

End of Life Care Working Party

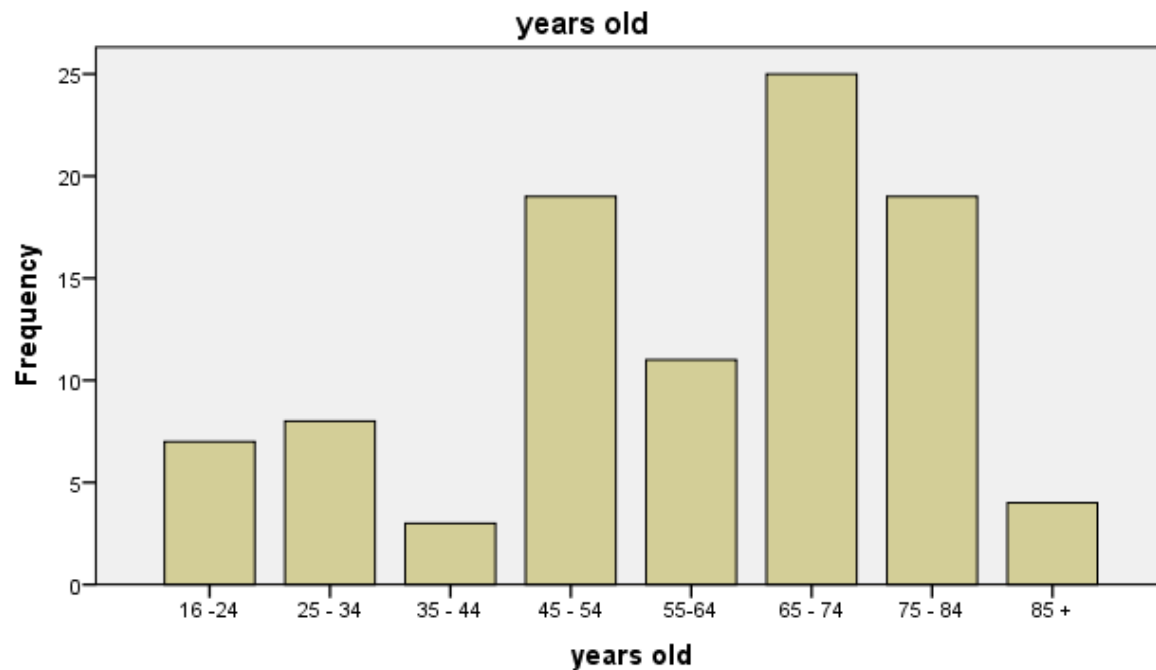
**Highlights of the results of
the Questionnaire
Quakers in Yorkshire,
Settle 19 July 2014**

Questionnaire

- Made available on line and at meetings
- 97 people responded
- Only simple descriptive statistics follow
- No correlations are shown
- Some comparison with national statistical surveys are indicated.

Quaker profile of Leeds Respondents

60 women and 37 men responded



Leeds profile (continued)

- 60.8% of respondents were over 55 years
- 34% are single
- 79.4% are educated to degree level or above
- Of all respondents ~ 25% work in care
 - ~ 6% in medicine/nursing
 - ~5% in law

Preparation for Own death

- Will written 69 %
- Advanced Directive 18.6%
- Spoken with family 35.1%
- Spoken to doctor 12.4 %

A Good Death

Ranked by importance

1. Painless
2. Dignified
3. Without fear
4. With Family and friends
5. With Spiritual Support
6. With time to come to terms with things
7. Quick

Barriers to a Good Death (Ranked)

1. Inadequate care
2. Inadequate pain control
3. Not being told the truth
4. Not having any choice in the matter
5. The medics will decide
6. Family is too widely spread
7. Other (kept alive unnecessarily)

Fears about Dying Ranked

1. Dementia
2. Loss of dignity
3. Being afraid
4. Loss of control
5. Let myself down
6. Fear of what happens after death
7. Other (being kept alive needlessly)

Quakers in Leeds have spoken to :

Partner (34)

Children (18)

Parents (7)

A friend (4)

A Friend (14)

Other (6)

(lovers, monks, siblings, other relatives, solicitor)

Would Choose to Die: Ranked

1. At home (84.2% put it 1 or 2)
 2. In a hospice (57.7% put it 1 or 2)
 3. In hospital
 4. In a nursing home
 5. In a residential home
- Other (outside)

NB. Office of National Statistics 71% prefer home BUT only 21% did die at home. 53% died in hospital, 20% in care homes 6% in hospices

Deaths experienced by Leeds Quakers

Partner 12

Child 4

Still birth 7

Parent 64

Grandparent 50

A friend 50

A Friend 24

A stranger 14

How deaths of others affected people

- Emotions

broken-hearted left a gap *joy* *peace*
helpless devastated grief sadness bereft
shock *less frightened* *privileged* drained
angry sleepless crying *sense of freedom* guilt
I blame myself

sense of not being able to ease the pain of
the family

How death of others affected people

Intentions for the future

I want to live my life well like they did.

I will be prepared so I don't leave a mess for others.

I don't want others to be unclear as to my wishes.

I want it to be quick.

Knowing that it could happen anytime made me aware

How death of others affected people

- Death is a vital and integral part of life.
- Profound natural process – sense of awe
- Took many, many years to come to terms with the death of my child.
- Became reconnected with my estranged wife.
- Death is a bit like birth – you can make plans but in the end it's often messy and events take over. Maybe that's inevitable.

How death of others affected people

- I've seen the inside of a nursing home):
- Fear my death will be prolonged like that
- Insufficient pain control
- Pressed to make decisions for another
- Colluded in euthanasia
- I fear lack of control
- Annoyed by the medicalisation of death

Would you go to Dignitas to die ?

- Yes 36.1%
- No 27.9%
- Don't know 34.0%

Do you want to law to be changed ?

- Yes (plus qualified yes) 79.4%
- No (plus qualified no) 8.3%
- Don't Know 3.1%

Comments concerning a change in the Law

- Absolutely not.
- 6 months is too long
- Some reservations – I like the Belgium model
- A change in the law could be dangerous resulting in abuse or pressure on the infirm.
- Given the current political debate it is exceedingly dangerous to introduce new means of persecuting and eliminating the vulnerable. I do not believe that any

Do you want those who accompany people to Dignitas to be prosecuted ?

- No (plus qualified no) 93.8%
- Yes (plus qualified yes) 2.1%
- Don't know 2.1%

Do you think Assisted Dying is related to the Peace Testimony ?

- Yes (plus qualified yes) 49.4%
- No (plus qualified no) 24.7 %
- Don't know 17.5 %

Comments that were made

- A and Q Numbers 29 and 30
- We make no war, not even a just war. We eschew violence. Killing or colluding in killing is a form of violence.
- Equality issues are relevant to access to medical care, especially hospices.
- The practice of not telling patients and families the truth.... Is clearly counter to Quaker values.

Comments (continued 2)

- Issues of dignity and respect – of seeing that of God in everyone – are key to finding a way forward on this issue.
- I don't know. I am cautious. The testimonies may be adjusted, manipulated to justify action.
- I'm inadequately informed so can't be specific.
- I try to live up to the Quaker testimonies and make rational decisions and want to do the same at my death

Comments (Continued 3)

- I am utterly opposed to all attempts to make it legal to take another's life or to help another take their own life. Such acts of murder are against the peace testimony.
- Legalising assisted suicide would make it more likely that disadvantaged and vulnerable people would experience discrimination and untimely death. This is against the testimony to Equality.
- Death is a natural process – in God's hands. It

What do you think ?

1. Is E of L C a suitable topic for BYM ?

Yes 86%

2. Is AD a suitable topic for BYM ?

Yes 73%

3. Should AD be discussed at BYM in 2014 ?

Yes 79%

Should AD be on the agenda at BYM

- AD should be discussed in an open way not as a ‘fait accompli’ as I think the debate on marriage was arguably conducted in 2009. The assumption should not be that of course Friends would go along with AD.
- Could be the time to discuss AD with “proper spirit –led discernment”
- To introduce a trendy policy to keep Quakers in line with an imagined societal liberal agenda – definitely not.

AD for BYM (Comments continued)

- There are more important things to discuss: how to stop the deaths of disabled people denied benefits and care due to government policies; how to encourage a society in which every life is valued.
- I would hope AD would form part of a discussion on End of Life Care and our approaches to death and suicide (not just in the elderly)
- We need a national threshing process to bring

Possible Issues to consider further

- Possible issues to consider further how to help people living alone manage the situation for themselves.
- Promote the use of advanced directives, wills etc.
- Encourage people to talk about it (no more “Sorry I can’t face that.”).
- What does ‘Spiritual Support’ look like at the end of a Quaker life ?

Further issues to consider

- Poor staffing levels and nursing skills
- Lack of choice about where to die – it is not possible to get 24 hr care at home in the UK .
- Number of skilled night nurses (Marie Curie nurses) is being reduced across the UK.
- Poor resourcing of non cancer services especially for dementia and mental health

- Thank you to everyone who answered and returned the questionnaire – it was not an easy exercise.
- I was honoured to receive such well considered and personal answers.