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Setting a patient-driven agenda for cancer research priorities in geriatric oncology: A qualitative study

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Abstract

Objectives: This study aims to explore older adults' perceptions of priorities for research in cancer and haematological malignancies, and propose an agenda of patient-driven priorities for cancer care research in the field of geriatric oncology.

Data Sources: Sixteen older adults (> 65 years) living with or after a diagnosis of cancer participated in a descriptive qualitative study. Participants were purposively recruited via a regional cancer centre and cancer advocacy organisations. Semi-structured telephone interviews explored participants' experiences of cancer, and perceptions of priorities for future cancer-related research.

Conclusions: Participants reported positive experiences of cancer care. However, positive and negative experiences of information, symptoms, and support both within and beyond the hospital setting were highlighted. Forty-two research priorities in six thematic areas were identified: 1) recognition of the signs and symptoms of cancer; 2) research about cancer treatment; 3) assessment and management of co-morbidities; 4) unmet needs of older adults living with and after cancer; 5) impact of COVID-19; and 6) impact on caregivers and family members of people living with and after cancer.

Implications for Nursing Practice: The results of this study provide a basis for future priority-setting activities which are culturally and contextually sensitive to the healthcare systems, resources and needs of older adults living with and after cancer. Based on the findings of this study, we make recommendations for the development of interventions which can build awareness, capacity, and competence in geriatric oncology among cancer care professionals, and consideration of the diverse needs of older adults in the development of interventions to address unmet information and supportive care needs.

Keywords

Older adults; cancer; research priorities; frailty; unmet needs; qualitative

Introduction

People living with and after cancer may experience complex physical and psychosocial issues requiring multidisciplinary support (Drury et al., 2017a, Drury et al., 2020a). Older adults over the age of 65 represent the group most frequently diagnosed with cancer, and yet, they are often under-represented in research (Scher and Hurria, 2012, Puts et al., 2017). As adults age, issues of multi-morbidity and social support increase the complexity of healthcare provision for this population, meaning older adults may be disenfranchised within specialist care services, compared to younger people (Darker et al., 2015, Lee et al., 2016, Moghaddam et al., 2016, Drury et al., 2017b, Drury et al., 2017a). Older adults may also experience shortcomings in continuity of care and unmet needs which undermine access to services addressing cancer- and treatment-related effects (Drury et al., 2017a).

Health research priority setting is essential to achieve optimal public health benefits from investment in research (Viergever et al., 2010). There has been a proliferation of cancer research priority setting over the past two decades; however, such studies are often limited by suboptimal reporting of methods and inadequate stakeholder involvement (Tong et al., 2019). While people living with and after cancer are consulted or involved in setting research priorities (Cuthbert et al., 2022, Schilstra et al., 2022, Haase et al., 2021, Cadorin et al., 2020), there remains a tendency for priority setting to be driven by literature reviews or consultations with professional stakeholders (Zanville et al., 2021, Nightingale et al., 2021).

Few published exercises in research priority setting involve older adults living with or after cancer as the primary stakeholders driving the agenda, and those that do originate in primarily continental North American contexts (Haase et al., 2021, Nightingale et al., 2021, Sattar et al., 2021, Lyons et al., 2017). Involvement and engagement of people affected by cancer and older adults in research has a positive influence on the feasibility and relevance of studies; however, optimal strategies to facilitate older adults' involvement in research remain underdeveloped (Puts et al., 2017).

Working with older adults as equal partners to prioritise areas of research is essential, as research agendas driven by policymakers, researchers, and healthcare professionals may not be congruent with the issues and outcomes prioritised by people living with and after cancer (Chalmers et al., 2013, Crowe et al., 2015). This incongruence may be of particular importance among older adults, as they may experience inequities in care and treatment

which impact outcomes (Darker et al., 2015, Lee et al., 2016, Moghaddam et al., 2016). Therefore, this study aimed to explore older adults' views on priorities for research in cancer and haematological malignancies.

Methods

Design and Participants

This descriptive qualitative study was undertaken between September 2021 and April 2022. People over the age of sixty-five, living with a diagnosis of cancer were purposively recruited via a regional cancer centre and cancer advocacy organisations in the Republic of Ireland. There are various definitions of "older" adulthood, with threshold for "older" ranging between 60 and 80 years in clinical and societal contexts; in the context of cancer care, the International Society of Geriatric Oncology recommend a threshold of between 70 and 75 years as defining older adulthood, but this may be lower when patients have additional comorbidities (Scotté et al., 2018, Ferrat et al., 2017). In the Irish context, older age is currently defined as over 65 years, and is operationalised consistently across political, healthcare and social care contexts (Central Statistics Office of Ireland, 2017, Department of Health Ireland, 2013, Department of Finance Ireland, 2018, National Clinical Programme for Older People, 2012). Therefore, to reflect current practice and policy regarding the working definition of older adulthood in Ireland at the time of this study, the threshold of over 65 years of age was adopted for this study. Gatekeepers in participating organisations distributed a letter of invitation, a participant information leaflet and consent form to eligible service users. Sixteen people expressed interest in participating and returned a completed consent form. This study received ethical approval from the University Research Ethics Committees (Reference: LS-21-31-Drury) and the Research Ethics Committee of the participating hospital (Reference: JREC-256 Drury).

Data Collection

Sixteen people were invited to participate in semi-structured telephone interviews with two registered nurses, experienced in qualitative research methods and interviews (AD, LR). Interviews were guided by a semi-structured interview schedule, exploring participants' experiences of diagnosis, treatment, and follow-up care, and their perceptions of priorities for research in cancer care. Participants' age, gender, diagnosis and time since diagnosis were also collected as part of the interview process. Interviews were recorded and transcribed verbatim, ranging between 19 and 56 minutes (mean: 36 minutes, standard deviation: 9.6). Reflexive field notes were maintained to enable critical evaluation of data collection activities and support data analysis.

Data Analysis

Data analysis was approached according to the principles of reflexive thematic analysis (Braun and Clarke, 2019). Data were coded inductively. Semantic codes were developed in the initial rounds of coding, reflecting the meaning of participants' narratives; latent codes were developed in subsequent rounds of analysis, reflecting the issues shaping priorities identified by participants. Table 1 presents an exemplar of the process of data analysis, synthesis and priority generation for the subtheme decision-making and advanced care

planning. Themes were generated based on the synthesis of codes, and a preliminary list of corresponding priorities were developed which were based on the narratives which formed the basis for each code and theme. Subsequently, the data was re-analysed deductively, in light of the identified themes and research priorities. Themes and research priorities which were not sufficiently supported by the data were discarded, and the final themes were defined and named.

Results

Sample Characteristics

Sixteen participants were interviewed. Men ($n=8$) and women ($n=8$) ranging in age from 66 to 81 years (Mean=72.8, SD=5.3) participated. Participants had predominantly haematological malignancies, including multiple myeloma ($n=6$), lymphoma ($n=6$) and leukaemia ($n=3$); one participant had breast cancer. Two participants reported two additional primary cancers that had previously been treated (prostate cancer [$n=1$]; lymphoma [$n=1$]). At the time of the study, eleven participants were on active treatments, including maintenance therapies. Five participants were in remission, and between three months and six years had passed since these participants had last received treatment.

The majority of participants ($n=12$) had never participated in research before this study; one participant had been involved in a clinical trial, three were involved in research related to other health issues and one participant described their experiences of conducting research as part of a programme of postgraduate study. The majority of participants indicated a willingness to participate in research to help others, with two participants acknowledging how others' participation in research had ensured the availability of wider treatment options. The research that participants had been involved in previously related to treatment or diagnostics, and suggested that those experiences influenced their decision to participate in future research.

Research seems to be so vital to understanding the many, many different forms of cancer and providing the best possible treatment for them. So, I was very well-disposed towards the idea of anything that helps in research and I can really see that a patient's point of view is a very important part of the equation.

(P005)

I wouldn't mind [taking part in a clinical trial], I would evaluate what I thought and like when the count went up you'd try anything ... within reason, I would take part in trials.

(P001)

Priorities for Cancer Research Identified by Older Adults Living With and After Cancer

While this project aimed to set priorities for cancer research broadly, participants' initial recommendations for future research focused almost exclusively on curing cancer, conceptualising research as a lab-based activity to develop and test treatments.

I think the research that you're doing right now, talking to me and others, I think that's very interesting and very important. [I thought] research in relation to, to my medical condition, was purely medical and scientific. It didn't occur to me that people like yourself, would be researching other hugely important aspects of patients, treatment effects and so on.

(P006)

Where these types of responses arose, probing questions were used to facilitate further exploration of the issues participants believed important for research, including asking whether there were any day-to-day issues they experienced which could benefit from further support, or which required greater understanding among healthcare professionals, researchers or communities. Eight themes, incorporating eleven sub-themes and forty-two priorities were generated based on the analysis. Research priorities derived from the analysis of interview data and participant quotations (Q) are presented in Tables 2–7.

Theme 1: Early Investigation and Recognition of Potential Cancer Symptoms

Ten participants discussed issues related to recognition, investigation, and diagnosis of cancer among older adults, highlighting the need for greater research in this area (Table 2). Several participants described protracted pathways to diagnosis, describing how pain and muscular symptoms were conflated with issues of ageing or minor injuries by themselves or healthcare professionals (Q1.1). For some, investigations of other issues contributed to the incidental diagnosis of cancer (Q1.2).

A small number of participants experienced a quick progression from initial symptoms to comprehensive investigations (Q1.3). However, in these cases, participants described severe symptoms and deteriorations in health. A small number of participants were aware they were at increased risk of cancer and were engaged in surveillance for dormant cancers. However, some suggested they were not fully aware of instances where they needed to seek further investigation. Despite this, all were engaging with annual or bi-annual monitoring, which they attributed to early recognition and diagnosis (Q1.4).

Although many participants described challenging experiences of diagnosis, many suggested that the diagnosis of cancer was not overly distressing to them. Several compared their own response to their diagnosis, describing peers who did not recover from the psychological impact of diagnosis. Furthermore, several reported that diagnosis had a much greater effect on their family members (Q1.5). Overall, participants described positive experiences of care during diagnosis and treatment, which they attributed to tangible and intangible reassurances that they were receiving the best possible care (Q1.6).

Theme 2: Research about Cancer Treatment

Narratives regarding cancer treatment research priorities related to the development of new treatment modalities, the impact of treatment toxicities on decision-making for treatment, and concerns regarding the consistency of criteria used to determine a person's eligibility for particular treatment modalities (Table 3).

Development of Treatment Modalities—The development of treatment options for older adults diagnosed with cancer was a consistent research priority stated by participants of this study (Q2.1).

Understanding Toxicities Associated with Treatments in Older Adulthood—The nature of toxicities associated with cancer treatments was also a notable priority, particularly among participants who had received more than one line of treatment. In these cases, participants discussed the balance between benefits and costs of toxicities associated with treatment. Participants shared diverse viewpoints regarding the impact of treatment-related toxicities and the motivations to continue particular lines of treatment. Where toxicities had an exceptional impact on quality of life, this drove participants' preference to transition to new treatment regimes (Q2.2).

Many experienced transitions or breaks in treatment recommended by cancer care professionals to reduce the potential risk of treatment toxicities or enable recovery for subsequent cycles of treatment. However, these participants described concerns about the potential for disease progression during breaks in treatment or when transitioning to what they perceived as less aggressive treatments (Q2.3).

Decision Making and Advanced Care Planning—Most participants provided insight into the issues that were of greatest importance to them for decision-making related to treatment. There was a notable divergence in the level of information that was preferred and made available to support decision-making for care planning. Those who desired more information felt complete information was essential to prepare for decision-making and to anticipate outcomes. However, several participants suggested that receiving that depth of information would not have been helpful in the early stages of their treatment and may have caused higher levels of distress (Q2.4).

Narratives surrounding preferences for information highlighted the potential impact of health efficacy on the individuals' ability to self-advocate in treatment-related decision-making. There was significant diversity in participants' ability and interest to seek further information, particularly information available beyond hospital settings (Q2.5). The significance of disparities in participants' information needs was most notable among those who raised concerns about their eligibility for particular treatment regimes. Although they considered themselves healthy and well aside from their cancer diagnosis, they felt they were not being considered for certain treatment options due to inconsistent recommendations from healthcare professionals about their suitability for treatments (Q2.6).

A small number of participants discussed their understanding of the trajectory of their disease, and their awareness that decisions may need to be made regarding the next lines of therapy or future care needs. Four participants were actively planning for their future care needs, and two others expressed a desire to have an opportunity to develop an advanced care plan (Q2.7). However, participants' experiences of planning were often focused on practicalities and logistics of cancer care, rather than preferences for future escalations and de-escalations in care. Some participants expressed shock when conversations about disease progression and planning for the future were raised, as they felt they were not forewarned

(Q2.8). Fundamentally, several participants emphasized that there was a need to understand individuals' preferences for care, and for healthcare professionals to endeavour to tailor treatment, care and follow-up care to align with the preferences of each person (Q2.9).

Theme 3: Supporting Assessment and Management of Co-Morbidities

Research priorities identified within the theme of assessment and management of co-morbidities focused on the need for integration of care, continuity of care, and the experience of frailty while living with or after cancer (Table 4).

Integration and Continuity of Care—The care and management of multi-morbidities alongside cancer treatment or follow-up was a feature of many interview narratives. While general practitioners were considered a logical central point of care and information, they were considered limited in their potential to provide support or investigate complex symptoms due to constraints surrounding resourcing, appointment availability and perceived risks (Q3.1). Several participants highlighted excellence in the efforts of cancer services to support them in managing complex health issues. Participants' narratives suggested there were efforts to implement ad hoc integration of care between cancer care and other specialities; as a result, participants believed they spent less time in hospitals and gained more rapid access to required care (Q3.2). However, there was also a small number of participants who described successfully self-managing co-morbid conditions with support from their cancer care team, without specialist or primary care involvement (Q3.3).

While participants felt well-supported in managing issues associated with multi-morbidity, several highlighted additional, practical challenges associated with complex care needs where co-morbidities required specialist input, which affected continuity of care. Three participants spoke about progressing frailty; as their need to engage with other specialist services increased, their capacity to maintain appointments related to their cancer became difficult, particularly where support for transport was unavailable (Q3.4). Similarly, where emergency care was required, participants often had limited choice about the location of care. Where emergency ambulance transport was required, participants highlighted that they could not redirect the ambulance to the person's treating hospital, which enhanced the complexity of continuity and navigation of care for older adults with cancer (Q3.5).

Frailty—Participants described comprehensive assessments of cancer symptoms during treatment, and support to manage complex treatment regimens including oral chemotherapies (Q3.6). However, several participants who were on long-term surveillance or maintenance therapies discussed the onset and progression of health issues which may benefit from specialist input. Falls, mobility problems, delirium, sarcopenia, weight loss and polypharmacy were identified by participants as new issues associated with frailty, which they attempted to manage themselves. While participants' narratives suggested that cancer care services attempted to provide some support to address declining function, it was not clear from participants' comments whether systematic approaches to initiating a comprehensive geriatric assessment and appropriate supports for people who met the criteria were in place, or whether medication review for people at risk of toxicities associated with polypharmacy were undertaken. The onset of frailty was associated with narratives

of distress, as participants sought to maintain their independence. Participants described varying levels of success in accessing support services and resources to manage emerging functional needs, due to fragmentation or limited availability of appropriate health services in the community or cancer care settings (Q3.7).

Theme 4: Unmet Needs of People Living With and After Cancer

The unmet needs of people living with and after cancer encompassed physical, psychological and social needs arising from the effects of cancer and its treatment, and the experiences of accessing and navigating care services and information needs within the cancer experience (Table 5).

Physical, Psychological and Social Needs—Participants described a range of symptoms and side-effects that they experienced regularly. Complex symptoms that participants identified as difficult to manage and directly impacting quality of life were identified as high priorities for future research, including peripheral neuropathy, fatigue, sleep disturbance, nausea, loss of appetite, weight loss, loss of strength and muscle tone. In some cases, participants felt they were inadequately prepared for these symptoms, which appeared to impact coping with effects in the longer-term (Q4.1).

By comparison, symptoms that participants felt well-prepared for and understood how to manage did not appear to receive the same level of priority, for example, lymphoedema and depression. Participants valued feeling informed and understanding the types of issues that might arise. Participants' ability to differentiate between issues that required intervention versus those that could be self-managed promoted their confidence to report issues. Participants placed high value on the accessibility of nursing staff to discuss symptom-related concerns. Many prioritised having opportunities to engage in open dialogue with healthcare professionals about symptoms and strategies to self-manage symptoms that affected their quality of life (Q4.2).

Participants highlighted general and age-specific psychosocial needs and suggested further interventions were needed to optimise the support available to them. Issues related to transport, mobility and social welfare were frequent priorities discussed by participants. While many suggested that their cancer diagnosis and treatment had not adversely impacted their financial status, those who described concerns regarding financial toxicity were more likely to be self-employed, highlighting the limited options for social welfare support available to them during their treatment. Those who raised this concern also described healthcare professionals' limited awareness of the specific implications of self-employment for social welfare entitlements. Specific issues that contributed to financial toxicity included costs of travel and car parking associated with hospital appointments. Furthermore, there was recognition that increasingly, people are continuing to work beyond traditional retirement age, and some participants highlighted the impact of treatments on their ability to work (Q4.3).

Access to and Navigation of Services—All participants expressed positive experiences of care and treatment, and while diagnosis was often a shock, many participants were explicit in their desire not to receive formal psychological support as they felt

reassured by the attention and support of healthcare professionals. The psychological impact associated with cancer was most keenly felt when there were fluctuations in health status and uncertainties about future treatment. For others, the psychological impact of cancer only became apparent at later points in treatment and follow-up (Q4.4). While not discussed widely, a small number of participants who experienced conversations about prognosis raised concerns regarding the settings in which sensitive discussions took place; and emphasized the need for spaces which ensured privacy and minimised the risk of distress to other people in clinical areas (Q4.5).

Several participants discussed missed opportunities for support related to their cancer when they experienced psychological distress. For some, this was related to geographical barriers to cancer support, and alignment between the culture of the support group and the persons' needs. Several participants' narratives suggested that they had limited awareness of wider supports that were available to them during the treatment period. In some cases services which would have been beneficial to them early in treatment only became apparent later in their treatment or follow-up. While male participants tended to express a preference for less formal and less structured support, a small number recognised the need and potential benefit of formal supports after encountering them (Q4.6).

Once participants identified relevant services and practical supports, some suggested that challenges continued as these services did not accommodate the complexity of their needs, including mobility and transport issues. Therefore, these participants remained reliant on the support of family or friends to access care (Q4.7). However, there were a substantial number of participants who suggested they were aware of support services, such as transport to care, but declined to use the services because they did not want to take it away from someone who may need it more, even where their travel needs created a financial or practical burden for themselves or others (Q4.8). In cases where users engaged such services early and they were appropriate to their needs, participants described the convenience of the service, and how they alleviated burden placed on themselves and their caregivers (Q4.9).

In the course of interviews, several participants discussed shortcomings in the user-friendliness of systems and services that were required at different points in treatment and surveillance. In particular, accessing social welfare benefits, having a clear point of contact during transitions from active treatment to surveillance and referral to other services were highlighted. Participants' recommendations surrounding these topics focused on fostering person-centeredness in the delivery of care, and the opportunities offered by technology to address gaps in care via telephone or virtual consultations and online information systems. However, the acceptability of online or telephone consultations varied among interviews, due to confidence with technology, suggesting this was an area which required further exploration and understanding (Q4.10).

Information Needs—Participants expressed information needs spanning diagnosis, treatment and outcomes. However, a frequently discussed priority was the methods of information provision, including the timing and format of information. While information about cancer and treatment were primarily discussed at the time of diagnosis, there were diverse experiences in how diagnostic and treatment information were received, understood,

and processed. Participants who discussed issues surrounding the timing and format of information emphasized the need for information to be revisited at structured intervals, led by healthcare professionals, and to provide information in multiple formats to support understanding and comprehension. Some suggested that this could overcome challenges that may be associated with stoicism or complacency, where an individual might be having difficulties managing symptoms, but not wanting or overlooking the opportunity to disclose these. Involvement of family members or friends in these discussions served a dual purpose, to support the person in receiving information and act as a point of reference later, but also so that the family member or friend could have clear and first-hand information on the diagnosis and have the opportunity to ask questions or revisit information at a later date (Q4.11).

Theme 5: Impact of COVID-19 on People Living With or After Cancer and Cancer Care Services

This study was conducted between Summer 2021 and Spring 2022, meaning the impact of COVID on care services and participants' daily lives was raised by the majority of participants (Table 6). Several participants highlighted how they, as a person vulnerable to COVID, were misunderstood, misrepresented, and forgotten in public health guidance throughout the pandemic (Q5.1). Participants highlighted the need for greater understanding of the impact of COVID on diagnostic, treatment and support services, as well as the impact of COVID on the psychological well-being of people affected by cancer (Q5.2). A small number of participants who had contracted COVID discussed the impact COVID had on their long-term health, and described the importance of research to understand the origin of symptoms (whether disease-related, COVID-related or treatment-related) (Q5.3).

Theme 6: The Needs of Family Members, Friends and Communities Supporting Older Adults with Cancer

The needs of family members, friends and communities supporting older adults with cancer was discussed by the majority of participants, with a particular focus on the psychosocial impact of cancer, and the lack of awareness of the long-term implications of cancer within the general population (Table 7).

Psychosocial Impact of Cancer on Family Members—Several participants highlighted the practical and psychological difficulties experienced by their spouse or primary caregiver/supporter in the course of diagnosis and cancer treatment. Often spouses and adult children took responsibility for taking their partner to and from hospital appointments, and experienced worry and distress for their partner and for their futures. Given the challenges experienced by family members and caregivers, many participants did not believe that there were sufficient formal supports in place for their partners (Q6.1). Furthermore, spouses and caregivers were often only present in consultations at critical moments, such as diagnosis, or scan results, and during the pandemic family members could not attend appointments due to restrictions, even where diagnostic information was being discussed. Several participants described the psychological and practical impacts of being responsible for relaying information from healthcare professionals to family members was discussed, and several suggested that family meetings should be arranged to ensure

family members received first-hand information on the persons' health and well-being and had an opportunity to ask questions about prognosis or care plans, or revisit information at later points with healthcare professionals (Q6.2). Three participants provided unique perspectives on the challenges of being a primary or secondary caregiver for an immediate family member with chronic health conditions and highlighted the specific practical and psychosocial challenges within their households as they navigated their own care needs while providing (and receiving) practical support to/from their spouse or other family members (Q6.3).

Raising Awareness of the Impact of Cancer Among Communities and Social Networks

—Several participants commented on how people who had no personal experience of cancer had limited understanding of its impact on the life of the person diagnosed and their family members. Indeed, some participants highlighted a perception that while older people were more commonly diagnosed with cancer, it was most frequent that younger people with cancer were profiled in the media, which limited the impact of awareness-raising (Q6.4). While close friends were often an important source of support, members of social networks often provided well-intentioned but unwelcomed support, as they did not understand the needs of the individual (Q6.5). This was exacerbated by a self-imposed stigma associated with cancer; participants feared being treated differently upon disclosure of their diagnosis, and several participants described introducing distance between them and their family members or friends to cope with treatment (Q6.6). Given the overarching context of COVID at the time of these interviews, some spoke about how society had failed to recognise and support those who were vulnerable to COVID, suggesting that this was an important area for future research (Q6.7).

Discussion

This study provides an insight into older adults' perceptions of priorities for cancer care research. The results of the thematic analysis of participants' interview narratives drove the development of 42 priority topics for future research in cancer care across six thematic areas, all underpinned by older adults' personal experiences of diagnosis, treatment and care. While this study provides only qualitative indications of patient research priorities, it provides a comprehensive picture of the topics that older people living with and after cancer consider to be important issues for future research. The findings of this study provide a basis for priority ranking, incorporating the views of patients, caregivers, healthcare professionals, advocacy professionals, researchers, policymakers and other key stakeholders in the areas of cancer and geriatric oncology.

While this study focused on priorities for cancer care research, there was a consistent tendency for people to conceptualise biological and therapeutic research as cancer research. Nevertheless, all participants proposed topics for future research in the broader context of cancer care. This is consistent with previous studies of cancer patients and survivors which identified advancement of treatment modalities and biologic targets as priorities in cancer care (Aldiss et al., 2019, Rossi et al., 2020). However, this initial finding highlights narrow conceptualisations of research in cancer and cancer care among older adults, which may influence opportunities to engage older people living with and after cancer in priority-setting

research. A key objective of current European cancer policy is to co-design interventions to address unmet needs and quality of life concerns with people living with and after cancer (European Commission, 2021). This objective is of particular importance in the context of participants' discussions of treatment-related effects, and the perceived impact of functional status and quality of life on clinical decision-making regarding treatment regimes for older adults. The predominant focus on treatment modalities as a research priority in cancer has potential to undermine consistent understanding and response to unmet needs at all points of the cancer trajectory from cancer prevention and diagnosis to survivorship and end of life care, and reflects trends in research funding which prioritise biological- and treatment-focused research in Europe over the past decade (Lawler et al., 2022). To ensure comprehensive priority-setting activities in the future, there is a need to enhance patient and public understanding of the diversity of cancer research, there is a need to promote visibility of research designed to support people living with and after cancer and associated impacts of such research.

Shortcomings in the timing and methods of communicating information was frequently described by participants of this study. Information and education are lynchpins of person-centred cancer care which drive informed consent and shared decision-making regarding treatment and care (Stiggelbout et al., 2015, Rawlings et al., 2020, Lawler et al., 2021). Despite this, unmet information needs remain one of the most pervasive unmet needs in cancer care from diagnosis to survival and end of life care (Thorne et al., 2013, Mirošević et al., 2019, Wang et al., 2018). This study highlights how the timing and methods of information delivery can contribute to unmet information needs. Within this study, unmet information needs contributed to difficulties surrounding planning for the future; anticipating treatment options which might be available to them, and decision-making surrounding future care needs and end of life care. Furthermore, the degree to which participants received and understood information related to potential symptoms and symptom management appeared to influence participants' coping with cancer and treatment-related side-effects. This aligns with the results of previous research (Drury et al., 2020b, Neter and Brainin, 2019). Within the domains of information and decision-making, participant-identified research priorities focused on the development of programmes that can enhance communication of information, and support shared decision-making, planning for the future, and advanced care planning. Within this study, participants' experience of unmet needs and their desire for further information was inter-related with health efficacy, which influenced their ability to enquire about, and advocate for treatment options which had not been discussed with them. While technology-based interventions have been identified as a potential response to unmet information needs (Haase et al., 2021), the results of this study highlight the need for caution with an agenda of digital solutions as a one-size-fits-all solution for older adults living with cancer. Older adults are a heterogeneous group, and in designing digital interventions, there must be recognition of diversity in the levels of digital literacy, preferences for technology and factors influencing accessibility of technology within this population (Bian et al., 2021, Schreurs et al., 2017)

While not expressly named by participants, the concept of and impact of frailty and comorbid conditions was evident throughout interview narratives. While participants described cancer care as being of high quality, with efforts to integrate care for co-morbid

illnesses, participants' narratives did not suggest that emerging indicators of frailty were recognised, or that referral to specialist geriatric services was implemented. This is a critical concern in cancer care for older adults; particularly where there is fragmentation of care for co-morbid conditions. There is substantial evidence highlighting positive effects of early recognition, comprehensive geriatric assessment, person-centred care planning and interventions on the maintenance of function and well-being among frail older adults living with and without cancer and comorbid conditions (Theou et al., 2011, Khor et al., 2022, Choi and Kim, 2022). However, where people may be receiving long-term specialist care for cancer, there is a risk that triggers for appropriate geriatric assessment or referral to specialist geriatric services may be overlooked in the context of cancer care, conflated with treatment-related toxicity (British Geriatrics Society, 2020, Ethun et al., 2017). Furthermore, there is mixed evidence regarding the impact of comprehensive geriatric assessment on quality of life outcomes and toxicity in the context of oncology, hypothesised to be influenced by the timing of assessment (Puts et al., 2023, Li et al., 2021, Mohile et al., 2021). Given the impact of frailty on patient-reported and survival outcomes (Morley et al., 2013, Lu et al., 2017), the priorities within this domain focus on the development and implementation of interventions which can support the recognition of and interventions to address the physical and functional impacts frailty. Research and care priorities which advance integration of care, and greater integration of geriatric and geriatric-oncology-specific expertise complement this, to ensure access to appropriate care for existing and emerging frailty.

Overall, the thematic priority areas for future cancer research generated within this study broadly align with prior priority-setting activities in cancer care (Cadorin et al., 2020, Cuthbert et al., 2022, Dowling et al., 2023, Zanville et al., 2021). However, the research priorities proposed within this study reflect the specific experiences and needs of older adults living with and after cancer, including perceived age-related influences on diagnosis, treatment options and decision-making, and considerations of co-morbidity, including frailty and integration of care. The priorities generated within this study provide an expanded view of the specific priorities of older adults living with cancer. Previous priority setting studies which proposed priorities for cancer research in older adulthood focused on specific aspects of rehabilitation (Lyons et al., 2017), polypharmacy (Nightingale et al., 2021) and falls (Sattar et al., 2021). However, the priorities generated within each of these three studies were generated based on evidence synthesis and consultation with clinical or academic experts, rather than older adults who are experts by experience (Lyons et al., 2017, Nightingale et al., 2021, Sattar et al., 2021).

With the exception of technology-based solutions, the priorities generated within this study encompass those proposed by Haase et al. (2021), which were also based on consultation with older adults living with cancer and their caregivers. When directly compared with the priorities derived from Haase et al. (2021), the results of this study provide additional insights on priorities for future research in cancer care, as perceived by older adults. This study adds several specific recommendations for future research priorities for cancer care in older adulthood, including research to understand and address disparities in access to diagnostic investigations; healthcare professionals' recognition of potential cancer

symptoms in older adults; advanced care planning; and recognition and management of frailty among older adults living with cancer.

The objective of this study is not to rank priorities. However, when interpreted in the context of wider evidence, and the most significant concerns and experiences raised by older adults living with and after cancer, priorities to understand and address topics within the thematic areas of unmet needs and assessment and management of co-morbidities remain among the most consistently raised issues among older adults living with and after cancer (Lyons et al., 2017, Nightingale et al., 2021, Sattar et al., 2021, Haase et al., 2021) and within cancer care priorities more broadly (Cadorin et al., 2020, Cuthbert et al., 2022, Dowling et al., 2023, Zanville et al., 2021).

Limitations

The results of this study must be interpreted in the context of its limitations. In particular, the results represent the experiences of older adults living with and after cancer in the Republic of Ireland, and therefore may not be generalisable to other geographical contexts. While this study sought to recruit people living with or after solid tumour malignancies and haematological malignancies, just two participants reported a prior diagnosis of a solid cancer diagnosis. This limitation is reflective of known limitations of purposive sampling methods. While the results of this study are not generalisable, the characteristics of the sample reflect the principles of qualitative sampling, where an in-depth understanding of a few cases can provide rich, textured understanding of phenomena (Sandelowski, 1995, Coyne, 1997).

While the context of the study and characteristics of the sample may limit the transferability of findings, several strategies were implemented to enhance transferability. Firstly, the representation of a diverse sample of older adults, in terms of age range, stages of treatment, surveillance and follow-up, alongside transparent reporting of research findings, including rich descriptions of the analysis process and outcomes, presentation of the priorities in the context of the thematic results, supported by participant quotations to facilitate interpretation of the findings enable the reader to determine whether the findings are applicable to their context serve to enhance the potential transferability of findings (Speziale et al., 2011, Shenton, 2004).

Within this study, there is a predominant representation of the views of people living with and after haematological malignancies. Nevertheless, people living with haematological malignancies are often an under-represented group in cancer research, and as such, the results of this study provide insight to the priorities for future research among a group who are at further risk for marginalisation as a consequence of being an older adult. While this study does not provide clear consensus or ranking on the specific priorities of this population, it provides a transparent analysis of data that has informed and provided a rationale for the research priorities generated within this study and provides a basis for future priority-setting activities which are sensitive to cultural and contextual issues influencing cancer research in geriatric oncology.

Conclusions

The generation of patient-driven research priorities with underrepresented and marginalised groups within cancer research serve to advance the utility of future cancer research, and quality of care for cancer patients and survivors within these populations. This study has identified forty-two priorities for future research within six themes representing each aspect of the cancer trajectory, and the key persons and resources who are integral to the supportive care of people who are living with and after cancer. The priorities for future research which have been generated within this project provide a basis for future priority setting exercises, which are culturally and contextually sensitive to the healthcare systems, resources, and needs of older adults living with and after cancer. Based on the findings of this study, we make recommendations for the development of interventions which can build awareness, capacity, and competence in geriatric oncology among cancer care professionals, and consideration of the diverse needs of older adults in the development of interventions to address unmet information and supportive care needs.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Highlights

What is Already Known?

- Older adults over the age of 65 represent the group most frequently diagnosed with cancer, but they are often under-represented in research.
- Research priority setting has increased over the past two decades, but is often limited by inadequate reporting of methods and stakeholder involvement.
- Few published research priority setting activities involve older adults living with or after cancer as the primary stakeholders driving the agenda.

What this Paper Adds:

- This study presents a patient-driven agenda of 42 priorities for cancer care research across six thematic areas.
- Each proposed research priority is underpinned by older adults' personal experiences of diagnosis, treatment and care
- The findings of this study provide a basis for future priority ranking, involving diverse stakeholders in the areas of cancer and geriatric oncology.

Table 1:

Sample of Coding and Analysis Process, and Priority Generation

Theme	Subthemes	Codes	Exemplar Quotations	Priorities
Research about Cancer Treatments	<i>Decision-Making and Advanced Care Planning:</i>	Preparation and support to engage in decision-making	I'm in remission since Christmas last. I'm led to believe that can last for maybe five or six years, so then I would like to know exactly what's facing me after that. And I haven't discussed it, I'm sure it's probably the same type of treatment that I got initially. But I'd like to know exactly about these things. (P003, Female, Non-Hodgkin's Lymphoma)	<ul style="list-style-type: none"> Projects to support older adults to make informed decisions about cancer treatment and care.
		Access to information	Maybe at the beginning it would be good to know the opinions of the patient and how they feel. Some people mightn't like to hear the whole story and there's others then would, like myself, I would like to have a full picture on the whole thing. (P003, Female, Non-Hodgkin's Lymphoma)	
		Preferences for information		
		Information needs		
		Advance Care Planning:	Until such time as I feel that I can't any longer function on my own, and I have to face that as somebody who is living on her own, I've got a tentative booking for myself into a nursing home ... the last thing in the world I would want to do would be to have a crisis and leave my stuff to be cleared for however few the days might be, by my poor friend. (P005, Female, Multiple Myeloma)	<ul style="list-style-type: none"> Research to understand older adults' preferences for advance care planning.
		Preferences for advance care planning	About eighteen months ago, {Oncologist} told me to get my affairs in order and that frightened the shit out of me ... I got a bit of a fright but then I tried to step back from myself and look at it and say, look, it's good, it's good advice, it's just good advice that if you do conk you, you don't leave people in the shit, trying to sort out bits and pieces. (P006, Male, Chronic Lymphocytic Leukaemia)	<ul style="list-style-type: none"> Research to support the development of programmes to help older adults living with or after cancer to plan for future care needs.
		Initiating discussions about advance care planning		

Table 2: Priorities and participant quotations [Q] illustrating Theme 1, Early Investigation and Recognition of Potential Cancer Symptoms

<p>Theme 1 Priorities: Recognition of the signs and symptoms of cancer:</p> <ul style="list-style-type: none"> • Projects to enhance public awareness of potential cancer symptoms. • Projects to promote awareness among healthcare professionals of potential cancer symptoms requiring investigation (e.g. GP's, nurses, physiotherapists, etc). • Research to understand the impact of a receiving a cancer diagnosis in an emergency department setting. 	
<p>Q1.1</p>	<p>Initially I had a pain in my shoulder for around two years ... It was just an ache really, so that was the shock, of going in for an MRI on a Friday and then suddenly saying, oh there's a big problem. (P010, Male, Lymphoma) I wasn't feeling well and I didn't feel right in myself. I started going into severe sweats at night and I was getting pains in my back and I went up to see my GP ... I was in and out, like I ended up in casualty about four times... I don't know how many doctors and different tablets they had me on. (P012, Male, Non-Hodgkin's Lymphoma)</p>
<p>Q1.2</p>	<p>While I was in {Treating Hospital}, waiting for them to clear up the sore leg, they were taking bloods of course and they told me that I had lymphoma. (P007, Female, Lymphoma)</p>
<p>Q1.3</p>	<p>[My cancer diagnosis] was something that came on very suddenly. ... I got a bad pain in my back ... Within a week I went to my own doctor. ... If I hadn't had that pain I would never have gone to the doctor anyway because I had no other symptoms, you know. And only he was good enough to send me for an x-ray. (P015, Female, Multiple Myeloma)</p>
<p>Q1.4</p>	<p>I was diagnosed, and it was kind of dormant, it hadn't kicked off. ... my daughter noticed that my lymph glands were up on my neck and they were going on my arms and my groin and my stomach was paining me and down me back but I, I was just kind of, I thought it was something that'd go away and I just couldn't get out of bed for a few days so my wife rang the hospital and they told me to call up. (P009, Male, Chronic Lymphocytic Leukaemia)</p>
<p>Q1.5</p>	<p>The cancer didn't frighten the life out of me. When I got the cancer, my first reaction was that's brilliant I know what's going to kill me now! Stupid but that's it, I talked to different people and I know some other people who have died since but anyhow, the diagnosis nearly killed them not the cancer. (P001, Male, Multiple Myeloma) It had a bit impact on my husband because I was an in-patient for about two weeks and when he used to come up, I used to think, my God, he doesn't look well and I used to say, don't come tomorrow now ... But he was, he was concerned, I know he was. (P007, Female, Lymphoma)</p>
<p>Q1.6</p>	<p>I think we're very lucky with {Oncologist} because even when I was diagnosed it was a worrying time ... she said look there's no need to worry, you don't worry about this, don't read up anything, don't Google it, don't, she said, that's my job, I look after you, you just get on with your life. (P009, Male, Chronic Lymphocytic Leukaemia)</p>

Table 3:

Priorities and participant quotations [Q] illustrating Theme 2, Research about Cancer Treatment

<p>Theme 2: Research about Cancer Treatments: Subtheme 2.1 Priorities: <i>Development of Treatment Modalities:</i></p> <ul style="list-style-type: none"> • Research to support the development of new treatment options for older adults diagnosed with cancer. <p>Subtheme 2.2 Priorities: <i>Understanding Toxicities Associated with Treatment in Older Adulthood:</i></p> <ul style="list-style-type: none"> • Research to understand the effects and outcomes of cancer treatments for older adults. • Research to understand older adults' preferences for cancer treatments and their potential side-effects. <p>Subtheme 2.3 Priorities: <i>Decision-Making and Advanced Care Planning:</i></p> <ul style="list-style-type: none"> • Projects to support older adults to make informed decisions about cancer treatment and care. • Research to understand the role of age and functional status in determining the cancer treatment options available to older adults. • Research to support the development of programmes to help older adults living with or after cancer to plan for future care needs. • Research to understand older adults' preferences for advance care planning. 	<p>Q2.1</p> <p>I would assume that [the priority] is looking into all the various treatments and how you can improve the treatments and look at various causes of cancer or whatever illness and then seeing what tools we have available currently to improve the treatment. (P002, Female, Breast Cancer)</p>
	<p>Q2.2</p> <p>The [drug] that I'm taking has the desired effect on what they want to do, but it is affecting me, my every day and I'm just wondering you know if maybe there is something else... I keep asking myself is would I be better off without [drug] or would I be better with it because my legs are weak and I get tired and I have various side effects with it. (P003, Female, Non-Hodgkin's Lymphoma)</p>
	<p>Q2.3</p> <p>I've been on four different types of treatment now because you know, when you're on it for a while they come to the conclusion that it's not working anymore... So out of the blue, you know, you suddenly think oh this is great now, I'm not going well on this treatment. (P015, Female, Multiple Myeloma)</p>
	<p>Q2.4</p> <p>I would like to know what the prognosis was totally with no holdback... I know that to give a definitive answer on an end game or as I keep calling it is nearly impossible in a lot of cases, I accept that, but I'd like an idea, a broad picture of where it is going. (P003, Female, Non-Hodgkin's Lymphoma) If I'd known what I was going to experience I think I would have been terrified... I definitely felt that I did well not knowing what was to come, you know the way they sometimes say knowledge is an empowerment right? In this case knowledge would have been horrendous. (P002, Female, Breast Cancer)</p>
	<p>Q2.5</p> <p>I know I done a course on the internet and all, but I've never got practicing. I'll ask me wife or one of the grandkids to look things up for me, but I don't be on [the internet] at all. (P012, Male, Non-Hodgkin's Lymphoma)</p>
	<p>Q2.6</p> <p>I'm not over-weight or anything, I try to keep fit. Having done that I felt that I was going places, as in I would make selection for transplant... When I reported back to my own team, [they] said no, we never said anything about you being a candidate, and I insisted that I had been told I was a candidate. (P006, Male, Chronic Lymphocytic Leukaemia)</p>
	<p>Q2.7</p> <p>I'm in remission since Christmas last. I'm led to believe that can last for maybe five or six years, so then I would like to know exactly what's facing me after that. And I haven't discussed it, I'm sure it's probably the same type of treatment that I got initially. But I'd like to know exactly about these things. (P003, Female, Non-Hodgkin's Lymphoma) Until such time as I feel that I can't any longer function on my own, and I have to face that as somebody who is living on her</p>

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Q2.8	<p>own. I've got a tentative booking for myself into a nursing home ... the last thing in the world I would want to do would be to have a crisis and leave my stuff to be cleared for however few the days might be, by my poor friend. (P005, Female, Multiple Myeloma)</p>
Q2.9	<p>About eighteen months ago, {Oncologist} told me to get my affairs in order and that frightened the shit out of me ... I got a bit of a fright but then I tried to step back from myself and look at it and say, look, it's good, it's good advice, it's just good advice that if you do conk you, you don't leave people in the shit, trying to sort out bits and pieces. (P006, Male, Chronic Lymphocytic Leukaemia)</p>
	<p>Maybe at the beginning it would be good to know the opinions of the patient and how they feel. Some people mightn't like to hear the whole story and there's others then would, like myself, I would like to have a full picture on the whole thing. (P003, Female, Non-Hodgskin's Lymphoma)</p>

Table 4:

Priorities and participant quotations [Q] illustrating Theme 3, Supporting Assessment and Management of Co-Morbidities

<p>Theme 3: Supporting Assessment and Management of Co-Morbidities Subtheme 3.1 Priorities: <i>Integration and Continuity of Care:</i></p> <ul style="list-style-type: none"> • Projects to support older adults living with or after cancer and one or more other health conditions to maintain their quality of life. • Projects to develop formal integrated care services to support the management of co-morbidities alongside cancer treatment and follow-up care. • Research to understand the issues which hinder and facilitate continuity of care for older adults living with or after cancer. <p>Subtheme 3.2 Priorities: <i>Frailty:</i></p> <ul style="list-style-type: none"> • Projects to introduce comprehensive geriatric assessment to cancer care services for older adults living with or after cancer. • Research to support healthcare professionals' recognition of and assessment of frailty in cancer care services. • Projects promoting medication review and reconciliation in cancer care services to reduce risks associated with unnecessary medications. • Projects to support older adults living with or after cancer to understand their medications and support optimal and accurate use of medicines associated with cancer treatment. 	<p>Q3.1</p> <p>I suppose it [x-rays/investigations] could be easily done by the GP too, just they don't have the equipment. I know they should have a lot more knowledge than me, but trying to cover every angle, it's probably impossible, isn't it? (P012, Male, Non-Hodgkin's Lymphoma)</p> <p>I didn't have to go to the GP because my immune system was shattered so rather than sitting in a GP's waiting room, the [day ward] would deal with it if they could at all, they were excellent to me. (P013, Female, Multiple Myeloma)</p> <p>Q3.2</p> <p>We worked out that the lady in Dermatology would come up and look at my leg while I was attached to the chemo... They probably thought I was coming from Dublin, just up the road, you know, a bus ride or a, you know, but my journey takes me over an hour, it could be an hour and a half. (P007, Female, Lymphoma)</p> <p>Q3.3</p> <p>I only see that nurse in [Treating Hospital] ... she asks me all the different questions, about how I am ... I have COPD, I have a thyroid problem and I have macular degeneration ... but I'm motoring around, I'm fine, you know. (P014, Female, Hodgkin's Lymphoma)</p> <p>Q3.4</p> <p>My husband's not well at all at the moment, and it's about a half hour drive [to hospital] ... until he's a bit better then I'm housebound ... Now there's no way I can go [to hospital] twice a week because it's too much of a torment on him and that upsets me then. (P007, Female, Lymphoma)</p> <p>Q3.5</p> <p>The ambulance came to take me because I was really unwell ... they said we can't go to [Treating Hospital], we're all on different routes. And so I had a week in [Public Hospital] and they just sent over all the notes and everything like that and it was a great nuisance. (P005, Female, Multiple Myeloma)</p> <p>Q3.6</p> <p>I'm lucky because there's a nurse specially assigned to this medication, so when you go up, I see [Oncology Nurse], and we go through it every month. They wrote out a chart for me and got me to fill it in, all the different medications, what time I've to take them at, how many a week, you know. (P009, Male, Chronic Lymphocytic Leukaemia)</p> <p>Q3.7</p> <p>[Oncology Nurse] said something to me about getting home help but sure there's nobody to come, there's no home helps now... We live in a bungalow and I have a path all around where I do my walking and I've got nervous now even doing the walking, you know. Because I've had a few falls, I've had a few bad falls and every</p>
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time I fall it makes me nervous. ... I'm having difficulty getting [the rollator]. The HSE, the lady at the clinic, the physiotherapist doesn't have any and she can't give them out. All she has is the frame with no wheels. Now that would be no good to me because I'd have to move the frame and then move myself. (P007, Female, Lymphoma)

Table 5:

Priorities and participant quotations [Q] illustrating Theme 4: Unmet Needs of People Living With And After Cancer

<p>Theme 4: Unmet Needs of People Living With And After Cancer Subtheme 4.1 Priorities: <i>Physical, Psychological and Social Needs</i></p> <ul style="list-style-type: none"> • Research to understand the impact of cancer on older adults' daily life (e.g. ability to self-care, ability to drive, ability to walk, ability to work/enjoy hobbies, financial impact of cancer) • Research to understand older adults' experiences of cancer and treatment-related side-effects and issues that might affect self-management of side-effects. • Research to support the development of programmes that help older adults to recover physically, psychologically and socially after cancer treatment • Research to understand the care and support needs of older adults living with and/or after cancer and frailty. • Research to support the development of services to support the management of symptoms related to cancer or cancer treatment that older adults living with or after cancer may experience. 	<p>Q4.1</p>	<p>I actually didn't know about [Peripheral Neuropathy] until it happened, and they had to stop giving me chemotherapy ... Obviously my outcome has been extremely good, but it was all the various side effects. I nearly felt that if I wasn't going to survive it was going to be chemo that was going to kill me rather than the cancer. (P002, Female, Breast Cancer)</p>
<p>Subtheme 4.2 Priorities: <i>Access to and Navigation of Services</i></p> <ul style="list-style-type: none"> • Research to understand what might affect an older adults' ability to navigate and access healthcare services • Research to support the development of services to support older adults living with or after cancer to cope with the psychological and social impacts of cancer • Projects to promote awareness and uptake of advocacy services available to people living with and after cancer (e.g. transport to appointments, counselling, cancer support groups) • Projects to support older adults living with or after cancer to access public health and social welfare benefits • Research to support the development and implementation of programmes that help older adults living with or after cancer to access and navigate healthcare services to manage symptoms or issues related to cancer. 	<p>Q4.2</p>	<p>I had the lymph nodes under my arm all removed and I would have a certain kind of vulnerability on my left side as regards lifting, and you know putting my arm into coats and things like that, but I mean you know somebody with arthritis would probably have the same thing. (P002, Female, Breast Cancer) Get patients to tell the nurse and the doctor ... the nurses would pick [issues] up and then go to the head nurse or to the doctor and tell him, and I suppose for patients to tell [them] every little side effect they have. (P001, Male, Multiple Myeloma)</p>
<p>Subtheme 4.3 Priorities: <i>Information Needs</i></p> <ul style="list-style-type: none"> • Research to support the development of programmes that enhance the methods of communication of information about cancer diagnosis, treatment, and treatment-related side-effects. 	<p>Q4.3</p>	<p>I was self-employed and being diagnosed with cancer it was only lucky that it had only come out, [prior to] that, being self-employed you could get no dole or social welfare. ... Unless somebody is self-employed, they don't understand that. (P001, Male, Multiple Myeloma) When I started treatment, I asked the oncologist if I could remain at work and he said no problem. But I actually only got into the second day of treatment; there was no way I could have continued working. I couldn't even get out of bed. (P002, Female, Breast Cancer)</p>
<p>Subtheme 4.4 Priorities: <i>Information Needs</i></p> <ul style="list-style-type: none"> • Research to support the development of programmes that enhance the methods of communication of information about cancer diagnosis, treatment, and treatment-related side-effects. 	<p>Q4.4</p>	<p>At the beginning you get a fright because once you hear the C word you think, oh my God, I'm gonna die. But as time goes on you become reassured, your team reassures you of where you're at ... Since last Summer, my anxiety went up a bit, with all this kerfuffling about whether I was or wasn't going for a transplant. (P006, Male, Chronic Lymphocytic Leukaemia) When you hear first it just, I think you are in such a state of shock it doesn't hit you for a while. And then it really does. (P004, Male, Multiple Myeloma; Prostate Cancer)</p>
<p>Subtheme 4.5 Priorities: <i>Information Needs</i></p> <ul style="list-style-type: none"> • Research to support the development of programmes that enhance the methods of communication of information about cancer diagnosis, treatment, and treatment-related side-effects. 	<p>Q4.5</p>	<p>I happened to be sitting or been in a cubicle next to a lady one of the times and I could hear that she was distressed ... there should be a side room or something where they are taken to, spoken to privately ... particularly where there are other patients around. (P003, Female, Non-Hodgkin's Lymphoma)</p>
<p>Subtheme 4.6 Priorities: <i>Information Needs</i></p> <ul style="list-style-type: none"> • Research to support the development of programmes that enhance the methods of communication of information about cancer diagnosis, treatment, and treatment-related side-effects. 	<p>Q4.6</p>	<p>When you get your diagnosis and your brain is all over the place. There is probably more help there than you realise but how to access it is a problem... I did go to [Support A] but they just never clicked ... The support group in [Location C] and [Location D] I did have to use them a couple of times, but I had nobody to drive me and I wasn't able to drive to the hospital. (P001, Male, Multiple Myeloma) There was a little centre down on the first floor of [Hospital]</p>

	<p>... and at first my nose went up when I saw {Advocacy Organisation}, but how wrong was I ... it seems so unimportant but it's wonderful ... you can pop in any time for a chat, I found it a wonderful support. (P006, Male, Chronic Lymphocytic Leukaemia)</p>
Q4.7	<p>I was using the wheelchair ... but the fact I had a wheelchair the [volunteer transport] wouldn't handle the wheelchair. Somebody would have to come with me; that defeated the whole purpose because if somebody had to come with me, they would bring their own car. (P004, Male, Multiple Myeloma; Prostate Cancer)</p>
Q4.8	<p>My wife usually drove me [to hospital]. And I'm lucky that I can afford the time and the money to do it. (P016, Male, Multiple Myeloma)</p>
Q4.9	<p>I didn't use [volunteer transport] straightaway but I thought about it and he's not good himself at the moment, he's having treatment for lung cancer... I'm so pleased with the drivers. Because there's no fussing... They come here to the door at the time, I ring, tell them the time, they come and pick me up, bring me to [Hospital], drop me at the door (P007, Female, Lymphoma)</p>
Q4.10	<p>I have to say that being in contact with the administration staff, looking for a medical card, was the worst experience I had. I got off the phone I'd say three times bawling my eyes out. (P013, Female, Multiple Myeloma) I could get a letter; I was wondering. I thought I'd get a letter in the post for the urologist, but I didn't. Now it could be maybe tomorrow or the next day, and for that again I mightn't get it, they might leave it 'til [Oncologist] sees me. (P011, Female, Lymphoma) Oh [the nurse] wanted me to do Zoom, there was somebody doing exercises ... I didn't go ahead with it, I'm not wasting me time because I wouldn't be into it, I just didn't like the idea of going on Zoom and doing exercises, I'm bad enough ... I'm not au fait with it, I'd look, I'm set up for Zoom, but I haven't used it at all. (P014, Female, Hodgkin's Lymphoma)</p>
Q4.11	<p>I had my wife and my daughter with me. {The oncologist} asked me to bring some family members. But a lot of the time at that initial contact when you're told, it doesn't always sink in until a while after and I think that something, maybe some kind of a follow-up, could be done ... everybody's different and different people take things in differently ... It doesn't have to be the doctor, it could be a nurse or somebody who would explain the whole thing again and explain the treatment and what it does and the side effects of drugs and that type of thing. (P008, Male, Lymphoma; Chronic Lymphocytic Leukaemia) I know my wife was allowed to come to lots of consultations, so she would have been made aware of what was going to be happening. (P016, Male, Multiple Myeloma)</p>

Table 6:

Priorities and participant quotations [Q] illustrating Theme 5: Impact of COVID19 on People Living With or After Cancer and Cancer Care Services

<p>Theme 5 Priorities: Impact of COVID19 on People Living With or After Cancer and Cancer Care Services</p> <ul style="list-style-type: none"> • Research to understand the psychological and social impact of public health strategies on people living with or after cancer (i.e. lockdowns, social distancing, vaccinations, use of face masks, etc). • Research to understand the psychological and social impact of the easing of public health measures on people living with or after cancer (i.e. ending of mask requirements, social distancing). • Research to understand the impact of COVID19 on investigation, diagnosis and staging of cancer since the start of the pandemic. • Research to understand the late effects of COVID19 experienced by people living with or after cancer. 	<p>Q5.1</p> <p>When COVID started, the government wasn't really worried about the vulnerable people, and even to today when they're letting people not wear masks... I'm locked inside again, I can't go back out because I don't know who has what anymore... the government has sort of forgotten about us, vulnerable, the older, vulnerable people. (P013, Female, Multiple Myeloma)</p>
	<p>Q5.2</p> <p>When the COVID came along and all these clinics were cancelled and delayed and everything, and that has caused untold damage, because people that are diagnosed with cancer, if they had been diagnosed earlier, they would have had a better chance ... there's a long wait for an appointment to see a specialist in the first place if you haven't got private health insurance. That's a big problem I think (P015, Female, Multiple Myeloma) I had hoped that [my wife] was going to be able to visit me in the hospital ... But because of Covid, it has made it very easy for hospitals to say no. (P016, Male, Multiple Myeloma)</p>
	<p>Q5.3</p> <p>If we were doing this interview three years ago, it'd be a totally different interview because with the COVID on top of all this. Besides getting the COVID, the way people have to go on in the last couple of year like was, you know, isolation and all that ... I've a chesty cough and I'm coughing up phlegm every day and I don't know if that's from the COVID or, I don't think it's nothing to do with the leukaemia. (P009, Male, Chronic Lymphocytic Leukaemia)</p>

Table 7:

Priorities and participant quotations [Q] illustrating Theme 6: The Impact of Cancer On Caregivers and Family Members

<p>Theme 6: The Impact of Cancer On Caregivers and Family Members Subtheme 6.1 Priorities: <i>Psychosocial Impact of Cancer on Family Members</i></p> <ul style="list-style-type: none"> • Research to understand the psychological impact of cancer on family members or friends who provide care to people living with or after cancer • Research to understand the impact of changes in roles when a family member or friend is diagnosed with cancer • Research to understand the experiences of people who are caregivers of people with chronic health conditions, and also living with or after a cancer diagnosis of cancer • Research to support the development and implementation of programmes providing psychosocial support to caregivers of older adults living with or after cancer • Research to understand the information needs of family members or friends who provide care to an older adult living with or after cancer related to cancer diagnosis, treatment or follow-up care. <p>Subtheme 6.2 Priorities: <i>Raising Awareness of the Impact of Cancer Among Communities and Social Networks</i></p> <ul style="list-style-type: none"> • Research to understand the impact of high-profile stories about cancer experiences on the understanding of cancer among members of the public • Research to understand the perceptions of members of the public about the needs of people living with and after cancer. • Research to understand the impact of a cancer diagnosis and its treatment on the relationships between the person living with or after cancer and their family members. • Projects to promote public awareness of the support needs of people with cancer • Research to understand the needs and preferences for support from community and friends among older adults living with or after cancer 	<p>Q6.1</p> <p>I was a bit out of it, if you know what I mean, I was kind of bewildered, as I said, and look it, {my family} are just amazing. I didn't know I had such a fabulous husband. I don't know if you know that time of the snow ... it was difficult for them to get to see me ... my husband brought me in and out and he was brilliant. (P014, Female, Hodgkin's Lymphoma) It's hard for [carers] ... I don't think there's any [support] in that line at all now ... they need support for the main carer, whether that be a husband or wife or partner or child or whatever. (P001, Male, Multiple Myeloma)</p>
	<p>Q6.2</p> <p>I think your immediate family might be something that could be taken into more, into consideration and explaining the type of cancer and that type of thing. (P008, Male, Lymphoma; Chronic Lymphocytic Leukaemia)</p>
	<p>Q6.3</p> <p>We've been coping, we've been coping as best we can. He gets a lot of reflux, and when that comes on, he vomits and I have to hold the bowl and hold him and clean up ... But I manage and of course I worry ... What could anyone do [to help] when, you know, when he wakes up at three o'clock in the morning and wants to throw up. (P007, Female, Lymphoma) [My daughter] calls in every evening to see do we want anything done, or bring home any shopping we need. She's excellent ... We're keeping fingers crossed because she is to go to [Hospital] for the results of a biopsy. So, we're keeping our fingers crossed that there will be nothing seriously wrong with her. (P015, Female, Multiple Myeloma)</p>
	<p>Q6.4</p> <p>[When] people were dying [from COVID]. I thought it was good when they put it on the television, whoever they were, what age she was and how she got it. When it's a person, you can relate to that, not just a number. So, the same with the cancer, it might help. But you hear that with lads that are fit, like footballers or hurlers and they get diagnosed and just the fact that somebody picked them up early makes all the difference. (P001, Male, Multiple Myeloma)</p>
	<p>Q6.5</p> <p>My pal would come down and pick me up and we'd go for a Happy Meal in McDonalds on our way home and we'd go to her house. ... I know her for the last fifty year. (P011, Female, Lymphoma) When I was very, very sick and a few friends were calling in and I was glad to see them but ten minutes and you'd be wore out. ... if they stayed too long or if it was two or three people every night, you can't regulate for that. ... Visitors don't recognise that, it was brilliant to be able to talk to somebody for the ten minutes but the repetition of it wasn't so good. (P001, Male, Multiple Myeloma)</p>
	<p>Q6.6</p> <p>I didn't like telling people I have it because, if they're standing beside you, because if you know them well and they're friends or workmates, they kind of look at you different. (P009, Male, Chronic Lymphocytic Leukaemia)</p>

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Q6.7	With the COVID, like there's things you, obviously, everyone would have like to do like, but someone immunocompromised, like travel or going anywhere, going to, even to a funeral, going in anywhere, obviously you can't. If you don't want to go inside anywhere, and visit people like you'd normally visit because, you don't want to put yourself at risk and your family in trouble ... you're kind of working everything around COVID and what you can do and what you can't do and you'd be inside more, you're not socializing and you wouldn't be meeting as many people. (P009, Male, Chronic Lymphocytic Leukaemia)
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