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In this session…

1. We will discuss the findings of a qualitative review that aimed to identify what helps/hinders self-management of cancer and multimorbidity in older adults, in order to develop a targeted self-management intervention that focuses on those aspects that are amenable to change.

2. We will lead discussion on the clinical implications of the findings, especially the role that healthcare professionals can play in supporting the self-management of cancer and multimorbidity in older adults.

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Background:

- By 2035, almost half (46%) of those who get cancer in the UK will be over 75.
- Almost a quarter of those living with and beyond cancer report poor health or disability after primary cancer treatment.
- The presence of co-existing conditions can further complicate the diagnosis, treatment, and management of cancer in older adults.
- Older people are more likely to have other long-term health problems.
- Individuals are increasingly expected to take a more active role in their own health care after a cancer diagnosis.
- **In the context of complex burdens of illness and burdens of treatment associated with cancer in older age, patients' capacity to self-manage may be reduced.**

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Why this review was needed:

- Currently, there is little evidence focusing on multimorbidity in the context of cancer specifically.
- The primary aim of this review is to identify what helps/hinders self-management of cancer and multimorbidity in older adults, in order to develop a targeted self-management intervention that focuses on those aspects that are amenable to change.
- This review will offer a distinct perspective by focusing primarily on the factors influencing supported self-management practices, specifically in the context of aging.

Registration: The protocol was registered with Prospero (CRD42018107272).

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FINDINGS

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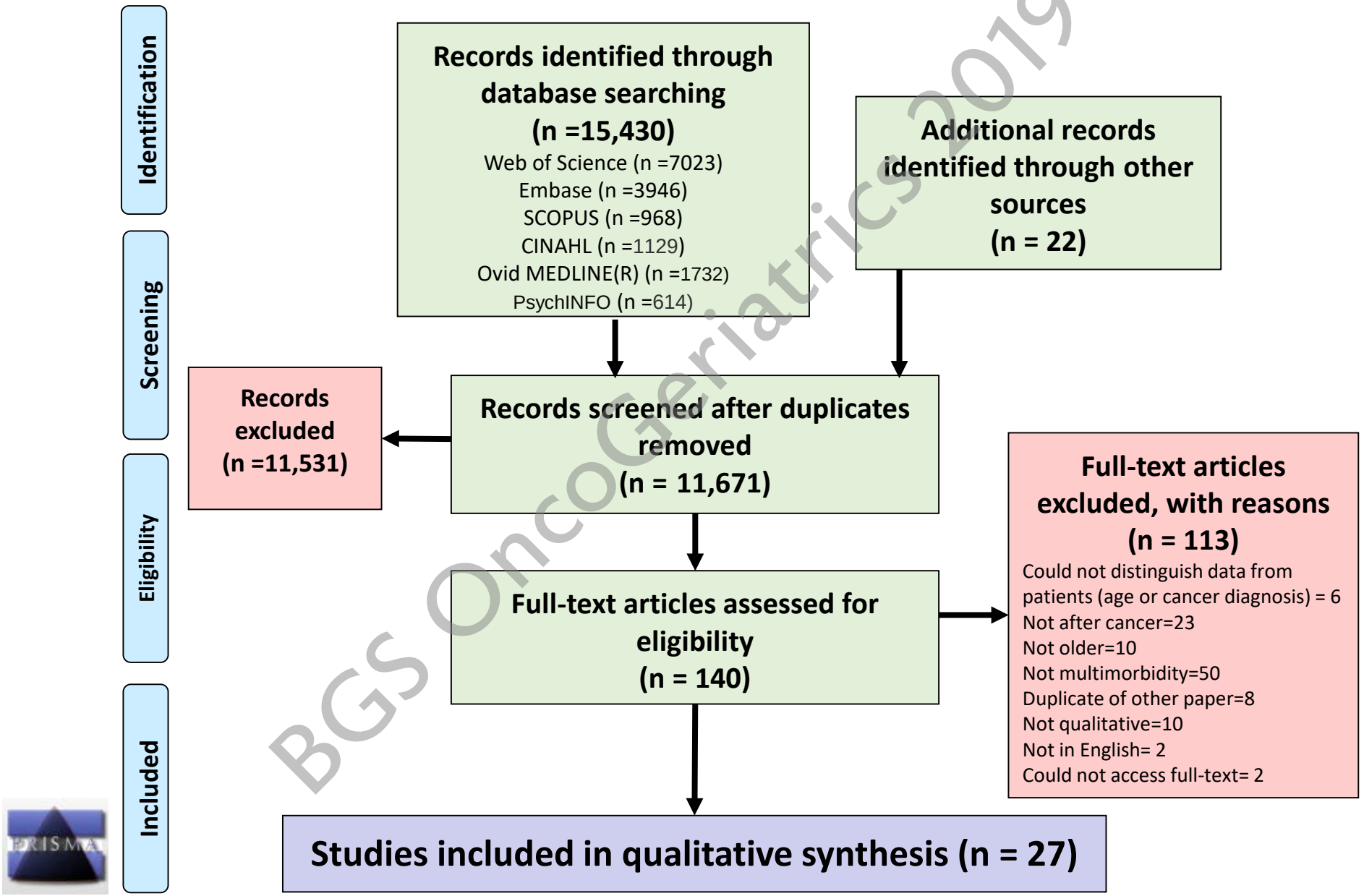

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Data Analysis

All data from the results/findings sections of the included texts was **open-coded.**

Codes were **categorized to the main constructs or 'dimensions of interest'** of the Cumulative Complexity Model

Thematic analysis was used to identify themes within each construct.

As themes were refined, the data was **reviewed to ensure that selected themes 'worked' with the theory.** Themes were discussed and iterated upon with co-authors until consensus was reached.

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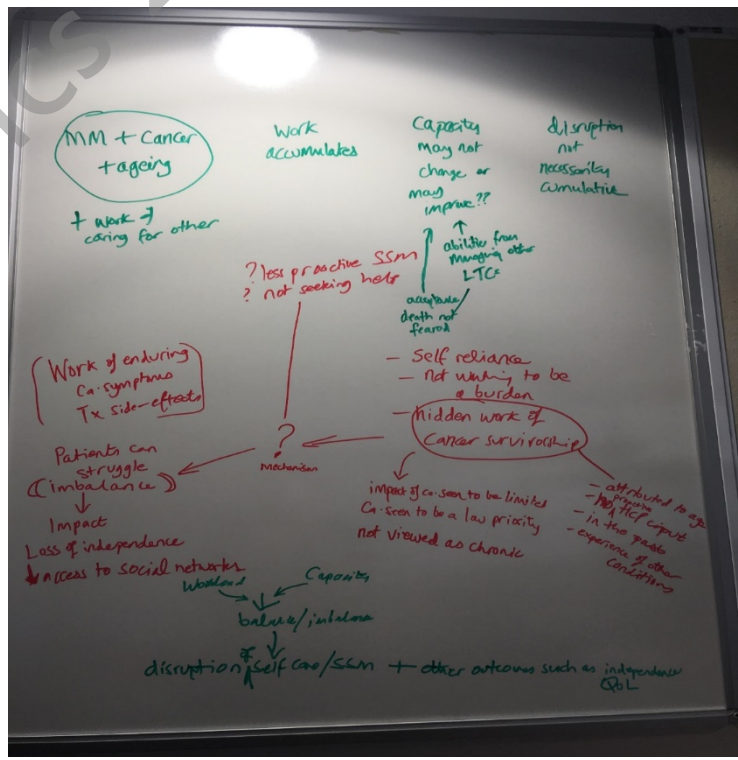

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Findings…

Older cancer survivors living with multimorbidity prioritise independent living as a key feature of quality of life, and this includes managing their health conditions themselves.

- In the survivorship period, cancer is rarely cited as having an impact compared to more invasive, disabling or challenging health conditions (such as osteoarthritis) that were perceived as interrupting daily activities and functional abilities.
- Older adults were likely to disengage with a healthcare plan that was perceived to be too challenging, unacceptable, or too difficult to integrate into an already busy and complex daily routine.
- Older cancer survivors found it difficult to balance their personal need for support with striving for control and maintaining autonomy.
- Access to healthcare and engagement with healthcare routines are impacted by difficulties in synchronising and coordinating fragmented care.

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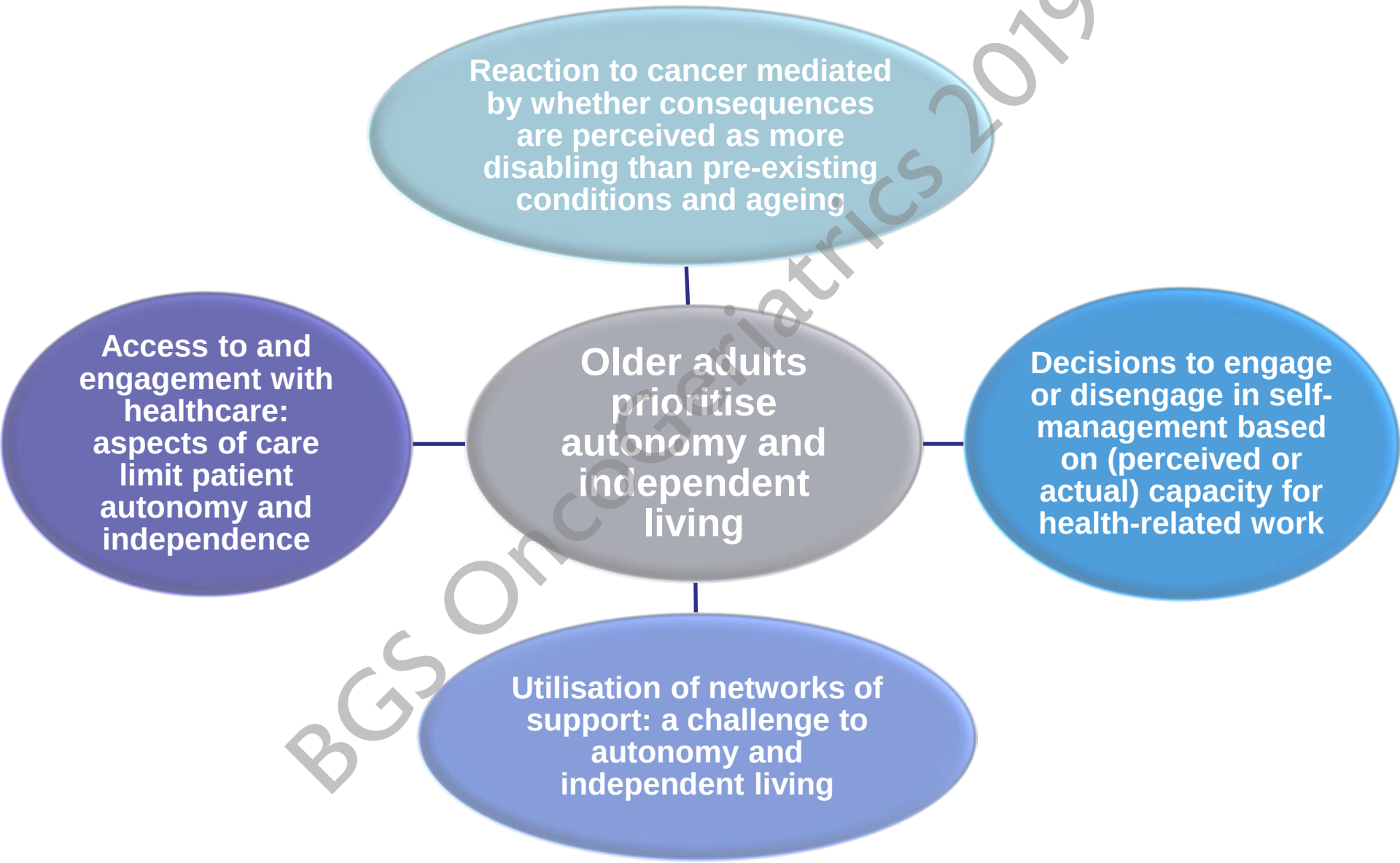

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Older adults prioritise autonomy and independent living

- Older cancer survivors living with multimorbidity prioritise autonomy and independent living as a key feature of quality of life, and this includes managing their health conditions themselves.
- Illness was largely expected and accepted as part of aging. Many had already come to terms with living with their complex health needs.
- Most prioritised conditions that seemed to be the most immediate, disabling or threatening.
- Concerns relating to becoming a dependent burden on others were predominant, often surpassing fears of cancer recurrence. Increasing reliance on others highlighted physical fragility.

"I want to be self-sufficient. I don't want to be sick. Until I'm overwhelmed, I want to be able to deal with it [my illness] on my terms" (CA1030)

Quote from: Naik, A. D., Martin, L. A., Moye, J., & Karel, M. J. (2016). Health values and treatment goals of older, multimorbid adults facing life-threatening illness. Journal of the American Geriatrics Society, 64(3), 625-631.

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Reaction to cancer mediated by whether consequences are perceived as more disabling than pre-existing conditions and ageing.

- Often unclear if workload-capacity imbalances were driven by cancer, their co-existing chronic condition(s), their age, or if it was the interaction of multiple factors
- Conditions which are burdensome - impact most on daily living are often of greater focus
- Overlapping consequences of cancer, ageing and MM can lead to increased burden, reduced capacity, and put patients at risk of negative outcomes.

"I never even think about cancer survivorship. I think of the term, survivor, surviving anything and everything to live another day. That's the name of the game: to survive, anything and everything. Once you're 82, going on 83, surviving has a different meaning because there has been so much surviving to do. Yeah, surviving to live another day!"

Quote from:Pieters, H. C., & Heilemann, M. V. (2011). " Once You're 82 Going on 83, Surviving Has a Different Meaning": Older Breast Cancer Survivors Reflect on Cancer Survivorship. Cancer Nursing, 34(2), 124-133.

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Decisions to engage or disengage in self-management based on (perceived or actual) capacity for health-related work

- Older adults required to undertake numerous practical tasks to manage their chronic illnesses, including pharmacy or doctors' appointments and symptom monitoring.
- Likely to disengage with a healthcare plan that was perceived to be too challenging, or too difficult to integrate into an already complex daily routine
- Pre-existing comorbidities and previous experience of health-related workload may enhance capacity to take on work associated with cancer.

Grant et al (2011) provided the example of a woman with a history of arthritis who switched from one selective estrogen-receptor modulator (SERM) to another because of "*a lot of hot flashes*". She then experienced worse side effects on the second SERM such as "*pains in my joints, a lot of knee problems."* She chose to restart the first SERM, saying, "*I'd rather have hot flashes and not the joint pain."*

Donna described cancer as *"just part of my history,"* while also describing a recognition that *"…a lot of that [internal strength] has come to light in these last few years because I've had a lot of medical issues."*

Quote from: Hannum, S. M., Clegg Smith, K., Coa, K., & Klassen, A. C. (2016). Identity reconstruction among older cancer survivors: age and meaning in the context of a life-altering illness. Journal of psychosocial oncology, 34(6), 477-492.

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Utilisation of networks of support: a challenge to autonomy and independent living

- Being older contributed to social isolation: Participants described the losses they were experiencing in their supportive networks, as many of their friends and close family were also falling ill and dying.
- It was difficult to balance their personal need for support with striving for control and maintaining autonomy
- Older cancer survivors faced a challenge in having to learn to accept and ask for social support.

One feels sorry for oneself, in the sense that one loses one's independence and you become dependent on others. My daughter has to drive me. I have to phone her and she has to adjust her schedule if she can. If she can't, I have to adjust my schedule … I do feel unduly restricted. I can't go where I want to go, when I want to go – even the short distances

Quote from: Clarke, L. H., & Bennett, E. (2013). 'You learn to live with all the things that are wrong with you': gender and the experience of multiple chronic conditions in later life. Ageing & Society, 33(2), 342-360.

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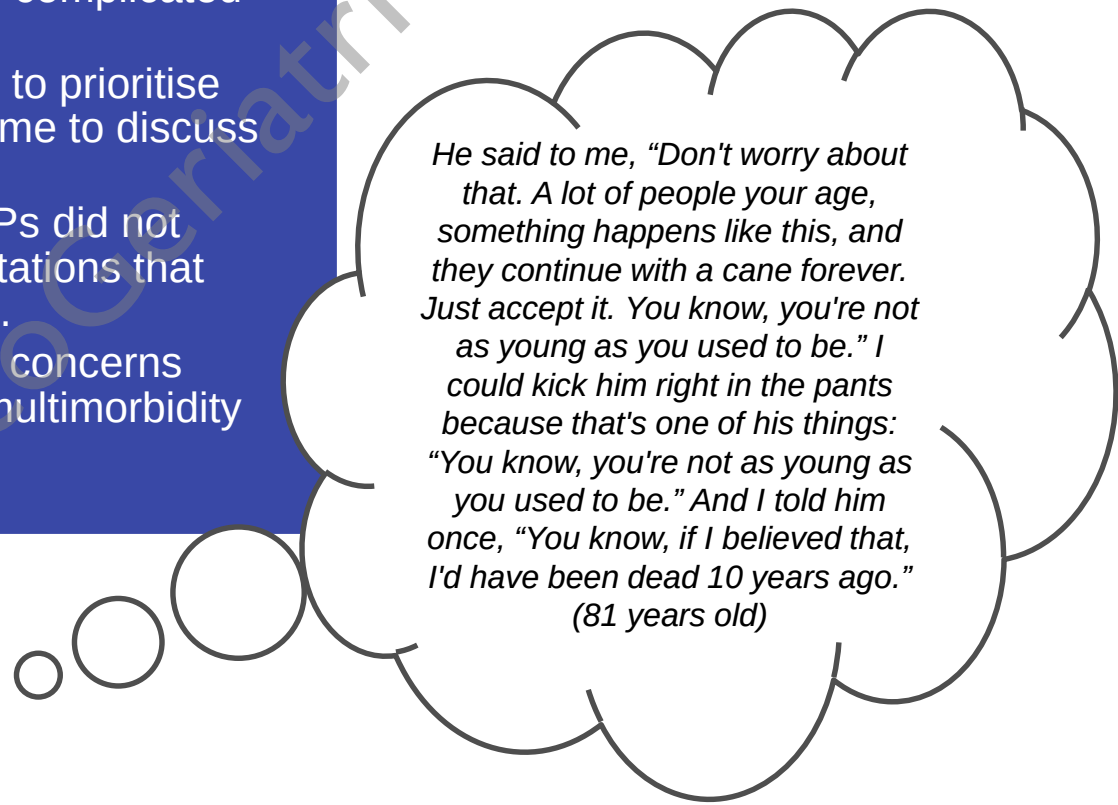
Access to and engagement with healthcare: aspects of care limit patient autonomy and independence

- Fragmentation of healthcare services complicated access to care for participants.
- Short appointments required patients to prioritise concerns, as there was not enough time to discuss everything.
- Many older adults perceived that HCPs did not always acknowledge age-related limitations that could interfere with self-management.
- Some individuals perceived that their concerns were minimised due to existence of multimorbidity and/ or age.



Quote from: Adler, S. R., Wrubel, J., Hughes, E., & Beinfield, H. (2009). Patients' interactions with physicians and complementary and alternative medicine practitioners: Older women with breast cancer and self-managed health care. Integrative cancer therapies, 8(1), 63-70.

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CONCLUSIONS

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Conclusions…

- At any age, cancer can have a substantial impact on an individual's independence, as treatment side effects can reduce their ability to maintain normal daily activities.
- Our review findings provide insights into the complex interplay between treatment burdens and personal capacity, with individual's priorities and beliefs about effective self-management.
- **Understanding values and priorities of cancer survivors is crucial to promoting positive supported self-management,** especially given the idiosyncratic needs of older adult cancer survivors with pre-existing conditions and functional disability, as well as variable levels of social support.

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Conclusions…

- Guideline-driven care for individual diseases is often used for patients with several coexisting health conditions. However, **what is good for a single disease may not necessarily be what is best for the patient**.
- There is a need to move beyond a focus on a single chronic diseases and instead, move towards a more **comprehensive approach that focuses on the cumulative impact of a number of conditions on daily activities and quality of life.**
- In order to deliver healthcare in a way that is minimally disruptive and maximally supportive, **care should be centred on values and preferences of patients.**

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Developing a targeted self-management intervention…

- Based on what we have learned in our review, we have developed a structured conversation plan that includes a list of topics that a patient could discuss with their healthcare provider, in order to maximise the support that the patient receives.
  1. Discussion and clarification of patient priorities
  2. Collaborative focus on goal-setting based on priorities set out by patient

- Next steps:
  - In a series of interviews, we will ask patients living in the community who have completed treatment for cancer to tell us what they think about the plan we have made. We will also ask their carers and healthcare professionals to share their thoughts about how a plan like this could be used in practice.

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ISSUES TO CONSIDER

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- What would help clinicians to have a patient-centred conversation with older patients who have complex conditions?
- If we were to develop a self-management intervention, what should the main outcomes be?

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Department of Health Disclaimer:
The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the NIHR, NHS or the Department of Health and Social Care

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- **Dr Hilary Boddington,** Macmillan General Practitioner, The Wessex Cancer Network
- **Dr Jane Winter,** Macmillan Consultant Colorectal Nurse, University Hospital Southampton NHS Foundation Trust.

- “I want to be self-sufficient. I don't want to be sick. Until I'm overwhelmed, I want to be able to deal with it [my illness] on my terms” Quote from: Naik, A. D., Martin, L. A., Moye, J., & Karel, M. J. (2016). Health values and treatment goals of older, multimorbid adults facing life-threatening illness. Journal of the American Geriatrics Society, 64(3), 625-631.
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- “Donna described cancer as “just part of my history,” while also describing a recognition that “…a lot of that [internal strength] has come to light in these last few years because I’ve had a lot of medical issues.” Quote from: Hannum, S. M., Clegg Smith, K., Coa, K., & Klassen, A. C. (2016). Identity reconstruction among older cancer survivors: age and meaning in the context of a life-altering illness. Journal of psychosocial oncology, 34(6), 477-492.
- “One feels sorry for oneself, in the sense that one loses one’s independence and you become dependent on others. My daughter has to drive me. I have to phone her and she has to adjust her schedule if she can. If she can’t, I have to adjust my schedule … I do feel unduly restricted. I can’t go where I want to go, when I want to go – even the short distances” Quote from: Clarke, L. H., & Bennett, E. (2013). ‘You learn to live with all the things that are wrong with you’: gender and the experience of multiple chronic conditions in later life. Ageing & Society, 33(2), 342-360.
- “He said to me, “Don't worry about that. A lot of people your age, something happens like this, and they continue with a cane forever. Just accept it. You know, you're not as young as you used to be.” I could kick him right in the pants because that's one of his things: “You know, you're not as young as you used to be.” And I told him once, “You know, if I believed that, I'd have been dead 10 years ago.” (81 years old) Quote from: Adler, S. R., Wrubel, J., Hughes, E., & Beinfield, H. (2009). Patients' interactions with physicians and complementary and alternative medicine practitioners: Older women with breast cancer and self-managed health care. Integrative cancer therapies, 8(1), 63-70.