ORIGINAL ARTICLE

Self-management by older people living with cancer and multi-morbidity: a qualitative study

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Abstract

Purpose Over half of individuals diagnosed with cancer are aged over 70 years, and more than 75% of those with cancer report at least one other medical condition. Having multiple conditions alongside cancer in old age may lower functional status, greater likelihood of treatment complications and less favourable prognoses. This qualitative study explored how older people with long-term chronic conditions manage their health and meet their health-related goals after they have completed treatment for cancer.

Methods One-to-one face-to-face qualitative interviews were conducted with 8 older people and 2 informal caregivers based in the UK. Older adults were eligible to participate if they were over 70 and had completed primary cancer treatment with curative intent and had at least one other chronic health condition.

A semi-structured interview schedule developed a priori based on Shippee's cumulative complexity model was used. We aimed to explore experiences that could influence self-management, utilisation of healthcare services and health outcomes. A framework analysis was used to describe and interpret the data.

Results Four overarching themes were identified in the analysis. These themes related to factors that influenced the everyday health-related workload and capacity of the participants. These factors included their health, resources, and opportunities, as well their motivation and sense of perceived control over their lives.

Conclusions Fragmented healthcare systems and relationships with healthcare professionals also influenced the participants' self-management of their health. Our findings highlight the interaction between an individuals' needs, capacity, treatment burden, and the services and resources available to them. These findings support calls to promote person-centred care to better support older adults to manage their health.

Keyword Cancer survivorship · Multimorbidity · Qualitative research · Late effects · Complex conditions · Older adults

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Background

Over half of individuals diagnosed with cancer are aged over 70 years [1]. Cancer can have a significant impact on an individual's wellbeing, leading to poor health or disability after primary cancer treatment [2, 3]. Older adults are at increased risk of side-effects from cancer-related treatments, and these can aggravate common characteristics of ageing including fatigue, memory loss and reduced appetite [3, 4]. After treatment, many older adults can be left with ongoing problems related to poor quality of life [5].

Concurrently, the number of people living with multimorbidity is rising with an ageing population [6, 7]. More than 75% of people with cancer report at least one other medical condition, and multimorbidity (defined here as the co-existence of two or more conditions) increases with age [3, 8]. Having multiple conditions alongside cancer may lead to delayed diagnosis due to masked symptoms, lower functional status, greater likelihood of treatment complications, less favourable prognoses [9, 10] and poorer quality of life [11, 12]. Older adults living with and beyond cancer may find it difficult to self-manage symptoms, complex therapeutic routines and interactions with healthcare providers [5, 7]. Needs that arise from other conditions must be managed alongside cancer, potentially leading to increased health-related work for the individual. For example, increased instance of polypharmacy is likely because this group is often prescribed many medications, for cancer management as well as management of other conditions [3, 5]. The older cancer population also face practical challenges in relation to physical barriers (e.g., poor mobility and transport) that limit their access to their care [3, 13].

Shippee's cumulative complexity model (CCM), outlines how factors at an individual level combine to influence self-management, utilisation of healthcare services and health outcomes [14]. Increasingly, people are encouraged to self-manage their health, and to balance the workload of everyday life alongside their health [15, 16]. This includes managing, mobilising, and coordinating resources, and attending to limitations to their own capacity to do this work. An imbalance between workload and the individual's capacity to address this is likely to result in poor health outcomes. Individuals may be less able to cope with demands placed on them as their workload accumulates and grows in complexity [17]. Treatment and illness burdens compound the picture, with negative outcomes leading to further imbalance, resulting in complexity accumulating over time [14, 17]. Complementing this perspective, Ruger's conceptualization of health capability [18] integrates health outcomes and health agency,

emphasing the influence of economic, social, and cultural circumstances. The availability of, and ability to mobilise, resources are impacted by social and institutional context. Bandura [19] defined personal agency as the perception that one is influencing their own actions and life circumstances.

Recently, there has been increasing calls for research into the experiences of older adults living with cancer [3]. We have previously conducted a review which found that for older people with cancer and multimorbidity difficulties may complicate self-management, increase burden and diminish capacity [5]. However, qualitative data on the experience of being an older adult with cancer and concurrent multimorbidity was often "hidden" in articles with a different principal focus [5]. Further, previous research largely focused on the experiences of older women who had a diagnosis of breast cancer [5].

To date, there has been insufficient research on the experiences of being an older adult with cancer and concurrent multimorbidity. This qualitative study aimed to identify how older people with long-term chronic conditions manage their health and meet their health-related goals after they have completed treatment for cancer. A secondary aim was to employ Shippee's cumulative complexity model (CCM) [14] to explore factors influencing workload and capacity in relation to managing their health, including interactions and imbalances between the two. We focused on older adults who have completed treatment for cancer alongside concurrent multimorbidity, addressing the gap in the literature as outlined above. We included individuals with different types of cancer, to build on literature that focuses largely on the experiences of older women with breast cancer. We also explored how a range of conditions and circumstances in old age can impact recovery after cancer.

Methods

This study formed part of a larger project targeted at the development of a structured conversational intervention to promote personalised care and support self-management by older adults with complex conditions [20]. One-to-one face-to-face qualitative interviews were conducted with older people or their informal carers between March and June 2019.

Older adults were identified through cancer follow-up clinics in a local National Health Service organization or from taking part in previous research by the team and giving prior agreement to be notified about other relevant studies. Adults aged over 70 (or their informal carers) who had completed primary cancer treatment with curative intent in the previous 2 years and had at least one other chronic health condition were eligible to participate. We

Table 1 Eligibility criteria (participants)

	Inclusion	Exclusion
Patient partici-pant	Adult, aged over 70 (as with similar studies of this kind [45])	Too unwell to participate
	Confirmed diagnosis of any cancer	Inability to communicate choices and preferences either verbally or non-verbally
	Have received cancer treatment of curative intent (radiotherapy, or chemotherapy or biological therapies delivered via any route e.g. oral, intravenous, subcutaneous, intrathecal) within the last 2 years; this does not include ongoing hormonal therapies	No confirmed diagnosis of cancer and at least one other condition
	At least one other chronic disease, which is "health problems that require ongoing management over a period of years or decades." (World Health Organization definition). This is in line with Fortin et al. (2005) definition of Multimorbidity—Coexistence of multiple chronic diseases and medical conditions in the same individual (usually defined as two or more conditions)- used in Cochrane reviews	Incurable/ metastatic cancer
		Currently hospitalised (i.e. Not self-managing within a community setting)
	Mental capacity to decide to take part in the study	Lacking sufficient capacity to consent or take part in the study
	Capacity to participate in the study	
Carer	Adult aged over 18	Lacking sufficient capacity to consent or take part in the study
	Informal carer of older adults living with multimorbidity and cancer (relative/spouse/friend/neighbour)	

excluded people who were too unwell to participate in a research interview and/or people who lacked the capacity to decide about taking part in the research (Table 1). An informal caregiver was defined as anyone working in an unpaid role for a friend or family member who cannot cope without their support [21]. Family members and caregivers were invited to take part once a patient agreed to participate in the study. Caregivers were included to support older adults during the interview if requested. They were also able to offer insights into what it is like to support older people with multiple conditions to manage their health.

Participants were given a research pack and interested participants asked to return the reply slip to the researcher to express interest in the study. They were then called by a member of the research team to discuss participation. This conversation also allowed the research team member to assess the capacity and eligibility of the patient to take part in the study. At the conclusion of this conversation, if the individual agreed, the researcher scheduled a date and time for the interview. Fully informed, written consent was obtained for all participants.

Interviews were carried out at the older adults' homes, as this was chosen by the participants as a convenient location to meet. Each interview lasted between 40 and 60 min. The interviewer used a semi-structured interview schedule developed a priori based on Shippee's cumulative complexity model (CCM) [14]. We aimed to explore experiences that could influence self-management, utilisation of healthcare services and health outcomes. (see Appendix 1). This semi-structured schedule was assessed for clarity and coherence by team members, including clinicians and a PPI (Patient and Public Involvement) representative in advance of the

interviews. All interviews were audiotaped and transcribed verbatim.

Analysis

Framework analysis was used to describe and interpret the data, as it offers a pragmatic, flexible and rigorous approach to data analysis [22]. The approach is not bound by a particular epistemological position, allowing for freedom in the analysis of our data and a range of viewpoints to be considered within our multidisciplinary team. This enabled us to explore some pre-defined areas, but to maintain an openness within the analysis [22]. Framework analysis follows a five-stage process [23].

Step 1. Familiarisation with the data set

TC conducted five of the interviews and AY conducted three. Both were able to also draw on what had been experienced during each interview and provided detailed field notes. Two authors (TC and KL) read the transcripts independently, then met to discuss initial features of the data that were of interest. This process was data driven using an inductive approach ensuring that the data were analysed comprehensively without trying to fit with a pre-existing model.

Step 2. Identifying a framework

Data were organised into framework categories informed by questions developed *a priori* based on the cumulative complexity model [14] (see Appendix 2). This allowed the

identification of categories fitting the research question, while also allowing flexibility to incorporate issues that were important to participants but not reflected in the CCM. Preliminary codes were discussed, similar concepts were grouped together, and agreed by study authors (JB, KL, AC and TC).

Step 3. Indexing

TC and AC systematically applied each interview transcript to the individual framework categories [23]. Themes and sub-themes were refined as the authors became further immersed in the data.

At this stage, it became apparent that the cumulative complexity model (CCM) [14] was not sufficient to help us to understand the experiences described. While the CCM facilitated our understanding of factors at an individual level, we also drew on health capability theory [18] to develop themes that captured the complex interaction between the participant's personal health agency and the influence of external contextual circumstances, particularly financial and social contexts [18].

Step 4. Framework matrices

A framework matrix was generated by the study authors (TC and AC) by reducing the material into brief summaries of what was said by participants [24]. Summaries were linked back to the full text in the transcripts, creating a clear audit trail.

Step 5. Mapping and interpretation

The authors looked *across* coded data to identify patterns to interpret the data as a whole [23]. AC and TC compared themes and sub-themes against original transcripts and field notes to see if any further changes or merging was required [24]. No changes were made to the themes or sub-themes at this stage and the final theoretical framework was agreed.

The study is reported using the consolidated criteria for reporting qualitative research (COREQ) checklist to ensure rigor in reporting in how the study was conducted [25]. Microsoft Excel was used to support data management and analysis.

Findings

Eight older adults and two informal caregivers participated in this study. Both informal caregivers were spouses of the participants. Demographic information is outlined in Table 2.

Four overarching themes were identified in the analysis. These are represented in Fig. 1 and discussed in detail below. Exemplar quotes for each theme can be seen in Table 3.

Personal Agency — older adults' motivation and perceived responsibility to have control over their lives and their health

Older adults held a strong desire to live their life with as few restrictions as possible, identifying the most troubling conditions as those which interfered with their daily lives. They prioritised activities that reduced interference or opted to disregard activities that impeded their lives. This illustrated an ongoing balancing act, weighing up the pros and cons of health-related activities against their impact on living the life they wanted.

Most were motivated to have personal control over their health and indicated a sense of responsibility for managing their conditions. Health management activities included scheduling appointments, organising medications, monitoring their conditions and keeping healthcare records. Individuals viewed self-management as necessary to stay well or minimize future risk.

Participants described challenges associated with changes in health status (e.g. a new diagnosis or change in condition), including attempts to assimilate these changes into their routine, as well as their identities beyond being a patient. This involved dynamically coordinating, and prioritizing activities relating to their health and everyday tasks. Often, the responsibility for balancing new and pre-existing conditions was viewed as being held solely by the individual rather than being shared with healthcare professionals.

Interestingly, cancer treatment was seen as an exception to this. During treatment, individuals described feeling that the situation was under control due to the support they received. The trust they had in the cancer team permitted individuals to disengage in some ways, as they ceded control of their health to professionals. Some expressed appreciation at not having to work to actively 'manage' their health by themselves during this time.

Cancer was described as an isolated, temporary disruption, rather than an ongoing chronic condition that required daily self-management. Many articulated that the cancer experience was behind them and their focus was on moving forward with a focus on managing the conditions that they perceived as chronic, enduring, and requiring ongoing management (e.g. arthritis).

However, individuals alluded to the emotional impact once cancer treatment ended, with some recounting the struggle of readjusting to independent self-management after receiving extensive support during treatment. This was particularly difficult for those adjusting to living

Table 2 Demographic information of participants in qualitative interviews

Healthcare recipients

Participant (PPT) ID	Gender	Age	Education	Cancer type	Cancer treatment	Completed treatment	Other long-term conditions/ symptoms
101	Male	76	Trade/technical/ vocational training	Colon	Surgery	7 years ago	Chronic obstructive pulmonary disease (COPD); Asthma; Sleep Apnoea; Prostate Cancer; Atrial Fibrillation (AF); stomach ulcer
122	Female	78	Trade/technical/ vocational training	Colon	Surgery		arrhythmia/atrial fibrillation, rheumatoid arthritis, fluid retention, walking problems
123	Female	83	Trade/technical/ vocational training	Rectal	Surgery	2 years ago	Overactive bladder, AF, other arthritis (e.g. osteoarthritis, psoriatic arthritis), myocardial infarction, heart failure, spinal compression (wears neck brace), osteoporosis, torn shoulder ligaments (bilateral), falls (fell day prior to interview- bruising)
124	Female	80	Trade/technical/ vocational training	Rectal	Radiotherapy, chemo, surgery	2 years ago	hypertension, hypothyroidism
126	Female	79	Secondary school/ college	Bowel	Surgery	2 years ago	Arthritis, hypertension, Diverticulitis, optic rotatory dispersion
127	Male	69	Secondary school/ college	Bowel	Surgery	Less than 1 year ago	asthma/COPD, chest pain, neuropathy
128	Female	88	Secondary school/ college	Colon	Surgery	Less than 1 year ago	Arrhythmia/irregular heartbeat, osteoarthritis, Diabetes, hypertension, hypothyroidism
129	Female	77	Secondary school/ college	Endometrial	Surgery (brachytherapy)	Less than 1 year ago	hypertension

Caregivers

Participant ID	Gender	Age	Education	Relationship to participant	Long-term health conditions
125	Male	82	Secondary school/college	Spouse of participant 124	Arrhythmia
130	Male	81	Secondary school/college	Spouse of participant 129	Other Arthritis (e.g. osteoarthritis, psoriatic arthritis)

with a stoma after treatment, with some noting the challenge of integrating stoma management alongside pre-existing conditions and routine activities. However, when the stoma was removed, individuals felt more capable of re-establishing personal control over their health management.

Resources/Opportunity — opportunities to achieve health goals were shaped by resources available

Findings illustrate variations between individuals in resources available to manage their health. More resources appeared to facilitate opportunities for older adults to
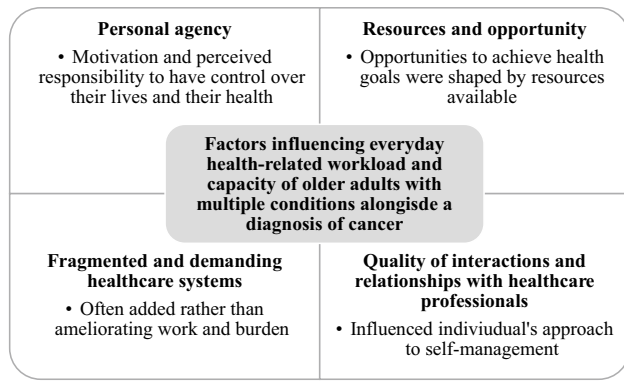
Fig. 1 Factors influencing everyday health-related workload and capacity of older adults with multiple conditions alongside a diagnosis of cancer

achieve their health goals. Internal resources identified by the participants included health knowledge, organizational skills, physical capacity, intrinsic motivation, coping mechanisms, and self-efficacy to carry out the work of health management. Participants linked positive mental attitudes, confidence and acceptance with better health, and despondency with a poorer quality of life.

Cognitive capacity was identified as important to facilitate health management. Some described apprehension about memory-loss and how this would impact future self-care (e.g. medication management). Education and health literacy came to the fore as a key factor in participants' abilities to draw on their external resources. Possessing apparent higher levels of health literacy seemed to enhance readiness to express concerns to healthcare professionals. These individuals presented themselves as being comfortable in their health knowledge, as well as organising and self-managing their health. Conversely, others expressed uncertainty relating to healthcare regimens and administration. Some did not feel confident to raise concerns, for example about potential interactions of multiple medications. Individuals described confusion about the meaning of symptoms, particularly in distinguishing the difference between 'normal' symptoms and those that may need to be attended to. Beliefs about the effects of ageing on the body complicated interpretation of symptoms. For example, beliefs that ageing inevitably caused fatigue and physical limitations delayed participants actively responding to potential symptoms of more serious conditions.

Key external resources were either economic or social. Financial capacity was seen as a key facilitator of independence. Those with greater financial capacity were afforded more choice in the type of healthcare (e.g. public or private) they received. They could also afford paid help (e.g. gardeners, cleaners etc.) and make adaptions

(e.g. pay for taxis to reduce reliance on others). Discussions regarding social resources tended to focus on access to and mobilisation of a supportive social network, often family members. Participants regularly described using family support networks to help with work associated with self-management. Some received support from networks of similar others—such as support groups or friends with similar health conditions, allowing people to maintain an active social life. Social comparison appeared to bolster a sense of competence and gratitude.

However, some described difficult relationships, isolation and loneliness. Social networks had shifted for many over time. As longstanding neighbours died, participants found it difficult to build relationships with new residents in their locality. Even when support was available, individuals did not always feel comfortable drawing on it. Participants consistently asserted a desire to maintain independence where possible and expressed that they did not to want to ask for help unless they felt they could repay the "debt." Some were reluctant to draw on family support from adult children who lived far away or who had busy lives, and others did not want to worry others by sharing concerns with them.

Fragmented and demanding healthcare systems

For many individuals, the contribution of formal healthcare systems to health and wellbeing was relatively peripheral to daily health work. Healthcare was often characterised as fragmented and difficult to navigate, adding rather than ameliorating work and burden. Some preferred to manage their different conditions as distinct entities, yet many voiced frustration at disjointed healthcare. Most believed that linking of specialist services could be improved, and frequently described communication failures across a fragmented system.

Older adults described challenges associated with attending, coordinating and organising multiple appointments with different people in different locations for follow-up, monitoring, blood tests and scans. Organisational work was required to book appointments in-line with timeframes requested by GPs (e.g. cannot book future appointments until a certain day).

Participants expressed difficulty coordinating district nurse visits, citing problems such as poor communication, not having an expected timeframe for pending visits, or nurses not turning up when expected. These issues forced individuals to wait at home, restricting their ability to carry out normal and highly valued daily activities.

Table 3 Illustrative quotes from participants in qualitative interviews

Theme quote pertains to	Participant quotation
Personal Agency — older adults' motivation and perceived responsibility to have control over their lives and their health	*It's mostly my arthritis that–- that gets to me [...] That's–- that's my worse thing. I've got other conditions, but they don't worry me very much [...] You know, you're restricted, and you can feel it all the time* (PPT 128)
	The person involved, the patient, they've got–- I'll say a responsibility to themselves [...] Because you're responsible for yourself and you should be able to speak for yourself. [...] And if you're offered medication and it's going to help you, you should be responsible in taking it. (PPT 126)
	They could have a dozen and one other things wrong with them but if they suddenly picked up something else like if you're tottering along with [chronic obstructive pulmonary disease] and you get cancer, it's a different ball game. [...] You don't understand your body yet. (PPT 101)
	I don't keep thinking that I've had cancer. I forget about it most of the time. And that's the truth there. (PPT 126)
	But the cancer went through so fast it didn't have time to–- feet to touch the ground. I mean, it was diagnosed. Bang bang bang. And you're suddenly a colon missing and you're out of hospital again. So, yeah. But it always [...] initially you had to be wary of coughing because COPD and that sort of thing could interrupt with–- will blow your colon wide open if you weren't careful and things like that. The things you had to learn. (PPT 101)
	"*I didn't really feel human if you know what I mean. But once they took that bag off and that, you know, I was chuffed to pieces. It was horrible. A couple of times the bag started to peel off. It's only stick. It started to peel off and they say change them every day. Sometimes, I was putting three on a day where one was peeling off. And it started to peel off. [...] But, as I say, once that bag was off, I was a different person. I was human. As far as I was concerned.*" PPT 127
Resources/Opportunity — opportunities to achieve health goals were shaped by resources available	*It does help too because –- if you've got a brain that works kind of thing and you know what you're doing and all the rest of it. I mean, I handle all my own finances.* (PPT 128)
	When I was a ward sister, I mean, it was in–- you're always filling out forms. [...] But I have a system –- for instance, medical things. I never send a form to a hospital for an anaesthetic or anything without keeping a copy. Because if you don't, you don't know what you said last time. Not secrets but you can't remember dates, for instance. So, that I'm efficient. [...] I have an office through there full of files but you've got to.[...] I've got a list that I simply take to the doctor with that's what I've had done and so, you know, I don't have to repeat it all the time. I just make a copy. (PPT 123)
	I have got bits of paper somewhere but, you know, it's knowing what bits to bring. But I saves it all. You see, I've got stacks of it up there. And you don't know what to chuck away and what not to chuck away. So, I tries not to chuck it away. And then if I needs anything, I've got it there. But it takes blimmin ages to find it (PPT 127)
	Yeah, I found it's just a vicious circle, you know. And, I think, in the end you get so despondent you just want to give up, you know. You feel like you're fighting a losing battle. [..] everyone keeps saying: "old age doesn't come alone". Things and problems. [..]Of course, it's not until you're older quite often that you do have problems. This is the thing. [..]– you lose confidence. This is the thing, you know, yeah, your confidence goes altogether (PPT 122)
	It's only one thing I want: more mobility. There's nothing that I lack because of either friends or paid help. That means cleaning lady or gardener. (PPT 123)
	I don't know how old people can do but I can do it perfectly alright. And my family are there anyway. If I get a problem over something, they are there to sort it for me. So, again, I'm so lucky with that kind of thing. If you didn't have–- if I didn't have that on my own, I'd be–- you know, it would be a bit more difficult for me. But my main aim is to stay in my own home 'til I go. I said they will carry me out in my–- my coffin from here kind of thing (PPT 128)
	I've got youngsters next door to me now –- and like you don't know anybody anymore. There's one girl I do know–- or a lady I know who's been here all her life –- lives right down the road but you've lost the community contact that you did have. I knew everybody. Now, you don't know–- because I don't get out a lot too. (PPT 128)
	I drive myself but there again, I leave home about half-past-six in the morning even if me appointment's nine o'clock because then I know that I can get a parking bay. If I goes nearer the time, you're about an hour trying to look for a car park space. So, I pays the extra money and just parks in the car park. Do you know what I mean? (PPT 127.)

Table 3 (continued)

Theme quote pertains to	Participant quotation
Fragmented and demanding healthcare systems	*I mean, it's just that that's one problem and the other's another. Sometimes, they know each other. Sometimes, they don't. But there's nothing really to link-in because you've got to deal with both. And you can't make one less because you've got the other one. You've just got to put up with it.* (PPT 123)
	You ring them up and honest, you can't have an appointment, you can't do this. You're number 23 in the queue. I gets down to 16 and, I thinks: "how much is this costing me?" and I ended up putting the 'phone down. It's stupid really because when you starts, you're on 23 or 24 again. So, if I wants to–- if it's that bad like I goes down and–- like if I want some blood thing, I actually goes down to them and sees them. […] It's still faster to do that than try to ring an appointment because half the time they thinks they're more important, I think, than the blimmin doctors. (PPT 127)
	The only thing is you can wait in all day and you don't know when they're coming which, I can understand they've got schedules and that but, I would have thought surely they know if it's going to be morning or afternoon. You know, because it's not as if they go in that morning and write out their schedule. They must do it the day before or whatever. You know, and I find–- I couldn't even go out the garden in case I didn't hear the door. You know, this is the thing. Sort of frightened to miss it (ppt 122)
Quality of interactions and relationships with healthcare professionals	*Most people with long-term illnesses know their illnesses very well and there's nothing worse than somebody trying to waffle them. and you don't want that because as soon as they do the patient will switch off* (PPT 101)
	The only thing I'll say is you saw one consultant who said one thing and then you saw another one who didn't agree with that one or something or other. So, you're going from one to the other and you think: "well, which one is right?", you know. (PPT 128)
	She said: "well, I haven't got any appointments". I said: "I'm sorry dear but I want one … I tell you now, I'm not hanging about… I was left for six months at your surgery and ended up in hospital for eight weeks. Had a cancer. And I had three major operations… so, I am not waiting". "Oh…" she said: "just a sec" and she come back. She said: "oh, is tomorrow alright?". Well, you shouldn't have to do that because, I felt I was–- I wasn't rude. I was firm. But that's what I've been told now, don't wait. Make sure you get an appointment. Yeah. So, you try and get an appointment somewhere. Yeah. I know they're struggling on the–- you know, but it's sad, isn't it? (PPT 126)
	You never see the same doctor like you used to. I mean, I know you shouldn't harp on: "how it used to be". But you never see the same doctor whereas before you'd have a rapport with them. Do you know what I mean? […] they'd know what was wrong with you and that […] I just feel I'm just a number around there. (ppt 122)
	If they've got time. […] I can't fault them for what they did. You know, they were brilliant. But they just never had time to talk to you or to do anything. (PPT 128)
	Well, I take diuretics for my heart. So, if you take diuretics either for lowering your blood pressure–- I mean, yes, or whatever, you pee all the time. So, if I'm going to go out in the morning or at lunchtime, I might defer taking these pills until after that because otherwise, I'm just going all day. I'm spending a fortune on Always pads of various kinds and–- I mean, you can't help it (PPT 123)

Quality of interactions and relationships with healthcare professionals

Individuals felt that they were experts in their long-term conditions and did not like being told what to do. They maintained that their personal priorities superseded the healthcare professionals' (HCPs) priorities for their health. Participants wanted to be involved in their healthcare and expressed a preference for HCPs who could relate to them.

In some cases, an explicit sense of collaboration with HCPs was described. Long-term relationships with HCPs led to greater awareness of older adults' goals, and alignment of care with patient wishes. Seeing the same HCP regularly led to increased trust and a better rapport. However, this experience was described as 'lucky' as opposed to the norm.

Some described how responsibility seemed to be diffused across several HCPs who did not liaise with each other. Self-management of multiple conditions often involved a range of activities that overlapped, contradicted each other, or accumulated to create or increase burden. Participants described attempts to negotiate the work assigned to them to manage their healthcare. Effective communication was seen

to be key, with some participants describing how they were successfully able to discuss feasible tasks and reasonable responsibilities with their HCP. Conversely, breakdowns in communication often led to difficulties, especially when the individual felt unwell. Some spoke about having to be 'firm' to get immediate appointments or to be tactful in using 'loopholes' to secure GP appointments.

Individuals were keenly aware of the demands on HCPs, noting time-pressure amongst staff. A number were hesitant to raise concerns that may be perceived as a 'waste of time'. Further, most noted they would be hesitant to speak to a GP about emotional or personal concerns — expressing a belief that GPs would only be able to help with physical ailments.

Unequal power relations were illustrated in descriptions of situations where HCPs did not listen, provided inconsistent or vague information, did not follow-up, and had poor communication with other HCPs. Participants described not receiving sufficient information about diagnoses or condition management, insensitive approaches to older adult needs, and improper medication scheduling. When participants experienced perceived poor quality of care, they reported lack of confidence in HCPs. Some participants described how they would engage in a strategic non-compliance and modify or ignore guidance as required, so they could live their life as they wanted.

Discussion

This study explored how older people with cancer alongside multimorbidity manage their health and meet their health-related goals. Using a framework approach to analysis informed by the cumulative complexity model (CCM) [14] and health capability theory [18], four overarching themes were identified. The first related to active agency –motivation to have control over their lives and their health. Individuals described how opportunities to achieve their goals were shaped by resources available. Participants also described their interactions with healthcare, illustrating that relationships with healthcare professionals and the healthcare system can serve as either a barrier or a facilitator to self-management of health.

During analysis, we considered "health capability," to aid description of the circumstances that ease or impede self-management of long-term health [18]. Availability of, and ability to mobilise, resources affected individuals' ability to self-manage their health conditions. Such capabilities are a function of choices and adaptions made within a complex social and institutional context. Simultaneously, health capabilities are reciprocally bolstered or hindered by these choices [26, 27]. Participants' economic and social resources, as well as cognitive capacity interacted to bolster independence, and self-management. Older adults' perceived sense of control over their health was intricately linked to

their capacity to balance their existing abilities alongside the constraints of their circumstances. Similar findings have been reported by Weaver et al. [27] who concluded that economic, social, and cultural resources may undermine or promote self-management in diabetes depending on resources available. In this study, we provide a unique insight useful for those supporting older adults who have had cancer. We highlight key factors that influence their capability, namely the interaction of old age and multimorbidity. Together with our previous review of qualitative literature [5], we have shown how these significantly complicate self-management after cancer, creating burden and diminishing capacity.

Due to paternalistic models of care, some participants felt they were restricted in how they self-managed their conditions and their lives. Delays in getting appointments, receiving diagnoses or referrals left participants in 'limbo', unable to exercise control over external factors that presented limitations for them. The complexity arising from living with complex and overlapping health problems is increased by current structures in healthcare – often focused on single disease specialisms. Such systems often fail to see the whole person as they aim to treat each health condition separately. In turn, there are more appointments, with more HCPs to get to know, in addition to more medications and regimens to monitor and manage [28].

Increasingly heavy treatment burden coincides with living with the effects of disease. Yet, the most pressing impact of living with multiple conditions was often on other aspects of life –maintaining independence, socializing and leisure activities [28]. Our findings support those of Ellis et al. [29] who found that some individuals find it appropriate to engage in "strategic non-compliance" in order to maintain everyday social roles [29]. This may come in conflict with HCP's ideals of a 'good' self-manager who adheres to medical advice even at the expense of freedom in their social life [29]. Such findings highlight variations in the fit between an individuals' needs and available services, raising questions about a "one-size-fits-all" model of healthcare. This demonstrates a need for services that are better integrated and more tailored, with care plans developed collaboratively with health service-users, something our ongoing work seeks to achieve [20].

As noted elsewhere [20], we planned to recruit approximately 30 participants. Despite efforts to contact several potentially eligible individuals over a period of some months, many opted not to participate. This may have been due to the nature of the study and the busy health-related workload experienced by those with ill-health [30]. However, a small sample may be advantageous in qualitative research, to facilitate the researcher's close association with the respondents, and enable in-depth inquiry [31]. Yardley notes that for qualitative research it is preferable to focus on adequacy of the sample—not in terms of the number of participants but in terms of their ability to supply sufficient

information needed for a comprehensive analysis [32]. In spite of recruitment difficulties, this study has generated rich and cohesive findings, providing a detailed insight into the experiences of these individuals. The systematic approach to analysis enabled by the use of a framework approach to analysis, lends further weight to our findings [24], demonstrating rigour in how we approached our data [32]. This methodical approach was particularly helpful due to changes in work environments at the onset of the Covid-19 pandemic, as the five distinct phases promote transparency, thus enabling the research team to continue work together despite external challenges [24, 33]

We attempted to recruit individuals with a range of different cancer types, yet the majority of those we interviewed were older adults who had completed treatment for colorectal cancer. In doing so, we have provided the perspective of a novel sample, building on previous research often focused older women who had a diagnosis of breast cancer [5]. We have shed light on the experiences of living with a stoma while managing multimorbidity in old age. This provided an example of an impactful treatment-related consequence, illustrating difficulties that those with cancer can face when integrating new routines into existing self-management regimes. In future research, it would be beneficial to gain an insight into the experiences of those with different diagnoses of cancer (alongside considerations of how improving sample diversity of other characteristics such as gender, ethnicity, socio-economic status, could improve the relevance of the research for the wider population of people living with and beyond cancer). For instance, there is a dearth of evidence relating to the experience of older adults recovering from lung and head and neck cancers [5]. Researchers may need to consider different methods of approach to encourage participation in research [34], perhaps by incorporating the use of patient representatives or ambassador referrals. Inviting past participants to help with recruitment has been found to be a cost-efficient way of recruiting older adults to participate in research [35].

The views of older adults reported here are all the more pertinent given recent findings highlighting that perspectives of people with multiple conditions are nearly completely absent in research to date [28]. Our findings indicate a need to consider the context in which an individual is self-managing their health and to design services that work for those they are intended to support. Efforts to self-manage health were often undermined by a healthcare system that assumed access to equal amounts of internal and external resource across individuals, and imposed barriers, rather than offering solutions, that would work for them. Frustration at a system that did not meet their needs impinged on individuals' motivation to self-manage their health as directed by their HCP.

Future interventions need to address the fit between an individuals' needs, capacity, burden, and the resources available to them, signalling a departure from a "one-size-fits-all" model of healthcare. Provision of person- centred care is key for supporting older adults due to the idiosyncratic needs and abilities, as well as health-related priorities and preferences. Some organisations, such as the National Health Service in the UK have committed to promoting person-centred care [36]. However, with the onset of the COVID-19 pandemic [37], challenges to care provision may have inavertedly promoted restriction and social isolation rather than person-centered care [38]. As noted elsewhere [39], while older adults living in the community are at an increased risk to COVID-19, the ongoing challenges associated with the management of non–COVID-19- related conditions cannot be forgotten.

Findings from this study highlight how the development of person-centred care services could support improved self-management and quality of life.

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