

Supplement 1, Table S1.1 Themes and subthemes emerging from patient priorities (heart failure treatment burden)

Theme	Subtheme	Quotes from participants
1P. Patient-doctor Communication	1.a. Clinicians' lack of empathy communicating with patient/family	Communication needs to reflect patient circumstances (deafness) and be less technical (jargon & fast); Bedside manner on telephone consultation not too empathetic (communication, arrogance, dismissiveness, speak to like people)
		Communication of information on support services available post-discharge (gym, physio, getting to appointments after hours, discussing condition with other patients) ; Communication to family on impact of illness and treatment, include them for understanding
		Would like to be taken seriously when patient makes suggestions. Respect patient's knowledge of their own chronic illness and treatment preferences
		Language barriers (foreign accents) getting embarrassed asking again if patient doesn't understand
	1.b. Loss agency due to information gap on medications	Insufficient explanation of why new medication is started or why a specific dosage is chosen (only explanation "It is good for your heart" is insufficient), for example patient does not understand why they need a blood thinner
		Would like explanation for medication purpose including side effects and medications and interactions
		Not knowing types of medication patient is on and what they're for; needing to take a partner to understand/remember about medications; large number of medications
		Understanding Medication side effects and inability for changing medication type (not being in control)
		Not knowing the medication patient has been prescribed (too many meds) or what they are for, and for how long (lifetime); Dr to know of patient allergies and needing to find correct medication
	1.c. Disease trajectory	Limited understanding of own disease: Patient wanting to know more about the condition itself to be reassured and more knowledgeable of what to expect about disease trajectory
		Lacks education/ information on condition, why disease is irreversible, impact of limitations
		Wished for better information about tests, limitations (impact on what can and cannot be done)

Theme	Subtheme	Quotes from participants
	1.d. Discharge planning	Insufficient communication during hospitalisation (about changes in medication, discharge planning)
	1.e. Prognosis	Patients not understanding disease process and not association between symptoms and prognosis or risk factor and outcomes e.g. smoking and heart attack (pt health literacy)
2P. Inefficiencies of healthcare system	2.a. System communication failures between hospitals and general practice	Poor communication between hospitals and GPs (re. medications, what's going on, test result, defib) results in loss of faith in clinicians; Conflicting information from different doctors (e.g. diuretics and weight gain)
		Need better coordination between hospital, GP, & other doctors no disconnect
	2.b. Poor communication amongst clinicians in the same service	Trainee doctors changing medications without consultation with specialists or supervisors
		Fragmented care of heart failure between GP, general physicians and cardiologist (other hospital specialist)
		Systems failure: burdensome having to repeat the same personal information at all appointments, e.g. what medication patient is on. Would like different clinicians/services to be able to access information
		Between-Doctors communication: Specialist unavailable when patient in the emergency department with a complication - patient needs fluids and puts on weight- Renal and CVD specialist giving conflicting advice (one Clinician wants patient to restrict fluid and the other wants more fluid). Also contradictions about medications -This makes it difficult for patient to manage condition.
	2.c. Low specialist numbers and sparse appointments	Delays on regular appointment with specialist; even every 12 months would be reassuring, to clarify symptom (waiting list, or COVID-related)
	2.d. Multiple laboratory tests and delays in results	Frequent blood tests (to monitor disease), long waiting times for tests to be done and to see a doctor to find out results
		Poor availability of information between providers about ordered tests, clinician not having results of previous/recent test and patient having to repeat blood or urine tests

Theme	Subtheme	Quotes from participants
	2.e. Inefficiencies in the ED	Long waiting times in ED after having tests; prefers cardiologist to OK patient after observation, not the ED; Waiting times for treatments GP/cardiologists/ public & private
3P. Healthcare Access	3.a. hospital location limits care continuity	Ambulance taking patient to a hospital far away from patient residence (be able to see Dr near own place where clinical record is) continuity
	3.b. Not knowing how to choose specialists	Finding the right heart specialist (unaware of how to go about it, including GP not knowing)
4P. Cost implications of treatment	4.a. Implications for travel insurance	Challenge of obtaining travel insurance (part of patient's prior lifestyle)- Need more information or update on current health status to fill up conditions for eligibility/activities allowed for travel insurance
	4.b. Lack of guidance on subsidies	Helpful to have someone at GP surgery to give guidance on recovering cost of medications, cheaper pharmacies, and patient entitlements such as safety net
	4.c. Non-rational scheduling of appointments	Large number of appointments, would like to streamline on same day, reduce inconvenience of travel and cost
5P. Psychosocial impact on patient and family	5.a. Impact on personal activities	Patient comorbidities (renal & heart) - makes it difficult to plan social life due to multiple hospital appointments and need to wait for test results; it impacts patient's and interferes with other relatives' lifestyle
	5.b. Impact on work	Inability to go to work due to appointments, surgical procedures and symptoms; limitations of everyday duties (i.e. gardening) and caring responsibilities for children
	5.c. Impact on family's social life	Needing family help at home for usual chores because of the condition and associated procedures that have limited patient physical abilities; possible impact on family eventually as family drives patient to appointments; and stress about whether an ambulance or another emergency visit is required
		Feeling guilty about having relative driving patient to hospital too early to reduce waiting time; interrupting their flow

Theme	Subtheme	Quotes from participants
	5.d. Restrictions on patient lifestyle impact on quality of life	Fluid restriction diet and CPAP machine which makes patient thirsty; getting up to drink and go to toilet in the middle of the night and having poor quality sleep and tired through the day- Has ruined his quality of life
6P. Impact of treatment work	6.a. Burdensome medication regime	Medication adherence including pill burden (number of medications), complexity of regime (Time sensitive, time critical medication)
	6.b. Side effects discourage compliance	Side effects e.g. diuretics leading to increased need to go to the bathroom and people may not take medications, impact on socialisation, ADLs, interrupted sleep, falls risks from hypotension
	6.c. Symptoms preclude implementation	Challenge of implementing Rx recommendations: Weight precludes patient from doing recommended exercise; physiotherapist gives instructions but symptoms preclude; need to plan when exercising outdoors (knowing where to stop/site, where public toilets are)
	6.d. Challenging dietary demands to adhere and monitor in and out of hospital	Adhering to nutritional and dietary advice e.g. asking patients to measure fluid intake, salt intake Dietary changes and weight loss are challenging in hospital and at home

Supplement 1, Table S1.2 Themes and subthemes emerging from doctors' perception of patient burden (heart failure)

Theme	Subtheme	Issues raised by participating doctors
1D. Impact of treatment work	1.a. Complexity of medication and laboratory regime	Medication adherence: pill burden (number of medications), complexity of regime (Time sensitive, time critical medication)
		Side effects e.g. diuretics leading to increased need to go to the bathroom and people may not take medications, impact on socialisation, ADLs, interrupted sleep, falls risks from hypotension
		Additional work/testing from blood thinners and potential adverse events from blood thinners
		Clinical inertia - physicians not taking action or keeping status quo i.e. ACE inhibitor/not up titrating and inappropriate prescribing e.g. NSAIDs, opioids
	1.b. Adhering to restrictions	Burden of adhering to nutritional and dietary advice e.g. asking patients to measure fluid intake, salt intake
2D. Patient-doctor communication	2.a. Clinician interactions	Fragmented care of heart failure between GP, general physicians and cardiologist (other hospital specialist)
		Absence of multidisciplinary approach around health education and health promotion, unclear whose responsibility this is e.g. is it the GP, general physician
	2.b. disconnect on progression	Patients not understanding disease process and not association between symptoms and prognosis or risk factor and outcomes e.g. smoking and heart attack
3D. Inefficiencies of healthcare system	3.a. Repeat encounters	Multiple hospitalisations and long length of stay
		Ability to attend appointments either face to face or telehealth e.g. frailty, transport, memory, ability to use technology may result in missed appointments
		Frequency and process (access) of undertaking blood tests
		Need to undergo additional testing e.g Cardiac echo
4D. Psychosocial impact on patients	4.a. emotional load of chronicity	Acceptance/ coming to terms with chronic disease and having unrealistic expectations around the end of disease and symptom management, lose faith in doctors
		Poor communication between patient and clinician can increase anxiety