Understanding factors which affect an older person’s capacity to complete the workload associated with living with cancer

Lewis, L. Farrington N, Patel H, Harari D Kalsi T & Bridges J

Published in Cancer Nursing Practice 2022

Background

Many older people who are living with cancer do so within the context of concurrent complex health and social issues. Assessment and planning treatment for cancer often focuses primarily on disease, missing opportunities to identify and address these significant wider concerns.

Aim

To gain an understanding of factors, which can increase or reduce an older person’s capacity to manage the workload associated with self-management of cancer and other conditions.

Methods

Secondary analysis of questionnaire data comprising responses to structured items covering health and daily living issues and analysis of free-text responses focusing on factors shaping an individual’s capacity to manage the workload consequent to living with cancer.

Results

Reduction in physical function affected people’s capacity to manage their health, other responsibilities and live their everyday lives. People worried about continuing to care for those dependent on them and identified enhancers to their capacity within their social network and from health care professionals. Organisational factors such as scheduled appointments, transport and availability of parking further affected an individual’s capacity.

Conclusions

These findings highlight the implicit need to identify and address important enabling factors that can increase an individual’s capacity to manage their own health which can then support delivery of a personalised cancer treatment and plan care.

**Keywords**

Cancer diagnosis, older people, workload, capacity, person-centred care

**Introduction**

Many people living with cancer are older (Hurria et al 2015), commonly with other health and social problems. These can impact on cancer treatment and support plans (Williams et al 2016; Marosi and Koller 2016), and include multimorbidity, increased care support needs, reduced independence and being a carer for a significant other. People have different preferences and health beliefs that can impact on personalised decisions about cancer treatment and support (Pisu et al. 2018, Corbett et al. 2020a). The danger is that cancer assessment and treatment planning may only focus on the cancer, missing opportunities to identify and address an older person’s concerns (Bridges et al. 2015, Wildiers et al. 2014). Diagnosis and treatment for cancer may not always be the most important priority for someone living with already burdensome health and social complexity. Also, individual preferences, hopes, fears and expectations may not match the treatment on offer (Soto Perez De Celis et al 2018, Shrestha et al 2019) meaning that it is important health care professionals (HCPs) understand the compromises older people may make regarding quality verses length of life.

In this article we use the Cumulative Complexity Model (CCM) to understand what may help or hinder older people living with cancer. The CCM highlights the demands on a person’s time and energy including family responsibilities, caring for others, remaining well, self-care, administration of medications, attending and scheduling clinical appointments (Shippee et al. 2012). This is called the ‘workload’. The CCM helps explain how the workload, as well as the resources a person has, affects how well they can manage their illness and life in general. This ability is described as their ‘capacity’. When a person’s situation becomes more complex, workload may increase beyond the capacity to manage, which could lead to poor outcomes (Figure 1). This model has been studied in individuals with stroke (Gallacher et al., 2014), lung cancer, chronic obstructive pulmonary disease (Lippiet et al. 2019) and multi-morbidity (Rosbach & Andersen, 2017). Here, we apply it to older people with a cancer diagnosis to better understand what makes it easier or more difficult for older people to manage living with cancer.

Corbett et al (2020a) found that older age and multi-morbidity increased workload and reduced capacity, which complicated self-management after cancer and threatened health and well-being. Older people often prioritise independence and quality of life over longevity. This systematic review found that older adults managed imbalance between workload and capacity by prioritising self-management practices they judged to be most likely to enable them to continue living independently.

Geesink (2017) found that older people and their family members wanted to be treated holistically including assessing their home situation, mental capacity and preferences rather than their physical condition alone when making treatment decisions. Having an opportunity to discuss treatment and life goals in context of managing expectations of life left to live was also seen as important. Knowing a persons’ preferences, values and beliefs can positively guide treatment plans while increasing the HCP’s understanding of the complex health needs of the individual (Alqurini and Alibhai 2019). The United Kingdom Independent Taskforce report ‘Achieving World-class cancer outcomes: A strategy for England 2015-2020’ highlighted the lack of priority given to psychosocial, functional, and complex needs of older people living with cancer. This report recommended that older adults benefit from improved assessment methods with increased collaboration between specialists in cancer and older persons medicine including specialist nurses.

However, few studies have been done to look at collaborative working between specialties (Puts et al. 2014, Cohen et al. 2016). Comprehensive Geriatric Assessment (CGA) is an established method of assessing and planning older people’s treatment and is associated with favourable outcomes (Ellis et al 2017). CGA is being used more commonly but the extent to which it effectively addresses individual concerns has not been well studied (Whittleet al., 2017, Wildiers et al. 2014). Kalsi and Harari (2020) recommend improving access to relevant professionals by connecting with existing support services for older adults with a diagnosis of cancer, considering the extra workload which cancer presents, and focussing on balancing patient capacity and workload. Further insight into concerns held by older adults at the cancer diagnosis stage would help inform the development of more personalised models of care, which can then be used in routine clinical practice.

**Aim**

This article seeks to gain an understanding of factors, which can increase or reduce an older person’s capacity to manage the workload associated with self-management of cancer and other conditions.

**Methods**

Study design

The original study was approved for ethics on 15/11/2016 and was completed at a United Kingdom teaching hospital. Eligible participants were aged over 70 and undergoing assessment and treatment for cancer within oncology services. They were identified using electronic hospital records from the oncology clinics and surgical cancer lists. Informed consent was implicit and implied by virtue of completion of the questionnaire with the Information sheet/consent form being the first page.

A 19-item structured questionnaire was used, developed from a longer version (CGA-GOLD, Whittle et al) by a multidisciplinary expert-consensus group including older people with cancer. It covered wide ranging issues not exclusive to cancer diagnosis and treatment, including functional and psychosocial problems. Older adults responded “Yes”, “No” or “Don’t Know” to items asking about social situation and potential difficulties with daily living activities. Respondents were then invited to answer the question: “Do you have any comments about your answers or are you worried about anything else?”. The questionnaires, given to participants in clinic or sent by post prior to their appointment were either completed by the individual themselves or assisted by HCPs.

**Analysis**

The primary analysis looked at feasibility of an onco-geriatric assessment, and asked participants to complete a questionnaire. This secondary analysis examines the questionnaire responses with a different goal in mind: better understanding the concerns of older people living with cancer.

Responses to the structured questionnaire items were analysed using simple frequencies and proportions to identify prevalence of the individual issues in this sample. Data were analysed using SPSS (version 25). The CCM was used to frame, guide and interpret the qualitative analysis enabling subsequent analysis to be focused (Shippee et al. 2012; Braun & Clarke, 2006). The free text comments were brief in nature, but they contain valuable data about what matter to older people receiving cancer treatment.

Analysis was influenced by the principles of thematic analysis as shown in Figure 2. We first read and inductively coded all the data. This resulted in broad categories. We then examined data in each of the categories to consider their relationship with the CCM, specifically findings relating to *work* (“I have extra work to do because of this”); findings relating to a person’s *increased* capacity to complete the work through additional resources (“This assists me to do something”); and findings relating to a person’s *reduced* ability to complete the work (“This prevents me from doing something”). Common themes and patterns of meaning were sought, using analytical processes including familiarisation, coding, generating themes which appeared in the data.

**Results**

Two hundred and twenty-four people responded to the questionnaire. Demographic information was not collected as part of the primary study.

*Quantitative results*

As shown in Table 1, most responses given were either “Yes” or “No”. The proportion of questions unanswered was small, ranging from 0.4% (n=1/224) to 5% (n=10). The item with the highest number of people who didn’t respond or selected “Don’t Know” was “Do you have difficulty shopping for food?” (n=14[6%]).

69 (31%) of respondents identified that they lived alone, 68 (30%) had a carer to help them and a high number, 188 (84%) had someone in their social network who could take care of them if necessary, while 24 (11%) were a caregiver for someone else.

 The proportion of people identifying mobility problems is notable. Nearly half of respondents had trouble with walking (n=109[48%]), 83 (37%) used a walking aid, 57 (25%) identified difficulty transferring from bed to chair or standing up. One hundred and five (47%) had difficulty climbing stairs and 31 (15%) had difficulty getting to the toilet.

A number of other issues were identified; 106 (47%) had experienced unintentional weight loss or were eating less, one-third (74[33%]) reported difficulty shopping for food, 61 (27%) reported urinary leakage and 28 (13%), stool leakage. Other problems reported included hearing problems (64 [29%]) memory/confusion (46 [21%]) and/or mood/other mental health issues (26[12%]).

*Qualitative results*

The findings below result from the analysis of the free-text responses to the question: “Do you have any comments about your answers or are you worried about anything else?” Findings illustrate the workload people may be expected to do either as an older person with cancer and/or in addition to other roles in their life. The data also provide information on the capacity those individuals may or may not have to deliver that work and what could be perceived as barriers to complete that work.  Analysis of free-text responses showed that concerns fell into three categories. A reduction in physical function, caring responsibilities, and organisational factors were identified, which affected people’s capacity to manage their health and other responsibilities in everyday life.

1. **Reduced physical function impaired capacity for self-management**

Some people already had reduced physical function because of pre-existing conditions, but many also reported physical symptoms directly resulting from cancer treatment or other clinical interventions. Physical symptoms diminished individual’s capacity to do the work of day-to-day life and to self-manage their cancer and, when present, other health conditions.

A number of people reported mobility difficulties resulting from leg weakness, attributed to the effects of chemotherapy. Other treatment effects reported included diarrhoea and peripheral neuropathy. These treatment toxicities had an impact on ability to complete every day functional tasks. For example, a person with peripheral neuropathy reported difficulty taking money out of an automated cash machine. Fatigue and weakness were commonly reported; one respondent stated that this had resolved since chemotherapy had finished. Other treatment effects reported that had an impact on daily living activities were diminished eyesight attributed to chemotherapy, and communication difficulties such as answering phone due to a hearing problem:

 “Eyes affected by chemotherapy this makes it difficult to read. This is difficult for the patient, as they like to read. Eyes affected badly but it does not affect their ability to get around”.

Capacity for self-management was also reduced by the effects of other health conditions. Several respondents listed the additional multi-morbidities they lived with alongside cancer including chronic obstructive pulmonary disease, diabetes and heart failure.

In addition to findings about diminished capacity, people’s responses also illustrated some of the work associated with cancer treatment. The physical difficulties that resulted from either cancer treatment or from other health conditions affected people’s ability to travel to hospital appointments reducing the person’s capacity to complete the workload of self-management:

“Due to chemotherapy has made them more unsteady on their feet. Unable to drive. Feeling breathless on climbing”.

 “Difficulty/weakness in legs and arthritic knees, 2 hip replacements, so difficulty climbing up and down stairs. It affects walking, takes things very slowly. Uses car a lot would find it difficult to get around otherwise.  Takes a long time to travel waiting for hospital transport”.

The work included dealing with medical devices that resulted from the cancer treatment:

“Urinary catheter due to chemotherapy”

“Have a permanent stoma bag after bowel cancer surgery”.

Overall, elements of physical function appear to affect the capacity of some older people living with cancer to manage their workload and self-management, at the same time as work increased because of the cancer treatment.

1. **Concern of being able to continue with the work of caring for others**

Social situations relating to an existing role as a carer for a dependent family member and the perceived disruption to the caring role was concern. Despite a cancer diagnosis, some individuals felt strongly about resisting help from outside agencies, preferring to keep the “work” of caring within the family. The extract below illustrates that, although their spouse was living in a care home, this respondent continued to have strong feelings of responsibility for her care despite his cancer diagnosis lessening his capacity to continue with this caring role.

 “Wife in nursing home with dementia, patient is very stressed about this trying to continue ongoing care for her”.

There was evidence that, although reluctant to relinquish their role as sole carer, individuals sought to sustain their capacity in their caring role by drawing on resources available to them in their social network or from formal agencies. This strategy enabled others to share in the work of caring, but there was a clear preference for keeping care within the family when this was possible:

“Patient provides all care for his wife but he manages with help of the family at present. I discussed with the patient if outside help would be beneficial but he declined at this stage, stating he would rather keep the care in the family”.

“Husband cares for wife who has dementia. Package of care 4 times daily. Has declined further help at this stage”.

For others, having the support from family members helped them to manage the workload of their previous role as carer and the workload of the symptoms associated with cancer treatment. The following person transitioned from being the carer to relying on her husband to fulfil the occupation she once had within the home.

“Patient was previously carer for disabled daughter and husband but now patient need to be cared for by husband. Pins and needles in hands and feet unable to cook clean or walk due to this. Patient needs help to get on to the commode at night (at least three times, husband helps with transfers). Loved to knit but cannot due to arthritis and pins and needles. Cannot get upstairs due to difficulty in mobilising. Has stair lift. Feels guilty about family caring for her, but husband has learned to cook to support her. (He has mobility problems also)”.

Findings suggest that the role of being a carer increased the overall work of living with cancer and diminished the individual’s capacity to self-manage. Permitting others to provide care for them when they were struggling with cancer treatment-associated symptoms and the impact this has on physical function appeared to be a challenging transition for some people. However, allowing others in their social network to help them appeared to increase their capacity to live well with cancer.

1. **Organisational factors**

*Contact with healthcare professionals improved capacity for self-management*

Healthcare professionals, in particular oncology specialist nurses, were viewed as a key resource to increasing capacity particularly when the person with cancer was feeling low or anxious. The detail of how they helped was not provided, but their presence was appreciated.

“I do have MacMillan nurses if I need them I can always call them if I needed”

Peer support in combination with specialist nurse input were identified as positive resources

“Felt very depressed, isolated and alone. Good idea to have chemotherapy centre. Social support and you can chat to people. Specialist nurse helpful”

“Depression is an issue-you get highs and lows-it is helpful to be able to phone and talk at that moment in time. Counselling for me is not the answer as waiting for an appointment -the moment would be gone”

“Patient called the Acute Oncology Service nurse and felt much better later, they spoke to X, patient called regarding treatment. Patient found it difficult to sleep after taking of different medications-for example anti-sickness tablets. This helpline was very helpful. Patient called 3 times over the bank holiday and found oncology helpful. A necessary and great service really needed for moral support. Felt isolated”.

The work of cancer described in the data included appointment attendance, medication administration and treatment side effects making daily activities more challenging. Cancer may reduce the person’s capacity to fulfil the work within their role as carer, requiring them to rely on others for help. The help may come from other family members, social care providers or health care professionals.

*Health system added extra work*

Respondents identified health system organisational factors that increased their workload, including appointment scheduling, transport and hospital parking.

“I find it confusing and unnecessary to have so many admin stations to which I have to check in. In the old unit one team of people at one desk, which seemed to work well, did everything. I am now having to use a wheelchair as since my final chemo I have restricted mobility + am unable to walk as far as I like”.

“Can climb stairs at station but difficult at railway station due to steep incline. Wants early morning appointments as 'hot flushes' due to side effects of treatment. It is difficult to take trains post treatment as trains are packed during peak periods. Early morning appointments easier to manage and plan time”.

“Appointment times important due to long travel times, especially in rush hour”.

Travel factors also had financial implications, which caused additional stress.

“Transport problem, travelling from [another county], travelling up in the car as cannot manage public transport. Very expensive”

 “Concerned about cost of travelling to [city centre]”

**Discussion**

We aimed to examine health issues raised by older people with a cancer diagnosis particularly focusing on the factors which impact upon or reduce an individual’s capacity to manage the associated workload.

Findings show that a reduction in physical function due to cancer and other health conditions affected people’s capacity to manage their health, other responsibilities and live their everyday lives. People worried about their continuing capacity to care for people dependent on them and identified others in their social network and health care professionals as potential enhancers of their capacity to self-manage.

The findings illustrate that workload includes self-managing cancer and, where relevant, other health conditions. There is work associated with other life roles, particularly caring for family members. A cancer diagnosis potentially increased the work that people had to undertake including attending hospital appointments, monitoring their condition and managing their symptoms. Their capacity to do work was also diminished by the cancer, either directly by cancer symptoms or by treatment side-effects. A reduction in physical function was a noteworthy factor that diminished an individual’s capacity. Health conditions other than cancer potentially increased the work and decreased their capacity to undertake work, leading to diminished quality of life. The findings from the structured part of the questionnaire support the free-text responses and indicate that these issues were quite prevalent.

Our findings support those from other research that older age and pre-existing multi-morbidity may complicate self-management of cancer, jeopardising health and well-being, creating burden and diminishing capacity (Corbett et al. 2020a). These studies provide particular insight into people’s concerns at the point of cancer diagnosis and during treatment, illuminating the factors that shape people’s experiences and outlook early on in their cancer journey. People commonly identified the physical limitations caused by the cancer itself or the cancer treatment, but also the physical limitations that were due to health issues other than the cancer. These limitations increased people’s workload and reduced their capacity to do the work of self-management.

Our findings indicate the extra work involved in accessing and using services are not necessarily person-centred in their delivery and highlight the need for health systems and services to be designed to minimise a person’s work, potentially improving experiences and outcomes. Reported difficulties getting to hospitals combined with diminished capacity from reduced physical function or fatigue are echoed elsewhere (MacMillan 2012) and highlight the importance of providing support with transport. Working with older people to encourage activation of their social networks to help with the work of self-management, including transport to hospital appointments, may be an important intervention by health care professionals.

Findings also highlight the important role social networks and HCPs can play in diminishing workload and improving capacity. The importance of a personalised approach, underpinned by shared decision-making underlines how HCPs need to assess and plan care that is tailored to that individual extending the scope of healthcare beyond the presenting cancer. Interventions that enable the individual’s priorities and preferences to be elicited and then addressed include CGA (Puts et al. 2014, Cohen et al. 2016), CHAT&PLAN to guide person-centred healthcare conversations (Corbett et al. 2020b) and GENIE to activate social network engagement in self-management support (Kennedy et al. 2016).

Strengths and limitations

This analysis adds value to the body of knowledge by improving understanding of older people’s perspectives on the impact of cancer and treatments on their lives. Our findings provide insight into the interactions between an older individual’s capacity to manage the work associated with cancer treatment as well as the social impact on their other roles and responsibilities. Our findings can help inform how oncology centres adapt their service to the needs of older people. The main limitations of the study are that data obtained from one hospital site may limit the generalisability of the findings and questionnaire responses may not necessarily be an accurate representation of an individual’s situation with literacy, cognition and other factors shaping the responses given. A lack of clarity in some qualitative questionnaire responses limited distinctions between problems that arose because of cancer treatment or were pre-existing problems. The questions were broad meaning the responses were potentially subjective. Yes/No/Don’t know options could have required further exploration.

Conclusions

The questionnaire has provided us with information about some of the factors that might increase the challenge of people managing the workload presented by cancer/treatment, which points towards using existing methods which allow needs/priorities to be elicited and understood would be beneficial in alleviating worries/concerns/practical difficulties.

Attending hospital-based oncology services and receiving cancer treatment places demands on people of any age. In older age, these demands are more likely to interact with other health and social problems including the requirement to self-manage other long-term medical conditions and life roles such as caring for a family member. Actively seeking to modify the factors which mediate an individual’s capacity to manage the workload associated with cancer and other health issues should be an important goal for cancer services for older people.

This insight highlights how specialist nurses could focus their assessment and care, working collaboratively with other professionals to support patients in managing workload. On an individual basis, nurses can use this learning to adapt appointments to understand the bespoke needs of the individual beyond cancer diagnosis and treatment. Whilst this study has contributed substantially to our understanding, further research is needed to better understand the experiences of older adults diagnosed with cancer and the key modifiable factors that shape these experiences and their health outcomes.

**References**

Al Qurini,N., Alibhai,S.(2019) Geriatric oncology: A new horizon in cancer management for older adults.

Braun,V,Clarke,V.(2006) 'Using thematic analysis in psychology', *Qualitative research in psychology*, 3(2),pp.77-101.

Bridges,J.*et al.*(2015) 'Cancer treatment decision-making processes for older patients with complex needs: a qualitative study', *BMJ open*,5(12),p.e009674.

Corbett,T.K.,Cummings,A.,Lee,K.,et al(2020). Planning and optimising CHAT&PLAN: A conversation-based intervention to promote person-centred care for older people living with multimorbidity. *PloS one*,*15*(10),e0240516.

Corbett,T.,Cummings,A.,Calman,L.et al(2020). Self‐management in older people living with cancer and multi‐morbidity: A systematic review and synthesis of qualitative studies. *Psycho‐Oncology*.

Cohen,H.J.,Smith,D.,Sun,C.L.,et al(2016). Frailty as determined by a comprehensive geriatric assessment‐derived deficit‐accumulation index in older patients with cancer who receive chemotherapy. *Cancer*,*122*(24),3865-3872.

Cramp,F.,and Byron‐Daniel,J.(2012). Exercise for the management of cancer‐related fatigue in adults. *Cochrane database of systematic reviews*,(11).

Ellis,G.,Gardner,M.,Tsiachristas,Aet al(2017). Comprehensive geriatric assessment for older adults admitted to hospital. *Cochrane database of systematic reviews*,(9).

Fried,L.P.,Tangen,C.M.,Walston,J.et al(2001). Frailty in older adults: evidence for a phenotype. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*,*56*(3),M146-M157.

Gallacher,K.I.,Batty,G.D.,McLean,G.et al(2014). Stroke, multimorbidity and polypharmacy in a nationally representative sample of 1,424,378 patients in Scotland: implications for treatment burden. *BMC medicine*,*12*(1), 1-9.

Geessink,N.H.,Schoon,Y.,van Herk,H.C.et al(2017). Key elements of optimal treatment decision-making for surgeons and older patients with colorectal or pancreatic cancer: a qualitative study. *Patient Education and Counseling*,*100*(3),473-479.

Kalsi T,Harari D.Assessment methods and services for older people with cancer in the United Kingdom. World journal of clinical oncology.2020Mar24;11(3):152.

Kennedy,A.,Vassilev,I.,James,E.et al(2015). Implementing a social network intervention designed to enhance and diversify support for people with long-term conditions. A qualitative study. *Implementation Science*,*11*(1),27.

Hurria,A.,Levit,L.A.,Dale,W.et al(2015). Improving the evidence base for treating older adults with cancer: American Society of Clinical Oncology statement. *J Clin Oncol*,*33*(32),3826-3833.

Lippiett,K.A.,Richardson,A.,Myall,M.et al(2019). Patients and informal caregivers’ experiences of burden of treatment in lung cancer and chronic obstructive pulmonary disease (COPD): a systematic review and synthesis of qualitative research. *BMJ open*,*9*(2).

MacMillan (2012) Cancer Services Coming of Age: Learning from the Improving Cancer Treatment Assessment and Support for Older People Project available at https://www.macmillan.org.uk/documents/aboutus/health\_professionals/olderpeoplesproject/cancerservicescomingofage.pdf

MacMillan (2020) Transport and parking available at <https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/benefits-and-financial-support/help-with-transport-and-parking>

Marosi,C,Köller,M.(2016). Challenge of cancer in the elderly. *Esmo Open*,*1*(3).

Pisu,M.,Azuero,A.,Halilova,K.I.(2018). Most impactful factors on the health‐related quality of life of a geriatric population with cancer. *Cancer*,*124*(3),596-605.

Puts,M.T.E.,Santos,B.,Hardt,J.et al(2014). An update on a systematic review of the use of geriatric assessment for older adults in oncology. *Annals of Oncology*,*25*(2),307-315.

Rosbach,M.,&Andersen,J.S.(2017). Patient-experienced burden of treatment in patients with multimorbidity–A systematic review of qualitative data. *PloS one*,*12*(6),e0179916.

Shippee,N.D.,Shah,N.D.,May,C.R.et al(2012). Cumulative complexity: a functional, patient-centered model of patient complexity can improve research and practice. *Journal of clinical epidemiology*,*65*(10),1041-1051.

Shrestha,A.,Martin,C.,Burton,M.et al(2019). Quality of life versus length of life considerations in cancer patients: a systematic literature review. *Psycho‐oncology*,*28*(7),1367-1380.

Soto-Perez-de-Celis,E.,Li,D.,Yuan,Y.,Lau,Y.et al(2018). Functional versus chronological age: geriatric assessments to guide decision making in older patients with cancer. *The Lancet Oncology*,*19*(6),e305-e316.

Whittle,A.K.,Kalsi,T.,Babic‐Illman,Get al(2017). A comprehensive geriatric assessment screening questionnaire (CGA‐GOLD) for older people undergoing treatment for cancer. *European journal of cancer care*,*26*(5),e12509.

Wildiers,H.,Heeren,P.,Puts,Met al(2014). International Society of Geriatric Oncology consensus on geriatric assessment in older patients with cancer. *Journal of clinical oncology*,*32*(24),2595.