

# Advance directives or living wills: reflections of general practitioners and frail care coordinators in a small town in KwaZulu-Natal

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## Abstract

**Background:** Living wills have long been associated with end-of-life care. This study explored the promotion of living wills by general practitioners (GPs) and frail care nursing coordinators who were directly involved in the care of the elderly in Howick, KwaZulu-Natal. The study also explored their views regarding the pro forma living will disseminated by the Living Will Society.

**Subjects:** Seven GPs and three frail care nursing coordinators; 10 in total.

**Design:** The design was qualitative in-depth interviews and analysis, using the Framework method.

**Results:** Both doctors and nursing staff understood the concept of living wills and acknowledged that they were beneficial to patients, their families and staff. They were concerned about the lack of legal status of the living will. They felt that the pro forma document from the Living Will Society was simple and clear. Despite identifying the low level of living will usage among patients, doctors and nursing staff felt that third-party organisations and individuals should promote living wills to patients, rather than promoting them to patients themselves.

**Conclusion:** GPs and frail care nurse coordinators were knowledgeable about living wills in general, and the Living Will Society pro forma document in particular. They valued the contribution that living wills make to the care of the elderly, as they benefit patients, their families, healthcare workers and the health system. They also valued the pro forma living will document from the Living Will Society for its clarity and simplicity. However, the GPs and frail care nursing coordinators viewed the living will process as patient driven. They viewed their main role to be that of custodians, and not advocates, of the living wills.

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## Introduction

A living will is a set of instructions that documents a person's wishes about intended medical care to sustain his or her life. It is used if a patient becomes terminally ill, incapacitated, or unable to communicate or make decisions. A living will protects the patient's rights and removes the burden of making decisions from family, friends and physicians.<sup>1</sup> It also represents a means of clarifying decision-making, while empowering patients and enhancing choice.<sup>2</sup>

In South Africa, the Living Will Society defines a living will more narrowly by noting that its main function is to aid in the "refusal of artificial life support when dying".<sup>3</sup> However, a living will might, in addition, contain specific directions regarding the use of antibiotics, analgesia, hydration and feeding.

Living wills are not a new entity and were first suggested by US attorney, Luis Kutner, in 1967. By 1992, all 50 states in the USA, as well as the District of Columbia, had passed legislation to legalise some form of advance directive.<sup>4</sup> In the UK, the principle of patient involvement in decision-making was a key recommendation in the 2004 guideline by the National Institute for Clinical Excellence, entitled *Improving Supportive and Palliative Care for Adults with Cancer*.<sup>5</sup> In 2007, the Mental Capacity Act 2005 provided a legal framework in the UK for various elements of advance care planning. This legal foundation became National Health Service policy in the form of a document entitled *Capacity, Care Planning and Advance Care Planning in Life-Limiting Illness*.<sup>6</sup> Professional guidance regarding advance care planning was subsequently produced in 2010 by the General Medical Council, and was entitled *Treatment and Care Towards the End of Life*.<sup>7</sup>

In 1999, a South African bill was proposed, entitled the End of Life Decisions Act 1999.<sup>8</sup> The section titled "Directives as to the treatment of a terminally ill person" covered the withdrawal or withholding of treatment in the event of terminal illness as directed by an advance directive or living will. This had still not been passed into law in 2011. Despite the lack of a clear legal framework for the living will in South Africa, Prof D McQuoid-Mason, a prominent legal academic, suggests that existing legal principle supports it.<sup>9</sup>

Advocates of living wills have suggested the following arguments for their use:<sup>10</sup>

- They respect patient autonomy and advance the ethical principle of beneficence.
- They require informed consent.
- They are perceived as important by doctors.
- They enhance doctor-patient communication.

However, the following criticism of living wills has also been expressed:<sup>10</sup>

- There is a lack of individualisation if a template type of living will document is used.
- They might not represent the patient's true and current wishes.
- They are automatically interpreted as a "do not resuscitate" order.
- They are unavailable in an emergency situation, e.g. casualty.

The challenge of educating and promoting living wills to the South African population has been taken up by the Living Will Society.<sup>2</sup>

The first author of this paper, a primary care clinician living in a community with a large number of elderly residents, was under the impression that the uptake and use of living wills was low. This research aimed to explore this impression by assessing the knowledge and attitudes of general practitioners (GPs) and frail care coordinators who are responsible for the care of Howick's elderly residents, on the use of living wills in general, and the pro forma living will from the Living Will Society, in particular.

## Aim and objectives

### Aim

The study aimed to explore the knowledge and attitudes of GPs and frail care co-ordinators on the use of living wills in Howick, KwaZulu-Natal.

### Objectives

The objectives were to explore the factors that influence the promotion and use of living wills by Howick GPs and frail care nursing coordinators who are involved in caring for the elderly, and to investigate impressions about the Living Will Society's pro forma document by the above stakeholders.

## Method

### Study design

Qualitative research methodology was used to explore attitudes, opinions and experiences.

### Setting

The town of Howick in KwaZulu-Natal is a retirement destination of choice for middle-income and above, predominantly white, elderly South Africans. Howick And District Care of the Aged (HADCA) is responsible for the provision of 33 assisted living units, 73 frail care beds and 12 dedicated beds for dementia patients. Three other independent retirement complexes, each with frail care facilities and which are administered by body corporates, comprise a total of approximately 1 600 residential units and 168 frail care beds. The frail care coordinators, five in total, are all professional nurses by training. Their role is to coordinate all aspects of holistic care for the residents. Eight doctors from three independent private general practices provide care for these elderly residents and have had to deal with the issue of living wills.

### Selection of participants

All seven GPs, excluding the researcher, who are involved in the care of these elderly residents were invited to participate in the study, and subsequently interviewed. No sampling took place. Of the five frail care nursing co-ordinators, three were purposefully selected for the interview. The selection was based on availability for the interviews.

### Data collection

Interviewees were approached personally by the researcher and invited to participate in the research. The date and time of the interview was decided by mutual agreement and all interviews took place in the participants' place of work or homes in September 2011. Individual interviews took place on one occasion only.

Each in-depth interview was conducted in English by the researcher, himself a GP who is involved in care of the aged in the area, using a standardised, pre-piloted topic guide and making use of facilitative responses and reflective listening. The living will pro forma document was shown to the interviewees for reference. Each in-depth interview was recorded electronically. Additional handwritten notes were made where required. The recordings were transcribed verbatim by the researcher.

### Data analysis

Data from the in-depth interviews were analysed using the Framework method.<sup>11</sup> This method facilitated systematic analysis of qualitative data and an explicit research process.

Familiarisation, the first step, involved reading the entire data set of transcripts to provide an overview of their depth and diversity. This overview allowed themes, both anticipated and emergent, to be recognised and annotated. A thematic framework was then developed from these themes. This resulted in an index that could be applied to the transcripts. Coded data were then lifted from the transcripts and charted, allowing comparison, mapping of themes and interpretation.

During the interview phase, concurrent analysis enabled unanswered issues and questions from earlier interviews to be addressed in subsequent ones.

### Ethical considerations

Informed consent for participation, confidentiality of recorded and transcribed interview material and the protection of participants' interests regarding time and convenience were key ethical considerations in this study.

Ethics approval for the study was granted by the Health Research Ethics Committee of Stellenbosch University (Reference No: N11/07/236).

### Results

Exploration of participants' understanding of the living will unearthed three major themes, namely its purpose, the timing or stage of life when it was drawn up and the legality of it.

All of the study participants, both GPs and frail care coordinators, were aware of the concept of the living will.

One of the frail care nursing sisters described a patient's living will as:

*"...while in a sound mind, giving some guidance or instruction with regard to their medical treatment when they are not necessarily able to speak for themselves, with regard to no heroics, not resuscitating, no prolonging of life unnecessarily."*-MJ

They all acknowledged that the living will is both a statement of wishes regarding end-of-life care, as well as a statement of refusal of certain treatment. All of the respondents felt that it is a document that is applicable to end-of-life or terminal care.

However, two GPs made the following observations:

*"... a lot of living wills are (made by) completely healthy people with maybe one or two chronic medicines."*- JP

*"... the majority are healthy when they come with it, but very often have had a family member who has been kept alive artificially and traumatically."*- SN

The GPs all stated that in South Africa, living wills have no legal status. The frail care nursing staff were unsure about

this. Living wills' lack of formal legal status affected their perceived value for some GPs.

For one GP, its lack of legal status prompted the response:

*"I guess that's why I haven't got too involved with it."* - CJ

Those who valued it felt:

*"It's not legally binding, but it certainly is a good directive."*- PD

Participants were then asked about the process of drawing up living wills in general, and in particular, their role in the process. The themes that emerged related to the sources of the living will document and the roles played by participants, whether nursing or medical, as well as the patient and their family.

The Living Will Society was the most frequently mentioned source of a living will document, and all respondents, both medical and nursing, were aware of it. Other suggested sources were lawyers and the Internet. The Internet, although proposed, was not thought to be commonly used by the elderly in the community. Both a GP and a nurse had experienced a verbal directive with witnesses. The nurse fulfilled the role of recording these wishes during the patient's acute deterioration. This recording of a verbal statement of advance care wishes was the most active role performed by any of the respondents with regard to roles performed in the drawing up of living wills.

Typical responses of the GPs were:

*"If a patient were to ask me: 'Should I have a living will?' I'd encourage it. But I must admit that I don't often go and actively promote it."* - EC

*"...they come to me with the document having been signed already, and just ask me to keep the document in their file."* - PD

They saw their role as custodians of the document, and not as promoters or initiators of the process.

The nurses facilitated a process that was patient driven.

*"I recommend to the family to get in touch with the Living Will Society and then go through their GP."* - RC

Participants were then asked to relate their experiences regarding the use of living wills, and to identify associated benefits or strengths and weaknesses.

The benefits of living wills, as identified by the respondents, can be divided into those experienced by doctors, nursing staff, families and the patients themselves. Living wills can also benefit the use of resources in the health system.

Doctors who thought that a living will was a useful tool spoke of its value in decision-making:

*"In my final decision for an end-of-life issue...it makes it easier and it weights a decision in favour of what a living will says." - EC*

They used the living will to show congruency between their proposed management plan and the patient's stated wishes. In this way, their management plan was reinforced.

Living wills were used:

*"...to let the family know that the decision-making is not so much from your side, but rather from the patient's side." - SN*

The nurses also highlighted the benefit that a living will offers when implementing a palliative care plan for a patient in a frail care facility.

*"I like the living will for the fact that it gives us guidance...it just enables us to do that without feeling guilty, we just know that it is what everybody wants." - MJ*

The doctors, including those who were not partial to the use of living wills, and the frail care nurses believed that living wills offered real value to families in terms of decision-making, conflict resolution and grieving.

*"...if they know what their mother or father's wish was, it's easier for them to accept that. They feel unfaithful if they give up every attempt of promoting life." - SM*

Lastly, and perhaps most importantly, one of the identified benefits pertained to the patients.

*"Having a formalised document, like a living will, helps people to think about the unthinkable." - CJ*

*"...it also makes people come to terms with their mortality." - SM*

One of the frail care coordinators felt that living wills helped with the appropriate use of healthcare resources.

*"I think if we had to send down to hospital everyone who had a stroke...there would be a lot of overflow in the hospitals and the staff cannot cope with it." - RC*

When addressing weaknesses in the living will process, both nurses and doctors agreed that living wills were not widely used. A recently opened frail care facility illustrated this point.

The nursing manager commented:

*"I've got 42 permanent residents...and only two of the permanent residents have living wills." - MJ*

The participants felt that this reflected a lack of exposure to and knowledge of living wills:

*"My impression is that the elderly are not well informed in South Africa about living wills." - EC*

*"I was just thinking of who my patients (are) who have got living wills. A lot of them are medical or paramedical and*

*maybe it's the background that they know...so that's why patients haven't gone into it, is it because they haven't been exposed to it?" - VP*

For those who had completed a living will, its use could still be compromised by problems of availability. Both the GPs and frail care sisters recognised their responsibility to keep living wills and make them available when needed.

However, one GP observed:

*"Sometimes it is not known that a living will is in place because they've changed the institution of care and the new institution is not fully versed with what the patient's wishes were." - SM*

One GP commented that even when availability of the living will was secured, it was appropriate and important to assess whether it still represented a current expression of the patient's wishes:

*"...it was long ago, it may be old and the context and situations may have changed. This may make the living will difficult to interpret." - EC*

Having considered the strengths and weaknesses of a living will, participants were then asked to deliberate ways in which the use of a living will could be improved.

The majority identified the need for improved knowledge and awareness among the population:

*"I think it is basically increased awareness. The bottom line: people are either going to be interested or not." - MJ*

The respondents identified a variety of ways in which to promote and educate people about living wills. It was suggested that promotional and educational materials could be made available in practices and hospital waiting rooms, frail care facilities, Hospice, organisations that are involved in care of the aged, e.g. HADCA, pharmacies, and communal activity areas at the various residential complexes. Educational articles in local newspapers were likely to be widely read. Community forums and focus groups could host educational talks. Specific input from the legal profession could educate medical staff and community members.

All the participants who considered a living will to be a useful tool identified the pro forma living will from the Living Will Society as the one that was most commonly used.

They commented favourably on its simplicity, standardisation and clarity:

*"I don't think you can itemise every situation you might find yourself with. I think it's broad enough to cover a lot of situations. If it is to itemise every situation, then it's going to be quite clumsy." - MJ*

*"It's a fairly standardised document. Otherwise, everyone puts in their own feelings and beliefs in what's going on." - SN*

Interestingly, one GP, who had had experience of a patient with a terminal diagnosis and predictable acute complications, felt that under these conditions living wills:

*“...can be improved if they are more specific.” - VP*

## Discussion

In this study, both GPs and frail care nurses were familiar with the concept of a living will and highlighted its role in preserving patient autonomy, allowing more patient-centred care, guiding clinical decision-making and the rational use of resources and facilitating family involvement in appropriate end-of-life care. Despite concern over a lack of legal status, the majority still valued the guidance that living wills provided. Even so, all participants agreed that very few were completed in practice. This observation has also been noted in other research.<sup>12</sup> A lack of awareness of living wills was put forward as an explanation of the poor uptake. Both nurses and doctors acknowledged that they acted as the custodians of living wills, rather than as promoters or advocates. Their proposal for the improvement of patient awareness revolved around educational and promotional talks and articles. Doctors and nurses were concerned about initiating the living will process because of the sensitivity of the subject and the time required. However, research suggests that the best uptake of advance care planning results from a physician-initiated process.<sup>13-15</sup>

The Living Will Society promotes the living will through a patient-driven process that focuses on a pro forma living will document that appears to be suitable for South Africans.

Although the legal status of a living will remains untested in South Africa, Emanuel comments that the value of the living will is in the process of advance care planning, and not its legal status:<sup>16</sup>

*“Moving away from the notion of a legal defence against aggressive doctors, the living will movement realised that it is the process that is the central issue. Eventually, living wills come to be seen as a vehicle for achieving greater wisdom and skill in a fundamental aspect of health care and a civilised approach to mortality. Advance care planning is a process of discussion, a component of care. Legal documentation has a small, but legitimate role.”*

There is a growing trend of international opinion towards implementing an advance care planning process, rather than merely completing a legal document.<sup>17-19</sup> Research also points to the value of physician-initiated advance care planning as a means to increase uptake. This suggests that it may be time for doctors and nurses to meet their patients halfway by embracing their role of initiating advance care planning. The living will could be an entry point into this process.

## Strengths and limitations of the study design

A strength of the study was the interviews with GPs who were involved in the care of the elderly through the various frail care centres in Howick. A weakness of the study was its lack of generalisability beyond a white, middle-class elderly South African population in a specific primary healthcare setting. It is also possible that nurse participants might have felt intimidated that a doctor conducted the interviews. Interview techniques involving facilitative responses and reflective listening statements helped to overcome this. The interviews and analysis were conducted by one person whose personal opinion favoured the use of living wills. This means that there was a possibility that bias was present. However, only two participants found no value in a living will. Both of those were GPs who were confident of their opinion, so this seems to be unlikely.

## Implications and recommendations

Insight into the knowledge of, attitude to, and use of living wills is likely to be valued by HADCA, Hospice, the frail care committees of the various residential communities, and the Living Will Society. The participants are likely to benefit from the insights of their colleagues. Primary healthcare providers who serve communities with a similar population demographic might find the results interesting and the discussion relevant. This research suggests that a plan of action to promote knowledge about and the use of living wills within the community is required.

Further research is needed to evaluate whether these findings are generalisable to primary healthcare clinicians who work with other cultures and in different socio-economic communities. It would also be appropriate to explore how advance care planning is conceptualised by stakeholder organisations and clinicians who are involved in aged care and end-of-life care.

## Conclusion

All the participants, both medical and nursing, were knowledgeable about the living will in general, and about the Living Will Society pro forma document, in particular.

The research showed that the majority of GPs and frail care nurse coordinators valued the contribution that living wills can make in the care of the elderly, and their benefit to patients, their families, healthcare workers, and the healthcare system. They also valued the pro forma living will document from the Living Will Society for its clarity and simplicity. However, both GPs and frail care nursing coordinators viewed the living will process as patient-driven, and their main roles to be that of custodians, and not advocates, of the living will. To overcome the challenge

in South Africa of a poor uptake of living will use, it is suggested that GPs and frail care coordinators consider the process of advance care planning and define their roles within it.

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