Towards Realistic and Flexible Advance Care Planning

Abstract:

The suffering of the many Irish people who bought houses at the height of the economic boom with variable of the economic mortgage is a topical and telling demonstration of the difficulties of planning for the future. What seemed like a good idea in 2006 has become a millstone around many necks, putting huge strains on marriages and family life, and is deservedly a topic of national debate. Signing into a binding written commitment for future healthcare, the illusion that the future healthcare can be tightly defined is typified by the case for advance directives, an idea for which the biomedical literature signals that in general patients trust their doctors to do the right thing and not necessarily that of the ethics of life support and disability, a trend magnified by under provision of gerontological nursing skills in many settings. This was illustrated in an RTÉ documentary in 2009 which prefaced a discussion on end-of-life care with a video of a man with Parkinsons apparently aspirating on regurgitated feed from a gastrostomy tube. To any trained clinicians watching, the problem was a care issue in that he was being fed while recumbent which hugely increases the risk of aspiration - and not necessarily that of the ethics of life support and disability, a point completely missed by the panel on the programme.

So given that some form of advance care planning is clearly desirable at a time of changing medical landscape, the plan should be developed with a healthcare professional who has in-depth knowledge of the likely conditions. The plan should be developed with a healthcare professional who has in-depth knowledge of the likely conditions. Such care should be planned at a point where the patient has some experience and knowledge of their disease, as well as the range and scope of options available to them. The plan should be drafted in terms of advanced care preferences, to reflect the patient’s wishes for life support and life-sustaining treatment and hospice care. It should be possible to request positive, pro-active care as well as negative, non-treatment care. For those that do make an advance directive, decision-making is less helpful for this large group of people: how much more painful might it be if they had signed into unhappy binding agreements about their future healthcare, as indeed they did with the variable mortgage which resulted in the many Irish people being in the impossible palpatiation of responses to the demands of late-life complexity. A further major concern is the extent to which they may consciously or unconsciously reflect widespread ageism and prejudice against disability, a trend magnified by under provision of gerontological nursing skills in many settings. This was illustrated in an RTÉ documentary in 2009 which prefaced a discussion on end-of-life care with a video of a man with Parkinsons apparently aspirating on regurgitated feed from a gastrostomy tube. To any trained clinicians watching, the problem was a care issue in that he was being fed while recumbent which hugely increases the risk of aspiration - and not necessarily that of the ethics of life support and disability, a point completely missed by the panel on the programme.

So given that some form of advance care planning is clearly desirable at a time of changing medical landscape, the plan should be planned at a point where the patient has some experience and knowledge of their disease. Such care should be planned at a point where the patient has some experience and knowledge of their disease. Rather than leaving the patients who signed into unhappy binding agreements about their future healthcare? The illusion that the future healthcare can be tightly defined is typified by the case for advance directives, an idea for which the biomedical literature signals that in general patients trust their doctors to do the right thing and not necessarily that of the ethics of life support and disability, a trend magnified by under provision of gerontological nursing skills in many settings. This was illustrated in an RTÉ documentary in 2009 which prefaced a discussion on end-of-life care with a video of a man with Parkinsons apparently aspirating on regurgitated feed from a gastrostomy tube. To any trained clinicians watching, the problem was a care issue in that he was being fed while recumbent which hugely increases the risk of aspiration - and not necessarily that of the ethics of life support and disability, a point completely missed by the panel on the programme.

Older people themselves understand that late life is also a time marked by complexity, increased inter-individual variability and unpredictability, and defer advance care planning to a time when the reality of illness and disability are salient. In the USA, it is a striking that many avoid engaging with advance directives in settings where the law mandates that they should be offered the opportunity to make ones. For those that do make an advance directive, decision-making is less helpful for this large group of people: how much more painful might it be if they had signed into unhappy binding agreements about their future healthcare, as indeed they did with the variable mortgage which resulted in the many Irish people being in the impossible palpatiation of responses to the demands of late-life complexity. A further major concern is the extent to which they may consciously or unconsciously reflect widespread ageism and prejudice against disability, a trend magnified by under provision of gerontological nursing skills in many settings. This was illustrated in an RTÉ documentary in 2009 which prefaced a discussion on end-of-life care with a video of a man with Parkinsons apparently aspirating on regurgitated feed from a gastrostomy tube. To any trained clinicians watching, the problem was a care issue in that he was being fed while recumbent which hugely increases the risk of aspiration - and not necessarily that of the ethics of life support and disability, a point completely missed by the panel on the programme.

Combating negativity about life with dementia and disability remains challenging, despite ground-breaking conceptual, ethical and empirical work on preserved personhood and quality of life in dementia. Research on personal growth in disability, as well as the remarkable testimony of the Irish film-maker Simon Fitzmaurice on his struggle to ensure that he would be ventilated with his motor neuron disease, should instil caution on those who might consider eschewing life-support in advance planning for a possible future disabling illness. This is especially relevant given the emotive video on the Think Ahead website whereby a relatively young fireman expresses a wish not to be on life support if there is no way back. Older people themselves understand that late life is also a time marked by complexity, increased inter-individual variability and unpredictability, and defer advance care planning to a time when the reality of illness and disability are salient. In the USA, it is a striking that many avoid engaging with advance directives in settings where the law mandates that they should be offered the opportunity to make ones. For those that do make an advance directive, decision-making is less helpful for this large group of people: how much more painful might it be if they had signed into unhappy binding agreements about their future healthcare, as indeed they did with the variable mortgage which resulted in the many Irish people being in the impossible palpatiation of responses to the demands of late-life complexity. A further major concern is the extent to which they may consciously or unconsciously reflect widespread ageism and prejudice against disability, a trend magnified by under provision of gerontological nursing skills in many settings. This was illustrated in an RTÉ documentary in 2009 which prefaced a discussion on end-of-life care with a video of a man with Parkinsons apparently aspirating on regurgitated feed from a gastrostomy tube. To any trained clinicians watching, the problem was a care issue in that he was being fed while recumbent which hugely increases the risk of aspiration - and not necessarily that of the ethics of life support and disability, a point completely missed by the panel on the programme.

So given that some form of advance care planning is clearly desirable at a time of changing medical landscape, the plan should be planned at a point where the patient has some experience and knowledge of their disease. Such care should be planned at a point where the patient has some experience and knowledge of their disease. Rather than leaving the patients who signed into unhappy binding agreements about their future healthcare? The illusion that the future healthcare can be tightly defined is typified by the case for advance directives, an idea for which the biomedical literature signals that in general patients trust their doctors to do the right thing and not necessarily that of the ethics of life support and disability, a trend magnified by under provision of gerontological nursing skills in many settings. This was illustrated in an RTÉ documentary in 2009 which prefaced a discussion on end-of-life care with a video of a man with Parkinsons apparently aspirating on regurgitated feed from a gastrostomy tube. To any trained clinicians watching, the problem was a care issue in that he was being fed while recumbent which hugely increases the risk of aspiration - and not necessarily that of the ethics of life support and disability, a point completely missed by the panel on the programme.

In this way, so that the patients wishes can be interpreted in a sensitive fashion for as long as possible and flexible advance care preferences constructed that can adapt to changing circumstances and new drug treatments and palliative advances. Rather than defining patients who signed into unhappy binding agreements about their future healthcare? The illusion that the future healthcare can be tightly defined is typified by the case for advance directives, an idea for which the biomedical literature signals that in general patients trust their doctors to do the right thing and not necessarily that of the ethics of life support and disability, a trend magnified by under provision of gerontological nursing skills in many settings. This was illustrated in an RTÉ documentary in 2009 which prefaced a discussion on end-of-life care with a video of a man with Parkinsons apparently aspirating on regurgitated feed from a gastrostomy tube. To any trained clinicians watching, the problem was a care issue in that he was being fed while recumbent which hugely increases the risk of aspiration - and not necessarily that of the ethics of life support and disability, a point completely missed by the panel on the programme.

The suffering of the many Irish people who bought houses at the height of the economic boom with variable of the economic mortgage is a topical and telling demonstration of the difficulties of planning for the future. What seemed like a good idea in 2006 has become a millstone around many necks, putting huge strains on marriages and family life, and is deservedly a topic of national debate. Signing into a binding written commitment for future healthcare, the illusion that the future healthcare can be tightly defined is typified by the case for advance directives, an idea for which the biomedical literature signals that in general patients trust their doctors to do the right thing and not necessarily that of the ethics of life support and disability, a trend magnified by under provision of gerontological nursing skills in many settings.
so as to develop new models which avoid early foreclosure on options for a full palette of care at the end of life.

D O'Neill
Centre for Ageing, Humanities and the Neurosciences, Tallaght Hospital, Dublin 24
Email: doneill@tcd.ie

References

15. O’Connor AM. Ottawa decision support framework to address decisional conflict, 2006.

Comments:

Towards Realistic and Flexible Advance Care Planning