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Addressing multimorbidity through personalised care

Danielle Nimmons, Emma Hyde and Kay Leedham-Green

Introduction

Multimorbidity is a term often used as a 'call to arms': to justify more generalist approaches to organisation and practice of clinical care, and similarly the need to support more generalist approaches to learning and workforce development. The terms multimorbidity and generalism, however, should not be conflated and are not synonymous. In this final chapter, we come full circle, showcasing elements of the generalist principles we describe in Chapter 1; illustrating some of the challenges and opportunities for production and use of research and evidence described in Chapters 4 and 5; ways to support learning and assessment described in Chapters 6 and 7; and implementation opportunities and challenges in how we organise care (see Chapter 8), prescribe (see Chapter 16) and embed patient partnership in clinical approaches (see Chapters 3, 11, 12 and 15). Done well, clinical care of patients with multimorbidity provides key examples of collaborative (see Chapter 13) healthcare.

Multimorbidity as a term is often challenged during patient and carer discussions within clinical encounters or research. Multimorbidity and related challenges have conversely been a persuasive and influential tool for change: introducing to a wide audience many of the important concepts outlined in this book. For example, strengthening person-centred healthcare priorities; 'lean' and sustainable systems to minimalise medicalisation and treatment burden for patients; and highlighting the tensions created by linear and compartmentalised approaches to care, which forefront and prioritise disease-specific notions of 'good practice'. Patients' dislike and the

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medical 'success' of this term are connected. We have talked throughout this book about the privilege and preferences attributed to disease-based knowledge: often at the expense of attention to additional knowledge forms (such as experiential knowledge of patient, carer or practitioner). There are myriad definitions for multimorbidity, but all embrace the existence of one or more disease(s). Some, in addition, use the term to mean broader (and often co-existent) issues such as social determinants of health (for example, homelessness, relationship breakdown, debt, loneliness) as discussed particularly in Chapters 8, 10 and 11. But the presence of disease is still the key factor to inclusion (or not) in this umbrella of attention (and potential care) within current clinical practice, research and education.

This chapter, then, examines a subset or instance of generalism. It is not, however, synonymous with, or the totality of, generalist possibilities for practice and learning. The current burgeoning of political attention to multimorbidity is by no means a bad thing. But we urge you as interested readers and participants in generalist approaches to be mindful not to limit your gaze to this disease-focused element of generalism, at the risk of forgetting the myriad additional lenses, knowledge forms and legitimate concerns a generalist encounter might require. Our key tenets of generalism (outlined in Chapter 1) include connecting knowledge; expansive exploration; adaptive implementation; and participatory approaches forefronting partnership and collaborative approaches to working with patients and colleagues. These can apply to patient problems attributable to a disease diagnosis, but also illness or problems with no formal disease label. This chapter showcases, then, ways in which these generalist principles might be examined, learned and implemented for patients labelled with multimorbidity.

A key area of current international interest relates to how generalists care for people with multimorbidity. Multimorbidity, or the presence of more than one long-term health condition, has been called the 'defining challenge' of our era (1) and is important for healthcare systems worldwide. How can rising multimorbidity be managed equitably and sustainably for current and future generations within a resource-constrained environment? How can we support people and carers who live with multimorbidity to live well to the best of their abilities? This chapter focuses principally on how generalism is enacted within a care-planning consultation for patients with multimorbidity to deliver what is known in the UK as 'personalised care'. It also touches on the healthcare systems and community-based resources that support people and carers who live with multimorbidity; however, these are covered in more depth in Chapters 8 and 11.

We invite you to consider how the core principles of generalism afford a different perspective on multimorbidity to the disease-centred

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approaches around which most healthcare, clinical research and clinical education are configured. Although patients are likely to need episodic input from specialists, this chapter argues that generalism needs to thread and weave through these intermittent encounters with specialists, as well as being complemented by primary care clinicians offering comprehensive, longitudinal, personalised approaches and coordination of care. Throughout the chapter, we will refer to a UK national workforce development programme led by the Personalised Care Institute, describing how it is transforming multimorbidity care through personalised approaches.

Background

Definitions

Multimorbidity has been defined in a number of ways, although the presence of two or more long-term health conditions is commonly used (1). This definition has come under scrutiny for many reasons, not least of which is its relevance to patients. How should comorbidities related to a patient's principal diagnosis be labelled? For example, complications of diabetes? At what point does an acute problem that may or may not resolve, such as pain or depression, become classified as long-term or chronic? The definition uses a simple count of conditions without a focus on one condition over and above the others, despite different conditions impacting people differently. For example, high blood pressure is usually asymptomatic and has little impact on people's lives, while a single diagnosis of dementia or stroke will have a much greater impact leading to greater care use, treatment burden and reduced quality of life. Further terminology and definitions include the use of predefined lists, the term 'complex multimorbidity' (2), 'condition clusters' and 'weighted indexes' where conditions are graded according to severity or impact (3). However, it is unclear if weighted indexes are superior to a simple count of conditions – for instance, when predicting population outcomes (4). While limited data shows certain condition clusters are associated with poorer health and higher healthcare needs, in particular those including mental health (5–7), further research is needed to explore multimorbidity clusters and their effects across different sociodemographic groups (8,9). There are likely to be multiple evolving interpretations of what constitutes a long-term condition. Ultimately, the best way to define what is (or isn't) a long-term condition, and so make decisions about care requirements, is through a conversation between an individual and their healthcare professional.

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Prevalence

The prevalence of multimorbidity is complicated by competing definitions, imprecise boundaries between health and illness, fluid disease definitions, and factors that impact on the accuracy of disease surveillance such as access to healthcare, socioeconomic status and study methodology (10). Some studies that include risk factors such as obesity and excess alcohol, estimate prevalence as high as 95 per cent (11), while more commonly used definitions place it at around 23–27 per cent in the UK (12,13). Despite various attempts, a precise unifying definition or monitoring strategy remains elusive (14). A unifying definition is also perhaps unhelpful, given the un-unified nature of people's needs and priorities – including young people with disabilities, tri-morbid survivors of complex trauma, and those with age-related frailty. Whichever definition one takes, the prevalence of multimorbidity appears to be increasing worldwide, driven by ageing populations as well as social, economic and environmental factors (15), although there are criticisms that some of this might be diagnostic creep as ageing, poverty, pain and distress become labelled, pathologised and marketised (14).

Causes and associations

The determinants of multimorbidity include genetics, ageing and the risks associated with clinical treatment. They also include potentially modifiable environmental and social factors such as poverty and poor housing, and 'behavioural' factors such as smoking, obesity, nutrition and alcohol which are all associated with and compounded by low socioeconomic status (4,16). The clustering of certain conditions, such as diabetes with heart failure and kidney disease, suggests that morbidity itself is a risk factor for further morbidity, either related to a common underlying cause, such as poor diet, or one disease causing the next, such as poorly controlled diabetes leading to cardiovascular and ophthalmic complications. Multimorbidity is also a risk factor for reduced mobility and socioeconomic participation, which can lead to frailty, depression and anxiety (17) and increased risk of mortality (18). Those with more than one long-term condition often experience more frequent hospital admissions with longer length of stay compared to those without multimorbidity (19,20). There is evidence to suggest quality of life can be impacted by the severity of conditions (21) and certain combinations of conditions can have larger negative effects on quality of life than expected compared to the sum of each condition considered independently (22).

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Mental health conditions also play an important role in multimorbidity. Not only is there evidence that the risk of mental health conditions increases as the number of long-term conditions increases, but also that mental health conditions can increase the risk of further multimorbidity (23). Moreover, symptoms of depression are thought to be predictive of multimorbidity in older people (24). Having physical and mental health conditions can lead to poorer quality of life, worse clinical outcomes and early mortality, compared to those who have physical conditions alone (25).

There is a clear association between increasing age and multimorbidity (12,26), although it is important to note that many young people are also affected (27), and in absolute numbers, there are more people with multimorbidity below the age of 65 years than above (12). The diagnosis is also more common in women (11) and those from low socioeconomic groups, where those in the most deprived areas experience higher levels of multimorbidity compared to wealthy areas, and develop it at a younger age (12). Self-management of many long-term conditions requires time, effort and skills, including literacy (28) and studies suggest low health literacy is associated with the presence of multimorbidity (6).

> [Health literacy] is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course. (29)

Impacts

Recognised complications of multimorbidity include reduced quality of life, which may be further reduced by increased condition severity (21) or by having certain combinations of conditions (22,30). Fragmentation of care is also potentially increased (31) as is the burden of treatment for patients and potentially their carers, as people may need to self-manage multiple conditions, attending multiple appointments, managing many drugs and engaging with many different healthcare professionals (32,33). Multimorbidity is associated with reduced life expectancy (34,35) and increased use of health services, including primary care and emergency care (19,36,37).

Multimorbidity is associated with polypharmacy and high healthcare utilisation, which leads to higher treatment burden for those affected and potentially increased costs to themselves and/or the healthcare system (37). Few single-condition guidelines explicitly address treatment burden

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or details on how to prioritise competing recommendations. These are crucial to consider in patients with multimorbidity, in whom treatment burden may become overwhelming (38,39). Multiple long-term conditions tend to result in multiple GP or hospital outpatient appointments, and it can be challenging to navigate healthcare services that are fragmented and designed for people with singular conditions.

Healthcare professionals can experience challenges managing the needs of patients with multimorbidity. This may include having to follow multiple clinical guidelines for one patient, managing conditions outside of their areas of expertise, as well as prescribing complexities (40). The complexity and volume of work and number of patients can also make it difficult, particularly for generalists who tend to provide continuity of care (41).

Researching multimorbidity

The case for a new research lens

Clinical research tends to focus on single diseases and/or clearly defined interventions (42): randomising one set of patients to one clinical pathway and comparing their outcomes to another. Guidelines are then developed based on a synthesis of these quasi-experimental studies. The development of evidence-based management guidelines for multimorbidity, however, is challenging.

Most research evidence focuses on single diseases. While some people with mutlimorbidity might be included in studies, this is rarely explicit. Often, people with multimorbidity are deliberately excluded: they may be too frail, ill or complex. This raises questions about the applicability of research findings to this population (43). Patients may also find themselves excluded from or dropping out of care pathways if services are not designed to address their 'entanglement of physical, mental, and social vulnerabilities' (14). When randomising patients to one arm or another, for example personalised versus non-personalised care, it may not be possible to blind either the patient or the clinician, raising questions of bias. How ethical is it to refuse personalised care in the non-intervention arm? And what is 'usual care' in the control arm? Humans are social creatures, and clinicians are likely to improve their practice based on what they see and hear others doing, so is the control arm ever effectively controlled? Effective multimorbidity interventions are likely to be complex rather than unifactorial, so it may be unclear whether all parts of the intervention are needed. Interventions often require adaptation to meet local or contextual needs, and these adjustments and necessary agility are important to enable and capture in research and evaluation.

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How relevant are predefined interventions, or indeed outcome measures, to personalised care? High-level outcome measures, such as 'quality of life' indexes, are necessarily based on proxy indicators. These indicators might well be associated with greater or lesser quality of life, for example chronic pain or reduced mobility, but are these proxy indicators fixed or remediable in patients with multimorbidity, and how accurate are these indices if quality of life improves in other ways or if people have multimorbidity without chronic pain or impaired mobility? Countable outcomes such as death or emergency admission may require very large sample sizes to confidently differentiate between the two arms of a study as the effect size may be small, the frequency of countable events low, inter-person variability high, not to mention problems with the accuracy of reporting or adherence to intervention. Individual confounding factors abound, but so, too, do regional and temporal ones such as the availability or quality of a service in a particular area, pandemics, recessions, geo-political conflicts and environmental changes. Even if confounding factors such as socioeconomic deprivation have been adjusted for, how is a clinician supposed to interpret the evidence if their patient or service is situated in an area of socioeconomic deprivation (4)? Although there have been some notable attempts to conduct high-quality trials based on complex interventions for multimorbidity (1), the use of multiple definitions, terminologies and indexes of multimorbidity make it difficult to compare and synthesise evidence across interventions (43).

These research challenges, which are bound within a positivistic deductive philosophy of science, have arguably led to a division within multimorbidity care and a mismatch between the needs of people living with multiple conditions and the resources offered by health systems focused on evidence-based care (44). The lack of evidence for more complex, personalised interventions does not mean that they do not work, just that they are harder to research within the prevailing clinical research paradigm (see also Chapters 4 and 5).

Embracing agility and subjectivity in multimorbidity research

The lack of evidence for multimorbidity interventions has often led to calls for 'more research' without addressing the above epistemological challenges. We argue that multimorbidity requires a different research lens. Instead of researching predefined and marketable interventions, perhaps we should be embracing local differences, allowing for agile evolution of services, and simply researching and optimising impacts locally instead? In addition to clinical trials that use objective measures, such

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as biomedical markers of disease control or countable events, perhaps we should also focus on more subjective patient-reported outcomes? These could be qualitative descriptions of what worked and why, or well-constructed quantitative patient-reported experience and outcome measures ('PREMs' and 'PROMs') (45).

PREMs, or patient-reported experience measures, have had a bad press (46). Simple ratings such as 'customer satisfaction' or 'would you recommend this service to friends and family' can be skewed by anything from the availability of car-parking to racial discrimination. Goodhart's Law also reminds us that 'When a measure becomes a target, it ceases to be a good measure' as incentivised ratings are easily manipulated by selecting who is asked to provide feedback (47). And fundamentally, there is little point in collecting un-actionable data: how can a global satisfaction rating inform what needs to change?

Although harder to create and use, more carefully constructed measures can pinpoint important areas of excellence or areas to improve. If aggregated over many patients, a validated index such as the 12-point Consultation Quality Index (48) can allow practitioners to monitor how a specific aspect of their practice is evolving over time or in relation to peers, for example shared decision-making, listening skills, or explaining. If combined with qualitative data, carefully constructed and validated PREMs can provide actionable information on how to improve, and whether a change is an improvement. If patient experiences are to be used effectively within research and evaluation, then practitioners may also need support learning to embrace and grow from feedback, which might otherwise feel critical (49).

Whereas PREMs (experience measures) tend to be reported at a single point in time, PROMs, or patient-reported outcome measures, are usually reported before and after an intervention to see if there has been an improvement. Validated outcome measures might be very targeted, for example pain, depression or exercise scales. There are also indices that aim to measure higher-level generic attributes that may be relevant to multimorbidity such as quality of life (50), wellbeing (WHO-5), health literacy (51) and illness perception (52). Patient activation (an individual's knowledge, skills and confidence for managing his/her health and health care) is associated with improved multimorbidity outcomes and is a potential outcome measure for health coaching interventions (53). The PACIC (Patient Assessment of Chronic Care) is a validated measure that integrates PREMS and PROMS to reflect the quality of care experienced by people living with one or more chronic conditions, and has been shown to be highly specific for multimorbidity interventions (54).

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The Personalised Care Institute invited patients and carers with experience of multimorbidity from the NHS Peer Leadership Academy for their input on how to evaluate personalised care (55). Participants from diverse socioeconomic backgrounds and with a wide range of conditions and disabilities were interviewed in depth about their best experiences and outcomes of care planning. The resulting themes were honed at a co-creation event involving 40 patients and carers. Their responses are thematically summarised in Table 18.1. Their ideal experiences are very similar to the Consultation Quality Index (48) with the added construct 'feeling supported', which further validates that measure. Their desired outcomes included learning to understand their conditions and treatments, strategies for reducing acute crises, adapting their care to their specific needs, engaging with supportive resources for health and wellbeing, and regaining or retaining some control so that they could engage with living rather than just coping.

Table 18.1 What do people with lived experience of multimorbidity want from their care-planning appointments?

How patients would like to experience personalised care	What patients hoped to gain from personalised care
• Feeling welcomed and respected by healthcare staff • Being invited to talk about what matters to them • Feeling listened to and understood • Being treated as a whole person, not just a case • Feeling cared for, preferably by someone that knows them • Having their concerns taken seriously • Having things explained clearly • Being involved in discussions +/− with their family/carer(s) • Feeling in control of their decisions and plan • Feeling supported	• Understanding of their conditions and/or treatments • Ability to reduce or prevent problems • Ability to problem-solve if challenges arise • Engagement with health and wellbeing • Access to helpful resources and support • Ability to adapt to their personal circumstances and needs • Ability to act on their own ideas and preferences • To feel more in control and less overwhelmed • Ability to focus on what matters to them rather than just coping

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Generalist approaches to multimorbidity

Replacing someone's knee is a complex process. Titrating someone's pain medication is a complex process. Even arranging a meeting can be a complex process. These processes, however, all have clearly defined outcomes. Everyone involved can see whether you have got it right or wrong. Addressing multimorbidity, however, can be considered a 'super-complex' problem. Not only are the processes complex, but the outcome is also not clearly defined. What is a priority from one perspective, may be different from another. Even for the same problem, the healthcare practitioner, the patient and their family/carer may have different perspectives on what is a good outcome.

We articulated the core concepts of generalism in Chapter 1. These include:

- Participatory values and practices: respecting and inviting the views and strengths of patients and carers.
- Embracing and integrating multiple ways of thinking and paradigms of knowledge.
- Leveraging distributed expertise by working collaboratively.
- Agile and responsive systems and processes.
- Working pragmatically and sustainably to address what matters to people and what is necessary for population health.

These principles have led generalists to design integrated services that are centred around people rather than diseases; to respect patients and carers as experts in their own needs and priorities, with their own strengths and problem-solving abilities; to work collaboratively with patients and carers to identify and address what matters to them; to work collaboratively across sectors, consulting specialists and guidelines as needed; and to focus sustainably on the determinants of health as well as disease. In Chapter 5, we looked at the different ways in which evidence informing decision-making about management and prevention of osteoporosis is framed and produced, focusing for example differently on cost-effectiveness, or patient outcomes. Here we use a similar decision about osteoporosis prevention to explore participation and engagement within decision-making (see Example 5.1).

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Example 18.1: Funmi

Funmi (she/her) is a 79-year-old retired administrator. She is frail, mobilises with a frame, falls regularly, and was recently admitted to hospital with a wrist fracture. She has urinary incontinence and occasional faecal incontinence following adjuvant chemotherapy for breast cancer five years ago and gets angry and distressed if she is unable to get to the bathroom on time. She has a history of self-harm, drinks alcohol to excess, has moderate hearing loss and mild memory loss. She has always lived alone and wants this to continue. She has weekly visits from her brother who has anxiety, a specialist continence nurse, and a daily carer who makes her lunch and does her laundry. Her carer says Funmi often refuses her medicines and lunch.

Funmi's brother phones the practice social worker who coordinates her care. He says Funmi has received an appointment for a bone density scan from the local hospital following her recent fall. He is concerned that the letter says she should come alone using hospital transport, but he doesn't think she will attend unless he goes with her. After a brief discussion, he agrees to bring Funmi to the practice so that they can go through the options together.

Her brother says that Funmi would be confused and distressed without him and explains the risk of incontinence if she is left waiting without easy access to facilities. Funmi is a bit annoyed about the scan as no one discussed it with her. The social worker calls the GP in for advice on the risks and benefits of the bone scan. The GP calculates Funmi's fracture risk and explains that she meets the NICE intervention guidelines for bone protection without the scan. They agree to cancel the scan.

The GP then asks Funmi whether she wants to discuss bone protection. Funmi says she wouldn't want any medicines as she has 'given up'. The GP explains that bone protection might halve her risk of another fragility fracture. Funmi agrees this is something she does want to avoid. They agree on an annual intravenous infusion at the local hospital, which, although slightly less effective than regular oral medication, she is more likely to tolerate. The GP then asks Funmi whether she would like to discuss her mood or drinking. Funmi roundly refuses.

After the GP leaves, the practice social worker opens the discussion up and asks Funmi 'What matters to you, and what would make a difference?' After a pause, Funmi says a new hearing aid would make a difference. Her previous one is no longer helping and doesn't fit

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very well. This is causing social isolation and worsening her mood. Her brother says he is more worried about her falls which are increasing in frequency. He explains that Funmi often spends the night on the floor as she doesn't want to disturb him by pressing her personal alarm (which defaults to his phone) and she can't get up alone. They agree on a referral to a local audiology service, and a separate referral to a falls service who will work with Funmi to prevent and recover from falls. The social worker checks how confident they are with the plan, and Funmi's brother admits he is worried about the audiology appointment. The social worker asks him what might improve his confidence. He says he will visit ahead to check where the toilet facilities are. The social worker shows them a resource for checking accessibility online which they are both pleased with and will use again. The practice social worker then shows them the local drop-in alcohol intervention service which includes an accessible community garden. Funmi says she will think about it. They agree to follow-up on this conversation at Funmi's formal care-planning appointment which is due in a month.

Pause and reflect

We invite you to reflect on the different approaches of the hospital team that requested the scan, the GP who negotiated an alternative, but directed the focus of discussion, and the practice social worker who simply asked, 'What matters to you, and what would make a difference?' What were the relative impacts on the patient and carer? What were the relative social, environmental and economic costs (triple bottom line)? How do you balance and integrate disease management with patient and carer priorities?

Structural approaches

The House of Care

There is a clear rationale for proactive care for people living with long-term health conditions regardless of multimorbidity. Apart from the obvious impacts of poorly controlled disease on a patient's symptoms and social participation, healthcare needs and costs rise if complications ensue. The socioeconomic rationale of proactive care led several health insurers in the USA to develop a range of models of care for people with long-term conditions such as the 'Kaiser Pyramid' which stratifies patients according to

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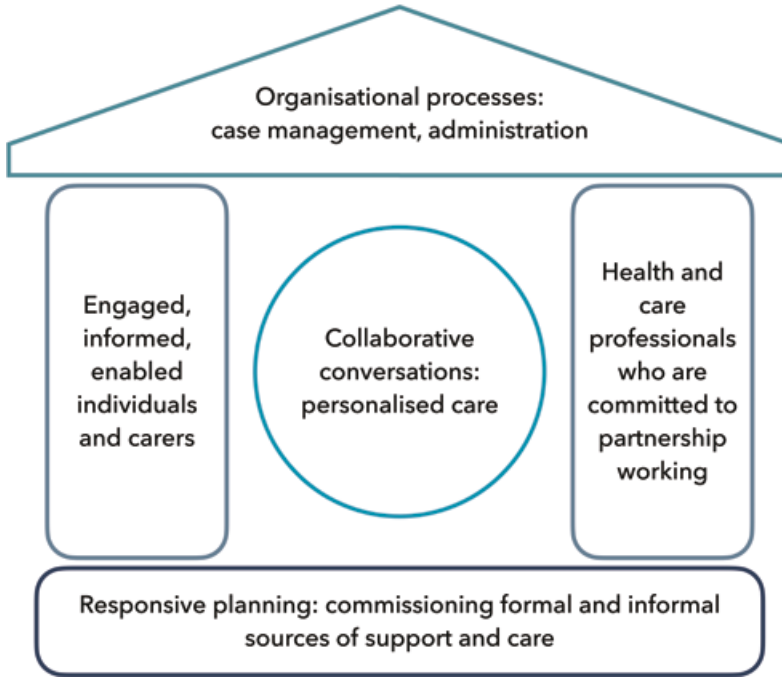


Figure 18.1 The House of Care model includes key organisational processes, collaborative conversations and responsive planning. Adapted from Roberts et al. 2019 (79)

need (56), and the 'Chronic Care Model' which aims to improve outcomes through integrated care (57,58). These models were adapted to the UK context and introduced as the House of Care (59,60) (Figure 18.1).

Organisational processes:

- Case finding and stratification of patients into tiers to identify people who can self-manage or who have risk factors (tier 1), people with health conditions that need regular review (tier 2), and people with multimorbidity or complex needs who require individual case management (tier 3).
- Ensuring healthcare is free at the point of need so that patients and carers are not disincentivised from engaging with proactive and preventive measures.
- Ensuring case management is integrated and organised around people rather than specialisms and managed by a healthcare professional that knows them (usually a generalist with specialist input as needed) to avoid duplication and repetition.

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- Separating routine tests, structured education and specialist investigations from care-planning conversations, so that there is time and headspace for forward planning.
- Sharing test results and information with patients and carers in advance of care-planning conversations so that they come prepared and informed and are able get the most out of their appointment.

Collaborative conversations:

- Healthcare professionals that are committed to partnership working and trained with advanced communication skills such as health coaching and shared decision-making.
- Sharing information and sharing decisions, so that no decision is made about a person without involving them, and they have ownership and control when planning next steps.
- Opening up care-planning conversations beyond the biomedical, to invite reflection on what matters to the patient, and what would make a difference to them.
- Assuming people have strengths as well as needs by inviting them to set personal goals that they find important, and to commit to specific actions that they find manageable and achievable, through coaching conversations.

Responsive planning:

- Supporting access to community groups and non-healthcare services through social prescribing (see Chapters 11 and 17) to support wellbeing and address the determinants of health in addition to pathology.
- Ensuring health and community services are aligned to patients' needs, through responsive commissioning, enabling choice, and patient and public involvement.

The partnership approaches (shared decision-making and care-planning conversations) that are central to this model are supported nationally in the UK through a workforce development programme known as Personalised Care.

Personalised care

Personalised care is considered one of the cornerstones of a sustainable healthcare system (61), and is being operationalised internationally (62,63). Personalised care is not to be confused with personalised medicine which aims to target therapeutics through genetic profiling (64). Rather,

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it is about engaging people as active partners in their own healthcare and wellbeing. The rationale is strong: patients and carers are arguably healthcare's most under-rated resource. Finding ways to engage people in the decisions that affect them, rather than applying a one-size-fits-all approach, has been shown to improve the quality of those decisions, reduce decision conflict, reduce unwanted interventions and improve adherence to chosen options (65,66). Coaching people who have difficulty managing their long-term health problems has been shown to achieve better outcomes than purely disease-focused case management (67). Giving people with enduring care needs the autonomy to spend their care budgets as they choose, helps them to achieve better quality of life, and leaves patients and carers feeling more confident and empowered (68). Involving people and communities in social interventions, rather than purely medical ones, can improve feelings of control and self-confidence, reduce social isolation and can have positive impacts on health-related behaviours including weight loss, healthier eating and increased physical activity (69).

This chapter introduces the core communicative strategies of health coaching and shared decision-making and discusses how these might be brought together in a personalised care-planning consultation. Chapters 11 and 17 describe how clinical generalists work collaboratively with link workers and other community and social care professionals to address the social determinants of health and wellbeing through community interventions.

Example 18.2: The Personalised Care Institute

The Personalised Care Institute (PCI) was commissioned by NHS England in 2019, to help achieve an ambition to deliver personalised care to 2.5 million people by 2024, a vision that was set out in the NHS Long Term Plan (70). The PCI was tasked with writing a national curriculum for personalised care, and training at least 75,000 health and care professionals by 2024. The personalised care curriculum was written by subject-matter experts and stakeholders including patient and carer representatives in 2019/20. It underpins the PCI's free open access e-learning courses (71) and the courses offered by accredited training providers. Since its launch in 2020, the PCI has steadily gained national attention, and at the time of writing, the PCI was on track to meet its educational targets. Feedback from health and care professionals who have completed

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the PCI's courses has been extremely positive about the quality of the resources, and the impact it will have upon their practice.

As well as providing training for clinicians and healthcare professionals about personalised care, the Personalised Care Institute accredits training providers to deliver training for new roles that support the implementation of personalised care in practice. These roles include social prescribing link workers, health and wellbeing coaches, and care coordinators. The training for these roles is underpinned by the Personalised Care Curriculum, and the workforce development frameworks for each of the roles (72). Understanding these roles, and learning how to collaborate with them, can be helpful when supporting people who live with multimorbidity.

The PCI curriculum (72) describes six components: shared decision-making, personalised care and support planning, social prescribing and community-based support, supported self-management, enabling choice, and personal health budgets. The target populations for each component are based on their stratified needs, illustrated in Figure 18.2.

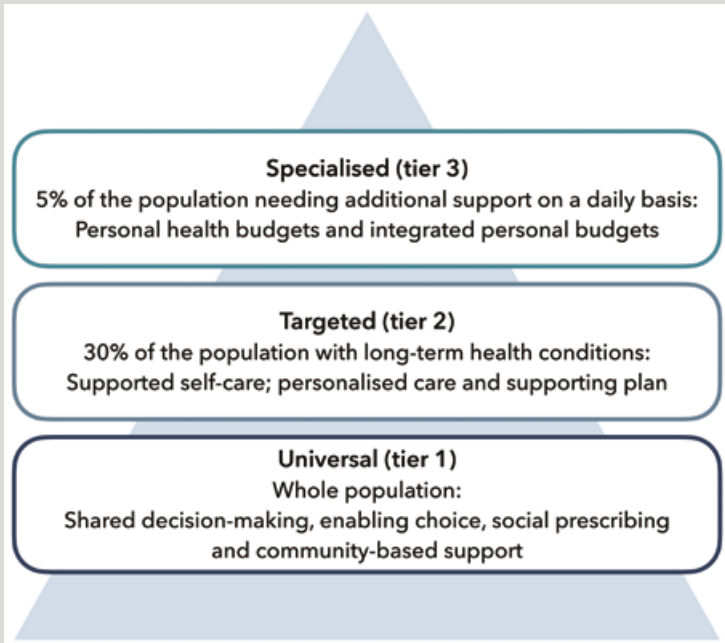


Figure 18.2 The interventions and target populations of the personalised care programme. Adapted from NHS England 2019 (62)

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Personalised care and support planning

Personalised care planning is not the same as treatment planning, which might focus on treating a specific condition or symptom. Nor is it a notification of what is going to be done to a person. It has been described as a systematic process of 'solution focussed forward planning, which acknowledges the experience and expertise of the patient/carer. It brings together traditional clinical issues with what is most important to the individual, supporting self-management, coordinating complex care and signposting to social prescribing' (73).

Care-planning appointments are part of the regular, proactive care offered to patients with multimorbidity. These appointments are typically longer than acute clinical consultations and are ideally separated from routine tests and structured patient education (such as how to use inhalers/insulin) so that the focus is on a personalised forward plan. It is important that patients and carers come prepared to these appointments with the information they need to make decisions, for example, having been sent recent test results or prompts for areas they might like to discuss.

Personalised care and support planning is underpinned by the organisational processes and responsive commissioning outlined in the House of Care, above. These processes support case finding, preparation before the appointment, and responsive commissioning that supports solutions after the appointment. The appointment itself involves generic communicative strategies such as listening and explaining, and more advanced strategies such as coaching and shared decision-making. Clinicians need to recognise which communicative processes are needed for which situation. In practice, shared decision-making often overlaps with health coaching as any plan involves a balance between risks, burdens, benefits and preferences as well as active forward engagement (74).

Health coaching

It can be tempting as a healthcare professional in a care-planning conversation, to tell people what the matter is with them and what they should do to improve their outcomes, for example, lose weight or take their medicines more regularly. Telling the patient what to do can create an illusion of progress, particularly for the clinician, as the patient now has all the necessary information they need to move forward. The chances are, however, that the patient already knows what they should be doing, and there may be complex reasons why they are not. Health coaching is a different approach which invites individuals to focus on something that is important to them, effectively setting their own agenda, and then to develop their own solutions through a guided process. Coaching can help

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to build a sense of ownership and is a process that can be repeated by the patient or carer, increasing their confidence in their personal problem-solving abilities.

There are many different models that fall under the broad umbrella term 'coaching', some of which are discussed in Chapters 15 and 17. Models include motivational interviewing (75), conversations inviting change (76), the StACC model (structured agenda-free coaching conversations) (77) and T-GROW (topic, goal, reality check, options, way forward) (78). Some are more directive (for example, focusing on a specific risk factor such as alcohol, or symptom such as pain), some more structured (for example, using defined steps and numerical importance/confidence scales) and some less structured (for example, focusing on personal narrative). However, they share many common features and communicative strategies. A structured, agenda-free approach is outlined in Table 18.2 (adapted from the StACC model (77) and Year of Care (79)).

Table 18.2 A structured agenda-free coaching model

Engaging	Relationship-building, setting expectations, the healthcare professional explaining their role and the purpose of the meeting
Information sharing	Patient and/or carer(s) telling their 'story': how they have been since the last appointment and why; what has been going well and less well. Health or care professional listening with curiosity, sharing relevant information and evidence as needed, discussing any test results and options.
Agreeing on the patient's agenda	The patient or carer deciding on what is most important to them now, or the area(s) they would like to focus on first.
Clarifying +/- importance scale	Confirming their agenda: how important is it to them? Repeat agenda-setting as needed. What would positive change look or feel like? What does the patient or carer think might help?
Goal setting	Turning their agenda into a specific, measurable, achievable goal. How will they know when they have achieved their goal?
Action planning	Exploring different ways of achieving their goal. Deciding on which strategy or strategies to take. Breaking the strategy into manageable steps and agreeing when and how to take the first step(s).

(*continued*)

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Table 18.2 (Cont.)

Problem-solving +/- confidence scale	Exploring their confidence in taking the first step. What might improve their confidence? What if … questions. What might get in the way of the first step, and what can they do about any barriers?
Follow-up	Recording and sharing the plan. Offering follow-up, with repeat agenda-setting or problem-solving as necessary.

Shared decision-making

Shared decision-making similarly involves a shift in the relationship between healthcare professionals and patients: respecting their autonomy, relationship-building, and curiosity about their values and needs (74). For busy clinicians who are used to a more prescriptive approach, negotiating decisions can initially feel burdensome; however, it also brings practical, ethical and psychological benefits. Patients are more likely to engage if they feel they have ownership of their decisions, and it can reduce 'decision anxiety' for clinicians if they know they are respecting their patients' informed wishes. Shared decision-making, however, is not simply shifting the burden of a decision on to the patient, but is a collaborative act: sharing information and building consensus. If clinicians are genuinely committed to partnership working and individuals are engaged, informed and empowered, then shared decision-making becomes both invited and expected.

At its most basic, shared decision-making about a specific test, treatment or course of action involves a discussion about the benefits, risks and alternatives, including doing nothing, as well as a discussion about the patient or carer's circumstances, values and preferences. Many common clinical decisions are supported by published 'patient decision aids' or 'decision support tools' which might include pictorial representations of risk/benefit ratios. In practice, however, statistics do not always govern how people make decisions or cover the kinds of decisions they need to make which may be multifactorial and highly personalised – for example, whether to move into assisted accommodation or remain at home. Furthermore, decisions are not always discrete events at one point in time, but rather distributed processes that may include other professionals, friends and family, involve autonomous information gathering and be revisited over time (80). Shared decision-making needs to address the power dynamics that are implicit within a practitioner–patient relationship; particularly so for people with multimorbidity who may have had their autonomy eroded through ill health. Elwyn suggests three types of

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Table 18.3 The 'Three Talk' model of shared decision-making

Team talk	Indicating choice Providing support Identifying goals	We need to decide together which option … /whether to … Let's work together to make a decision that suits you. What matters to you? Who might you want to discuss this with? What information do you need? [Provide information e.g. patient decision tool]
Option talk	Comparing alternatives Discussing harms and benefits	What did you think of the information? [+/- clarification] What are your concerns about each choice, including doing nothing? What would the benefits of each choice be for you?
Decision talk	Getting to informed preferences Making preference-based decisions	Can you exclude any choices? Which choice are you leaning towards? Are you ready to decide?
Active listening	Attending closely to what is said with curiosity, checking understanding	Tell me more about … What do mean by …
Deliberation	Thinking carefully about options and preferences	Deliberation: often away from the consultation, with friends and family, over time, supported by self-directed information seeking.

talk within shared decision-making: team talk, option talk and decision talk which are underpinned by two processes: active listening and deliberation (Table 18.3 – adapted from Elwyn and colleagues (74)).

Example 18.3: Aran's personalised care-planning appointment

Aran (they/them) is a 20-year-old college student who has anxiety, obesity and recently diagnosed type 2 diabetes. Aran mobilises with a wheelchair following a childhood spinal injury. Aran was recently prescribed an array of tablets but takes them infrequently. Aran lives at home with their mother, but finds this difficult.

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Aran received a letter inviting them to a 20-minute personalised care-planning appointment at their GP practice in two weeks' time. Aran's GP practice has various care-planning invitation letter templates for different conditions. The practice sent Aran a letter that was tailored for mobility impairment, mental health and diabetes. The letter included a visual prompt asking Aran to rate how they were coping. Next, it listed a range of topics that might or might not be important: washing, eating and drinking, exercise, pain, falls, mobility, memory, feeling down or stressed, loneliness, relationships and sex, feeling scared, sleep, continence, smoking, alcohol or drugs, taking medicines, preventing future health problems, their care package, support from family and carers, finances.

Aran was invited to list what was going well, what needed to change, what was important to them, and any ideas they had. The letter also included results from a check-up two weeks ago: glycosylated haemoglobin, lipid profile, renal function, body mass index, blood pressure, foot checks, and a prompt for an eye test. The letter explained and graded each test result into high, medium or low risk. There was a space for Aran to write their questions or thoughts against each result. Aran's glycosylated haemoglobin, cholesterol and body mass index were graded as high risk. Aran spent some time going through the letter and looked up cholesterol and glycosylated haemoglobin online. Aran noted that both could lead to serious complications over time, but could be improved by taking medicines more regularly, or by dietary change and exercise, or both. Aran wrote on their letter that losing weight felt important, but impossible and took it to their appointment.

After greeting Aran and ensuring they were comfortable, the practice nurse explained that they would spend about half the appointment discussing how Aran had been since they last met and going through any questions they had, and the rest of the appointment planning ahead. Aran shared the completed prompt letter and said they felt generally OK but were anxious to lose weight as they wanted to avoid taking medicines if possible. After exploring this, the nurse asked if there was anything else. Aran explained that living at home had become difficult since starting college. Aran felt their mother 'fussed' a lot since the spinal injury. After exploring this, the nurse asked what Aran wanted to focus on first. Aran felt that losing weight might solve several issues, so they agreed to start there. Aran

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explained that losing weight felt impossible as their mobility problem meant they had difficulty exercising. The nurse asked if Aran had any other ideas about how they could lose weight. Aran said eating differently might be easier. The nurse asked Aran to describe a typical day's food and drink. Aran said their mother provided healthy meals, but also offered up to six snacks each day, mostly crisps, snack bars and soft drinks. The nurse asked Aran what an achievable change might be. Aran thought they could cut down to one snack each day and try drinking tea instead of soft drinks. The nurse asked how confident Aran was in achieving this. Aran admitted, not very. Aran didn't want to cause offence by refusing snacks from their mother. The nurse asked what Aran felt would help. After discussing several options, Aran settled on involving their mother in the plan and getting them to count the snacks. Aran and the practice nurse spent a few moments designing a snack diary. The nurse asked Aran if there was anything else that might improve their confidence. Aran said no, they felt confident they could do this. The nurse asked if a follow-up phone call in a couple of weeks would be helpful. Aran agreed. They also agreed to repeat Aran's tests in a few months' time to see if there had been an improvement.

Pause and reflect

We invite you to reflect on the above example. Who was doing most of the work in this appointment? Do you feel Aran had sufficient understanding of the risks and benefits of the different options (medicines, lifestyle changes, or both) for addressing their risk factors? What were the risks and advantages of sharing test results with Aran before the appointment? Would change have happened without this care-planning process? List the factors that led to Aran's dietary change. Compare these factors to the default consultation: telling Aran to take their medicines more regularly and to lose weight. Both aim to attend to biomedical and lifestyle factors, but which approach is more likely to support action or change?

Educational approaches

Chapter 6 articulated some of the challenges that clinical education can produce for generalism. A clinical learner is taught to diagnose, treat and

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be 'the expert'. Teaching, learning and assessment often focus on systems and conditions, instead of focusing on the unique circumstances of the person. The limitations and constraints of a technical biomedical model when dealing with the epistemological uncertainties of multimorbidity can be associated with significant distress in learners (81). Learning to practise personalised care, however, can be a challenge for health and social care professionals, especially if they are used to being advice-givers or if they do not see personalised approaches being modelled around them.

For learners to 'buy into' personalised care and develop as 'person-centred' clinicians, a realist review suggested three key educational elements are needed (82):

- Priming: information should be given on what person-centredness is, what it means for learners and their patients, and why it is important.
- Meaningful experiences: learners need an active role in the clinical workplace, where they can understand patient narratives over time.
- Opportunities to process experiences: learners need a safe space to reflect, process and challenge their previous assumptions.

The cognitive apprenticeship model of learning (Figure 18.3, adapted from Stalmeijer after Collins and colleagues (83)) outlines the tacit steps in a learner's journey from novice to expert within a community of practice and embodies the steps outlined above.

For personalised care, a cognitive apprenticeship might start with watching these approaches modelled by experts, supplemented with pre-reading or an online course such as the modules provided open access

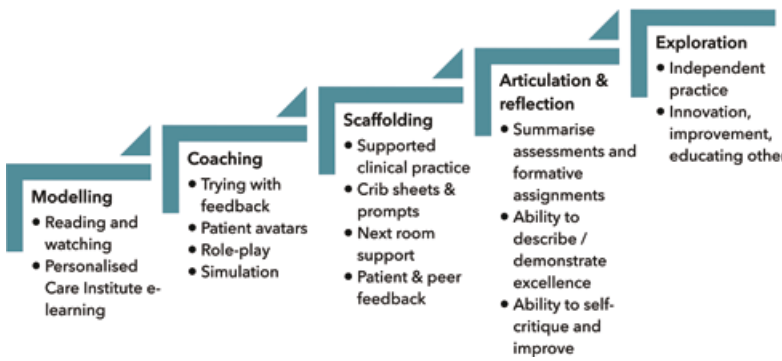


Figure 18.3 A cognitive apprenticeship in personalised care. Adapted from Stalmeijer (83) after Collins and colleagues

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by the Personalised Care Institute (71). This could be followed by initial skills development, for example through role play using the Personalised Care Institute's patient avatars, or simulation-based learning opportunities with direct feedback from patient educators and/or advanced practitioners. Once the learner feels able to find the right words, they might progress to clinical practice, scaffolded by crib sheets, patient and peer feedback, or next-room support. Once learners can articulate and reflect on their developing practice, they progress towards independent exploration and mastery learning, finally becoming experts themselves.

Assessment approaches

It is important to assess whether the clinicians of today and tomorrow have the skills, knowledge and confidence to support people who live with multimorbidity. If multimorbidity and personalised care do not feature in a learner's assessment, then learning about them is likely to become marginalised. Chapter 7 articulated the tensions between reductionist assessment methods and the complexities of generalist forms of clinical practice. Internationally, written examinations, including many national licensing examinations, are increasingly based on multiple-choice formats (84). These typically invite the learner to select 'the single best' management option for a given clinical presentation, whereas in multimorbidity there may be differing perspectives on what the most appropriate way forward is. Practical assessments such as OSCEs or PACES promote standardised approaches to clinical skills and tend not to assess more complex practices associated with multimorbidity care such as collaborative working and relationship-based care. There is a need for more complex assessment formats that drive learners and teachers to engage with multimorbidity and personalised care (see Chapters 6 and 7 for further discussion).

Chapter 7 introduces a range of assessment modalities that are potentially more suited to generalist forms of clinical practice. These include structured workplace-based assessments such as case-based discussions (85,86). Workplace-based assessments are not without challenges, including failure to fail, but can be helpful as formative assessments (to promote reflection and growth) or hurdle assignments (to drive learning behaviours by requiring tasks to be completed) (87). The Simulated Consultation Assessment (SCA), recently introduced by the UK's Royal College of General Practitioners, is a form of assessment that is potentially suited to assessing generalist approaches to multimorbidity in pass/fail examinations. The SCA involves 12 short whole

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consultation simulations over a 9-month period, each marked by a different examiner with opportunities for feedback to promote reflection and growth. Ideally, an authentic assessment would allow a learner to work with all the resources that a generalist would normally use, including patient records, online guidelines, local referral options and other sources of support.

Bridging the gap between education and practice

The House of Care is a whole systems approach and 'clinicians committed to partnership working' is just one pillar. Training alone is unlikely to be enough to change the delivery of care in practice. In addition to attending training, practitioners must also *want* to change *and* have the right structural and cultural opportunities (see Chapter 9). They need to believe that new ways of practising are better than the alternative, and feel encouraged that change will be acceptable to others. It may also be necessary to make physical changes to working environment or changes to their working processes to ensure appointments are long enough, that the right patients are identified and invited for care planning, that patients and carers come prepared for collaborative conversations, that distractions such as form filling and requests for diagnostic tests are minimised, and that there are community referral pathways and resources to support the full spectrum of people's needs.

Conclusion

People who live with chronic ill health or disability have highly individualised strengths and needs. These can fluctuate and vary not only according to a person's health and condition(s), but also in relation to their social, environmental and economic contexts. Multimorbidity is challenging to address through protocolised approaches which are the mainstay of evidence-based medicine. This has arguably led to a mismatch between the needs of people who live with multimorbidity, and the prioritisation of interventions to support them. A breadth of research methodologies are needed to explore the experiences and strategies necessary to meet the needs of people negotiating multimorbidities. One key effective approach is personalised care, which treats people as experts in their own situation, and works with them to address what matters to them. It involves professionals, patients and carers integrating and using a range of available knowledge, and sharing information, power and responsibility. Personalised care is built on core

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communicative competencies including coaching conversations and shared decision-making and is supported through proactive systems, coordinated teamworking, and engagement with social and community resources as well as healthcare.

Example 18.4: Multimorbidity module, intercalated Primary Care BSc at UCL

This module was established in 2021 and jointly led by the Centre for Ageing Population Studies and the School of Pharmacy at UCL, encouraging interprofessional learning between undergraduate pharmacy and medical students. It runs over a term and explores core debates and challenges, introducing and critically evaluating how health and social care systems support patients with multiple long-term conditions. During weekly interactive workshops, students hear from leading researchers about: ageing and illness, frailty, mental health and loneliness, polypharmacy, social prescribing, health inequalities, drugs and alcohol, and finally complementary medicine. Assessment includes a group presentation and a two-thousand-word essay, based on any aspect of the lectures. Feedback shows the learners value learning with and from others from different clinical courses. This encourages interprofessional learning and builds on previous interprofessional education experienced in earlier pre-clinical years.

For further information: www.ucl.ac.uk/epidemiology-healthcare/study/undergraduate/ibsc-primary-care-research-and-clinical-practice/ibsc-primary-care-and-clinical

Further resources

The Personalised Care Curriculum and e-learning resources

- www.personalisedcareinstitute.org.uk/

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