

Online Supplementary Material

Gallacher K, May CR, Montori VM, Mair FS. Understanding patients' experiences of treatment burden in chronic heart failure using Normalization Process Theory. *Ann Fam Med*. 2011;9(3):235-243.

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Supplemental Table 1. Taxonomy of Treatment Burden	
Component and Tasks	Examples of Quotations
Learning about treatments and their consequences	
Developing an understanding of the diagnosis and differentiating between illnesses	"It's emphysema and heart failure, that covers the lot really you know. Including in that you've got the bad veins, your legs and all." (patient 20)
Developing an understanding of tests or treatments	"Well I know they are water tablets, but I always thought that that was a heart tablet, but it's to do with the blood pressure....It does strengthen the heart as well but it's mostly for blood pressure." (patient 24)
Developing an understanding of the role of health professionals	"I'm under X. I'm under Dr X in Y as well for the valves." (patient 41)
Learning about diagnosis, tests, or treatments from health professionals	"I've asked him (doctor), he has just explained that all it is really is that the arteries are narrowing and that the blood can't pump round your body as quick as it should be and the reason with the medication is supposed to open the arteries for the blood supply to go better than what it is, but whether it is or not...." (patient 36)
Learning about illness through friends and family	"My granddaughter says I shouldn't eat salt because that retains water, but they never told me any of that and I never did see a dietician. I must admit I am a bit more on the salt, so I could really do with asking one of the doctors in the surgery about what I should or shouldn't eat." (patient 24)
Reaching one's own personal view of the illness and its management	"If I get a chest infection the actual infection might stop but it's still on my chest, so unless I get antibiotics almost immediately that I get the infection, if it starts with flu or whatever—a cold—it's hard to distinguish between them at time—but it invariably goes onto my chest and the chest is clogged up...and unless I get a dose of antibiotics when I get a cold or whatever, it will invariably go onto my chest and will stay there." (patient 10)
Researching the illness and its management through medical resources or other media	"The only information that I get...is when you get these tablets in box form and they try and explain it to you. You get a bit more information that way than you would do in any other cases.... Reading the leaflet the print is that small and they use very big words for the likes of me—it's foreign, I don't know what it means." (patient 23)
Relating how one feels about the illness, treatments	"When I get up I feel tight in the chest...coughing up phlegm and mucus, and since then I've been taking the water pills and that and it seems—with these other drugs now—it seems to have cleared up and it seems to be improved since then." (patient 10)
Taking responsibility for your own actions	"I am a smoker so I suppose that doesn't help my condition, well I realize it doesn't, but the condition of shortness of breath, I have that but I think a lot of it is due to my age and obviously when you get older you can't run around and sometimes I run around a bit too much and then I'm a bit puffed." (patient 4)

Developing an understanding of when to seek help and one's own limitations	"Well if I got them now, the symptoms I get now if I'd have got them years ago I would be going to see my doctor, but as it is now over the years, I more or less know how far it can go. I'll know when it's gone too far and then I'll ring a doctor or an ambulance...." (patient 36)
Engaging with others	
Engaging with friends and family or health professionals for support or advice	"If I feel I need anything I'll ask them and I have the nurse coming in every fortnight, they used to come in...well they come in every day, but they used to come in 3 times and then they cut it down and I ask the nurses more because they'll ask the doctor then themselves. But if it's necessary and I feel I have to, then I'll ask the doctors." (patient 22)
Arranging help (eg, logistical, administrative, or expert) from health professionals, social services, or friends and family	"My young lad keeps them in the car, the prescription...the note and he then goes, hands it in and picks it up the next day." (patient 6)
Arranging appointments, tests, and treatments	"My daughter took it (prescription) up to the doctors, when I go to the doctors I get my prescription from them. If I'm getting a repeat, my daughter (takes) it up to the chemist and X in the chemist (takes) it to the doctor, (gets) everything signed and it will be ready today, so my daughter will bring it down. I can't get up there...." (patient 25)
Self-organizing social care	"Well the doctor didn't give me the walking stick or anything like that, I bought the walking stick myself not because of the angina but for my back, so I won't put any weight on my back all the time." (patient 33)
Seeking reassurance about treatments from friends, family, or professionals	"Obviously you discuss things with friends.... Because you are not always sure that you are getting the right information anyway, I prefer to go to the people that know." (patient 22)
Adhering to treatments and lifestyle changes	
Developing methods for coping with therapeutic interventions	"I've got a book and I note everything down. I note down when I've taken it, the dose, I note the time, the drug, and when I've taken it." (patient 10)
Developing a routine for self-monitoring	"I get weighed every day because I was weighed in the hospital and I was 5 lb more than I am now, so it must have been 5 lb of fluid and I can see the difference too." (patient 19)
Developing coping strategies for symptoms, exacerbations or emergency situations	"I've got a spray there and I only use it in emergency. They gave me one of them for if the feeling gets too bad I'll just use that. When I was really bad I was doing it every single day, but now I only do it once every couple of days if it's really bad I'll use it, but I don't use it unless I've got to." (patient 38)
Installing adaptations to the home or for mobility	"I wanted a shower put in and that would have helped me, but of course the corporation have got no money....I can get into the bath but it's a struggle.... I just wash myself right down in the wash basin in the bathroom, from top to bottom twice a week and then of course I always well wash myself every morning but in a shower it's different." (patient 27)
Altering social activities because of illness or its management	"The furosemide is a pest, but it's a necessary pest...if I had 3 places to go, say I want to go the supermarket, the library, and call at the doctors for a prescription.... I have a car and if I was a fit man with no problems at all, I would just do the round trip and that would be it, but I don't. I can only go to the supermarket which is only down over the bridge here, I have to come home because I want to go to the toilet." (patient 18)
Financial organization	"You have to pay for the pens, you get everything free, all the medicines are free, but the pens you are supposed to pay for." (patient 48)

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Visits and tests related to the provision of the treatment or admissions	"You see I go there (hospital) all the time for appointments, I have loads of them." (patient 8)
Enacting treatments, for example, the work of taking multiple medications	"One time I was on 20 tablets a day and I'm only on 11 or 12 now." (patient 9)
Enduring adverse effects of treatments	"The losartan is one of the ACE inhibitors, isn't it, there have been various ACE inhibitors, but they seem to be giving me side effects, I get a lot of itching, extreme itching feelings, and that was unpleasant." (patient 10)
Coping with changes in medication due to prescribing policies or pharmaceutical industry	"But you see the point is that some of the tablets are made by different manufacturers, and if you've no medical knowledge you don't know whether you are doing the right thing." (patient 23)
Developing relationships with and confidence in medical professionals	"I go to Dr X now every 3 months for a checkup, because she won't give me the tablets if I don't, so that makes me go. She just won't give me any tablets if I don't go. So I think I'm very safe there you know." (patient 21)
Coping with multiple health professionals as caregivers and poor communication between professionals	"The thing is, it's wasting my time asking any doctor in the practice because they don't know. It's because I see Dr X and she says that she's had nothing from the hospital for months. I'm going down to see a specialist all the time, but it's just that they are slack in telling my doctor...there is definitely a breakdown in paperwork." (patient 8)
Overcoming barriers to gaining access to care	"I'm 87 and they never come out to see me, I have a heck of a job to get a doctor out to me. ...trying to get past the receptionist is like trying to get...I wanted an appointment for Dr X, and they said can't you get down to the surgery, and I said no I can't." (patient 15)
Monitoring the treatments	
Altering treatment regimen to fit in with daily activities	"If I'm going on a long trip on the bus well I never take one (furosemide) in the morning because you have to keep going to the toilet, so if I'm going a long way I miss the morning." (patient 33)
Rearranging appointments	"I was supposed to go the Monday after I came out of hospital, but I rang them to say I didn't feel able and I told them where I'd been and what had happened, and they said that they would give me another appointment and that came this morning in the post." (patient 19)
Discussing or altering management plans in discussion with others (either professionals or friends and family)	"He said he could take me off the pink tablet and try me on something else, but he didn't really want to because everything is working out as it should be, so it's just a case of I have to put up with the cough. He might have put me on something else which might not have worked, so I was willing enough to stay on it." (patient 24)
Making decisions about whether to follow medical advice and treatments	"I just went (to rehab) for the one day. It was just talking about what to do, exercise and diet. I took up the exercise for about 3 weeks, but I was exhausted and I stopped." (patient 14)
Reflecting on social care needed	"One of the doctors said to me: Do you think you would be better in sheltered accommodation? And I said no." (patient 23)
Keeping up to date with new treatments	"The doctor knows what I'm going to ask him, I'm like a record, he knows every question. I ask him is there any fresh news for people with a heart condition, anything else that can take the place instead of taking the tablets. That's what I look forward to, and if the tablets are the only thing to keep me alive and well then I'll take them, but there is a possibility that there may be some help in other ways, in other treatments, and I look forward to them." (patient 20)

ACE = angiotensin-converting enzyme.