Exploring the provision of services to support those living with cancer-related pain: a UK perspective.

Abstract

Background.

Cancer-related pain is the most reported symptom across all cancer types. Its impact on the person experiencing it is significant and reduces their quality of life. Cancer-related pain is complex, to ensure optimal management, it requires specialist support from the multi-disciplinary team.

Aim:

To map the current provision of these specialist services that focus on the management of cancer-related pain.

Method:

An online survey was developed by a team of specialists with expertise in cancer-related pain. The survey was circulated via social media platforms for a period of 4 weeks.

Results:

There were 63 survey responses from across England, with no responses from the other nations of the UK. 54.7% (n=35) services were multi-professional, the remaining services contain either one or two different professionals. 37% (n=23) did not accept referrals for those with late effects cancer pain and 20% (n=13) did not accept referrals for those undergoing palliative treatment. All respondents agreed more education and support is needed regarding cancer-related pain.

Conclusion:

The results of this survey indicate that the provision of cancer-related pain services across the UK is inconsistent. More work is needed to improve access to these services and healthcare professionals education of cancer-related pain.

Keywords

Cancer pain, pain, living with and beyond cancer

Background

Cancer-related pain is the most reported symptom across all cancer types (Bubis et al 2018). The exact incidence of cancer-related pain is difficult to determine as this will vary depending on the primary diagnosis however, it is estimated that 55% of patients will report cancer-related pain during treatment, this increased to 66% in those with advanced disease and 34-47% will report persistent pain as a late effect of cancer and/or its treatment (Haenen *et al.*, 2022; Fitch, Lockwood and Nicoll, 2021; Jiang *et al.*, 2019; Van Den Beuken-Van Everdingen *et al.*, 2016). Therefore, throughout all stages of cancer treatments the incidence of cancer-related pain continues to be significant.

Cancer-related pain impacts the individual and those around them (Armoogum *et al.*, 2020; Tanay and Armes, 2019) and is associated with a higher risk of feeling depressed, worried, nervous, or anxious, and poor quality of life (Poço Gonçalves, Veiga and Araújo, 2020; Bamonti, Moye and Naik, 2018; Cramer, Johnson and Nilsen, 2018). However, whilst it is increasingly recognised that people living with and beyond cancer have unmet needs regarding pain (Dupoiron *et al.*, 2022; Sodergren *et al.*, 2019) they can experience challenges when trying to access and receive support (Armoogum, 2020; Fitch *et al.*, 2019). Managing cancer-related pain can be challenging as it is complex, multifactorial and multidimensional and requires specialist input (Galligan, 2022). Multidisciplinary team working is essential for chronic pain rehabilitation in cancer (De Groef *et al.*, 2019), however, little is known about the provision of services to support those living with cancer-related pain in the UK.

A group of professionals with an Interest and experience in cancer-related pain formed a special interest group to explore and understand the needs of people living with cancer-related pain and the services available to support them. Following discussion, the group identified its priority was to map the current provision of cancer-related pain services across the UK and understand the support available within those services.

Aim

To map the current provision of cancer-related pain services across the UK and understand the support available within them.

Method

The specialist interest group formed of specialist nurses with clinical and research experience in cancer-related pain developed an on-line survey consisting of 23 questions using Microsoft Teams Forms software. These included demographic questions and questions exploring the type of services provided (table 1). Three members of the specialist interest group developed the initial draft of the survey with the remaining four members conducting a peer review of the content to ensure meaning and feasibility. Following this review minor changes were made to the content and grammar of the questions to improve readability and feasibility. Ethical approval from gained prior to starting data collection via King's College London Ethics Committee Minimal Risk Registration Number: MRA-21/22-31796.

Following ethics registration, the survey was promoted and distributed via social media with support from national organisations throughout the UK. The social media recruitment was shared via The Pain Nurse Network, The British Pain Society, and the UK Oncology Nursing Society twitter accounts. This was then reshared on via other national organisations such as The Royal College of Nursing Pain and

Palliative Care forum. Data collection took place over a period of 3 months in early 2022 with regular reminders on Twitter every four weeks to improve reach and response rate.

Descriptive data analysis was used to identify trends and map the current provision and location of cancer-related pain services within the UK and Northern Ireland. All responses were anonymised and entered on an Excel spreadsheet. They were then analysed to provide demographic data and to compare variables of services available within this convenience sample. The principals of thematic analysis were used to review the responses to the free text questions, this one completed by one researcher with experience In thematic analysis.

	Question
1	What kind of Service do you currently work in?
2	Where is your service based?
3	What health disciplines make up your service?
4	Are those working within your service full time?
5	How much time is spent focused on cancer-related pain?
6	Do you accept referrals for those undergoing active treatment?
7	Do you accept referrals locally or nationally?
8	Do you accept referrals for those undergoing palliative treatment or those already being seen by palliative and supportive care services?
9	Does your Service accept referrals for those who primarily present with post treatment cancer late effects pain?
10	What are the common reasons for referral into your service?
11	How often are you seeing referrals for adults presenting with late effects pain as a direct result of cancer treatment?
12	What types of cancer-related late effects pain are commonly being referred to your service?
13	Are those presenting with cancer-related pain offered a multi-disciplinary pain assessment?
14	What types of management strategies does your Service offer those impacted by cancer-related pain? (tick which apply to your Service)
15	What interventional pain procedures do you offer?
16	When noticing a functional deficit associated with cancer-related pain, how likely are you to refer to rehabilitation services?
17	Why are you unlikely to refer to rehabilitation services?
18	Which other services are you most likely to signpost those living with cancer-related pain?
19	How satisfied are you with local provision of cancer-related pain services?
20	If neutral/ dissatisfied, why so?
21	Any broader comments/additional details you might wish to share about provision for those presenting with cancer-related pain:
22	Would you be happy for us to contact you further about this issue? (Please provide contact details)
23	Would you be willing to share a copy of your service referral criteria?

Table 1 Survey Questions

Findings

Across the 3-month data collection period the original social media post hosted on Twitter by The Pain Nurse Network social media account gain 15 retweets and 21 likes. A review of the analytics of the post found that the tweet reached 3,430 users. It was not possible to gain the analytics from the other posts shared by the other organisations. This engagement resulted in 63 participants completing the survey.

Demographic information was collected to map the current service provision across the UK. Based on the results from this survey there were no responses from Scotland, Wales and Northern Ireland therefore we are unable to report availability of pain services in these nations (figure 1). The remaining services were spread across Northeast England 11% (n=7), Northwest England 35% (n=22), Yorkshire 11% (n=7), West Midlands 3% (n=2), London & Southeast 9% (n=6), Southwest 29% (n=18), East of England 2% (n=1).

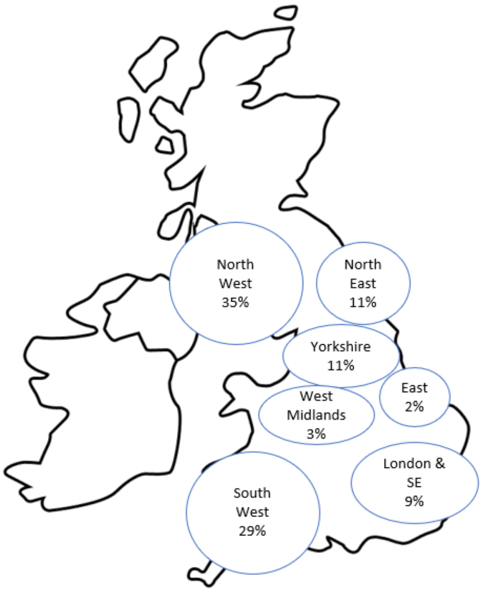

Figure 1 Distribution of services

The types of services responded to the survey was variable across different settings (Figure 2) these included pain services 11% (n=7), late effect services 5% (n=3), oncology services 41% (n=26), haematology services 2% (n=1) and the remaining selecting other 41% (n=26).

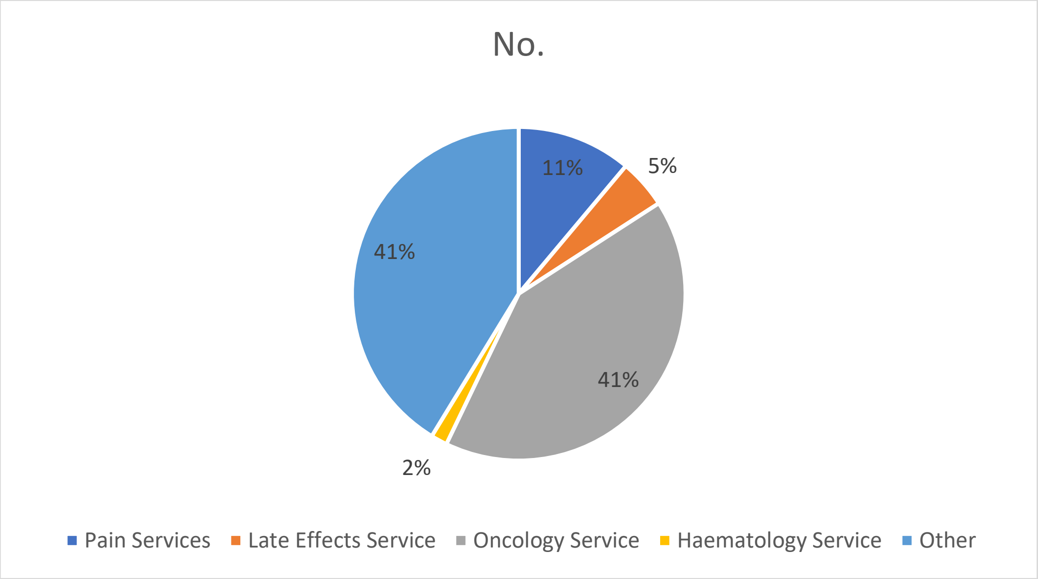

Figure 2 Type of service

Further analysis was performed of those that responded to other regarding type of service (Figure 3). This included palliative & supportive care (n=10), lung cancer services (n=3), upper GI/colorectal services (n=2) breast care services (n=2), rehabilitation services (n=2), surgical care (n=1), hospice (n=1), physiotherapy (n=1), urology services (n=1), oncology & haematology (n=1), independent services (n=1) and neurological rehabilitation (n=1).

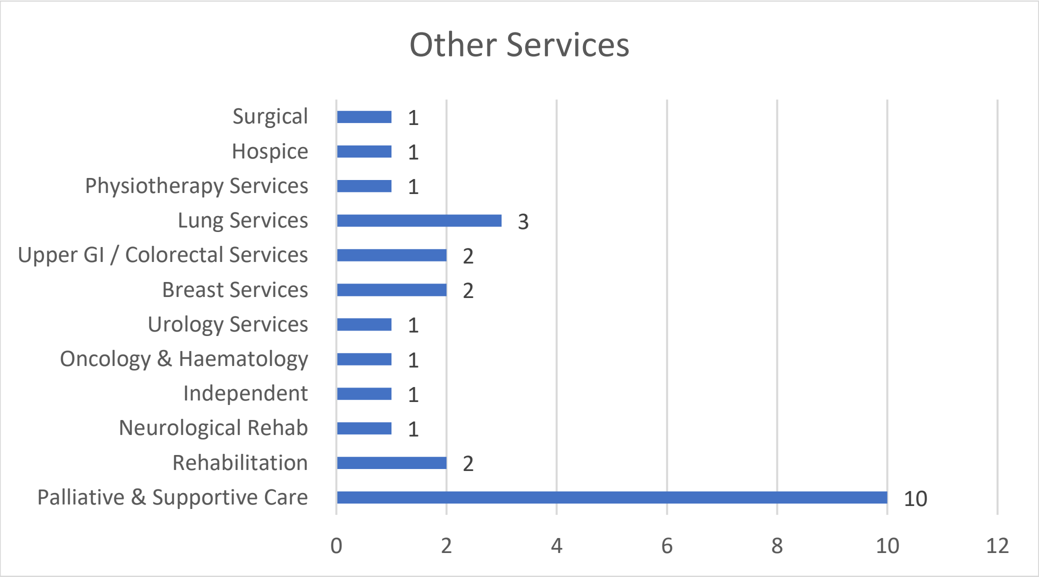

Figure 3 Other services

Many survey respondents indicated very specific eligibility criteria to access their services. This is evident in response to question 8 *"do you accept referrals for those undergoing palliative treatment or those already being seen by palliative and supportive care services?"* with 20% (n=13) of respondents answering no, and question 9 "does your Service accept referrals for those who primarily present with post treatment cancer late effects pain?" with 37% (n=23) respondents answering no.

Across the services that responded, there was a mix of professional groups involved in delivering support (Figure 4).

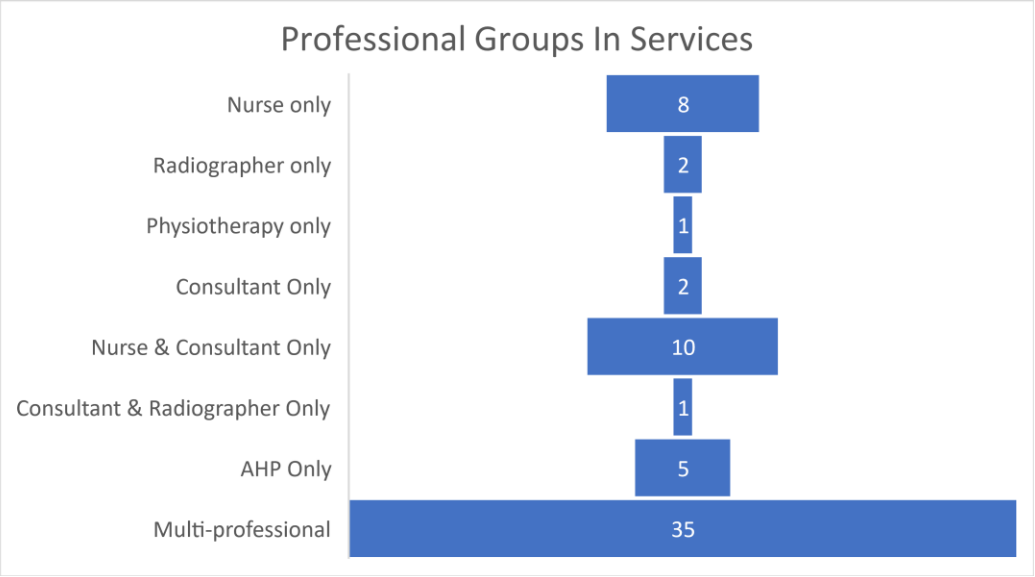

Figure 4 Professional groups working in services

Participants were asked to state the types of pain that they commonly see within their service. Figure 5 outlines the presentations that were reported across the survey. Across the reports, most services listed multiple causes of pain commonly seen within their service. There was a high incidence of neuropathic pain states reported as either neuropathic pain or chemotherapy induced peripheral neuropathy (n=32). Musculoskeletal and bone pain (n=26) was the second most common presentation seen followed by pain following radiotherapy treatments (n=20).

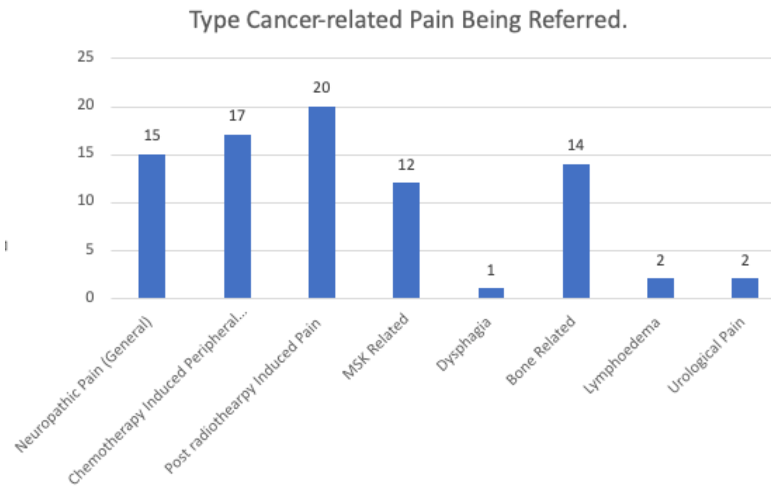

Figure 5 Late effects pain being referred

Following referral into the service participants were surveyed to establish if a multi-disciplinary (MDT) assessment was being offered to patients (Figure 6). Forty-seven percent (n=30) reported that an MDT assessment was offered following referral into their service with 44% (n=28) reporting that an MDT assessment was not offered. The remaining 8% (5) were unsure if MDT assessments was being offered on a routine basis.

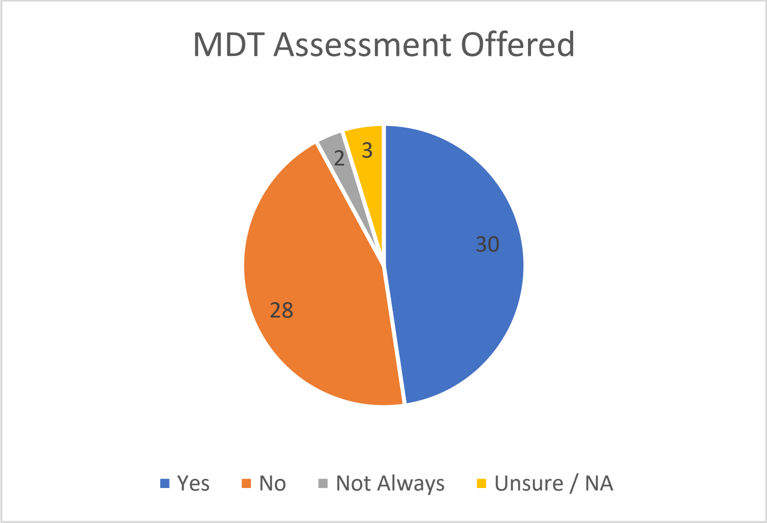

Figure 6 Prevalence of MDT Assessment Offered.

Most respondents (39% n=25) were *somewhat satisfied* with their local provision of cancer services (Figure 7). Those who expressed a certain level of dissatisfaction provided reasons for their answers such as limited access, long waitlists, low service capacity or lack of pain service, generalist approach to pain management, lack of understanding of pain and available pain services among clinicians and lack of integrated care.

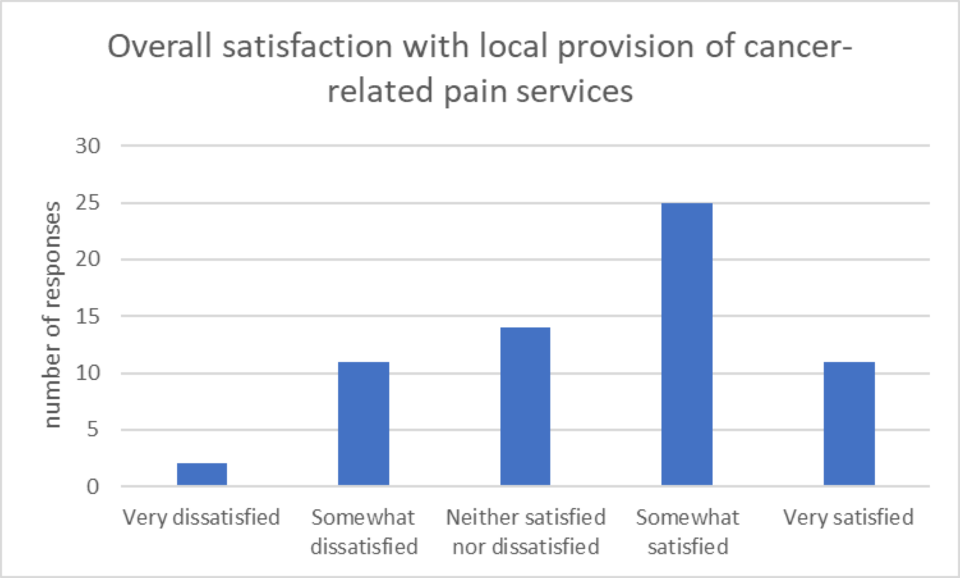

Figure 7 Satisfaction with local provision of cancer-related pain services

Additionally, participants were also provided with free text boxes to share further comments regarding their thoughts on the provision of cancer-related pain services. Themes from their responses where collated and are presented in Table 2.

Broad Theme	Exemplar quotes
Examples of good practice	• Working alongside proactive consultants who liaise with and support supportive care team about pharmacological and non-pharmacological management. • Having an enhanced supportive care team that offers a holistic approach to cancer related pain but referral to chronic pain services has a long waiting list. • Seeking help from other areas when presented with patient with long term pain. • Offering a service that provides support for patients from pre diagnosis to end-of-life care therefore see patient through disease trajectory. This approach enables cancer pain to be addressed promptly and in timely manner. • Consideration of referrals for those on active treatment on a case-by-case basis to ensure that the hospice services are the most appropriate for the patient and those seen are accepted based on their level of complexity of their pain/symptoms. • Working closely with the MDT is vitally important for the patient having a wealth of experience to offer.
Areas of improvement	• Availability of cancer related pain services are inconsistent, but more inconsistent or lacking is the assessment at primary presentation in whatever service that occurs (i.e., oncology, primary care, etc). • Management is ad hoc, often depending on who a patient is seen by. Often, pain is not addressed but accepted as 'how it is' by both patient and HCP. • There is no formal referral pathway for pain within breast primary breast cancer. • It is difficult to refer to community palliative care service if out of area. For example, postcode lottery for patients with advanced cancer and access to intrathecal pumps • Access to pain/ late effects services is not equitable across the UK and often access to specialist services for those with post treatment late effects pain is difficult. • Long waits following referral to palliative care. • Difficulty to refer to some GP's due to their capacity and communication getting through to them. • Initial focus on diagnosis and treatment.
Patient and carer experience related comments	• Patients are often isolated, and the problem persists for some time. • Pain is often normalised as part of post treatment recovery with reassurances given that it will resolve with time. • Include carer support and assessment.
Key disciplines for cancer pain specialist service	• Nurses • Oncologists • Functional rehabilitation • Pharmacist • Psychology input for long-standing cancer-related pain • Complementary therapy • Allied health professionals for acute pain • Palliative care services • Tumour specific services • Stronger links with complimentary therapist as engagement as high link to psychological impact of pain, including sleep management, reduced independence, isolation
Potential solutions	• A clear pathway for people with cancer related pain is needed and education and training for staff where these patients present. • Address lack of knowledge generally about cancer related pain among healthcare professionals

	• A trust e-learning on pain services would be useful to guide staff on what is available and when or how to refer. • Need for better assessment tools. • Promote pre-treatment education such as about late effects of radiotherapy. • Acute pain teams should have a close working relationship with palliative care teams in an acute setting. • A late effects service would be such a good way of ensuring these patients get early accurate assessments for their pain. • Most oncologists need support from supportive and palliative care services. It would be good if oncologists had a service to deal with patients with long term complications from chemotherapy or radiotherapy as the surgeons are often left trying to sort the problems out.

Table 2 Themes from participants free-text comments

Discussion:

Cancer-related pain continues to be the most reported symptoms across all disease types and its prevalence remains high across all stages of cancer (van den Beuken-van Everdingen 2016). The impact of cancer-related pain is significant and wide reaching including the individual, those around them and healthcare services (Armoogum *et al.*, 2020; Tanay and Armes, 2019, LeBaron etl al 2014). However, despite this it remains underestimated and undertreated by healthcare professionals (Nijs et al 2023, Faculty of Pain Medicine 2019).

There has been a drive to improve the support offered to those living with cancer-related pain such as the Framework for Provision of Pain Services for Adults across the UK with Cancer or Life Limiting Disease, which provided operational guidance for improving pain services for people living with cancer (Faculty of Pain 2019). The Framework recommended an integrated approach between pain and cancer services and encourage a greater emphasis on multi-disciplinary working between specialist pain services, oncology services, supportive and palliative care. This echo's the recommendations by the standards for the management of cancer-related pain developed by the European Pain Federation (EFIC) (Bennett et al 2019). Despite these national and pan-European recommendations the findings from this survey suggests that there Is potentially a variation in the provision and availability of specialist services to support those impacted by cancer-related pain.

National Variation in Cancer-related Pain Services

Responses from the national survey suggests that there could be areas of the UK which do not have access to specialist cancer-related pain services despite the recommendations from national and pan-European guidelines (Faculty of Pain 2019, Bennett et al 2019). However, it is important to note that the recruitment via social media platforms could have restricted some services from taking part in this survey. None the less this survey does help to provide some insight into the current provision of services across the UK.

Further Examples of this varied provision of cancer-related pain services were seen in the free text responses. One respondent stated that there was: “no equitable access to pain services across the UK and access to specialist services is difficult.” Some respondents stated that they were using the services of palliative care teams and the local hospice for support with cancer pain management. While this can be considered a positive step towards multi-disciplinary working this may not always be an appropriate option for those with late effect persistent pain following completion of curative cancer treatment.

Respondents also shared concerns regarding demands on services: "most pain clinics cannot cope with the volume of cancer-related work". As the incidence of cancer increases so will the incidence of those living with cancer-related pain as a direct result of cancer and/or its treatment. This growing population will require additional capacity within existing services to ensure they are able to access specialist support. Currently there is an estimated 3 million people living with cancer in the UK and it is anticipated that this incidence will increase to 5.3 million by 2040 (Macmillan 2022). This in combination with the rise in 10-year survival rates is creating a growing population that will be living longer with the consequences of cancer treatment and will require the support from specialist services (Cancer Research UK 2023). More research is needed to explore the impact of this growing population on service demand and to explore the role of integrated working between specialist pain and cancer services.

Despite being disseminated to pain nursing and late effects networks, only a small number of respondents replied to the survey from these clinical areas. Most respondents worked in oncology, hospices, and palliative care services. This could suggest that most cancer-related pain is predominantly managed by these services. It is not possible to make any firm conclusions regarding the role of specialist's pain services based on this survey due to the limited responses. However, the findings are suggestive of earlier work by Faculty of Pain (2019) in which they found that referrals for cancer-related pain to specialist pain services was inadequate and more work is needed to integrate these services within palliative care and oncology services.

Access to services

Accessing support regarding cancer-related pain can be challenging for individuals depending on the type of pain they are experiencing and their cancer diagnosis. As cancer-related pain is complex it can be a mixture of acute, persistent and breakthrough pain states at any given time (Galligan 2022). This means that you may have individuals with advanced disease with persistent pain because of cancer and/or its treatments alongside those who have completed curative treatment suffering persistent pain because of cancer treatment. Armoogum et al (2020) captures this in their study exploring the experience of people living with persistent late effects pain, they reported that this cohort often struggle to find appropriate services that can meet their needs.

We can see some indications of this within this survey with 20% (n=13) respondents not accepting referrals from those undergoing palliative treatment (not on a curative pathway). In addition, those patients who have completed curative treatment face similar challenges in accessing supporting with 37% (n=23) services reporting they would not accept referrals for those with persistent pain because of cancer treatment.

Further exploration is needed to fully explore how patients are accessing specialist services to manage pain across the continuum of cancer treatments. This allow us to understand if there are barriers to accessing services across all types of cancer-related pain.

Access to a Multi-disciplinary Assessment:

We know from the literature that cancer-related pain is complex and impacts all aspects of an individual's activities of daily living. Due to this complexity its essential that we offer a multi-disciplinary approach to our assessment and management to ensure that patients receive optimal care (Bennet et al 2019, Faculty of Pain Medicine 2021).

However, the results of this survey suggest that those services that took part are not able to offer a multi-disciplinary approach, with 44% (n=28) not offering a multi-disciplinary assessment (Fig 4). 42% (N= 26) acknowledged they could not or only sometimes offer a fully multi-disciplinary pain assessment.

Although most services (79%; n=50) reported that they would refer to local rehabilitation teams if they noted a functional deficit, 21% (n= 13) were unlikely or neither likely/unlikely to. These services mainly consisted of oncology services, and they cited a lack of awareness of services/pathway, difficulties with access and a feeling that their patients were not suitable for rehabilitation, either too frail or with advanced cancer. While rehabilitation is not appropriate for all people experiencing cancer-related pain (for example terminal patients), there are clearly documented benefits to rehabilitation at many stages in the cancer pathway (Sleight et al 2022). More exploration of healthcare professionals awareness of the impact of rehabilitation services in cancer-related pain is needed to understand if there are barriers to referring to these services.

Satisfaction with the Provision of Local Cancer Pain Services

The final aspect of the survey was to explore the participants satisfaction with current provision of cancer-related pain services. 57% (n= 36) of respondents reported they were satisfied with the provision of local cancer pain services, with 21% (n= 13) reporting they were dissatisfied (fig 7). Interestingly, 22% (n= 14) reported that they were neither satisfied/dissatisfied regarding the quality of services. More work is needed to explore this concept in more detail and perhaps explore if these services are aware of additional services available within their setting. This could be a potential means of Improving satisfaction and access to cancer-related pain services if there was a local directory that could be accessed by healthcare professionals and service users.

Findings from the free text box at the end of the survey allowed participants to identify potential ways in which to improve access to specialist cancer-related pain services (Table 2). Notable there was a focus on improved awareness of services and their referral pathways, this could potentially take the form of a national/regional database that both patients and professionals could access to identify services that are available to them in their area. There was also a call across all the participants for improved knowledge and understanding of the assessment and management of cancer-related pain to ensure that healthcare professionals have adequate knowledge, confidence, and skills to support those impacted by cancer-related pain.

The chronic lack of education available to healthcare professionals regarding cancer-related pain is well documented throughout the literature and there is a strong argument to address this at all levels of practice (Galligan & Wilson 2020, Bouya et al 2019). There was an argument across the respondents for one dedicated service staffed with clinicians with cancer-related pain expertise as a gold standard however, analysis of other comments suggest that pain should be addressed in all settings and should become part of standard care. This idea is echoed by Faculty of Pain (2019) in which they state all healthcare professionals should be able to recognise and assess the impact of cancer-related pain. Those that then require more specialist input and advice should then be able to access services that have a collaboration between pain and cancer services with weekly multi-disciplinary meetings, for example.

Limitations of the Survey

To our knowledge this was the first national survey to map the current provision of cancer-related pain services within the UK. The most significant limitation to this survey was the response rate, with limited responses from across the four nations. As only one social media platform was available at time of recruitment for the survey, this has limited the reach and response rate. A future version of this study using multiple platforms and directly contacting pain, palliative care and oncology service leads across the UK could help to improve the response rate and gain a better understand of the services currently available.

In addition, the survey focused on all types of cancer-related pain from pain during treatment to palliative and chronic late effects pain. They are clearly managed differently and access to services and levels of satisfaction may vary for each type. Therefore, it is not possible to draw conclusions regarding the management and provision of cancer pain services across the UK. Nonetheless, it does appear that in some areas there are difficulties with provision of services for people with cancer-related pain.

Recommendations for Practice:

Based on the findings from this survey and the wider literature more research is needed to understand the current provision of cancer-related pain services within the UK. This will then enable for the development of a directory that will not only highlight the services that are available in each region but also identify the referral pathways into that service. Through making this an open source for both the public and healthcare professionals to find and access adequate support to live with cancer-related pain.

Finally great emphasis is needed on supporting all healthcare professionals in the assessment and management of cancer-related pain. This will ensure that regardless of the setting all healthcare professionals should have the knowledge, skills and confidence to recognise and assess the impact of cancer-related pain of the individual and those around them.

Conclusion

The incidence and impact of cancer-related pain continues to be significant and far reaching. This survey has identified that more research is needed to not only develop cancer-related pain services but to support healthcare professionals in gaining the knowledge, skills and confidence necessary to adequately care for those impact impacted by the complexity of cancer-related pain.

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