professionals need to be closer to patients and relatives in order to provide proper assistance and safety to those who need or wish to take care of relatives who are severely ill at home. In such context, the Family Health Strategy (FHS) teams as well as the Family & Community Physicians (FCP) are important agents in this type of care, strengthening bonds and participating in shared assistance of those patients and relatives6. In addition to the physicians and other professional categories that integrate the technical team, health community agents (HCA) play fundamental part in the follow-up and care of those people while holding the core duty of performing home visits (HV), which allows for understanding the family’s life condition as well as for the strengthening of bonds3.

In all scenarios of contact between a healthcare professional and the dying process, the most objective meeting is perhaps the visit for the issuance of the death certificate, when death occurs at home. It is worth highlighting that, in general, the PHC doctor must certify deaths of a known cause and, preferably, of patients who were under the referenced healthcare team’s follow-up. Therefore, deaths for an unknown cause, sudden and/or of suspected violence, must be carefully analyzed by other professionals and services, such as the Forensic Medicine Institute.
In a non-systematic review of the literature, no publications were found describing the subjectivities behind these visits, be it from the professionals’ or relatives’ perspective. Thus, we may reflect upon the challenges that a such visit demands from the professional who is present to certify the death, from technical issues (body examination, anamnesis for the investigation of the cause and time of death, certificate completion) to more subjective issues, such as those related to communication within situations of profound grief and the approach to the family’s process of mourning. The development of competences is supported by a three-piece set composed of: knowledge, skills and attitudes. So, by considering that FCPs seek to develop competences to tackle a more person-centered approach and care, what kind of knowledge, skills and attitudes are required in order to carry out a visit for the issuance of a death certificate? Is there a desirable balance to be struck between a more practical problem-resolution approach and listening to relatives, their grieving, ideas and expectations in such an acute moment of loss? Also, it is necessary to think about how these professionals, and the team, tend to face such visits, for these situations may evoke feelings of loss, helplessness and failure.

Considering the intricacies within the dimensions and scenarios of health care in PHC, it is paramount to ponder the practices and tools that may be useful at exploring the subjectivities of the visits, thus magnifying the dialogic dimension of healthcare professionals. Medicine has always used narratives as a means to access individuals’ subjectivities, assisting doctors and patients in understanding processes of becoming ill and handling. The narrative process transforms the experiences and thoughts lived by the narrator within a story that may be shared with their listeners, who, on their turn, may relate with the story of others. In this sense, the use of narratives may be a potent “reflexive and operative tool in the development of knowledge and practices connected to the clinical visits on a daily basis” (p. 481).

This article is aimed at reporting, by means of a narrative, an experience of home visit for the issuance of a death certificate (DC). We do not aim to tackle technical issues related to the completion of the DC form, but rather to focus on the subjective elements of the narrative, as well as the scenario and the characters involved in order to discuss the challenges related to this type of assistance. The excerpts of the narrative that are cited will be quotation marked and in italics in order to facilitate the identification by the reader. The person from this case was accompanied by an FHS team from the northern zone of Rio de Janeiro. This publication had its Free Consent Form signed by relatives and further people who are mentioned herein. Real names were replaced with other names so as to preserve their identities. We hereby emphasize that every narrative report is based upon the perspective of the author/narrator, therefore, it is permeated by ideas, values and other elements held by the subject at issue.
Narrative – case report

Today, the bird hasn’t sung

It was a hectic morning when wife and sister-in-law appeared at the clinic requesting the presence of the doctor in order to certify Mr. Raí’s recent death. “Sure, very soon the doctor will be there. You must wait a little”, says community agent, Elis.

We walked together, Elis and I, reflecting upon the ephemerality of life while we were under the mild heat of the sun at about 10 in the morning. Fortunately, today seems a fairly calm day in this region, which is normally impassable during the week due to armed violence. The small building, an old construction, whose paint was peeled off, hosted, on the second floor and above a narrow and winding set of stairs, Mr. Raí’s family. He lay on a hospital bed adapted into the sitting room which was simple, with a big, carefully-lined sofa, an armchair, a rack packed with small decorative keepsakes and family photos. The bed where Mr. Raí lay was placed in a noticeable area, aligned with the other furniture in a way that looked like a closing circle. His death bed was leaning against the wall, beside the door. His wife, daughters, sons, granddaughters, grandsons and a couple of other relatives gathered in the kitchen and in the aisle leading up to the bedrooms. One of his daughters was carrying a dog that was clearly agitated. No one was in the room but for Mr. Raí’s body. I greet everyone and ask to enter into the sitting room, which was nearly empty, thus inviting those who were able to or would like to talk to me. I sit at the corner of the sofa, the widow, Mrs. Alice, sits on the armchair next to me and her daughter, Bia, sits on the other corner of the sofa, near me. I ask them what happened and Mrs. Alice, whose eyes were misty and fleeting, explains that she woke up fortuitously at around 2:30 a.m. and realized he was not breathing any longer. She, then, tells me that she often heard his noisy breathing from her own room, which was behind one of the doors that led into the sitting room, now Mr. Raí’s bedroom. She says that, in the previous night, her husband’s condition was better than usual. He received the touch and care from his sons, who shaved him and trimmed the hair from his nose and ears. He had a good meal, and was even able to assist with his own bath, supported by his sons. He smiled at his grandchildren and watched his beloved soccer team’s match. At this very moment, one of his children says: “Hasn’t he been able to cope with yesterday’s tie?”. They had a shy and refraining laugh. Late at night, into the small hours, at around 1 a.m., before going to bed, Mrs. Alice checks whether her husband needs something else. “I don’t need anything else. You may go to sleep.” Mrs. Alice continues her narrative and tells me that Mr. Raí’s condition had worsened in the past months. He had severe “enlarged heart”. His sister-in-law says it was as if a candle were burning out progressively. His daughter sobs on my side. I get emotional with such metaphor, but regain my attention to the story, which I need to further investigate in order to presume his causa mortis as well as his clinical background. “Have you noticed whether he grew wearier in the past days? Had he been straining to breathe?”, I asked his wife. Her answer was positive and, so far, it sounded like he probably had been suffering from decompensation, secondary to a heart failure, but without any evidence of associated infections. At this moment, as I listen to the widow, I briefly swerve my eyes to the farewell ritual performed by his grandson of approximately 10 years old, who approaches his grandfather and kisses his face, embedded in affection and tears. I get emotional once again.
Before examining the body and moving on to the completion of the certificate, I ask them how they are feeling at that very moment. Mrs. Alice and her daughter start crying and tell me that Mr. Raí was a great father and husband. He worked very hard and was very considerate. Mrs. Alice shares about her pain and says she is feeling ‘at peace’ to know that Mr. Raí left them at ease, under no suffering, and above all, being loved and cared for. ‘What a privilege’, I think and state. I kindly ask them if I may examine Mr. Raí’s body, to which I was promptly granted permission. Mr. Raí is well-positioned, covered by the bed sheet up to his chest, in supine position, legs extended, hands crossed on the chest, eyes closed, peaceful expression. I examine him quickly, looking for further pieces of evidence that may be associated to his death. Nothing else. His skin is in integral state and very clean, his beard was very well-shaved, his clothes were washed and comfortable. I share my impression with them and inform them I will start the completion of the death certificate, checking for consent on probable cause and time of death. The atmosphere is calm and peaceful. Then, I invite Mrs. Alice to join the grieving group of our unit and also reinforce that the team is available to help the whole family whenever necessary. I verify whether I can help with anything else and, upon their negative reply, I say farewell and hug them.

As I return to the clinic, I talk to my team colleague, who says:

“I remember Mr. Raí’s bird would sing oftentimes. I saw the bird was crestfallen in the bird-cage and asked one of the relatives what had happened. The reply I got was: ‘today, the bird hasn’t sung’”.

Discussion

Thus, by assuming that PHC must offer an integral, longitudinal and coordinated care to users, it is necessary that all healthcare professionals are trained to provide thorough and quality assistance to populations under its care, from birth to death of individuals. Palliative care refers to furnishing subjects’ and their relatives’ health with integral attention in situations where there is no more hope for cure and, oftentimes, take place at home. People who are severely ill have singular needs that encompass several dimensions of care and are not specific at the moment of finiteness, therefore, most of the issues are conditional upon the context in which the person lives11. As complexity escalates in terms of rendering care to severely ill patients, “the teams are faced with the need to develop skills in order to deal with life’s finiteness, as well as with all the suffering from incoming death and from the bonds strengthened with patients and relatives”12 (p. 2). However, palliative care as an assistance modality in PHC, underpinned especially by the principle of integrality, is still inceptive and fragile in Brazil. Literature ratifies the urgent need for professional training in PHC on this type of care as well as a labor process review4.

A more recent discussion is on the possibility of these people to choose their own place of death, and their home is one of the options13. In the past decades, families were overthrown from the role of main caregivers of their members by the hospital institution, which has taken over this duty14. In the present days, death hospitalization may yield suffering due to excessive interventions in hospitalized patients and distancing from relatives and the community, by whom these individuals could be cared for with more affection and comfort. Nevertheless, not always is the choice of death at the hospital inadequate since, many times, it is the best environment for people who do not have a good family or
community network or if there is a need to soften physical suffering and control symptoms at the end-of-life stage. In addition to that, when death takes place at home, it may cause feelings of anguish and impotence on relatives, which may lead to complications in their grieving process. The choice to experience the finiteness process and death at home may represent a great challenge for relatives and caregivers because, in general, end-of-life health care demands intense and ongoing support in addition to requiring adequate assistance coverage of primary health services as well as proper articulation with other care levels. It is worth mentioning that not all people who die at home are severely ill or of advanced age, actually, some of the deaths are completely unexpected and happen for unknown causes, individuals are, sometimes, young and have no previous knowledge of severe illnesses they might hold – such situations are even more sensitive and complex to tackle.

An important care action is the issuance of the death certificate, which is often requested by the PHC professionals. In the brochure of services warranted by PHC in the city of Rio de Janeiro, the issuance of the “certificate of deaths that occurred in the Basic Health Units and homes within the areas covered by the Family Health Strategy” is foreseen (p. 108). When it comes to the Family and Community Medicine, proper training for palliative care is foreseen in the Curriculum Based on Competences, published by the Brazilian Society of Family and Community Medicine, thus considered as essential competences the ‘preparation and guidance of relatives and patients as to the arrangements related to death, knowledge on the importance of assistance outside the working hours due to severe and fatal events; and the issuance of a death certificate. Also, featuring as a desirable competence is the ‘support in death events at home’. In this sense, it is worth adding quotes to the term “Statement of Death” used incorrectly since doctors may only issue “(Medical) Death Certificates”17. However, future FCPs may face difficulties and challenges in the development of such competences which are often inherited from their education. Some of the feelings experienced by doctors before death are rage, impotence and guilt. These feelings, whenever associated to the difficulty in facing life’s finiteness, may cause these professionals to stand back from their patients, deeply affecting their bond as well as the ‘individual-professional’ relationship in such a crucial moment of one’s life cycle.

Whether in situations of health or illness, caring for others is paramount before anything else, just as being present and providing care in a generous way even in moments when we might think we are no longer useful. We must understand that “even when we feel that there is nothing else left to be done, we must be prepared to stay”19 (p. 26-7). Furthermore, especially in the PHC scenario, care goes on even after death since the family will continue to be assisted by the team and shall need even more attention and support throughout the grieving process. So, it is essential that professionals duly acknowledge the signs of suffering from mourning people so that the best care measures may be taken according to each case and suffering level20. I, therefore, invite Mrs. Alice to join the mourning group in our unit and reinforce that the team is available to help the whole family, whenever they need. The mourning people group cited by the doctor in the abovementioned narrative – “I, therefore, invite Mrs. Alice to join the mourning group in our unit” – is a place for welcoming and counseling on mourning, which may be provided by health units in the scope of the PHC and hospital facilities.
As the narrative follows, we observe a few important elements that assist at telling the story, such as the context, scenario and participants.

The narrative is set in a northern district of the city of Rio de Janeiro, which is marked by countless social contrasts and is known for being a territory of intense armed violence. As healthcare professionals who are used to working in such territory, we tend to notice the extent to which social vulnerability and violence directly influence patients’ and relatives’ health and illness. An evaluation of the socio-economic context as well as the social determinants involved in family contexts is extremely important so that the team can clearly identify vulnerabilities and, as a result, offer more adequate care to people. Home health care is, in general, costly and may lead to a process of impoverishment within families. Thus, it is crucial to evaluate how much these conditions determine maintenance and quality of the home care provided to individuals who are severely ill.

The beginning of the narrative draws us closer to the daily work performed in PHC, which is faced with unexpected situations that often demand a pause on a “hectic morning”, packed with assistance events at the Family Clinic. Elis features as the first person mentioned in this narrative, and such detail serves as a piece of evidence on the relevance of a healthcare professional at providing support as well as lending ears to the initial demands. If, on the one hand, this moment is rather convenient to offer support and care, on the other hand, the place where support is to be offered is also a potential tension generator for the healthcare professional – especially in a context of brittleness and in which public healthcare resources are decaying. Not rarely do HCAs describe their experiences as very uncomfortable and painful for they are often unable to meet users’ demands due to the lack of resources and professionals available for assistance. Still regarding HCAs’ work, the narrative shows the importance of being close and knowing the subtleties in users’ scenarios and contexts. The narrative title expresses Elis’s perception on the bird’s silence – a detail that would not be easily noticed by a professional who had not established previous connection with the family. However, over the past years, after publication of the National Policy of Basic Attention, 2017 and other documents, the role of HCAs in PHC has been profoundly weakened, not only reducing their operation within the territory and in developmental and educational healthcare measures, but also placing them in rather utilitarian and bureaucratic activities.

The narrative sheds light on elements that illustrate a domestic scenario of a low-income family who lives in a highly vulnerable social territory. Another element depicted is the “hospital bed adapted into the sitting room”, which represents the family’s dedication to providing more suitable and quality home care, consistent with the needs of their severely ill patient – even though the circumstances required some physical adaption and the sitting room was forced to take up a hospital ward function. In spite of their evident dedication, both patient and family did not quite seem to have opted for home death, however, circumstances led them to such outcome. This is the reality of countless families we support, who need to take care of an ill member at home without getting proper healthcare assistance that suits the level of complexity required and, often, do not have the chance to decide on the place of death. If life-long assistance is already complex, death support is not be any simpler. Home death requires relatives to arrange bureaucratic details that are inherent to that event and, therefore, they need the assistance of healthcare professionals and funeral services so that the death certificate is issued and the body may be removed.
The last scenario experienced by Mr. Raí was filled up with care and mutual affection shared with his inner-circle relatives. He had the chance to receive the loveable touch of his children and grandchildren, who were present at all times, who looked out for his appearance and hygiene and partook of joyful and relaxing moments by his side, such as watching the soccer match of the team he supported. The concept of end-of-life dignity refers to, above all, the autonomy held as an individual as well as the essential human rights ever discussed so that we can reflect upon the arising issues that may maintain, rescue or even threaten the dignity held by an individual in their finiteness process. People who lose their sense of dignity or have it impaired may show symptoms of anxiety, depression and hopelessness. Self-identity and autonomy, which are both important elements connected with dignity, may be seriously affected when there is a deterioration of the physical appearance, reckless hygiene and the sensation of being a burden to the family. Therefore, the description of Mr. Raí’s final moments seemed to have provided him with the support and family experience he needed, which contributed for preserving his dignity.

Also, in regard to Mr. Raí’s last day of life, we have observed signs that may represent an improvement in his overall clinical condition, a situation that is often noticed in several patients who draw near death. His wife said “… [his] condition was better than usual in the previous night”, furthermore, “he had a good meal and was even able to assist with his own bath, supported by his sons. He smiled at his grandchildren and watched his beloved soccer team’s match”. In an excerpt of Ana Claudia Quintana’s book “Death is an event worth living”, she tackles the dissolution of the four elements of nature throughout the dying process, according to the eastern beliefs. Initially, there is dissolution of the earth, which represents physical deterioration caused by the development of the disease. After that, water dissolves, which represents natural dehydration that overtakes a few patients at the end-of-life stage. The third element is fire, or one’s body cells vitality, which may show an improvement in terms of activity and function, thus providing the individual with an improvement in conscience and overall strength in the very last moments of life.

By retrieving the beautiful metaphor externalized by Mr. Raí’s sister-in-law regarding his process of becoming ill just “as if a candle were burning out progressively”, the moment of dissolution of fire, on its turn, intensifies this final light and “the famous visit by health (i.e., sudden improvement in one’s health) is the last beautiful strength impetus derived from the last flame of one’s candle”. People who have the chance to experience such clinical improvement in one’s final moments also get the precious opportunity to share affection and express their feelings of forgiveness and farewell. The last element is air and it represents the last sighs of an individual, the most distressing moments for both patients and relatives. Dissolution of air by Mr. Raí, in his final moments, appears to have happened without much anguish on the part of his relatives for his wife only “realized he was not breathing any longer [at around 2:30 in the morning when she woke up by chance]”.

People stood out in Mr. Raí’s death scenario since he was mourned over by many relatives who were present at that moment, as depicted in this excerpt: “wife, daughters, sons, granddaughters, grandsons and a couple of other relatives gathered in the kitchen and in the aisle leading up to the bedrooms.” Elisabeth Kübler-Ross.
mentions that when relatives are able to share their feelings and emotions, both loss acceptance and the mourning process are calmer and less painful for everyone. An interesting aspect concerns the presence of kids who also had the permission to take part in this farewell ritual, such as “his grandson of approximately 10 years old, who approaches his grandfather and kisses his face, embedded in affection and tears.” When it comes to tackling the topic of death with kids, we know we tend to avoid such approach, and therefore this taboo construction is underpinned since the earliest years of life and helps strengthen the belief in immortality during adulthood. Nonetheless, death, loss, rupture and grieving are part of all development phases of life, hence, they are often faced during childhood. In the early years of life, children do not possess the necessary thought concreteness in order to attribute sense to death, which may be regarded by them as something reversible. As the child grows mature and experiences losses, they are able to understand death as something concrete and irreversible and may, potentially, experience profound feelings of separation and loss. When a child experiences the death of a close relative, the tendency to avoid the topic by adults may evoke feelings of melancholy, abandonment and insecurity in this infant.

At last, we cannot fail to reflect upon the animals’ reactions, one of which has even served as title of this narrative. After all, are animals aware of death? Do they experience a mourning process when they are faced with a loss? In this narrative, both the bird and the dog seem to have felt Mr. Rai’s death somehow and/or the profound grieving from relatives and tend to behave silently or in an agitated fashion. Allan Kallehear supports that “every animal understands death” and he believes that it is a mistake to underestimate the experiences related to death and loss in animals, and that there may be greater complexity in animals’ mourning and attachment patterns. Kallehear critically reinforces that “we are animals and all animals know death. Considering the order of those things, we are even latecomers.” We may assume, then, that the image of “an animal that is evidently agitated” represents the common feeling of grief and anguish related to a recent death, since animals are directly affected by humans’ behavior and the environment around them. Or, also, that the small animal is only expressing its feelings, even though they are largely considered as irrational, towards the loss of their beloved caregiver. The bird’s absence from one typical corner could be a reflex longing and solitude which hovered over the environment, or it could even be the animal’s mourning expression. Concerning this, we are not bound to find any responses substantiated scientifically. However, we may as well open our hearts and broaden our views and ears not only to people’s tears and sobbing but also to the silence of birds, which, on their turn, may fail to sing on that very day.
Conclusion

The process of death and dying, in the western world, is not only influenced by social, historical and cultural contexts, but also permeated by several unique aspects. PHC is underpinned by essential and derived attributes, which represent the baseline for providing health care in every phase of individuals’ and families’ life cycle, thus, it needs to offer quality assistance from birth to death. FCPS and HCAs are professionals who work in PHC and, therefore, they have attributions and competences which are singular and necessary for bonding with users, thus favoring a better healthcare scenario. Death-related issues tend to unleash great expectations and concerns in healthcare professionals and patient’s relatives. However, it is essential that, as healthcare professionals, we continue to offer follow-up assistance as well as welcome them and deliver the support required. The approach in a moment filled with grieving is highly complex for healthcare professionals because they have to assist both in bureaucratic issues, such as issuing the death certificate, and also get a sensitive perspective of relatives and friends in the attempt to cope with a recent loss, thus alleviating their pain and making themselves available in a gentle and empathic way. The first person narrative, from the physician’s view, reveals the extent to which such professionals are affected and it may be a strong tool so that they can access their feelings in relation to the visits. Hence, in spite of it being an action that demands both a technical and an objective approach, the home visit with the purpose of issuing a death certificate invites us to tackle a highly subjective territory, which evokes many reflections towards the process of death and dying and also causes transformations in our lives both personally and professionally. The first person narrative, from the physician’s view, reveals the extent to which such professionals are affected and it may be a strong tool so that they can access their feelings and also acknowledge their attitudes towards these visits. For this reason, the inclusion of narratives may be an important and powerful tool to assist in the exploration of the elements that permeate the moment of death and may be present in practical scenarios and whenever training healthcare professionals so that we can offer integral care more adequately and with a sensitive view of the PHC scenario.

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All authors had actively participated in all stages of the manuscript preparation.

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References


A Atenção Primária à Saúde (APS) é um cenário capaz de produzir cuidado em todas as fases da vida, desde o nascer ao morrer. Porém, o cuidado de saúde de pessoas gravemente enfermas requer uma abordagem complexa e holística desses sujeitos e famílias, sendo muitas vezes prestado em domicílio. Uma das atribuições relacionadas aos cuidados em fim de vida é a emissão da declaração de óbito quando este ocorre em domicílio. Pela perspectiva de uma médica de Família e Comunidade, relatou-se, de modo narrativo e reflexivo, uma experiência de um atendimento domiciliar para emissão de declaração de óbito. A partir dessa narrativa, discuti-se sobre como a visita para declaração de óbito nos convida a entrar em um território repleto de subjetividades, que nos evoca muitas reflexões sobre o processo de morte e morrer, provocando transformações em nossa vida pessoal e profissional.


La Atención Primaria de la Salud es un escenario capaz de producir cuidado en todas las fases de la vida, desde el nacimiento hasta la muerte. No obstante, el cuidado de la salud de personas gravemente enfermas requiere un abordaje complejo y holístico de esos sujetos y familias, siendo muchas veces realizada a domicilio. Una de las atribuciones relacionadas con los cuidados al final de la vida es la emisión del certificado de defunción, cuando la misma ocurre en el domicilio. Bajo la perspectiva de una médica de Familia y Comunidad, se relató de modo narrativo y reflexivo una experiencia de una atención domiciliaria para emisión de certificado de defunción. A partir de esa narrativa, se discutió sobre cómo la visita para el certificado de defunción nos invita a entrar en un territorio repleto de subjetividades que nos evoca muchas reflexiones sobre el proceso de la muerte y el morir, causando transformaciones en nuestra vida personal y profesional.

Palabras clave: Atención Primaria de la Salud. Certificado de defunción. Medicina narrativa.

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