# Withdrawal of life support and chaplaincy in Australia

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**ABSTRACT**

**Objective:** To explore the role of health care chaplains in providing pastoral care to patients, their families and clinical staff considering decisions to withdraw life support.

**Methods:** Quantitative data were obtained retrospectively from a survey of 327 Australian health care chaplains (both staff and volunteer chaplains) to initially identify chaplaincy participation in withdrawal-of-life-support issues. Qualitative data were subsequently obtained by in-depth interview of 100 of the surveyed chaplains and thematically coded using the World Health Organization Pastoral Intervention (WHO-PI) codings to explore chaplains' roles.

**Results:** Over half the staff chaplains surveyed (57%) and over a quarter of the volunteer chaplains (28%) indicated that they had been involved with patients or their families in withdrawal-of-life-support decisions. Over a third of staff chaplains (37%) and 16% of volunteer chaplains had assisted clinical staff concerning withdrawal-of-life-support issues. The qualitative data revealed that chaplains were involved with patients, their families and clinical staff at all levels of pastoral intervention, including "pastoral assessment", "pastoral ministry", "pastoral counselling and education" and "pastoral ritual and worship". The specific nature of chaplaincy involvement varied considerably depending on the idiosyncratic issues faced by patients, families and clinical staff. These activities indicated that pastoral care could be provided for the support and benefit of patients, their families and clinical staff facing a complex bioethical issue.

**Conclusions:** Through a variety of pastoral interventions, some chaplains (mostly staff chaplains) were involved in assisting patients, their families and clinical staff concerning withdrawal-of-life-support issues and thus helped ensure an holistic approach within the health care context. Given this involvement and the future potential benefit for patients, families and clinical staff, there is a need to develop continuing education and research on pastoral care and chaplaincy services.

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The literature on the role of chaplains in the withdrawal of life support is limited. Some potential roles have been suggested for chaplains following a decision to withdraw a patient's life support[1] (Table 1). Given the paucity of available research, we explored the role of chaplains in providing pastoral care to patients, their families and clinical staff considering withdrawal of life support in Australian hospitals. The exploration was based on two questions: Are chaplains involved in assisting patients, families and clinical staff with issues regarding withdrawal of life support? If so, what is the nature of that involvement?

## Methods

As part of a larger study,[2] members of the Australian Health and Welfare Chaplains Association (AHWCA) were asked to volunteer information on their involvement in withdrawal-of-life-support issues by completing a survey and then undertaking an in-depth interview about their perceptions of their involvement.

Data were collected between June 1997 and June 2000 by a two-stage non-experimental "parallel paradigm" cross-sectional study.[3] This study collated quantitative[4] and qualitative data descriptively,[5,6] using the in-depth interview process.[7] Given the emerging literature on the influence of religiosity and spirituality on an individual's state of health and well-being,[8-14] triangulation of quantitative and qualitative methodologies was used to facilitate the most valid assessment of the pastoral role of chaplains.

### Quantitative study

Lists of all chaplain members of AHWCA in all Australian states and territories were obtained with the permission of AHWCA. Surveys were individually distributed to each member either in person or by mail.

### Qualitative study

The qualitative component of the research involved in-depth semi-structured interviews of 100 volunteer chaplain informants.[7] The interview was based on the survey and sought to explore more deeply the clinical and ethical experiences of chaplains with regard to patients, their families and clinical staff making decisions to withdraw life support. The interviews, following signed consent, were audiotaped. Most lasted about 2 hours.

Given the limited literature on this topic, we considered it important to include qualitative data to clearly demonstrate the involvement and broad opinion of chaplains, which in turn would provide greater objectivity and assist future research.

To assist with coding the substantial amount of qualitative data obtained, the information derived from chaplaincy

**Table 1. Possible roles of chaplains and clergy given a decision to withdraw life support***

- Informing relatives of the medical decision to "turn off" life support.
- Relating to family concerns about how an apparently living unconscious person can be "dead".
- Gaining the relative's acceptance of withdrawal of vital support once, for example, brain death has been ascertained.
- Relating and empathising with a relative's perception that switching off life support may be viewed as killing the patient.
- Discussing pragmatic concerns about the decision to withdraw active therapy occasioned by medical concerns for cost, the need for additional beds, or just the medical profession's unwillingness to try.
- Exploring theological concerns that the person who has died may have been denied an opportunity to repent, or to believe, as a result of withdrawing life support.
- Providing counselling to relatives, given feelings of guilt, inadequacy and hopelessness which accompany normal grieving.
- Discussing issues of life support and prolongation of suffering.

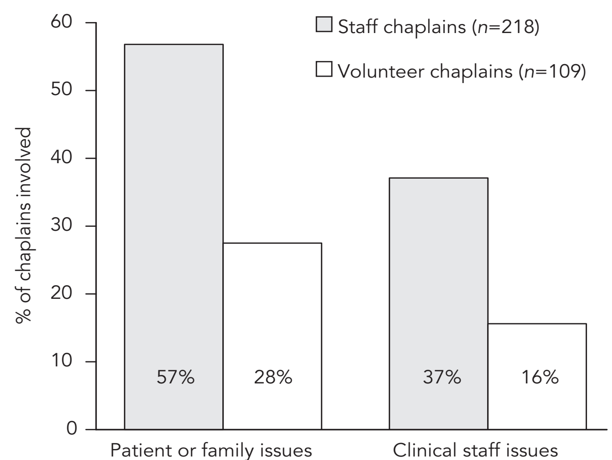
* Derived from Vere.[1]

**Table 2. Number of respondents to the Australian Chaplaincy Survey, by state**

| Type of chaplain | NSW/ ACT | SA | VIC | QLD | WA | TAS | NT | Total |
|---|---|---|---|---|---|---|---|---|
| Staff | 57 | 43 | 43 | 40 | 26 | 4 | 5 | 218 |
| Volunteer | 28 | 22 | 19 | 14 | 14 | 8 | 4 | 109 |
| **Total** | **75** | **65** | **62** | **54** | **40** | **12** | **9** | **327** |

NSW/ACT = New South Wales and Australian Capital Territory.
SA = South Australia. VIC = Victoria. QLD = Queensland.
WA = Western Australia. TAS = Tasmania. NT = Northern Territory.

**Figure 1. Percentage of chaplains involved with patients, family or clinical staff in issues about withdrawal of life support**




informants was thematically categorised using the World Health Organization Pastoral Intervention (WHO-PI) codings.[15] These codings have proven useful in previous pastoral care research.[16-19] They comprise four categories: Pastoral Assessment, Pastoral Ministry, Pastoral Counselling and Education, and Pastoral Ritual and Worship.

## Results

Because of the large amount of data gathered, not all the results of either the quantitative or qualitative study are presented here.

### Quantitative data

Of the 410 chaplains surveyed, 327 completed a survey (80%). Of these, 218 indicated that they were staff chaplains (employed by hospital, government, church or mixed funding), and 109 that they were volunteer chaplains (Table 2).

Nearly half the respondents (47%) indicated that they had been involved in assisting patients or their families in decision-making about withdrawal of life support. There was a statistically significant difference between the proportion of staff chaplains (57%) and volunteer chaplains (28%) involved with patient or family about withdrawal-of-life-support issues ($\chi^2 = 25.1$; $df = 1$; $P = 0.001$). Nearly a third of chaplains surveyed (30%) indicated having had some involvement with clinical staff about withdrawal-of-life-support issues. Again there was a statistically significant difference between the proportion of staff chaplains (37%) and volunteer chaplains (16%) involved with clinical staff ($\chi^2 = 16.1$; $df = 1$; $P < 0.001$) (Figure 1).

Cross tabulations were also undertaken comparing involvement between Catholic ($n = 129$) and Protestant ($n = 196$) chaplains. About 48% of Catholic respondents and 47% of Protestant respondents indicated involvement with patients and families, while about 33% of Catholic respondents and 28% of Protestant respondents had provided some form of pastoral intervention to clinical staff. However, $\chi^2$ tests showed that the differences in involvement between Catholic and Protestant respondents were not statistically significant (patient and family involvement, $\chi^2 = 0.25$; $df = 2$; $P = 0.88$; and clinical staff involvement, $\chi^2 = 0.85$; $df = 2$; $P = 0.65$).

### Qualitative data

One hundred chaplains volunteered as informants for the interview, comprising 79 staff chaplains and 21 volunteer chaplains (Table 3). Of the 100 interviewed, 60 chaplains provided in-depth information on their experience of withdrawal-of-life-support issues. Thematic coding of the interviews showed that chaplains were involved at all levels of pastoral intervention among patients, family and

staff, both before and after the decision to withdraw life support (Table 4).

### Pastoral assessment

Pastoral assessments undertaken by chaplains with regard to withdrawal-of-life-support issues usually involved, at some stage, the skills of listening and discerning to assess where patients and families "were at" emotionally and spiritually, and subsequently discovering what information was needed to assist them with decision-making. More specifically, the primary reason for patients and families seeking a pastoral assessment from a chaplain was to explore theological and religious ethical issues either before making a decision (eg, chaplaincy informant [CI] 4) or immediately after making a decision but before enacting withdrawal of life support (eg, CIs 5, 41 and 68). Some families seemed to need a chaplain's assessment to be assured that a decision to withdraw life support would be considered acceptable within religious, theological and moral boundaries.

Some chaplains were also involved in helping patients with self-assessment. For example, some patients receiving life support, yet fully cognitive, would request termination of life support because they perceived themselves to be a burden on others. Even given a patient's autonomous decision to terminate life support, and the support of medical staff for its withdrawal, such decisions nevertheless posed an ethical concern in terms of "defining quality of life" (eg, CI 54), for which some patients sought chaplaincy discernment.

Chaplains also indicated providing assistance to clinical staff seeking advice as to "where a family were at" with regard to their decision-making (eg, CI 14) or advice on whether the clinical staff's assessment to proceed with withdrawal of life support was "doing the right thing" (eg, CIs 39 and 83). Several chaplains expressed concern about medical staff "making decisions far too quickly" in favour of withdrawal of life support without allowing sufficient time for proper assessment (eg, CI 40). Indeed, one chaplain noted that some nursing staff were concerned about medical practitioners autocratically determining the decision to withdraw life support, leading nursing staff to protest about the "lack of consultation" (eg, CI 72). Other chaplains noted that they worked as a team with medical staff to assess the various issues to ensure that "the patient's and family's best interests were the priority" (eg, CIs 24 and 72).

### Pastoral ministry

Chaplaincy informants indicated that there were several reasons for chaplains "coming alongside patients and families to support them" at the time of withdrawal of life support (CI 25). Some chaplains found themselves provid-

**Table 3. Number of informants for the Australian Chaplaincy Interview, by state**

| Type of chaplain | NSW/ ACT | SA | VIC | QLD | WA | TAS | NT | Total |
|---|---|---|---|---|---|---|---|---|
| Staff | 19 | 22 | 16 | 7 | 9 | 3 | 3 | 79 |
| Volunteer | 6 | 3 | 2 | 4 | 1 | 3 | 2 | 21 |
| **Total** | **25** | **25** | **18** | **11** | **10** | **6** | **5** | **100** |

NSW = New South Wales and Australian Capital Territory. SA = South Australia. VIC = Victoria. QLD = Queensland. WA = Western Australia. TAS = Tasmania. NT = Northern Territory.

**Table 4. Pastoral interventions undertaken by chaplains involved in withdrawal-of-life-support issues**

Pastoral assessment
(Major heading, 1824; ICD code, 96186-00)
- Assessed holistic well-being, needs and resources of patient.
- Encouraged patient–family consultation to consider issues.
- Helped patient or family to define "quality of life".
- Helped to define or assess patient and family priorities.
- Explored theological, religious and ethical issues concerning the "right thing to do".
- Provided feedback about the patient's or family's perspective to clinical staff.

Pastoral ministry
(Major heading, 1915; ICD code, 96187-00)
- Engaged "alongside" patient and family to provide support when confronted with profound issues such as death, dying and loss.
- Facilitated patient, family and staff meetings.
- Provided patient advocacy and support.
- Provided independent presence or support to family during brain testing and organ harvesting.

Pastoral counselling and education
(Major heading, 1869; ICD code, 96087-00)
- Provided personal or familial counsel, ethical consultation, and education about religious belief and practice.
- Explored religious issues concerning terminating life.
- Provided theological education or clarification about removing extraordinary life support.
- Counselled or educated about religious and theological issues regarding organ donation.
- Counselled clinical staff concerning personal moral and professional issues.
- Debriefed or counselled clinical staff following withdrawal of life support or death.

Pastoral ritual and worship
(Major heading, 1873; ICD code, 96109-01)
- Provided prayers, blessings, sacraments, anointings, baptisms and last rites.
- Conducted rituals that assisted the decision-making transition.
- Conducted funerals and memorial services.

* Interventions are categorised according to World Health Organization (WHO) ICD-10-AM Pastoral Intervention Codings. Full descriptors are available in reference 15.

ing support to families if "hostilities" developed when medical doctors attempted to "pressure families into withdrawing life support" (eg, CI 23). Such support could extend to chaplains facilitating meetings between families and doctors so as to improve communication, particularly when families felt "doctors were being unhelpful" (eg, CI 17). The chaplain's role could also extend to being an advocate on behalf of patients and families, particularly when "wanting more time" to make and accept a decision to withdraw life support (eg, CI 1).

A common role requested of chaplains after a decision to withdraw life support was to be with families and patients during the process of brain testing (eg, CI 63) and harvesting of organs (eg, CIs 7, 13, 15, 16, 20 and 58). This role provided comfort to families and a sense of assurance that clinical staff could be scrutinised and challenged by an independent person if the tests or harvesting were not undertaken in accordance with the family's wishes.

Further, while chaplains usually initiated consultation with clinical staff about other bioethical issues,[20-22] the opposite was common for withdrawal of life support. That is, it was often the clinical staff who initiated the request for chaplains to support families, particularly when issues demanded time.

### Pastoral counselling and education

Most chaplaincy informants indicated that their involvement with patients and families in withdrawal-of-life-support issues was mostly before the decision to withdraw life support. Yet, whether before or after the decision, chaplaincy informants indicated being involved in:

- education and clarification of issues concerning the withdrawal of life support;
- provision of theological, ecclesiastical and specific chaplaincy perspectives on withdrawal of life support;
- exploration of issues regarding organ donation; and
- consequences of decisions.

*Clarification and education:* Chaplaincy informants indicated that a main role of chaplains was that of educating or clarifying for families the distinction between the act of "killing a loved one" (which some families perceived the medical system to be approving) and the act of "removing extraordinary life support" that was preventing a natural death (eg, CIs 5, 29, 32, 53, 64, 61, 77 and 95).

*Religious and theological issues:* Some chaplains noted that during the critical last stages of a person's life, the patient or family may consult a chaplain because "they … want the expert opinion about it from the church point of view" (CI 64). Other chaplains noted that some families with religious concerns about withdrawal of life support would struggle with the concept and decision to terminate life support. Several chaplains noted that their pastoral counselling and educational intervention helped people explore the religious and theological issues (eg, CIs 4, 5, 14, 27, 39, 53, 56 and 58).

*Organ donation:* Chaplains were sometimes recruited by families or clinical staff to facilitate patient and family decisions about the withdrawal of life support and subsequent consideration of organ donation (eg, CI 40). Some chaplains indicated that families who were hampered in their decision-making by the ethical dilemmas of withdrawal of life support, which were then compounded by organ donation issues, could feel "overwhelmed" and "frozen" in their decision-making. Chaplains noted that families seemed to appreciate their non-medical perspective that encouraged a holistic perspective about life and death.

*Decision-making:* Another noticeable aspect of withdrawal of life support was that, while chaplains were trained in and generally practised non-directive counselling, some chaplains were more directive by encouraging families to consider the long-term consequences of their decisions, particularly the challenges of prolonged life support. However, given the intensity of a complex "life and death" situation, some volunteer chaplains refused to become involved at all with withdrawal-of-life-support issues, believing that it was "beyond their boundaries" and the "domain of social workers, family and the staff hospital chaplain" (CI 10).

*Clinical staff:* Similar to their involvement with patients and their families, chaplains would also assist clinical staff concerning withdrawal-of-life-support issues, particularly with regard to explaining theological, ecclesiastical or chaplaincy perspectives. In some cases, chaplains noted that medical staff would regularly consult with chaplains to learn the theological perspective and teaching of religious organisations before engaging with families concerning withdrawal-of-life-support decisions (eg, CIs 63 and 70). This might even result in a request for chaplains to be involved in meetings between medical staff and families (eg, CI 56).

Pastoral counselling was also provided by chaplains to some clinical staff who may have been professionally struggling with justifying to families the consideration of a decision to withdraw life support. Several chaplains noted that some clinical staff were sometimes reluctant, or perhaps nervous, to engage with relatives about withdrawal-of-life-support issues. Thus, staff had used chaplains as a reference point to clarify their professional concerns before they talked with families.

Another area of pastoral counselling for chaplains was to help staff cope with issues relating to their own personal ethics. Chaplains identified that some staff professionally supported the logic of withdrawing life support, yet it conflicted with their sense of personal morality, causing them considerable stress. Another area of support identified

by some chaplains was that of providing pastoral counselling to clinical staff who, given long-term clinical support, had become emotionally attached to a patient, and consequently struggled with the decision to withdraw life support.

### Pastoral ritual and worship

Various rituals were frequently conducted given the nature of withdrawal of life support and, in most cases, the inevitability of death. Rituals before the decision to withdraw life support included prayers (eg, CIs 27, 35 and 70), blessings (eg, CI 58), sacraments and anointings (eg, CI 70) and preparing the funeral ritual (eg, CIs 14, 17 and 31). Rituals after the decision were mainly prayers (eg, CIs 68 and 86), last rites (eg, CI 40), baptisms (eg, CI 41) and the conduct of funerals (eg, CIs 7 and 31). One chaplain noted that, until an appropriate ritual had been conducted, one family was "unable to move on" in their decision-making to withdraw life support from a loved one (CI 14).

Some chaplains noted that, on rare occasions after withdrawal of life support, the patient continued breathing and "came through okay" (eg, CI 53). However, chaplaincy informants did not mention any rites that celebrated a "return to life". They also did not mention any requests from clinical staff for rituals or acts of worship to assist them to cope with or debrief from the stresses of withdrawing life support.

## Discussion

Over the years, there has been considerable anecdotal evidence about chaplains assisting patients, their families and clinical staff with bioethical decisions. Our study found that most of the Australian chaplains surveyed had been involved in withdrawal-of-life-support decisions in a variety of ways. For the majority of both staff and volunteer chaplains this involvement was predominantly with patients and their families, providing recognised pastoral interventions (ie, pastoral assessment, ministry, counselling and education, ritual and worship).

However, both staff and volunteer chaplains were significantly less involved in assisting clinical staff. Nevertheless, chaplains seemed to provide a level of resource and support for some clinical staff that enabled them to gain additional and fundamental insight and feedback about patient and family concerns and beliefs that evolve due to withdrawal-of-life-support issues. This is particularly important in health settings that embrace a holistic concept of the human person.

The significantly lesser involvement of volunteer chaplains, particularly with clinical staff, is understandable as all volunteer chaplains were part time or casual and, in most cases, did not have the same frequency of exposure nor access to "restricted" areas as officially appointed staff chaplains. Further, while most staff chaplains have postgraduate training in clinical pastoral education (76%), only about half of all volunteer chaplains have any graduate training (52%).[23] Given the specialist competency and experience of most trained health care professionals, the contribution of volunteer chaplains may not have been as highly valued and therefore not sought or appreciated by some clinical staff.

Nevertheless, given that potentially over a quarter of volunteer chaplains engage with patients and families regarding withdrawal-of-life-support issues, the impact of pastoral intervention by volunteer chaplains should not be underestimated and needs to be taken into account by health professionals when considering the utility of these chaplains. Likewise, given the percentage of staff chaplains who have participated in withdrawal-of-life-support decisions with patients, their families and clinical staff, it is important to note that these chaplains could offer important tacit knowledge and support to those affected by withdrawal-of-life-support decisions. Further, given this knowledge, any continuing education about withdrawal of life support should perhaps include chaplaincy involvement, to help health care institutions maintain a holistic perspective.

Data from chaplains revealed unique and important information about the holistic nature of chaplaincy involvement in the withdrawal of life support. At the assessment level, it was possible to identify a common chaplaincy strategy of initially listening and helping patients and families to identify information needed to validate a potential decision, particularly with regard to non-clinical concerns, such as theological, religious and ethical issues. This role might also include assessing patient and family readiness, providing feedback to clinical staff and, if necessary, advocacy with regard to potentially hasty medical determinations or conflict between a family's religious or cultural beliefs and medical judgements.[24]

At the pastoral ministry level, chaplains noted their provision of emotional support and independent scrutiny, predominantly through being present at significant times to ensure patient and family interests were being honoured. The counselling and education level was found to be considerable, evidenced by chaplaincy pastoral care to patients, families and clinical staff who were challenged by professional or personal moral, theological and ethical issues arising from withdrawal of life support.

Finally, a particular pastoral intervention identified by this research, usually regarded as a purely "religious" activity at the end of life and subsequently often undervalued, is that of pastoral ritual and worship. Chaplains provided evidence

that, when appropriate, ritual and worship activities were implemented to facilitate patient and family decision-making, during both the process of this decision-making, and then later to help families and staff cope with feelings of grief and loss.

### Future research

The role of chaplains, particularly in withdrawal of life support, requires further research. It could be argued that each of the chaplaincy pastoral interventions used during the process of withdrawal of life support helped provide a balance between facilitating difficult decision-making, and thus saving valuable and limited resources, and maintaining an appropriate and respectful value for individual and community life.

Nevertheless, while our study affirms the potential value of chaplains in the clinical context, particularly in withdrawal-of-life-support issues, it raises questions for future research: What training and continuing education should chaplains (particularly volunteer chaplains) be given about withdrawal-of-life-support issues? Could chaplains be involved in the continuing education of clinical staff about withdrawal-of-life-support issues? Finally, if chaplains are to be more involved, what strategies should be in place to more effectively integrate chaplaincy?

This research is likely to highlight the potential utility of health care chaplains — not as a separate practice but as part of a system committed to holistic care in the 21st century.

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