Role of non-governmental organisations in physician assisted suicide

Could right to die organisations be part of the solution to the many ethical difficulties doctors face over assisted suicide? **Stephen Ziegler** and **Georg Bosshard** examine two such organisations

The legalisation of assisted suicide and the extent of doctors' involvement in the practice continue to generate heated debate within the medical, political, and religious communities. Historically, the discussion was strongly influenced by the Dutch model that permitted a doctor actively to hasten the death of a suffering patient.¹ By the 1990s, however, an alternative model had emerged—physician assisted suicide. This increases patient control by enabling self administration of drugs and limits the doctors' role to assessment and prescribing while involving non-physicians and non-governmental organisations in the dying process.¹⁻⁵

Recent attempts to make it legal for UK doctors to help patients die failed.⁶ Although the legalisation debate is likely to continue in the United Kingdom and elsewhere, a new debate focusing on the use of people other than doctors in assisted death seems to be emerging.^{4 7 8}

Non-governmental organisations occupy a central role in facilitating physician assisted suicide in Switzerland and Oregon (USA) and also help to limit the role of doctors. Despite their importance, little is known about their services, controls, and how they fit into the larger medical system.

Terminology

Throughout this article we use the phrase “physician assisted suicide” to describe a procedure where a doctor lawfully provides a lethal dose of drugs to a patient for self administration. Although the description of this process as suicide continues to generate controversy in the United States,^{9 10} physician assisted suicide does not carry the same connotation in the Swiss culture, is often used in the academic literature, and is distinct from active euthanasia.^{5 11} Consequently, in the interest of consistency and comparative analysis, we have retained the term here.

Right to die organisations

Assisted suicide in Switzerland and the US (Oregon) accounts for less than 1% of all deaths (0.36% in Switzerland and 0.12% in Oregon).^{3 12} Most assisted suicides in both countries are facilitated through private non-profit organisations (92% and 75%, respectively).^{5 12} Exit is the largest Swiss organisation with independent offices in Zurich (www.exit.ch) and Geneva (www.exit-geneve.ch),^{2 13} and Compassion and Choices is the biggest in the US (www.compassionandchoices.org).

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Both are private, charitable organisations with around 50 000 members. Dignitas, a smaller Swiss non-profit organisation has gained notoriety by helping residents of Germany, the UK, and other countries.⁵ Although there are other right to die organisations throughout the world,¹⁴ we have concentrated on these two organisations as prototypes for societies who lawfully facilitate physician assisted suicide.^{2 13}

Exit's services are available only to Swiss citizens. People must join the organisation and pay a small membership before they can get any type of help. New members are not screened because most simply want to file advance directives with Exit and have them enforced should the need arise. Members seeking help with suicide must be legally competent, exhibit a constant and consistent wish to die, and be experiencing “unbearable suffering or be disabled in a serious manner.” Exit workers follow a protocol and use a checklist to document what was discussed at the initial visit and all subsequent contacts. Most members who are considered eligible for help are close to death, and Exit routinely recommends both hospice care and notification of the family. Difficult cases are referred to Exit's ethics committee for review (Exit, personal communication).⁵

Everyone who seeks assisted suicide must be examined by a doctor, who will not prescribe the lethal dose of barbiturates until he or she has assessed the patient's medical condition and decisional capacity. If the member is eligible, but their own doctor declines to participate, Exit can refer the member to a collaborating physician who would consider assessing the patient and prescribing the lethal drugs. The prescription will be obtained at a local pharmacy by an Exit volunteer and stored at Exit headquarters until the day of use, when a volunteer will again assess the member's decisional capacity. If the member continues to assert a desire to die, the volunteer will mix the drugs in liquid or food and hand it to the person to swallow. If the person is incapable of swallowing, the drugs can be self administered through a percutaneous endoscopic gastrostomy catheter or intravenously.^{2 11}

Most suicides occur in the person's home, with only a few taking place in nursing homes or a dedicated room at Exit in Zurich. At the time of death, the volunteer notifies the police, who attend with a medical officer. Provided that there are no indications that the assistance violated Swiss law, the case will be closed. The body is usually released to the coroner at the scene, although the rules and procedures vary between cantons.^{2 11 13}

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Table 1 | Services and responsibilities of doctors, right to die organisations, and others in physician assisted suicide in Switzerland and Oregon (US)

Role	Switzerland (Exit)			Oregon (Compassion and Choices)		
	Doctor	Organisation	Others	Doctor	Organisation	Others
Discusses eligibility	Yes	Yes		Yes	Yes	
Provides basic medical information to patient (diagnosis, prognosis, treatment options)	Yes			Yes		
Refers to counselling or provides information on alternatives (eg hospice)	Yes	Yes		Yes	Yes	
Assesses concomitant factors (eg depression)	Yes	Yes		Yes		
Assesses decisional capacity	Yes	Yes		Yes		
Assesses and confirms absence of coercion	Yes	Yes		Yes		
Provides information to doctors		Yes			Yes	Yes*
Provides information about lethal drug	Yes	Yes		Yes		Yes†
Prescribes lethal drug	Yes			Yes		
Dispenses lethal drug			Yes†	(Yes)		Yes†
Delivers lethal drug for self administration		Yes	Yes‡			(Yes)†‡
Offers support during administration of lethal drug	(Yes)	Yes		(Yes)	Yes	
Manages complications	(Yes)	Yes		(Yes)	Yes	
Reports the death		Yes§		Yes		

*Oregon Department of Human Services (www.oregon.gov/DHS/ph/pas/index.shtml).

† Pharmacist.

‡ Family member or designated agent.

§To police.

Compassion and Choices

Compassion and Choices was formed by a recent merger between Compassion in Dying (Portland, Oregon) and End-of-Life Choices of Denver, Colorado (formerly The Hemlock Society). It is treated as a tax exempt organisation, and its purpose is to support, educate, advocate, and litigate for improvements in end of life care and end of life choices. Membership is not required to receive services, and the organisation is funded through private donations. It has a team of trained counsellors who screen calls for assistance in all US states except Oregon, Washington, and New York (which have independent and self supporting affiliates). We have limited our discussion to physician assisted suicide in Oregon provided under Oregon's Death with Dignity Act.¹⁵

Since physician assisted suicide is lawful in Oregon, the primary function of Compassion and Choices staff and volunteers in the state is directed at ensuring access and providing information as well as emotional support to patients and families. The law requires that two

doctors are involved, one to prescribe and the other to consult.¹⁵ The organisation plays no part in assessing a patient's legal capacity since that responsibility rests with the doctor.¹⁶ Rather it helps ensure access to assisted suicide by discussing the eligibility process with interested parties and by providing information and assurance to doctors who want to comply with the Oregon law and qualify for its protections. However, some Oregon doctors are hesitant to assume the lead role of the prescribing physician and would rather be the consulting physician.^{16 17} In these cases the organisation will suggest that the patient asks to be referred to another doctor who would consider being the prescribing physician.

Unlike Exit, Compassion and Choices does not permit assisted suicide on its premises; nor does it take the lethal drugs to the client or facilitate suicide outside the client's home. However, clients often request that its representatives are present at the time of ingestion. After the death, the volunteer will help the family and notify the hospice or the client's doctor if requested. The doctor will fill out a death certificate and list the underlying disease as the cause of death (deaths are not considered suicide under the Oregon act).^{15 17} Consequently, the police do not investigate each death as they do in Switzerland (table 1).

Recruitment, training, and quality control

Although Exit has a team of paid staff, most of its workers are volunteers drawn from the community and recruited at seminars hosted by the organisation throughout Switzerland. People who are interested in becoming volunteers complete an application form, have an interview with Exit staff, and must pass psychological tests and in-depth interviews with two psychologists at the Institute for Psychology (Basel). Approved volunteers receive training in counselling, technical matters, and the policies and procedures of the organisation and are subject to continuing education and supervision. Volunteers are assigned a mentor, who works with them for several months to evaluate their progress.

Compassion and Choices' recruiting methods, training, and internal controls are similar to those of Exit. Volunteers receive training from clinical nurses and doctors and are required to attend monthly case review meetings. However, volunteers do not have psychological testing. Applicants who have recently experienced a death in their family are not accepted as volunteers because of emotional considerations.

Both organisations control quality through screening and training of volunteers, adherence to eligibility and practice guidelines, retrospective review of cases, and ethics consultations. The organisations will refuse to provide consultation or support for an assisted death if the person does not meet their eligibility criteria. In these cases the person is referred to counselling, hospice, or other appropriate agency.¹⁶

In the late 1990s, after a series of internal rows and scandals that resulted in it losing several members, Exit created an ethics and a compliance committee to deal with difficult cases and to review all assisted suicides and

The means to the end

apply what was learnt to future cases.^{5 13} In 2002, Exit instructed a private ethics institute to draw up a report summarising the viewpoints and experiences of its ethics committee. The box summarises the report, which was intended to improve Exit's services and was distributed to Swiss governmental and medical bodies.¹⁸ In November 2006, the Swiss National Advisory Commission on Biomedical Ethics issued recommendations regarding right to die organisations in Switzerland and the need to comply with due care.¹⁹ Compassion and Choices does not have a standing ethics committee because physician assisted suicide in Oregon is regulated by state law and doctors are the primary gatekeepers.^{7 15 17} However, ethics consultants are available if needed.

Regulation

Assisted suicide in Switzerland is regulated by the criminal law and the laws and policies regarding medical practice. Technically, assisting or inciting a suicide is illegal in Switzerland, and no distinction is made between doctors and other people.^{2 4} However, according to article 115 of the Swiss Penal Code, a person commits an offence only if he or she was motivated by selfish reasons. Moreover, since almost all assisted suicides in Switzerland are accomplished with prescribed barbiturates, Swiss doctors who write lethal prescriptions must also comply with health and drug laws.¹³ Although Swiss health laws do not exclude a doctor from assisting a terminally ill patient in suicide, it remains unclear whether participating in the suicide of a non-terminally ill patient would also be excluded. Nevertheless, when prescribing a lethal drug, the doctor must act with due care and document the patient's condition and decisional capacity in the medical records, along with justification for the decision.^{19 20}

In Oregon, physician assisted suicide is regulated by the Death with Dignity Act (1997), which permits competent, terminally ill adult residents of Oregon to request a lethal prescription from their doctor for self administration.¹⁵ Self administration is mandatory, and although

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oral ingestion is the most common method, parenteral routes are arguably permissible for those unable to swallow.^{15 17 21} The act requires a 15 day waiting period, oral and written requests by the patient, and specific reporting requirements for the prescribing doctor and a dispensing pharmacist. Patients do not have to have their request validated by a mental health professional. Family notification and participation by doctors and pharmacists is voluntary, but if professionals do participate, they must complete the required paperwork.^{3 15 17 21}

Although the law permits doctors to prescribe, pharmacists to dispense, and designated agents to take the lethal medication to the patient, any other help will generally be illegal. Although Compassion and Choices volunteers cannot provide or administer the lethal drugs, the law does seem to allow non-physicians in Oregon to mix the drugs in soft food or liquid to facilitate oral ingestion (table 2).^{22 23}

In both Switzerland and Oregon, right to die organisations are inextricably intertwined in the medical system and the care of the dying. Both serve as a resource to patients, families, healthcare providers, and regulators, and, at least in Oregon, it is practically impossible for a terminally ill client not to be receiving some form of medical care. Compassion and Choices does not consider decisions about physician assisted suicide to be dichotomous but rather a choice along a continuum of options at the end of life.⁵ Both organisations note that their services enable clients to speak openly about suicide without fear of involuntary commitment. Compassion and Choices also believes that it has prevented violent, impulsive suicides not only through counselling, but also by urging the use of hospice, advance directives, and aggressive palliative care.⁵ Both organisations respect the doctor-patient relationship and its place in the medical system, as well as the primary reliance on the use of doctors in assisted suicide to assess and, if appropriate, prescribe a lethal dose of medication.⁵

SUMMARY OF EXIT DOCUMENT ON QUALITY ASSURANCE IN ASSISTED SUICIDE¹⁸

Key goals of assistance in suicide

- A non-paternalistic, individual directed approach
- Ensure that decisions are not rushed or taken under external pressure
- Ensure sufficient knowledge
- Ensure humane and dignified circumstances for the dying person and their relatives
- Respect relatives and involve them whenever possible
- Facilitate official inquests
- Avoid asking too much of Exit's volunteers

Attributes of Exit volunteers

- Patience, sensitivity, and openness to dialogue
- The ability to distance themselves and avoid over-identification with one point of view
- Must not be enamoured by death in any way
- No particular professional qualifications are required, but volunteers should have sufficient experience of life in general

Table 2 | External and internal controls of right to die organisations

External controls	Switzerland	Oregon
Statute regulating assisted suicide	None. Assistance is permissible provided that assistant was not motivated by selfish reasons. Person seeking assistance must have legal capacity to make request	Death with Dignity Act and concomitant administrative regulations. Any help outside the act is considered second degree manslaughter
Statutes controlling lethal drugs	Law on Pharmaceutical Products relating to dispensing, Swiss Narcotics Law	Federal Controlled Substances Act and state Pharmacy Practice Act
Statutes regulating organisations	None	Federal internal revenue codes regarding political activities of non-profit organisations
Persons permitted to provide information and counselling on assisted suicide	Anyone	Anyone
Persons permitted to assist a suicide	Anyone	Doctors may assess, prescribe, and dispense lethal dose; pharmacists can dispense
Internal controls		
Internal guidelines	Yes	Yes
Board of directors	Yes	Yes
Standing ethics committee	Yes (as needed)	No (but consultants available)
Post-assistance review	Yes	Yes

Conclusion

Although the Swiss and US organisations have developed independently, and in different historical and cultural contexts, they are more alike than they are different. True, Oregon has a law on physician assisted suicide and the Swiss do not; and the Swiss permit anyone to assist in another's death regardless of whether they are terminally ill, whereas Oregon does not. However, when we consider the activities of both; the roles of doctors and others; and the concerns of patients, families, and regulators the differences no longer seem black and white but rather as shades of grey.

Discussions over the extent of doctors' involvement in assisted suicide will continue. Although the doctors' role is often limited to assessment and prescribing, they are still participating in an activity that many argue violates professional integrity.⁷ Could right to die organisations help solve the ethical problems doctors face by sharing responsibility in screening, assessment, and exploration of alternatives? Perhaps, yes. But because doctors occupy a special position in assisted suicide, the use of non-governmental organisations could also become part of the problem since organisations, like humans, are imperfect. Physician assisted suicide will always involve people other than doctors; the unanswered questions relate to the setting and extent of that involvement.

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SUMMARY POINTS

Debate on the use of non-physicians in assisted suicide is increasing
 Right to die organisations use trained volunteers to help people to die
 The doctors' role is limited to assessing patients and prescribing the lethal dose
 Existence of such organisations in Switzerland and Oregon reduces doctors' involvement

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