Supplementary Table 2. Extracts from the included studies and codes

Author	**Extract**	**Codes**
Audulv et al. (25)	For other participants lifestyle changes were harder to maintain in their daily lives. For example, exercise could be difficult for participants with chronic or episodic pain and/or fatigue. Some participants with rheumatism described how they adapted their exercise, depending on current symptoms. For example, X alternated between walks, gym exercise, and swimming depending on her levels of pain: "If I have pain, then I notice that the only exercise I can do is swimming […]. I do not go out and take walks if I have a whole lot of pain in my feet" (rheumatism, 30 months after diagnosis). Other people with chronic pain struggled during the two and a half years to find an exercise they could perform despite their pain. For Y, exercise had been an important part of her life before she developed rheumatism but after her diagnosis it was difficult for her to maintain fitness: "Because I can't move the way [I used to]. I can't go on speedy walks or bike or so. I don't use the weighting machine, but can feel it [increased weight] on the clothes" (12 months after diagnosis).	1. Not understanding symptoms and modify exercises accordingly, to maintain the same lifestyle as before. a) some give up b) some find and alternative
Bowling et al. (26)	Finally, Environmental Factors added layers of complexity to patients' self-management activity (Figure 1, Environmental Factors box). In keeping with the ICF, these factors included the patient's social and medical environment. Participants described wanting to fit into social structures (i.e., families) in which the majority of the group ate high sodium, high-protein foods and described real pressures of social acceptance. On the other hand, positive social support could aid the patient ("my wife sometimes will prepare different meals for me than she does for herself and my daughter"). When it came to the health care system, patients described deficient provider support (i.e., rushed physicians, little continuity). In addition, whereas patients are often concerned about these interacting factors and their "overall picture," they described each provider as having a narrower focus on the relationship between the specific disease and the self-management recommendations of interest to their medical specialty ("I see four doctors here at the VA, so I can never remember who is doing, checking, for what").	1. Family acceptance. They want to fit in, a) some people are supportive (e.g. wives) 2. Fragmented recommendations, difficult to keep up. Therefore, a challenge to integrate them. a) no support and continuity of information form health professionals
Corcoran et al. (27)	Difficulty identifying exacerbations Six participants reported difficulty with identifying exacerbations of CHF and making decisions about how or when to act. A woman in her 80s said: 'I had a silly pain in the middle of my chest. I wasn't gasping for my breath or anything like that, I just had the burps. I rang my daughter up. They got the ambulance to me and took me to hospital. They said I had a heart attack' (APT027).	1. Responsible to detect, understand and make a decision on accordingly to a symptom a) a family member can provide help
Dixon et al. (28)	Some interviewees, including one at level 4, simply lacked self-belief that they could make the changes or were despondent as a result of a lack of success. One female interviewee felt that the changes that her provider was asking her to make were too radical and she did not feel capable to make the recommended changes at the pace required. Those with low levels of activation generally seemed to see themselves as the main reason why	1. No confidence to implement recommendation. a) does not agree. Not realistic

	they were not managing their condition well or doing the things that they were recommended to do by their doctor. The inability to take regular exercise was commonly blamed on being lazy, particularly by those with low activation. When interviewees expanded on the reasons in their responses they were able to identify practical constraints or barriers in the external environment, e.g. television, time constraints, and difficulty of scheduling exercise around work and domestic tasks or social engagements.	2. Difficulty scheduling and fitting exercises around work, domestic tasks and social engagement.
Duguay et al. (29)	The physical limitations their health imposes — such as respiratory problems, joint pain, or lack of muscular endurance — affect their ability to perform many daily activities and even to hold a job. A father with obesity, chronic lower back pain, and osteoarthritis (among other diseases), which cause problems with mobility, mentioned that: “When it comes to my work, it’s really hard, I’m limited physically in what I do compared with what I was doing before, not easy at my age” (male, five chronic conditions). Physical limitations also affect participants’ social lives, because they are constantly worrying about disease management(medication, treatment, restriction), even while participating in social activities, and could feel excluded. “My cousin has a cabin in the woods 2 hr away and doesn’t dare invite me anymore because of my health” (female, six chronic conditions). In general, participants in this sample preferred to do things alone rather than to deal with the pressure of spending time with others. Finally, some participants said that multimorbidity also affects their sex life, another dimension of social life: “I find it difficult not being able to do the same activities as before, both in terms of going out and having sex” (male, five chronic conditions).So, I endure the pain. [Drug A] and [Drug B] raise my sugar level. Let’s say I want to buy myself a treadmill to exercise so that I can improve my strength. I can’t do it; I’ll have too much pain in my knees. I’ll still have some pain everywhere” (male, five chronic conditions).	1. Physical limitations are not managed enough to be able to perform other activities in daily life (work, social). a) not being invited in trips b) accomplish activities alone to avoid social pressure.
Fuller et al. (30)	Skills and Knowledge In both groups, there was general lack of understanding regarding the intensity and duration of physical activity required to confer health benefits. Many saw the intention to undertake regular activity as being sufficient, but there was limited knowledge and understanding of how to monitor physical activity levels and set appropriate targets. Whilst some Active Living participants had previously acquired a degree of motivation for physical activity from their attendance at pulmonary or CR programs, few were confident that they had the skills or knowledge needed to maintain ongoing regular physical activity.	1. Not understood the intensity and duration of the physical activity. No skills how to measure activity levels
Gardsten et al. (31)	Health issues Both groups, expressed uncertainty about how blood glucose levels are affected by exercise, eating habits and medication. Medical treatment and physical reactions contributed to a complex picture of how blood glucose levels should be balanced. For example, one challenge was to understand how blood glucose levels are	1. Difficult to understand, read the symptoms. Also, how do daily routines influence symptoms?

	affected during physically demanding work. Both groups also had to manage medication, and thus needed to understand the effects of the drugs on them individually and the different names used for identical drugs. It was also challenging to realize that diabetes is a chronic disease and to understand how blood glucose levels and daily routines affect each other. Healthy living Other challenges for both groups involved physical activity, such as how to balance physical activity in leisure with physical activity at work. One participant in the recently diagnosed group assumed that physical activity in terms of walking or climbing stairs at work only affected blood cholesterol values. The participant (Table 3, quote 3.2) was asked how he engaged in physical activity even though he often travelled to different construction sites. He assumed that physical activity needs to be exercised in another way for maximum health benefit. The experienced group had tried to learn to live healthily and, especially, to avoid complications based on the information they had received. Healthy living Both groups faced challenges in learning how to plan meals and develop regular and healthier eating habits (quote 4.2). Shopping for healthful products such as bread, yogurt, and beverages was also challenging, especially reading the small text of lists of ingredients and relating the content to their own health status. For those who lived alone, it was challenging having to cook and eat alone, since eating at restaurants contributed to higher costs of living. At work, both groups tried to minimize stress. Travel was also more challenging as they had to plan meals and balance sleep and stress while away from home. Both groups described challenges in finding suitable everyday routines for healthy living. The experienced group perceived challenges in translating general knowledge to their individual circumstances, such as balancing insulin therapy with their particular personal needs. To change their eating habits more easily, they wished that the diabetes nurse had taught them what they could or should eat, rather than what they ought to avoid.	2. Difficulty scheduling and fitting exercises around work, domestic tasks and social engagement. Difficulty with other self-management activities like planning meals (at home, at work, in travels). a) not able to translate general knowledge an apply in in individual circumstances b) wished more practical information from health professionals
Gary, R (32)	Married women and those with caretaking responsibilities described preparing what their family members preferred rather than food items on their recommended low-sodium diet. For example, one woman jokingly remarked, “if I fixed food like I am supposed to eat, no one would show up at the table and I don’t blame them using no seasoning.” Women were reluctant to give up culturally influenced dietary practices. For example, they commonly used pork for seasoning in vegetables such as greens and beans despite being aware that pork contained high sodium amounts. Eating at restaurants was considered a rare treat for many participants and a time when most women admitted they did not adhere to sodium restrictions. For example, one woman said, “Eating out is something special and I like eating my favorite things salt or no salt.”	1. Not part of family routine

Haverhals et al. (33)	Several participants in the study visited practitioners of alternative forms of health care that included nutritionists, chiropractors, acupuncturists, or homeopaths. Many of these participants were frustrated about conflicting information that they received from their primary care doctor and alternative care providers regarding their health, the etiology of their illnesses, and the safety and effectiveness of their conventional and complementary medication regimens. In general, these participants did not feel that their allopathic doctors supported alternative care and therefore did not always tell them about alternative medications or therapies that they were pursuing. For 2 participants in particular, this was a source of confusion and stress regarding medication management and decision making: The biggest problem in my mind for my personal planning and decision making is the kind of conflict between my primary care doctor, traditional medicine man and this alternative [practitioner] — who happens to be a chiropractor— but he has done a big study of supplements. Consequently, I take 20 or 25 pills a day. My primary care physician just doesn't care a hoot about all those supplements ... Most people do not take all the pills I take, I've discovered. They take prescription pills, but I take magnesium and calcium and some brain pills and all kinds of stuff, and those are very important to the alternative medicine person in my life. But they are just uh ... minimized totally by the primary care doctor so I feel like I'm fighting two sides. [Confirmatory focus group 2 participant]. Another participant asked: If you don't follow the regimen, do you feel any different? Response: "Yes, I do...But then I don't know which one to blame or credit!"	1. The challenge of making sense of conflicting information, decision-making about the right medication a) search alternative health care b) not feeling supported by their doctors 2. Difficulties in understanding which medication brought which effect.
Janevic et al. (34)	Pain and mobility limitations have direct and indirect effects on asthma and asthma management. Several women described pain or mobility limitations resulting from comorbid conditions as interfering with the physical tasks involved in asthma management, such as housecleaning, or even inhaler use, as described by one woman: Another woman described not being able to discern if her symptoms were caused by her anxiety issues or because her asthma was ''being really weird''. She thought at the time it was her asthma but later found out that her symptoms were due to her anxiety.	1. Physical limitations are not managed enough to be able to perform other physical tasks (e.g. housecleaning). Difficulty understanding the cause of her symptoms.
Jerant et al. (35)	Poor communication with physicians Several participants reported feeling ''rushed'' through doctor visits: ''The doctor doesn't have time to be thorough,'' and ''I just can't talk to my doctor because there isn't time.'' Several mentioned that, as a result, they had not been able to develop an adequate understanding of what caused their diseases, what their effects were, and how best to manage them. Many participants also had concerns about aspects of their physician's communication style. Some were global (e.g. ''My doctor doesn't communicate well''), while others were more specific (''The doctor doesn't listen to me'' and ''The doctor won't consider any alternative options, just pushes pills''). Other family-related issues concerned spousal support.	1. Not being attended properly in order to understand information and being able to apply it. a) health professionals rushed 2. Challenge to follow diet. a) some lack of support from family members b) some were helped by family members

	Some participants mentioned spouses who would not cook appropriate foods or help support weight loss efforts, or who expected homes and families to be cared for in the same way as before the participants had developed their illnesses. Losing a job or having to quit work because of illnesses created problems at home for many participants, particularly men who found themselves suddenly at home all the time without much to do. While participants who perceived strong support at home seemed better able to cope with their conditions, some expressed distress related to depending on others. For example, one woman spoke of her 21-year-old grandson having to care for her and still go to school (''It's so hard on him''). A few participants lived alone and had little or no support from family or friends but had found others to help met their needs. For example, one elderly woman who lived alone had the delivery man put the wood for her stove on a bench on the porch because she could not bend over and lift it from the floor of the porch. Pain Pain kept many subjects from doing what they most wanted to do by making it hard for them to stand, walk and sit for long periods of time. As a result, some had dropped highly valued social engagements such as going to church or get together.	3. Physical limitations are not managed enough to be able to attend social engagements
Majeed-Aris et al. (36)	Supporting family is a barrier to self-management An important role for participants was supporting their families in their roles as wife, mother and daughter-in-law. Women perceived putting the family's needs before their own as a key barrier to self-management: Looking after him would affect my health. Sometimes I would be unwell in myself and I would be tired and would not want to do any work. But my husband was so poorly that I had to. He stayed in hospital a lot, going, coming back, visiting, doing everything with young children. All participants considered the most important familial responsibility to be the care of young children. Mothers with young children talked about feeling rushed and having conflicting priorities. Older women recalled that management of their diabetes had been harder when their children were younger. Women with grown-up children talked about feeling generally supported by their offspring, although two women offered an alternative view. X and Y, the two participants with the most limited English, held views that suggested they sometimes felt unsupported by their families: Things looked blurry, lop-sided. I was in bed, and the pictures hanging on the wall, I couldn't see them well. I told my daughter "I can't see well". Before they all used to think I was just saying it, just joking, but one day I was sitting and I said "Seriously I can't see, take me somewhere" and they took me to the optician. The optician said "Yes, it's leaking at the back", now they are trying laser treatment but it's not working. First and second generation women frequently commented that men with diabetes sought and received more practical family support than they did, particularly from spouses. Two of participants' husbands had T2D and	1. Wives, mothers, and daughters-in-law prioritize family needs first even though it affects their health. a) sometimes the husband is also sick b) sometimes the family is not supportive c) sometimes children are young and need care

	they spoke from that experience: My husband had diabetes after I got it. He got it later on you can say 10–12 years back.... So I have to control his diet and his things, “You should take care of your feet. You should go for a walk. You should eat this. You should eat not this one.” So my experience is that um men they don’t care for you but you have to care for them.	
Mickelson et al. (37)	A striking observation was that many patients, caregivers, and clinicians had incomplete or incompatible knowledge regarding medication management. Patients do not always know what medications they were taking, their medications names, directions for use, or what effects to expect (Table 3a). Several patients lacked knowledge about the relationship between medications and symptoms, and, therefore, when it was appropriate to take medications. We observed several instances of “misfit,” in which artifacts were incompatible with patients, other artifacts, routines, and environments of use. Instances of artifact-artifact misfit included differences between patients’ and clinicians’ artifacts. For example, patients’ scales or BP cuffs produced readings different from their clinics’. Patients’ homemade or modified medication lists often differed from those generated by the EHR. Artifact-person misfit occurred when cognitive artifacts were ill-suited for older users, their experiences, mental models, limitations, and daily routines. There were also four major disadvantages. The first was related to integrating or reconciling multiple representations. Clinic visit communication was rarely structured around patient artifacts such as personal medication, lists and both clinicians and patients showed difficulty understanding each other’s lists. The multitude of lists and frequent updates was challenging, with some patients using outdated or incorrect lists. Once a pillbox was filled, it took effort to verify and identify the dispensed medications; patients described medication errors due to similar-looking medications or misfiling the pillbox.	1. Incomplete knowledge on what to expect from medications. What symptoms were affected by medications and how did they change? 2. Recommendations and artifacts not customized to environment, age, daily routines a) health professionals did not take these aspects in consideration
Mphwanthe et al. (38)	During social events such as weddings and when travelling, participants expressed concern that they could not consume recommended foods. As such, they improvised or ate what was available at that moment and often reduced the amount consumed. Some participants also indicated that the food served during special events such as weddings and parties is considered delicious and difficult to resist. At parties, I do eat the foods that are there because the foods are usually delicious. On Christmas day, I neglected my condition and I ate delicious foods with my children, and my blood sugar is always high. Additionally, when travelling to different areas within the country, participants found it difficult to find appropriate food to purchase because most of the food sold along the way [street foods] are often not recommended for T2DM management. Fear of public ridicule Although involvement in physical activity is required for diabetes management, fear of the potential negative connotations from society acted as a setback to freely participate in different forms of activities. ‘I sometimes	1. Difficult to follow diet recommendations in another circumstances (e.g. travel, weddings). a) ate something else b) modified the portions c) ate the available food, prioritized family 2. Challenge in performing exercise because of fear of public ridicule. a) family not supportive b) society stigma

	[once in a while] dance in my bedroom as part of exercise, because my children and other family members including the neighbors laugh at me when I dance as exercise outside the house' Indeed, neighbors disappoint us. One day a neighbor said, 'Why do you do all the household chores as if you don't have children? But for me this is part of my exercise'.	
Munce et al. (39)	Caregiver burnout Caregiver burnout was identified as a major barrier to self-management on the part of individuals with traumatic SCI and this was well-recognized across all participant groups. Given the role that family members/caregivers play in care processes and overall well-being of individuals with traumatic SCI, several participants believed that caregiver burnout could threaten the sustainability of these critical supports. Indeed, the dual role of family members – most often wives in the current study – as both a spouse and performing the duties of a nurse was highlighted as a stressor. A lack of specialized or targeted services/programs for family members/caregivers to address this burden was also noted.	1. Caregiver burnout as a key obstacle to self-management. undermine the sustainability of crucial assistance.
O'Conor et al. (40)	Patients reported frequent lifestyle limitations as a result of their asthma such as a limited ability to do daily tasks or housework, inability to have pets or engage in formerly enjoyable social activities, such as dancing or sports, in an effort to avoid possible triggers. Lastly, they reported restricted freedom of movements due to their asthma, such as the inability to leave their home, especially during extreme weather. Some stated that they purposely avoided locations where they might encounter a trigger, while others stated that they needed to modify activities that required physical exertion. Self-monitoring was another patient-reported strategy. Facilitators of active self-monitoring included checking peak flow to assess symptoms and determine changes in asthma control. Additionally, patients reported staying within their known limits and not exerting themselves in a manner that would bring on asthma symptoms. One challenge to self-monitoring is the uncertainty about whether shortness of breath, fatigue, or cough was due to asthma or some other chronic illness. One patient also reported being unable to discern when her asthma symptoms are worsening and received no warning signs before an asthma attack, "I worry because it is silent, suddenly I feel suffocated. I worry because I don't feel symptoms to warn me." The patient did not recognize that daily albuterol use was indicative of poor control. Consistent with this perception, a theme of marginalized expectations of health status was identified. Patients had accepted a level of shortness of breath or restricted freedom of movement as a result of asthma and did not recognize the potential quality of life he or she could achieve with greater asthma control.	1. Physical limitations are not managed enough to be able to perform activities (e.g. housecleaning, having pets, social activities). a) chose to avoid them 2. Self-monitoring is difficult. Unclear if shortness of breath, exhaustion, or cough (symptoms) are caused by asthma or another chronic condition. a) not being able to achieve self-management made them to depend on medication.
Paterson et al. (41)	Participants concurred that despite the compassionate and competent manner of many health professionals, their response to patients' experiential knowledge often betrayed their essential allegiance to professional dominance. Several indicated that attempts to assume an active role in decisions about their care were met at	1. Lack of trust between patient and provider. The way of delivering information can affect their ability to make decisions.

	times with obvious skepticism and, at other times, with anger by health care professionals. For example, many participants told stories of episodes where health care professionals encouraged them to participate in decisions about their care, but then immediately discounted what the patient offered in terms of data. Participants perceived such incidents as `not walking the talk' of empowerment. They stated that until they know that they can be open with a health care professional about their ideas and experiences, they cannot engage in participatory decision making. Participants stated that practitioners most often communicate their distrust of experiential knowledge in their response to patients' statements about what they believed or desired in their disease management. Three participants indicated that some practitioners respond to such statements by emphasizing the unpredictable nature of diabetes and the complexities of diabetes management that are beyond patients' knowledge and abilities. Inadequate resources for decision making Participants identified a number of resources necessary for them to engage in participatory decision making with practitioners. This included information, time and monetary. Participants stated that the way information is given to persons with chronic illness could affect the willingness and ability to engage in decision making with the practitioner. For example, when practitioners spoke in medical jargon they could not understand, they perceived it as accentuating the power differential between the practitioner and themselves. `If he can't be bothered to talk so I can understand him, he doesn't really want me to make the decision with him'. Five participants stated that practitioners who do give information irrelevant to their unique situations impair the ability to use that information. A common example was when health care professionals suggested interventions to be used at home without considering the architectural, social or financial constraints that prohibit such a plan.	a) jargon b) not relevant to their unique environment and situation
Salim et al. (42)	Stigmatizing experiences were challenging and inevitably influenced self-management decisions. Sports and physical activities such as playing football were identified as essential activities in embodying health identities, particularly among two young men in this study. Thus, for these participants, using an inhaler before a game or during a match demonstrated ‘weakness’ and invited unwanted social reactions.	1. Stigmatizing events were difficult and impacted self-management.
Steinman et al. (43)	Although individuals and PEs knew about evidence-based chronic disease management strategies, there were deficits in IMB skills to carry out these strategies on a regular basis. Knowledge gaps included misunderstandings about what constitutes the appropriate frequency, intensity, and duration of physical activity and how to incorporate dietary changes into their lifestyle. As one patient shared: For me, the most significant content is about physical exercise—how to do physical exercise properly and what are the advantages of doing physical exercise?	1. Knowledge gaps included frequency, intensity, and duration of physical activity and dietary modifications. Lacked the skills to incorporate the recommendation to daily routines .

	Challenges to incorporating recommended dietary changes into their daily routine included that household meals are prepared by other household members and that other household members prefer more salt and sugar for better taste, they work long days and get fatigued when they do not eat their typical foods, and healthier foods are more expensive and harder to access.	
Van de Bovenkamp et al. (44)	For other patients, quality of life means that they are less active self-managers. They take their prescribed medication and speak up in medical consultations only when something is very important to them or when relatives push them to do so. However, generally, they do not play an active role in consultations, do not look for information about their condition or make adjustments to their medical regimen to fit their daily lives better. These patients value medical paternalism; they tend to follow doctors' orders and expect professionals to decide in their best interests. They feel that the professionals know better than them and to play a more active role would limit their quality of life.	1. Difficulties in fitting medical regime to daily life routines because they are passive in asking for knowledge and information. leave the decision to health professionals .
Williams et al. (45)	However, some participants had traditional roles caring for the family, which interfered with their self-care. A Greek participant stated: I have three (grown) men to look after and it influences my medicine taking. (Participant 36). Other participants cared for sick family members which was an added stress, and prioritized their care over their own at times. A participant stated: Carer for parents. Blood pressure up to 240 [mmHg] systolic- 'stressful'- and father has tumor of the liver. I put out tablets for parents and myself. . . I give pills to Mum. Sometimes Mum forgets she has already had them so I keep them in my room. (Participant 11).	1. Prioritizing family need over self-care.
Zanini et al. (46)	What distinguished the Delegators from the Thoughtfuls and the Selectives was their preference for passive (e.g. air-flow bed) versus active preventive measures (e.g. skin inspection), their tendency to act under the guidance of caregivers and not on personal initiative, and their preference for handing over responsibility prevention to others (e.g. homecare service) Additionally, the Delegators had high expectations from the performance of assistive devices (e.g. no need to change position in bed) and could consequently be annoyed if a PI developed despite their use. Selectives reported contacting experts for timely support and had a network of HPs that they could turn to for advice or care if they believed it necessary. Expertise in SCI seemed to be crucial especially for the Selectives, as some participants stated that they preferred to find solutions on their own rather than turning to HPs who had no expertise (e.g. general practitioners) In line with their preference for delegating the responsibility of prevention, the Delegators seemed to prefer more supervision (e.g. regular checkups in the outpatient clinic, home visits from the specialized counseling service).	1. Different ideas of responsibility for self-management. a) guidance of caregivers or health professionals b) found solutions themselves (problem-solvers)

ICF – International Classification of Functioning, Disability, and Health, CHF – chronic heart failure, HF – heart failure, CR – cardiac rehabilitation, T2D – type two diabetes, SCI – spinal cord injury, PI – pressure injury