

Health & Social Care Committee: Gynaecological Cancer Inquiry

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Organisation: Marie Curie

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Happy for response to be publicly shared? Yes

Introduction

Improving prevention and treatment of gynaecological cancers is a vital part of ensuring women and those assigned female at birth (AFAB) are living well for longer. However, it is also important to recognise that some gynaecological cancer diagnoses are terminal. Where those diagnoses are terminal, we need to ensure that the best end of life experience possible is achieved, in line with the person's wishes and preferences, and that no disproportionate barriers are facing women and those AFAB when they need end of life care and support. Therefore, we urge the health and social care committee to consider palliative and end of life care (PEOLC) throughout this inquiry and that evidence gathering takes a truly cradle to grave approach.

Research exploring gender inequalities at end of life is still fairly limited, particularly in relation to the situation in the UK and in Wales. As a result, this response is unable to present the specific challenges faced by patients with a terminal gynaecological cancer diagnosis but will put forward the challenges facing women with a terminal illness more generally, many of which will apply to those with terminal gynaecological cancer.

Context

Research has previously forecast a drastic increase in demand for PEOLC in the next two decades¹. The Office for National Statistics project that by 2040, there will be an additional 5,000 deaths per year in Wales (from 36,136 in 2021 to 41,000 in 2040-41)². This is partly due to an ageing population and a rise in the number of people living with more than one complex condition.

By 2040, the biggest proportion of those in need of PEOLC is likely to be those over 85 years old, and the leading cause of death is set to be dementia^{i,3}. We know that women typically have a longer life expectancy than men, but also live with a greater number of 'years with a disability'ⁱⁱ.

The above research and projections point towards an increasing number of women in need of PEOLC in the imminent future, and with 546 females dying from gynaecological cancer in 2021 alone⁴, it is crucial that the health and social care committee's inquiry includes a focus on women with a terminal diagnosis.

Challenges faced by women at end of life according to international research

ⁱ Estimates show that by 2040, dementia deaths will be more than three times higher than the current mortality rate.

ⁱⁱ In Wales, [life expectancy at birth for males in 2017 to 2019, is 78.5 years old, whereas for females it is 82.3 years](#). Between [2017 and 2019 in Wales, females lived an average of 22.1 years with a disability, in comparison to males who lived with an average of 17.1 years](#) with a disability.

Pain management and symptom burden

Recent Marie Curie research asked people in Wales what their biggest priority would be when thinking about the end of their life; being pain free was most people's top answer⁵. One of the key pillars of PEOLC is a focus on quality of life and pain management as being pain free enables people to experience a good quality of life for as long as possible. However, research shows that there are factors relating to sex and gender which have led to discrepancies in how some women report symptoms, the pain they experience, and the treatment they receive as they approach end of life.

Evidence shows that women often report more severe daily feelings of pain, nausea, and fatigue^{6,7,8}, but may also have to report greater symptom distress than men for their pain to be acknowledged⁹. Evidence suggests that this is partly a result of gender bias and women's pain sometimes being underestimated, with healthcare professionals being less likely to document symptoms¹⁰. Research also discusses how women are more likely to have pain attributed to psychological rather than physical needs and to then be prescribed sedatives rather than the appropriate pain relief¹¹. The gender bias at play when it comes to how women and men are expected to cope with symptoms can directly affect some women's access to pain management medications, meaning some women may be suffering from unwarranted pain and severe unmet palliative care needs when approaching the end of their life.

Biological differences when it comes to how females and males experience pain and respond to pain management is not a new phenomenon¹², but research now suggests that this could negatively impact women right up until their death. Studies have demonstrated that there are disparities in how the male and female body receives and responds to the main pain relief drug prescribed at end of life - opiates¹³. If women are prescribed opiates with no consideration of how their biology could be impacting the effects of the drug, their quality of life could be disproportionately affected. However, more research is needed here to fully understand how women could be responding to end of life pain management differently to men, to ensure no one is suffering from avoidable pain in their last months, weeks and days of life.

End of Life Care Interventions

PEOLC can be initiated at any point during a patient's journey and can include a range of holistic treatments focusing on psychological, social, and spiritual aspects of care¹⁴. When it comes to choices around end of life care interventions, the understanding and views of women appear to be affected by social norms and gender bias. While some research shows that terminally ill women tend to be more open, accepting of palliative support, and engaged with their end of life journey^{15,16}, other studies show that some women are less likely than men to state a preference for end of life care treatments such as chemotherapy, cardiopulmonary resuscitation and artificial feeding^{17,18}. The evidenced reasons behind this are not yet substantive and should be fully explored, however such findings do highlight potential inequalities in the way women are approaching, deciding on, and ultimately accessing treatments which could improve their quality of life.

One example of this is how females may not be benefitting from early palliative care (EPC) in the same way as males¹⁹. EPC is believed to be best practice and is attributed to better

quality of life and lower rates of depression^{20,21}, but findings have shown that females in some instances report lower quality of life and mood than male counterparts receiving similar treatment²².

End of life care clinical decisions continue to rely on research and assumed best practice which is majorly based on male biology, neglecting any potential differences in sex and gender. To ensure everyone is able to access the EOLC interventions which will benefit them and enable a better quality of life for longer, more research is needed into how sex and gender impacts on care and treatment decisions.

Place of care and death

We know that over half of all people would prefer to die at home²³, but research suggests that for many women this is often not possible or the case. Social norms have dictated a society where it is women who are the natural caregivers and many even feel it is their duty when it comes to providing care²⁴. Nonetheless, many women express fears around feeling like a burden if they themselves need care from family and loved ones²⁵. In fact, studies report more women receiving care and support from healthcare professionals and specialists rather than unpaid carers²⁶.

The fact that women have longer life expectancy and are more likely to outlive their partner (in a heteronormative relationship), reinforces this trend. Additionally, those who have been carers (of which the majority are women), are less likely to want to die at home²⁷. This is assumed to be due to a greater understanding of the reality of caring for someone at home.

A wider challenge in supporting women to die at home if this is their preference, is insufficient resources and capacity in health and social care community provision. Recent research projects a substantive increase in demand for care in the community by 2040 in Wales and England, with deaths at home increasing by 88.6%, and deaths in care homes projected to increase by as much as 108%²⁸. The insufficient capacity in community provision could also be impacting on women's ability to die at home if this is their preference. Everyone in Wales should be able to die where they wish, if safe and feasible, and more research is needed to understand whether gender norms are currently inhibiting this.

Ongoing work

For future reference, Marie Curie Cymru is currently carrying out research looking into any potential gender differences in access to their services across Wales; diagnosis and reason for admission are two of the many variables being analysed and may be useful and relevant to the inquiry into gynaecological cancer. Findings are expected to be published in early 2023.

In addition, the Marie Curie Palliative Care Research Centre at Cardiff University are working on developing a PEOLC data dashboard. This is likely to be public in 2023 and will be able to provide data on how patients with gynaecological cancer interacted with end of life care services in their last year of life. Initial research show some interesting insights but are currently unable to be formally published.

If these current pieces of work are of interest to the health and social care committee in gathering evidence for the inquiry, please get in touch with bethan.edwards@mariecurie.org.uk to ask for updates over the coming months.

Conclusion

Although the above international findings are not specific to terminal gynaecological cancer patients, it is likely that many of the issues discussed are hugely relevant. With the increasing numbers of people reaching older ages, and with complex conditions, it is vital that we are able to provide sex and gender-specific care to women and those AFAB who are approaching the end of their life with terminal gynaecological cancer.

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