Symptoms of total pain experienced by older people with advanced gastrointestinal cancer receiving palliative chemotherapy

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Abstract

Objective: Little is known about concurrent physical, psychological, social and spiritual distress experienced by older patients during early stages of advanced cancer while receiving life-prolonging treatment. Drawing on the concept of total pain, this study explored the multi-faceted symptoms of pain in older patients with advanced gastrointestinal cancer while receiving palliative chemotherapy.

Methods: A total of 14 in-depth interviews with seven participants were conducted, one interview at the beginning and one after completion of chemotherapy. Participants were ≥70 years, diagnosed with advanced gastrointestinal cancer and receiving palliative chemotherapy.

Results: Thematic analysis revealed four themes: variability and inevitability of physical pain, ways of coping with psychological pain, mitigating social pain through contributions to social life and the anticipation of existential pain in old age. Conducting two interviews with each participant foregrounded the changing nature of the participants’ experienced symptoms and life perspectives while receiving palliative chemotherapy. Further, old age was experienced as integral to how participants described their situation and indicated an acceptance of old age.

Conclusion: Older adults with advanced cancer are affected by multiple-faceted symptoms resulting from cancer and its treatment. The concept of total pain is suggested to guide interdisciplinary palliative care in earlier stages of advanced cancer.

KEYWORDS
advanced cancer, chemotherapy, old age, palliative care needs, symptom identification, total pain

1 | INTRODUCTION

A growing number of older people are diagnosed with cancers of the gastrointestinal tract, some with non-resectable cancers, making palliative chemotherapy the most common treatment (Bjerregaard et al., 2016; Brøndegaard Winther et al., 2016; Dekker et al., 2019; Derakhshan et al., 2016; Schønnemann et al., 2016). Palliative chemotherapy is given in non-curative circumstances in order to optimise symptom control, improve quality of life and prolong survival (Roeland & LeBlanc, 2016). The decision to treat with palliative chemotherapy...
entails ongoing trade-offs between symptom relief, desired effects and the prolonging of life with possible disadvantages of demanding and time-consuming treatment schedules and various adverse chemotherapy effects (Engelhardt et al., 2018; Valentí et al., 2020).

For older patients with cancer who receive palliative chemotherapy different symptoms, problems and causes of distress might be at stake. Patients might experience symptoms from disease progression, adverse effects from ongoing cancer treatment and possible late effects of, for example, earlier operations or radiation therapy and chemotherapy (Deimling et al., 2007; Hurria et al., 2016; Mandelblatt et al., 2014; Rowland & Bellizzi, 2014). These experiences might potentially be aggravated by additional symptoms of old age and comorbidities (Bellizzi & Rowland, 2007).

Early integration of palliative care into standard oncology care has been suggested to further optimise survival, symptom control, quality of life and reduce caregiver burden (Ferrell et al., 2017; Jordan et al., 2018; Kaasa et al., 2018; Smith et al., 2012). From the perspectives of older cancer patients, maintaining different aspects of quality of life, such as physical functioning, social relations and roles and personal autonomy, might be more valuable than prolonging life (Matelot et al., 2021; McCaffrey et al., 2016; Soto-Perez-de-Celis et al., 2018; Wedding et al., 2007). During the trajectory of terminal cancer and in palliative care settings, these competing priorities are often acknowledged, and the resulting distress is described as a state of total pain, which is characterised by physical pain and psychological, social or spiritual problems and distress (Clark, 1999; Dunham et al., 2017; Krawczyk, 2018; Saunders, 1964).

Cicely Saunders, the founder of modern hospice and palliative care, introduced the concept of total pain in the early 1960s to describe patients’ lived experience of suffering due to a combination of aspects of physical, psychological, social and spiritual pain (Clark, 1999; Krawczyk, 2018; Richmond, 2005; Saunders, 1964). As a physician, Saunders developed specialist knowledge of analgesics for specific types of terminal physiological pain and elaborated this clinical approach to address other kinds of problems, such as in the psyche (e.g., worries, sadness and feeling lonely), in social networks (e.g., economic obstacles for close relatives to stay off work to provide care) or in the soul (e.g., feelings of hopelessness and guilt) (Clark, 1999). In contemporary healthcare provision, total pain is now regarded as crucial for the recognition of the interdependence of physical, psychological, social and spiritual distress and acknowledged to require multiple interventions for its resolution (Clark, 1999, 2002). Total pain can be used as a nomenclature, by which problems and symptoms can be diagnosed and addressed (Clark, 1999; Krawczyk, 2018). This informs and facilitates clinical practice, for example, when treating neuropathic pain, alleviating anxiety, giving advice on social problems and providing spiritual comfort. However, as a theoretical concept, total pain should be regarded as more than a list of separate pathologies needing treatment. Rather, it is the interrelatedness and interdependence of different experiences of pain, which are central to understanding the multi-faceted burden and suffering of terminal illness (Krawczyk et al., 2018). For details of the concept of total pain and the interrelatedness between the four aspects, see also Figure 1 (Mehta & Chan, 2008; copied with permission).

FIGURE 1 The total pain experience: an interactive model (Mehta & Chan, 2008)

The concept of total pain emerged in the context of palliative care in hospices with a focus on quality of life for those in the terminal stages of illness and is a recognised approach to understanding and holistically treating pain in people living with terminal cancer (Clark, 1999; Greenstreet, 2001; Krawczyk, 2018; Mehta & Chan, 2008). However, whether older patients during earlier stages of advanced cancer and while receiving life-prolonging treatment, such as chemotherapy, also experience multiple aspects of pain as described in the concept of total pain, remains under-researched. Therefore, drawing on the concept of total pain, this study aims to explore the multi-faceted symptoms of pain in older patients with advanced gastrointestinal cancer while receiving palliative chemotherapy.

2 | METHODS

2.1 | Design, setting and participants

This qualitative study was conducted from January 2017 to January 2018 in an oncology department of a Danish university hospital. Participants were older patients (≥70 years), diagnosed with gastrointestinal cancer and referred to an outpatient clinic for oncologic treatment. Participants could be starting first-line palliative chemotherapy or proceeding to further treatment lines during their trajectory of receiving palliative chemotherapy. Maximum variation sampling was used to ensure a diverse range of participants (Patton, 2014). The variables included sex, civil status, gastrointestinal cancer types and line of palliative chemotherapy (further details, see Table 1). To strengthen rigour and validity, members of a supporting research group consisting of the interviewer, first and second author and a fellow researcher, contributed to the development, conceptualization and design of the study.
2.2 | Data collection

In-depth, individual interviews were conducted with seven participants. To understand the participants' evolving experiences during the trajectory of chemotherapy, they were interviewed twice, once at the beginning of chemotherapy after the first treatment and again after finishing chemotherapy, irrespective of whether the treatment was completed or discontinued due to disease progression. On average, 5 months lapsed between first and second interviews. The 14 interviews were conducted by a research assistant with experience in qualitative interviews of people living with advanced cancer. To create a relaxing atmosphere away from the hospital environment, the interviews took place in the participants' homes.

An open-ended interview guide aimed to explore participants' reflections on living with advanced cancer and palliative cancer treatment. The guide was theoretically driven by the four aspects of total pain and how these were experienced bodily and in relation to activity and participation in daily life (for the interview guide, see the Supporting Information). Two pilot interviews were conducted but are not included in the analysis. The interview guide was reviewed and discussed between the interviewer and the first and second author.

All interviews were conducted, transcribed and analysed in Danish; the authors carried out the translations into English.

2.3 | Data analysis

The interviews lasted 1 to 2 h, were audio-recorded and transcribed verbatim; personal identifiers were removed from the transcript. To identify, analyse and report patterns and themes within the data,
thematic analysis was carried out, following six phases (Braun & Clarke, 2006). Thematic analysis is a progressive and iterative process. In general, Phases 1–3 seek to ensure that the analysis is closely grounded in the empirical data. This was achieved by reading and rereading transcripts, generating initial codes and collating codes into potential themes. In Phases 4–6, themes were reviewed in-depth and included consideration of the theoretically informed notions of total pain. The purpose of Phases 4–6 is to ensure that data within themes cohere meaningfully and result in clearly distinguishable themes. Through this process, themes are refined, expressing their essence (Braun & Clarke, 2006). To strengthen the validity and increase trustworthiness and reliability of the analysis, the interviewer and the first and second author read and grouped subthemes of two interviews. This was followed by a discussion of the results until consensus was obtained. The themes identified in this way were presented to a group of six patients similar to the interviewed participants, who recognised the findings from their own cancer trajectory. Lastly, the whole data set was analysed and jointly discussed by the author team.

2.4 | Ethics

The study was approved by the Danish Data Protection Agency and conformed to the principles of the Declaration of Helsinki. All participants gave written informed consent.

3 | RESULTS

In the face of advanced cancer and receiving chemotherapy, all seven participants experienced different aspects of physical, psychological, social and spiritual pain, irrespective of gender, civil status, gastrointestinal cancer type and treatment outcomes. The analysis revealed the following four themes: the variability and inevitability of physical pain, ways of coping with psychological pain, mitigating social pain and problems impeded their everyday lives. Accordingly, participants described periods of living life almost as usual and periods of putting their usual life on hold, albeit in different patterns and intensities.

All participants mentioned physical symptoms from comorbidity and/or ageing as competing limiting factors. Ageing in particular was considered an explanation for various events, such as falling off the bike, being tired, experiencing musculoskeletal pain and no longer being able to carry out the same amount of housework, gardening and other physical activity. Karin, for example, said:

‘I have more symptoms from my back than from the cancer’. When asked later whether tiredness kept her from doing her usual activities, she raises these questions: ‘What is cancer and what is feeling tired? What is aging, what is it to become older?’ (First interview)

The above highlights that participants experienced physical pain as varied and inevitable, partly due to cancer and its treatment and partly due to their age and ageing processes.

3.1 | The variability and inevitability of physical pain

Participants described fluctuating physical symptoms relating to the cancer disease and/or chemotherapy in both first and second interviews. Fatigue, loss of appetite and weight, sleep disturbances and stomach pain were mentioned repeatedly. Cancer pain and symptoms tended to be most pronounced at the beginning of chemotherapy and symptoms relating to the treatment, such as skin problems, neuropathy and nausea, seemed more pronounced just after finishing chemotherapy. For example Peter, explained why he had been sleeping upright in a chair for the last 16 nights:

Yes, there have been some stomach problems. Those cancer cells that are circulating are irritating the intestines. That’s what caused the pain. When I sat in the chair like this I only felt a slight ache in my stomach, but it did not hurt. But it hurt insanely when I tried to lie down. (First interview)

In his second interview, Peter described his stomach pain as under control but mentioned adverse treatment effects, such as loss of taste and appetite, reduced muscle strength, numbness in fingers, skin problems, nausea and fatigue. He also mentioned the fluctuating nature of symptoms during the cycles of chemotherapy as follows:

The first 2–3 treatments did not really bother me that much, but then it started … It’s been in cycles of 3 weeks, you know, I felt bad for 14 days and then the last week [before the next treatment] I started to feel better with 1 or 2 days feeling good. And then it started again, and it became worse and worse after each time [each chemotherapy cycle]. And the last time I thought now I cannot be bothered with this [chemotherapy] anymore. (Second interview)

Participants experienced variability in how physical symptoms and problems impeded their everyday lives.
3.2 | Ways of coping with psychological pain

When touching upon the emotional distress of living with advanced cancer and going through cancer treatment, the participants tended to focus on what they wanted from their lives, rather than what they had lost or were losing. There was a strong desire for maintaining life as close to usual as possible, though individual approaches to maintaining a sense of normality varied.

Even participants, who experienced several limitations due to cancer and its treatment, seemed to focus on those activities they were still able to carry out independently. Peter noted:

> Well, just the fact that I can do things on my own, so I do not need help from outside. As long as I can get up, have a shower and be independent, then it's not so bad at all. (First interview)

Frequently, participants compared their personal situation and disease prognosis with cancer trajectories among family and friends or stories mentioned in the media. Sometimes these experiences of others were used to think either positively or negatively about one's own future. Susan was close to several people who survived cancer, which she said gave her hope:

> I had a brother-in-law who had a colon cancer operation and my niece's husband has gone through a lot of cancer too and got through that very well. So, we have to think positive. (First interview)

Jane, on the other hand, feared a painful end of life. She was close to her mother when her mother died from cancer aged 63 after a burdensome disease trajectory and with symptoms similar to Jane's experiences:

> The only thing I wish for is to leave this world reasonably pain-free. Because it was not very nice how my mother died. She was also alone, lived in an old house and could not really manage it. And she had no strength and, yes, it [cancer tissue] grew. And that's the reason why I do not like that my stomach grows [she is afraid that cancer tissue extends her stomach]. (First interview)

The above illustrate that participants coped with psychological pain by holding on to everyday life as independent and close to usual as possible. Thoughts and worries about one's own disease prognosis were affected by comparing to the cancer trajectory of others.

3.3 | Mitigating social pain through contributions to social life

The participants experienced that having cancer and receiving chemotherapy influenced their social life. Without exceptions, they mastered this by adapting their activities and setting priorities. The participants strove to hold on to social activities they particularly valued, such as long-term relationships, family traditions and their social roles in the local community. At the same time, participants largely seemed to accept that things could change due to having cancer.

Participants emphasised the importance of feeling supported and being able to communicate openly. Close relatives were generally described as supportive and helping participants to get through the challenges of chemotherapy, for example, by accompanying them to hospital appointments, helping out with heavy cleaning and gardening tasks, cooking special food and being emotionally supportive. All but one participant emphasised that they felt supported by family, their network and health professionals. Indeed one participant, Sofie, mentioned that feeling the love and care from her children and husband was a positive experience about her having cancer. Sofie also made an effort to maintain her weekly voluntary work in a Red Cross thrift shop.

> Yes, I have been there [in the thrift shop] for 7–8 years, so I will do it as long as possible. Because I want to, as long as I have the strength to be there, I really want to be there. (First interview)

Three participants experienced a kind of paradox of being old and seriously ill but still feeling relatively well and privileged, compared to family and friends, who either had died or became physically disabled for various reasons. Also, both relatives and health professionals' perceptions on how participants were doing seemed to be shaped by how well they looked physically and how independently they managed life. Jane, who has lived with advanced cancer for 3 years, reflected:

> Well, they [children and grandchildren] do not believe I am ill. Good heavens, I can still cycle and do my shopping and I can do a lot on my own, so they do not think I am ill. That's how it is. So, I'm allowed to manage on my own. (Second interview)

Summing up, feeling supported and being able to contribute to social activities was important to managing how cancer and receiving chemotherapy influenced social life. The paradox of being old and seriously ill but yet managing independently could lead to contradictory expectations from one's surroundings.

3.4 | The anticipation of spiritual pain in old age

The participants, aged 70 years or older, indicated that death could be expected at their age. Still, they hoped and believed that chemotherapy might prolong their life. They had a strong belief in the health care professionals but were also aware of treatment limitations. Peter, when informed that his cancer was incurable, said:
Of course, that was discouraging, but then I thought ‘I’m 81 years old. If I go away, I go and if they [the oncologists] can save me, I will let them have a go’. Then I say ‘let us take one day at a time’. I am not going to sit down and say that I cannot do it anymore. (First interview)

Age was used to explain the plausibility of serious disease and death not being far away. Jane, for example, expected the last years to be tough:

Life can be hard every now and then. We simply have to go through it. And I am really getting old and as I said to the doctor at the hospital: ‘Good Heavens, I am really old, so it is no big deal if I kick it’. (Second interview)

In addition, examples of spiritual pain and its effect on life were presented. It appeared to be worrying to imagine dying, when some life circumstances seemed unresolved, such as difficult relationships in the immediate family. For instance, Karin was very worried about two of her grandchildren whom she perceived to be vulnerable and of whom she had taken special care. She mentioned:

It is those things [worries about grandchildren] that make me want to hang on. The others [other family members] will be all right. They have their own life. But it is those children, yes. (Second interview)

Hopes and perspectives on expectations of life could change during the trajectory of palliative chemotherapy in a continuum from perceiving death as imminent to hope of the cancer to stay stable for a long time (Table 1). During the first interview, John felt hopeful and recounted that he thought he still had 1 to 2 years to live. Three months later, chemotherapy was discontinued because of disease progression; at that point, he described himself as an old man who was going to die soon:

Now I know what the situation is and I live with that. And if it stops, that’s okay as well. Because, as I said to the doctors, ‘you have done your best and if I close my eyes, then do not do anymore. No resuscitation or anything like that’. And the children know that as well. (Second interview)

Overall, participants seemed prepared and accepting that severe disease and death would be inevitable at their age; for some, unresolved life circumstances were a source of existential pain.

Participants’ overall changes in life perspectives during the course of palliative chemotherapy are presented in Table 1, alongside participant characteristics. The temporal aspects foregrounded the fluctuating nature of experienced symptoms, problems and life perspectives during the trajectory of receiving palliative chemotherapy (Table 1).

4 | DISCUSSION

This study explored the multi-faceted symptoms of pain in older patients with advanced gastrointestinal cancer while receiving palliative chemotherapy. Drawing on the concept of total pain, our findings highlight that the participants experienced aspects of physical, psychological, social and spiritual pain in fluctuating patterns during palliative chemotherapy. Alongside, findings also point towards participants’ perceptions of old age and ageing as an integral part of how they experienced and evaluated aspects of total pain.

Our study highlights that for these participants coping with physical symptoms related to the cancer disease and treatment was part of life while undergoing chemotherapy. Some symptoms appeared to be perceived as reminders that the cancer was physically present in their body, while other symptoms were interpreted as adverse effects of chemotherapy. There seemed to be a high degree of acceptance of adverse effects, even though they at times decreased quality of life. Other studies have suggested that chemotherapy, regardless of adverse effects and patients’ age, seems to shift patients’ attention away from an approaching late stage of life and might be a way of ‘buying time’ and ‘doing something’ (Buiting et al., 2013; Gerber et al., 2012).

The participants in our study coped with emotional pain related to living with advanced cancer by maintaining life as close to usual as possible. A Norwegian study, interviewing patients aged 70 to 88 with various advanced cancer diagnoses and receiving various treatment modalities, similarly identified a strong wish to maintain life as usual (Haug et al., 2015). In the present study, emotional pain was present in circumstances where the participants felt that they were unable to resolve outstanding personal issues, such as unresolved family circumstances, fear of being a burden to the family or experiencing physical pain. Aspects of personal autonomy, control of physical symptoms and the ability to resolve outstanding personal issues are all domains that are important to quality of life in people with advanced cancer (McCaffrey et al., 2016).

The participants compared their experiences to those of other people in similar disease situations and evaluated their own situation based on such comparisons. Social comparison is well known in relation to ageing, where comparisons with peers or the preceding older generation inform personal expectations (Staudinger, 2015). Especially comparisons of functioning, both cognitively and physically, contribute to older people’s self-ratings on age and health (Benyamini et al., 2000; Hughes & Lachman, 2018; Leinonen et al., 2002). Despite a life-limiting cancer disease, the participants held favourable perceptions of their own situation, based on their functional health and autonomy remaining largely intact. This is in line with findings from large cohorts of community-dwelling older adults, where the perception of good health relies not merely on the absence of disease but a wide range of physical, psychological and social components (Benyamini et al., 2000; Leinonen et al., 2002).

Our findings on the importance of feeling supported and having a role to play in family and social networks as ways of minimising social pain are consistent with earlier findings on important quality of life.
aspects among adults with a life-limiting illness. Across several studies, the relationship with others is emphasised as essential to feeling valued and maintaining dignity (McCaffrey et al., 2016).

The participants’ contradictory feelings of, on the one hand, being old and seriously ill and, on the other hand, appearing well to relatives and living independently, to our knowledge, not been reported previously. However, this finding resonates with findings of a large cohort study that documented that cancer patients were highly functional even in their final year of life, with marked disability experienced only 3 months before death (Lunney et al., 2003). This suggests that, even though it may be desirable to remain functionally independent in late life, independence may also lead to the extent of total pain being underestimated and its alleviation not being prioritised by patients, relatives and health professionals.

Old age, rather than cancer, was repeatedly mentioned in our study as a possible explanation for some of the experienced physical symptoms and bodily limitations. Similar ways of foregrounding age in order to explain limitations have also been noted in a British study with participants from hospices (aged 67 to 88) (Dunham et al., 2017). The authors proposed this to be a coping strategy, since the identity of being old may be preferable to being a person living with advanced cancer (Dunham et al., 2017). While this might explain some of the emphasis on old age, participants in the present study also draw on their age in order to adjust expectations about functioning, medical possibilities and life span.

Though aspects of total pain are prominent in this study, participants appear to manage and constrain their impact. This contrasts with people with terminal cancer who describe total pain as an overwhelming experience, often consisting of a complex web of uncontrolled and disordered physical and psychological problems (Clark, 1999; Krawczyk, 2018; Krawczyk et al., 2018). Our findings thus contribute significant new knowledge about cancer patients’ experiences of total pain. These findings point to the importance of identifying the nature of total pain in earlier stages of advanced cancer in order to qualify early palliative care interventions.

Despite the relatively small number of participants, the study included both genders, different civil status, gastrointestinal cancer types, lines of chemotherapy and a wide range of treatment effects, including disease regression, progression and stability. However, palliative chemotherapy is only considered suitable for patients who are deemed physically fit, and our findings may therefore not be transferable to old people with advanced cancer, who do not qualify for such oncological treatment. The interviews at the end of chemotherapy allowed for explorations of issues that might not have been present at the first interview. Importantly, interviewing each participant twice enabled insights into the various ways in which the experience of total pain might change during the cancer trajectory.

In summary, older participants with advanced gastrointestinal cancer experience different aspects of total pain during their trajectory of receiving palliative chemotherapy. Integral to these experiences is the expectation that old age entails possible losses, decline and death.

The concept of total pain is useful to understand the multi-faceted impact of cancer disease and treatment on the individual. Different aspects of total pain might be at stake and need to be considered in order to disentangle the effects of cancer disease, its treatment, ageing and individual needs in older patients with advanced but not terminal cancer. In the clinical setting, the concept of total pain might therefore prove useful in guiding interdisciplinary palliative care in earlier stages of advanced cancer.

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CONFLICT OF INTEREST
The authors hereby declare that they have no conflicts of interests to declare.

DATA AVAILABILITY STATEMENT
Data are available on request due to privacy/ethical restrictions.

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SUPPORTING INFORMATION
Additional supporting information can be found online in the Supporting Information section at the end of this article.

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