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OLDER PEOPLE LIVING WITH CANCER

July 2015

**Exploring the attitudes
and behaviours of older
people living with cancer**

Research conducted by Ipsos MORI
on behalf of Macmillan Cancer Support



Ipsos MORI

Executive summary

Methodology

Between January and June 2015, Ipsos MORI Social Research Institute carried out a study on behalf of Macmillan Cancer Support to better understand how patient attitudes influence the outcomes of older people living with cancer. For the purposes of this research older people are described as:

- working age (55-64)
- post-retirement age (65-74)
- older retired (75 and over).

The pre-retired group were included in the study so as to assess the attitudes of those people who will be the older age groups of the future, and to provide a comparison group to show if patient attitudes change as age increases.

The study entailed:

- A rapid literature review and scoping workshops with key stakeholders.
- Two linked surveys of people aged 55 years and over, living in Great Britain: one among a sample of 1,004 people living with cancer, and the other among a sample of 500 people who have never had cancer covering similar questions.
- In-depth interviews with 26 older people living with cancer across the UK.
- Two focus groups with older people who have not had cancer, recruited through Age UK.

This research examines the patient attitudes and behaviours that can impact on cancer treatment and patient experience, which in turn, may affect clinical and non-clinical outcomes. Attitudes and behaviours are believed to have a significant impact on some of the key determinants of cancer outcomes, including stage of diagnosis,

decisions about treatment and support during recovery.

The full findings from the study are presented in a detailed report. This summary highlights some of the issues identified that will be of particular interest to those involved in efforts to improve the outcomes of older people affected by cancer.

It is important to note that – by necessity – this research has primarily involved people affected by cancer who are in relatively good health and therefore may have a more positive experience of treatment and care. Efforts have been made to engage with older retired people but, again, people have to be well enough to participate so the views of older retired people with multiple comorbidities may be understated.

Study objectives

In recent years there have been welcome developments in the evidence base on outcomes for older people affected by cancer. This includes how they vary compared with younger age groups, as well as to those of older people in other countries. It is clear that poor outcomes in older people are a major explanation for the survival gap with other countries and that the disparity in outcomes extends beyond survival to encompass quality of life and patient experience¹.

We also know more about variations in access to different forms of cancer care, including those relating to referral and diagnosis, treatment and support. In addition, work has been undertaken to explore both clinical attitudes towards treatment in older people² and the interventions that can make a difference to older people³.

1, National Cancer Intelligence Network (2014) Older people and cancer.

2, Department of Health (2012) The impact of patient age on clinical decision-making in oncology.

3, Department of Health, Age UK & Macmillan Cancer Support (2012) Cancer Services Coming of Age: Learning from the Improving Cancer Treatment Assessment and Support for Older People Project.

However little is known about the attitudes of older people themselves towards cancer, including their knowledge, beliefs and behaviours, and how these might impact upon outcomes. The purpose of this study is to begin to fill this gap.

Key themes

This study identifies a range of attitudes and perceptions which will shape the way that older people access cancer services, influencing when and how they seek help, as well as the outcomes they experience. These findings will be of interest to all those with a stake in improving outcomes for older people, including, policymakers, commissioners and providers of health services, health professionals and charities.

It is important to recognise that older people do not respond to cancer in a homogenous way however. Previous research has recognised a 'dichotomy or continuum of empowerment'⁴ in relation to the way that older people react to a cancer, as to many other things in life.

A number of key themes emerge from the research, including:

- There are differences in the views of older people with cancer and those who have not been diagnosed with cancer, with those with direct experience of the condition having more positive perceptions about it.
- Some of the preconceptions that people may hold about older people's attitudes have been challenged, for example older people are no more likely to choose not to have treatment than younger people, and no more likely to be concerned about the consequences of having treatment.
- A series of misconceptions about the risk of cancer and eligibility for screening may impact upon early diagnosis efforts and should be addressed.
- Older people are more likely than younger people to place trust in their health professionals but at the same time believe that discrimination against older people does exist (albeit not necessarily in their personal experience).
- Independence matters to older people.
- Nonetheless, older people say they are willing to seek help, but are not necessarily aware of the services that exist to support them.

Attitudes to health and cancer

There appears to have been a shift in attitudes towards cancer.

Only a small minority of those aged 55 or over living with (3%) and without (8%) cancer agree with the statement that cancer is a 'death sentence'. This compares with a study of the general public, patients and carers, which found much larger numbers of people (42%) who thought so as recently as 2012⁵.

'People used to see it as a death sentence. You've got to understand, this is a generational thing as it was not spoken of when they first discovered it. But people know that treatment has improved, that you can recover, and people now talk about it.'

Participant in a focus group of older people without cancer, Northumberland.

4, 'Experiencing cancer in old age: a qualitative systematic review', Hughes et al., Qualitative Health Research 2009, 19:1139 <http://eprints.whiterose.ac.uk/83251/3/Hughes%5B1%5D.pdf>
5, http://pacenetwork.co.uk/pace_index



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A small majority (51%) of those people interviewed also believe that their life experience better equips them to cope with cancer, while responses to other attitudinal questions covered later on also suggest greater resilience. The qualitative research revealed that as people get older, family and work become less central to people's lives, and so they perceive themselves as having less to worry about than younger people.

People living with cancer aged 55 or over expressed similar opinions to those who have never had cancer when describing their health as excellent or very good (38% vs 34% respectively), to say that they look forward to each day (78% vs 74%) and that they enjoy doing what they used to (76% vs 75%).

More generally, older people tend to have a more positive outlook on life, with 79% of the post-retirement age group stating that they look forward to each day, compared with 74% of those in the working age group. While this is not a huge divergence, it is significant.

Satisfaction with health increases with age amongst those living with cancer (33% of those aged 75 or over report excellent or very good health, compared with 25% of the working age cohort). This may reflect the fact that older people in general tend to report higher levels of satisfaction⁶, **possibly linked to the common belief** that disease and disability are inevitable as people age (43% agree with this statement compared with 29% who disagree).

A majority of those living with cancer aged 75 or over (56%) feel that they've achieved as much in life as they wanted to (compared with 23% of those of working age).

Attitudes towards risk of cancer and diagnosis

The overwhelming majorities of all age groups over 55 both living with (90%) and living without (84%) cancer do not think that cancer is an **age-related disease**. This is despite a wealth of evidence that shows older people are at greatest risk⁷. Instead, the qualitative research suggests that people perceive diagnoses of cancer as random, unexpected events that can affect anyone.

'It was a shock. You think it won't be me – I'll be one of the lucky ones. It's a bit strange.'
Female, 66, South England.

The fact that older people do not realise that their age is a significant risk factor for cancer may have implications for efforts to encourage earlier diagnosis of cancer; if people do not believe they are at greater risk, this may impact upon their help seeking behaviour⁸. This is particularly significant given the impact that late diagnosis has on cancer survival. It is particularly relevant for older people as treatments for more advanced cancer are often associated with more invasive or toxic treatment.

Qualitative interviews show there is also confusion around the role of screening for cancer in older people. There was confusion about the age ranges for screening and the options that exist for people who are above the screening age range to 'opt in' to screening. Responses suggest that there may also be confusion amongst some healthcare professionals. For example a 75 year old male in Scotland reported that, 'I was told it [bowel cancer screening] wasn't open to people over 75' and a female of 69 in England said, 'I was not given the choice. I was told I could not have screening anymore'.

⁶, Ipsos MORI Generations – <https://www.ipsos-mori.com/Assets/Docs/Publications/sri-understanding-society-generations-october-2013.pdf> 7, Page 2, 'The Rich Picture on older people with cancer', Macmillan Cancer Support
⁸, Help seeking for cancer 'alarm' symptoms: a qualitative interview study of primary care patients in the UK Katrina L Whitaker, Una Macleod, Kelly Winstanley, Suzanne E Scott, Jane Wardle [Feb 2015]

Attitudes towards treatment

Evidence shows that older people are less likely to receive active anti-cancer treatment, be it surgery, radiotherapy or chemotherapy⁹. Very few people in this study reported that they declined treatment (2%) or even opted out of some treatment (14%), and this does not increase with age. However people of working age did report receiving more lines of treatment than people above the retirement age. This supports the notion that younger people may receive more intensive treatment than older people, but also suggests that **patient preference is not a major factor in determining treatment rates**.

All age groups over 55 appear to have significant concerns about the consequences of cancer treatment. However, perceptions about the impact of treatment appear to be more negative amongst those older people who have not had cancer than amongst those who have actually received cancer treatment, with 46% of those with cancer agreeing with the statement that the side effects of treatment may be worse than the cancer itself, compared with 53% in the non-cancer group. Furthermore, attitudes towards treatment do not become more negative as age increases.

The research revealed some negative attitudes from older people without cancer specifically towards treatment. For these people, these attitudes may impact upon help seeking behaviours, with a fear of cancer treatment resulting in a reluctance to seek help for symptoms. These negative perceptions may be based on the experience of others, who may have been treated a long time ago and therefore may not accurately reflect the realities of modern treatment.

'Some of my friends have had treatment which has put them through a lot and ruined their quality of life, and ultimately they died.'

Older person without cancer, Northumberland.

'Treatment in the NHS can be bad. For example, they are afraid to medicate and relieve pain. You want to be treated with dignity.'

Older person without cancer, Leicester.

Personal and direct experience of treatment appears to help to dispel fears and misunderstandings around 'side effects'. This suggests that providers of cancer services may wish to consider how they could tailor information on treatments to educate about potential side effects but also reassure patients about the management of potential consequences. Given the impact that personal experience appears to have, there may be a particular role for peer-to-peer support in this respect.

Information on the many varied consequences – physical, social and emotional – was identified as an area for improvement, with a number of participants in the depth interviews stating that they would have liked more information and regretted not asking more questions of health professionals. This supports the findings of the National Cancer Patient Experience Survey, which shows that older people are less likely to report being given information on the side effects of treatment¹⁰.

The consequences of treatment go beyond short-term side effects. Older people are particularly concerned about maintaining independence and the longer-term consequences of cancer treatment that can impact upon this. Attitudes towards independence are explored in more detail below¹¹.

9, National Cancer Intelligence Network (2014) Older people and cancer.

10, National Cancer Patient Experience Survey (CPES) – those aged 66-75 are more likely than their younger counterparts to feel their views were taken into account when clinicians were deciding treatment options (73% 66-75s vs 67% 16-25s), yet they are least well informed about side effects (51% of those aged 76+ report being told about side effects that could affect them in the future, compared with 65% of 16-25s).

11, http://www.macmillan.org.uk/Documents/AboutUs/Health_professionals/OlderPeoplesProject/CancerServicesComingofAge.pdf

Attitudes towards healthcare professionals

Contrary to received wisdom, people of working age who are living with cancer are actually more likely than older people to avoid going to the doctor because they are worried about wasting their time. For working age people, 3 in 10 (29%) agree that there have been times during their cancer journey they have not gone to see healthcare staff because they didn't want to waste time, compared with just one in six (16%) of those over the age of 65. Evidence from the National Cancer Patient Experience Survey¹² suggests that older people are more likely to have confidence and trust in health professionals than younger patients. This is supported by this study; 71% of people living with cancer in the older retired age group stated that healthcare professionals know what's best for them when it comes to their care, compared with only 58% of those in the working age group:

'I did think, why did they do that [remove tonsils without permission]? But they explained it well afterwards and I could see why they did it. I did not feel it was necessary to argue.'

Male, 66, Northern Ireland.

This trust appears to manifest itself in older people adopting a more passive role in decisions about their treatment. This is supported by previous Ipsos MORI research, which has shown that older people are less likely than younger people to say that they would search for information about possible treatments if they were diagnosed with cancer¹³. As one participant in the qualitative research said:

'My son always goes to look things up and find out more; I would never think to do that if a doctor told me something.'

Male, 75, Belfast.

The majority of those living with cancer agree that they feel involved in decisions about their care (84%) and also that staff know what's best for them when it comes to their cancer care (66%).

Attitudes towards health services

There is a perception that older people may be treated differently by the health system due to their age, with a majority of those aged 55 or over in both groups surveyed stating there is at least some prejudice against older people with cancer in the UK (62% of those living with cancer; 58% of those without cancer). However, in terms of personal experience, a relatively small proportion feel that they have experienced this directly, with only one in eight (11%) agreeing that sometimes healthcare staff made decisions about their cancer care based on their age and not how fit they were.

Older age groups have a more positive initial view of their care and treatment, although evidence from the National Cancer Patient Experience Survey shows that a more detailed exploration of their experience often reveals significant issues, for example in relation to information and communication, coordination of care and access to specialist support¹⁴.

12, <https://www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey> 13, A 2006 survey showed that people aged 65 or over (41%) are less likely than the population more generally (68%) to say that they would search for information on the internet or the library about possible treatments, if they can cancer. <https://www.ipsos-mori.com/Assets/Docs/Archive/Polls/cancerbackup-report.pdf> 14, <https://www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey>



Attitudes towards independence

As noted earlier, older people feel that they are better able to cope with cancer than younger people. Two thirds (67%) of the older retired group living with cancer agree that the life experience of older people allows them to cope better than younger people. Perhaps unsurprisingly this figure is markedly higher than for those people in the working age group, where the figure agreeing with the statement falls to 38%.

Statements about the ability to 'cope' with cancer may be driven by the desire to maintain independence, which is particularly apparent in older people. Although maintaining health is listed as the most important priority for most people living with cancer, this changes for the older retired group, who state that continued independence (44%) is just as important as maintaining health (43%).

Our research shows that older people are less likely to worry about requesting help and support. This is despite recent research from Macmillan Cancer Support which shows that they are less likely to receive support¹⁵.

Indeed one third of respondents to this study report a perception that older people receive less support than younger people. This suggests that appropriate support is often not available for older people living with cancer. Our interviews also suggest that older people may not be aware of the support that is available to them.

'In the hospital, on the oncology floor, there is a very large Macmillan room. We often looked at it as we went past, but we never felt we were in a bad enough situation to go in...'
Male, 79, South England.

Attitudes towards friends and family

Contrary to received wisdom, older people are more likely to be comfortable seeking help than younger people. Half (53%) of people living with cancer in the post-retirement age group state that they sometimes do not ask for help because they do not want to be a burden to other people, which is somewhat lower than for those of working age (63%).

Next steps from the research

The findings from this research will be relevant to efforts to improve outcomes at every part of the cancer pathway, including:

- Early diagnosis, including raising awareness of how the risk of cancer increases with age and how older people can access screening services.
- Treatment, challenging some of the preconceptions that people may hold about older people's attitudes towards cancer and its treatment.
- Assessment, ensuring that older people with cancer receive a comprehensive assessment of their overall physical and mental wellbeing so that treatment decisions are not made based on age alone.
- Treatment, including reassuring people about the realities of modern cancer treatment, whilst educating them about its consequences and tailoring treatment approaches to reflect what matters most to older people, including maintaining independence.
- Delivering information and support older people to be active participants in their care.
- Support, designing services which better meet the needs of older people and ensuring that they are better signposted to this support.
- Experience, acting on intelligence from the National Cancer Patient Experience Survey to ensure that gaps in services for older people are addressed.

The National Cancer Director has indicated that improving services for older people affected by cancer is a personal priority and, as part of this, Macmillan Cancer Support is working in close partnership with him and a multidisciplinary group of clinical experts and patients to initiate research and design interventions to better support older people. The findings from this study will be used to support this process.

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