ORIGINAL ARTICLE

Barriers to cancer care for people with significant mental health difficulties: What healthcare staff say?

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Abstract
Objectives: Despite similar rates in cancer morbidity, patients with comorbid significant mental health difficulties (SMHD) experience higher mortality rates. This population has largely been neglected in cancer care research. Little is known about how to improve cancer outcomes for patients with SMHD. The aim of this research is to explore the views of healthcare professionals concerning the provision of cancer care to individuals with SMHD in an Irish context.

Methods: Semi-structured interviews were conducted with healthcare professionals (n = 28) providing care to people with SMHD and cancer. This included oncology and psychiatry consultants (n = 10); clinical nurse specialists (n = 8); clinical psychologists (n = 6); and medical social workers (n = 4). Data were analysed using thematic analysis.

Results: Four overarching themes were generated from the data highlighting the challenges associated with healthcare provision for this cohort. The themes were: Fragmentation of Care, Healthcare Providers’ Understanding of SMHD, Complex Nature of Presentation, and Specialised Care Needs.

Conclusions: The findings contribute to advancing our understanding of cancer care provision for patients with SMHD. They identify important barriers and facilitators to cancer care provision for this population from the perspective of healthcare professionals in Ireland. These findings will help to shape future research and contribute to improving the quality-of-care for people with SMHD and cancer.

KEYWORDS
cancer, cancer care, health inequities, medical oncology, mental health, mental illness, oncology, psychiatry, psycho-oncology, quality of health care

1 | BACKGROUND

Individuals with significant mental health difficulties (SMHD), including schizophrenia, bipolar disorder and major depressive disorder, experience additional challenges in receipt of healthcare. Irrespective of factors such as individuals’ lifestyle and the risks that long-term use of psychiatric medications pose to health, individuals with SMHD have poorer physical health compared to the general population and experience higher mortality rates. Indeed, almost half of all chronic medical conditions go undiagnosed in individuals with SMHD.
Despite continuous advances in screening, detection, treatment, and survivorship for cancer patients overall,\textsuperscript{10,11} individuals with SMHD continue to present with more advanced cancer progression at diagnosis and are less likely to be offered specialised treatment interventions.\textsuperscript{12} Furthermore, mortality levels remain higher for individuals with SMHD despite similar cancer incidence rates to the general public.\textsuperscript{1,13,14} Although there is growing evidence highlighting inequalities in the provision of healthcare for individuals with SMHD, in-depth exploration of the barriers to adequate cancer care provision has been largely neglected.\textsuperscript{10,15}

Previous research has identified patient-, provider- and systems-based factors that impact cancer care for individuals with SMHD, ultimately impacting their survival and quality of life.\textsuperscript{10} Patient-related factors identified in previous research include lower rates of family support, motivation, seeking out preventative cancer screening, and higher rates of cognitive impairment, social isolation, self-neglect, and socio-economic factors.\textsuperscript{1,2,16,17} Despite the recent shift towards biopsychosocial perspectives on health,\textsuperscript{16,18} considerable emphasis is still narrowly placed on the individual's behaviour in relation to their healthcare outcomes.\textsuperscript{10} For example, individuals with schizophrenia are often understood to be more violent and less adherent to medical recommendations, and are therefore often considered responsible for their own poor health.\textsuperscript{10} Such attitudes contribute to potentially stigmatising behaviours towards individuals with SMHD in cancer care settings.\textsuperscript{10,19}

Systems-based factors which negatively impact outcomes for individuals with SMHD and cancer include lack of clarity surrounding patient advocacy and responsibility, fragmentation of care, lack of continuity of care, and under-resourcing of mental health care.\textsuperscript{20} The implications of the common chasm between medical and psychiatric services for individuals with SMHD have been widely acknowledged.\textsuperscript{15,21,22} For instance, the period between diagnosis and commencing treatment is longer for individuals with SMHD.\textsuperscript{12,23}

Provider-level factors impacting healthcare for individuals with schizophrenia with other health conditions include time and resource constraints, prejudiced attitudes towards SMHD, and the possibility of misinterpreting physical symptoms as psychosomatic complaints.\textsuperscript{24} However, there has been little research investigating the provider-level barriers and facilitators to cancer care for individuals with SMHD. Furthermore, while quantitative studies have demonstrated disparities in cancer care for individuals with SMHD, there have been few qualitative studies with healthcare professionals (HCPs) regarding why these inequities exist. To give insight into how care for this population might be improved, this study aims to explore the views of HCPs in relation to the provision of cancer care to individuals with SMHD.

2 | METHOD

2.1 | Participants

Participants were recruited through purposeful sampling from three acute hospitals in Dublin between January and April, 2017. Invitations were sent via email to several healthcare professionals providing care to people with SMHD and cancer. Twenty-eight individuals consented to participate in the study (85.71% female). The sample consisted of clinical nurse specialists ($n = 8$), clinical psychologists ($n = 6$), medical social workers ($n = 4$), oncologists ($n = 4$) and psychiatrists ($n = 6$). Participants’ ages ranged from 30–62 years and they had between 8 and 34 years of experience in their respective roles.

2.2 | Context of healthcare system in Ireland

This research was conducted with HCPs working in the Irish health system. In Ireland, healthcare is accessible through the public or private health system, though long waiting lists often exist for public patients. Individuals with psychiatric diagnoses are commonly supported on a continuous basis in community or out-patient hospital settings and by primary care professionals.

3 | MATERIALS

A semi-structured interview schedule was adapted from previous research conducted by Irwin and colleagues (see Supporting Information S1).\textsuperscript{26} Questions covered all stages of cancer treatment, including screening, diagnosis, the process of cancer treatment, and end-of-life care. Open-ended questions were used with the freedom to ask unprepared questions, allowing for a conversational style and adaptation to the dialogue in the interview.\textsuperscript{25}

3.1 | Data collection

Interviews were conducted either in person or via telephone by members of the research team who were unknown to participants. Interviewers received training in qualitative research methods from the Principal Investigator prior to conducting interviews. Interviews lasted approximately 30–40 min and were audio-recorded using a smartphone.

3.2 | Data analysis

Interviews were transcribed verbatim and uploaded to computer software NVivo 11. Thematic analysis was conducted on the data, with adherence to the six phases of thematic analysis, as described by Braun and Clarke.\textsuperscript{26} This entails familiarisation with the data; generating initial codes; searching for, reviewing, and defining themes; and reporting on the findings.\textsuperscript{26} Themes were generated at a semantic level. An inductive approach was taken, whereby shared patterns of meaning were identified in the data. This allowed for exploration of novel research and the collection of rich and meaningful data, thus permitting significant depth of understanding of individuals’ attitudes and opinions.\textsuperscript{26}
3.3 | Ethical issues

This study received ethical approval from University College Dublin’s Ethics Committee (UREC-SPsy-LR-16-Langford). Participants were provided with an information letter describing what participation entailed and they provided written informed. To ensure anonymity, participants were assigned IDs\textsuperscript{27,28} corresponding to their occupations, outlined in Table 1.

4 | RESULTS

Four themes were generated from the data, namely Fragmentation of Care, Healthcare Providers’ (HCPs’) Understanding of SMHD, Complex Nature of Presentation, and Specialised Care Needs (see Table S1).

4.1 | Fragmentation of care

A prominent difficulty highlighted by participants was the absence of shared information between different disciplines. The importance of having open lines of communication between teams, particularly considering the lack of clear pathways for treating patients with SMHD and cancer, was discussed. Across the board, participants called for ‘more transparent and direct’ (P5) communication between healthcare teams.

Medical staff reported significant gaps in their knowledge of patients’ mental health histories, while mental health professionals reported that they are often unaware of patients’ physical health statuses due to poor communication between specialty teams. Participants expressed that patient care would be more efficient if everyone involved with the patient could directly access their medical notes: ‘Sometimes you don’t know what’s happening, because...we don’t share notes...there’s no shared information so it would take someone from the team to say someone’s in hospital to let us know, so we might hear on the grapevine’ (P1).

Participants discussed the importance of being able to contact the other teams quickly to manage patients’ care efficiently. However, they indicated that difficulties can arise in this regard: ‘It can be hard to get in touch with people and everyone’s so busy’ (O3).

Participants said they often must ‘jump through several hoops’ (P5) before they can reach the person they need.

Participants emphasised that the various services within hospitals are not well connected and there is an urgent need for greater collaboration between different disciplines: ‘I think it’s a huge gap. I think the services are very separate. Psychiatry, psychology, medical, social work - we’re all operating separately, but we could all be seeing the same person for the same reason’ (CP5).

4.2 | HCPs’ understanding of SMHD

Some participants reported feeling ill-equipped to deal with the mental health needs of patients with SMHD. In general, low levels of confidence in terms of managing mental health difficulties were reported. One participant stated: ‘I struggle around people who would have suicidal ideation, I really do, because I’m not sure I’m good enough to be working with them. Have I enough skill and expertise?’ (MSW1).

Stigma was also reported as a significant issue in cancer care for patients with SMHD. According to participants, while stigma may have decreased somewhat in recent years, it is still present, and they indicated that this stigma can impact cancer care for individuals with SMHD. Participants claimed that SMHD are not always considered by medical staff and said that staff’s limited understanding of the impact of mental health can sometimes influence their behaviour towards patients with SMHD. For example, some patients’ complaints can be dismissed because they have SMHD: ‘When somebody has mental illness documented in their notes, all sorts of alarm bells go off with other professionals’ (P5). Furthermore, some responses suggested an overgeneralised perception of people with SMHD in relation to patients’ presentations, reduced adherence to treatment, and neglect of self-care needs: ‘I think even from the point of view of people attending appointments, adhering to medication, engaging in positive health behaviours, I mean that’s all challenging for people with any of those (SMHD)’ (CP5). One participant’s claim that: ‘Often, people with mental illness are quite isolated in the community or lead quite singular, lonely lives and they don’t have the social support or the back up of family members to take them to appointments or to follow up on investigations’ (P5), indicated stereotyped perceptions of people with SMHD and their life circumstances.

These preconceptions about individuals with SMHD were described as having a significant impact on the care provided to patients. For example, participants reported that cancer treatments are often altered in the instance of SMHD due to concerns that patients’ reduced capacity may impact their ability to manage standard treatment or due to the potential risks that treatment may pose to patients’ mental health. In addition, patients with SMHD were reportedly less likely to be granted access to clinical trials. Some participants reported needing to ‘fight’ for their patients to get them equal treatment: ‘Very often there will be treatment decisions made if you felt that the risk posed to that patient may outweigh the benefits’ (O4).

| Participant ID | Occupation         |
|----------------|--------------------|
| P              | Psychiatrist       |
| O              | Oncologist         |
| CP             | Clinical psychologist |
| MSW            | Medical social worker |
| CNS            | Clinical nurse specialist |
Participants believed that more education about cancer and mental health should be provided both formally and informally within hospitals considering the specialised nature of this area. They believed that increasing healthcare staff’s understanding of SMHD would result in more effective care for patients with SMHD. Medical staff identified a need for expertise in monitoring patients’ mental health status during their cancer treatment, highlighting the potential benefits of ‘greater involvement from psychiatry services while [patients] were undergoing their treatment’ (O3). Psychologists identified that ‘a significant part of the work [they] would do would be around the education of [their] medical colleagues, around the Psycho-oncology needs of patients’ (CP4).

Several participants emphasised that multidisciplinary team (MDT) working would allow for informal education and the development of strategies for managing physical and mental health simultaneously. Participants highlighted the importance of an integrated approach (MSW1) to treatment given that ‘the outcome [with cancer] can be so serious’ (P6) for the patient. For example, one participant reported feeling that they were not up to date with treatments outside their field, reinforcing the need for collaborative working: ‘I wouldn’t be up to date with any of the treatments for cancers obviously, so I really have to rely on the other teams to just let me know that we’re doing the right things’ (P3).

### 4.3 | Complex nature of presentation

Several participants commented on the complex presentations seen in individuals with comorbid SMHD and cancer. Participants reported several reasons why patients with SMHD and cancer often present as particularly complex cases: ‘They’re more challenging patients for a number of reasons... it can be difficult to obtain valid consent and also if they are hospitalized or if they have other issues...it is difficult to manage their comorbidities’ (O1).

The associated challenges can include communication with patients regarding their diagnosis and treatment plan as patients may struggle to comprehend the information. In addition, participants reported difficulties in relation to determining how much information patients want to know and there are often questions such as, ‘How much do they understand? How informed is that [consent]?’ (CNS6). Challenging behaviours, high levels of distress, and treatment compliance were also highlighted as being very challenging for staff to deal with and...consistency around engaging in treatment was a big challenge for the whole team’ (MSW2). Additionally, in some cases patients do not disclose their psychiatric history initially which can create problems when prescribing medication and managing their diagnostic pathways. Participants mentioned the critical roles that family members often assume as liaison between patient and professional, ‘I can’t reiterate that enough, that you rely on family and carers, who know the patient best, to be able to advise us’ (CNS6).

Participants reported occasionally having difficulty distinguishing between mental health and cancer symptoms and determining which team is responsible for patients’ care. Cancer medication can sometimes increase the likelihood of psychotic episodes, which participants reported can make it difficult to determine whether SMHD or cancer care should be prioritised. Concerns about steroid treatments specifically were also raised by participants.

Participants reported that patients with SMHD are more likely to have a delayed diagnosis, having a life expectancy of ‘often a year or even less’ (O3) at the time of presentation. Participants speculated whether this delay could potentially be explained by patients’ neglect of their self-care needs. They highlighted the additional vulnerability that is present for individuals with a pre-existing mental health difficulty in relation to their ability to cope with treatment and the self-care required. Participants highlighted concerns about self-neglect in terms of symptom-checking, self-care, and support when undergoing chemotherapy. Practical concerns relating to patients becoming unwell at home following chemotherapy were discussed: ‘That they go to hospital if their temperature is up, in certain cases you know, somebody’s not able to do that, and it’s a significant thing you have to look at, is it safe to give the person chemotherapy if they haven’t sufficient support’ (CNS2). Once again, the vital role undertaken by patients’ families in these instances was highlighted.

### 4.4 | Specialised care needs

Participants described the specialised nature of care required by individuals with comorbid SMHD and cancer. Several participants discussed the fact that patients with SMHD need additional attention and care during the course of their treatment. They expressed that without additional, tailored input, this cohort could be at greater risk of treatment non-compliance. Participants reported that patients with SMHD can feel uncomfortable attending hospitals for cancer treatment in unfamiliar settings: ‘Very busy wards that are full of people running around the place can be quite difficult for people with serious mental illness and actually having a peaceful spot where they feel they know someone would be better’ (P1).

Participants indicated that communication with the patient needs to be explicit, and aftercare support needs to be arranged to ensure the patient understands the information regarding the diagnosis, treatment, and follow-up: ‘We do spend a lot of time with our patients and a lot of time talking and a lot of time just making sure that they’re feeling ok. Communication, that’s our most basic tool that we use’ (CNS4).

Participants highlighted the importance of ensuring that patients with SMHD and cancer have an advocate on the healthcare team to support them and to be ‘their voice at times where they’re finding it challenging to do that’ (CP5). Participants emphasised the importance of this individual having expertise in mental health; someone who understands the patient’s experience and acts as a representative for them. The majority of participants reported taking on this role to ‘ensure [patients’] mental health care is maximized and supported so there is minimal interruption of their mental health care during their physical intervention’ (P4).

Participants described how, because of these specialised care needs, it can be necessary to have additional resources available for
patients with SMHD. Greater time, funding, and personnel are required to cope with the number of patients availing of the services and the pressures that accompany this. However, participants reported that insufficient resources are available to meet the needs of this cohort: ‘Even if the intention is fantastic or even if the skill of the psychiatrist and the team is excellent, there just isn’t the numbers to manage all of the psycho-oncology needs of the patients within the service’ (CP4).

Participants outlined how a lack of resources can impact on the quality-of-care patients receive in the community. One participant described community-based services as being ‘quite patchy’ and reported that ‘there are discrepancies in how [community mental health] is resourced from area to area’ (MSW3). Unfortunately, a postcode lottery often determines whether an individual has access to community mental health services.

5 | DISCUSSION

This study is the first to qualitatively examine the views of healthcare professionals in Ireland in relation to the provision of care to individuals with comorbid SMHD and cancer. Four important themes were identified, namely Fragmentation of Care, HCPs’ Understanding of SMHD, Complex Nature of Presentation, and Specialised Care Needs. Significant intersectionality was observed between the four themes; structural issues including mental health-related stigma and the demarcation between medical and psychiatric services and the considerable impact of these factors on quality-of-care cut across the different themes. Our findings give insight into how the current system of cancer care might be adapted for patients with SMHD to improve health outcomes for this population.

Results indicate that the fragmented nature of existing cancer care and the inadequate communication and coordination between disciplines pose significant challenges to the quality-of-care provided to patients with SMHD. This supports previous findings that fragmented systems of care for mental health and physical health are often unable to meet the complex medical and social needs of patients with co-occurring SMHD, and highlights the need for an inter-disciplinary and ‘whole person’ approach to care. Participants’ comments suggest that the establishment of MDTs and multidisciplinary grand rounds, as well as the use of electronic patient records to provide a collective overview of patients’ cases, may improve communication between disciplines and therefore improve patient outcomes.

Results suggest that many HCPs have a limited understanding of SMHD, which often has a negative impact on the care provided to this population. For example, participants described feeling ill-equipped to cope with the mental health needs of patients with SMHD. This study supports previous findings that some HCPs may hold stigmatising attitudes towards individuals with SMHD, including pessimistic views regarding treatment outcomes, and doubts about their ability to adhere to treatment and self-care. Many participants suggested that HCPs’ limited understanding of SMHD and resulting stigmatising attitudes may be the result of insufficient suitable training concerning SMHD. Our results indicate that stigma needs to be addressed at patient, provider, and structural levels for change to occur, and previous research suggests that positive leadership within organisations can facilitate cultural change in this respect. Educational interventions, such as anti-stigma training and increased contact with persons with SMHD who can share their lived experiences of interacting with health services, could potentially enhance HCPs’ awareness of unconscious biases towards people with SMHD and improve competency in working with this population.

Participants’ comments in relation to difficulties distinguishing between psychiatric and cancer symptoms corroborate prior findings that diagnostic overshadowing, whereby patients’ physical symptoms are incorrectly ascribed to their mental illness, can occur in the case of cancer patients with SMHD. Additionally, participants’ reports regarding alterations in treatment and reduced opportunities for participation in clinical trials for patients with SMHD and cancer are consistent with previous findings that HCPs sometimes make decisions contrary to typical care standards due to SMHD-related stigma, whereby patients are excluded from clinical trials due to staff’s beliefs regarding patients’ capacity to make medical decisions and provide consent, and due to difficulty communicating with patients.

It is possible that there is, at times, an outdated paternalistic model of care for people with SMHD: such paternalism may account for participants’ reports that cancer patients with SMHD are often excluded from clinical trials. In fact, patients with SMHD could benefit significantly from being included in clinical trials due to the structured nature of care, increased contact with oncology staff, and the potential to facilitate treatment adherence. Moreover, in a recent study, researchers successfully boosted the retention of people with SMHD in a clinical trial by addressing common barriers to recruitment and retention, including access to transportation and conflicting medical appointments. However, data informing optimal treatment for this cohort is still lacking.

Continuity and coordination of care for individuals with comorbidities is associated with a variety of challenges for both patients and clinicians. Participants in the present study speculated whether higher mortality rates and delayed diagnoses in individuals with SMHD were influenced by patients’ reduced capacity for adequate self-care. Previous research reports that self-stigma and anticipation of stigmatisation by HCPs can deter people with SMHD from seeking healthcare for physical symptoms, which may contribute to findings regarding delayed diagnoses and higher mortality rates in this cohort. Additionally, consistent with the present study’s findings, previous research reported issues regarding inconsistency with attendance and treatment compliance as well as reduced capacity in people with SMHD. However, research shows that diagnoses are delayed for patients with SMHD even after symptoms are reported, showing that patients’ behaviour cannot fully account for the disparities in outcomes.

To address issues relating to the complex presentations of some individuals with SMHD, increased cooperation between community mental health teams and hospitals could facilitate the delivery of educational supports for people with SMHD in relation to physical self-care, symptom monitoring, and the importance of attending.
cancer screening. Furthermore, greater collaborative working within hospitals could enhance HCPs’ ability to manage potential challenges that arise in relation to providing cancer care to people with SMHD.

This study supports previous findings that some patients with cancer and SMHD require additional attention and care from staff and that greater resources are often required to meet these additional care needs. Participants in this study recommended that these patients be assigned a navigator within the MDT to provide additional support and ensure patients receive the medical and psychiatric care they require. Previous research suggests that the allocation of a specialist nurse key worker to oversee and coordinate different aspects of treatment may facilitate greater coordination of care and the appropriate sharing of patients’ information between disciplines. Navigators can also enhance patients’ ability to access healthcare services through patient education, follow-up care, and connection to community mental health services. The assignment of peer navigators may also lead to improvements in patients’ physical health and their ability to engage with health services.

5.1 Study limitations

Participants in the present study were recruited from three hospitals in Dublin, Ireland. While this study shone a spotlight on existing issues within the Irish healthcare system regarding cancer care for people with SMHD, the generalisability of findings is limited due to the specific context of the study. Additionally, due to the demanding jobs of participants and the highly specialised area of study, small numbers from each professional group participated in the study. Future studies should attempt to recruit a larger sample of healthcare professionals and should consider including additional HCPs involved in the multi-disciplinary approach to cancer care such as primary care and palliative care physicians. The findings of the present study represent the views of healthcare professionals. Future research should recruit patients with comorbid cancer and SMHD, as patient narratives could provide powerful insights and deepen our understanding of this issue. Finally, it is possible that the interview schedule contributed to participants’ overgeneralised responses regarding people with SMHD. The term ‘SMHD’ was used throughout rather than naming the specific diagnoses encompassed by the term. It is possible that this caused the degree of overgeneralisation detected in participant responses. The authors recommend regularly re-orienting participants throughout the interview to the specific diagnoses encompassed by the term SMHD to reduce the likelihood of this drift in focus.

5.2 Clinical implications

Although unintended, it appears some patients with SMHD are not receiving optimum cancer care. The data suggests that barriers and facilitators include patient-, provider-, and system-level factors. A concerted effort is required to adapt the system of cancer care provision for this patient population to improve the quality-of-care provided to people with SMHD and cancer. Difficulties arise when there are comorbid medical and mental health diagnoses, and where HCPs and systems are separate. The present study suggests the need for a specialised, integrated team to provide care to individuals with SMHD and cancer, as well as targeted interventions to improve HCPs’ understanding of the needs of individuals with SMHD, and to address stigma towards people with SMHD in healthcare settings. See Table S2 for additional suggestions regarding how the core issues identified in the present study could be addressed.

6 Conclusion

The findings of the present study give insight into the barriers and facilitators to effective cancer care provision for patients with SMHD, by exploring the views of healthcare professionals working with individuals with cancer and co-occurring SMHD in Irish hospitals. Four themes were generated from the data, namely Fragmentation of Care, HCPs’ Understanding of SMHD, Complex Nature of Presentation, and Specialised Care Needs. These findings will help to shape future research in the field and contribute to improving the quality-of-care for people with SMHD and cancer.

Acknowledgement

None.

Conflict of Interest

The authors have no conflicts of interest to declare.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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