



The work of managing a chronic illness: A job description

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Abstract

Rationale: Self-management of a chronic illness is a struggle for many patients. There is substantial evidence that patients are not as successful as they and their providers would like. Considering patient self-management through an innovative and diverse lens could help patients, providers and the health care system to consider novel changes to improve success.

Aims and Objectives: To provide a complete view of patient work by utilizing the human resources management practice of job analysis to develop an initial job description for patients suffering from chronic illness.

Methods: Study design was descriptive qualitative with analysis aiming to identify those reoccurring ideas from the data. Thirty patients, with at least one chronic illness, in three focus groups were assembled for this study. Verbatim recordings and notes were used to categorize the data provided. Five coders analyzed the data independently, and jointly met to discuss the themes identified. Demographic data was collected via surveys.

Results: Patients with chronic illness engage in five primary 'job' duties including self-care (actions taken to effectively manage physical and psychological symptoms), managing relationships (effective management of relationships with employers, family, friends and providers to ensure the best outcomes), managing resources (understanding and managing finances, health and prescription medication insurance), coordination (managing and scheduling visits to providers) and research/education (gathering information and conducting research relative to all aspects of managing one's illness). Relevant knowledge, skills, abilities (KSAs) and other resources were identified that are necessary for patients to effectively perform the five job duties.

Conclusions: Creating a job description for the 'job' of patient is a crucial step in understanding the work chronically ill patients undertake. Knowing the duties, their associated tasks and KSAs, and resources required to perform those tasks enables patients and their providers and advocates to better identify ways to assist, relieve and encourage these patients in order to maximize patient success.

KEYWORDS

chronic disease, focus groups, human resources, job description, self-management, work performance, workload

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1 | INTRODUCTION

Recent estimates suggest over 60% of American adults have been diagnosed with chronic illnesses for example, hypertension, diabetes, heart disease, arthritis, migraines, with 40% having two or more.¹ More than 40% of Americans will be managing their chronic illness for a significant portion of their lives.^{2,3} Unfortunately, the COVID-19 pandemic's long haul syndrome is likely to further augment the prevalence of chronically ill Americans.⁴

Chronically-ill patients often struggle beneath the heavy workload that goes into managing their illness including regular monitoring, adjusting diet and lifestyle risk factors, scheduling/attending provider visits, researching their illness/providers/treatments, managing insurance/finances and so forth—and often describe this work as a full-time job.⁵ Since chronic-illness management is not the only life role for which they are responsible, many of these patients cannot afford to devote their limited time, physical, emotional and financial resources to the full-time management of their illness, despite its importance. Many others simply are unable to navigate often-conflicting instructions, treatments and prescribed medications. These and other constraints often leave chronically-ill patients with a Hobson's choice, deciding what they can do to manage their illness and living with the consequences of what they cannot manage, including being labelled as 'non-adherent' by the health care providers.

Both providers and patients contribute to this 'non-adherence' problem. It is unlikely that providers, patients and their advocates, fully grasp the scope and nature of the tasks, duties and responsibilities involved in this work, or the knowledge, skills, abilities (KSAs) and other resources required to successfully navigate it. Moreover, given their different perspectives and experiences, it is even less likely these parties similarly prioritize various aspects of the work. The situation is further complicated to the extent multiple providers and diagnoses are in the mix. It is not surprising that many patients perceive their providers have 'thrown them to the wolves' in managing their illness, and many providers perceive their patients as failing to follow-through on their advice.

In an effort to begin to reconcile these disparate perspectives and to identify proactive ways in which providers, patients and advocates can work together to improve chronic illness management, we utilized focus-group methodology combined with human resources management (HRM) principles to conduct a qualitative analysis of the 'job' of managing a chronic illness from the patient's perspective. By clearly delineating the scope and requirements of this work, health care providers and patient advocates can begin to identify innovative solutions for helping their patients better manage a difficult yet necessary set of tasks. Thus, the aim of this study is to provide a more complete and practical view of patient work by looking at the work of managing a chronic illness through the eyes of the patient as if it were a job. This will contribute to our collective understanding of the scope and nature of the tasks, duties and responsibilities associated with patient work as well as the necessary KSAs, and other resources that are necessary to effectively and efficiently meet the demands of this complex and difficult job.

1.1 | Job analysis principles applied to patient work

Human resources professionals know that designing appropriate work-related support and systems must begin with a thorough job analysis followed by a detailed job description. Understanding a job (i.e., duties and tasks) and what it takes to do that job (i.e., KSAs) is the first step in identifying training interventions and solutions for maximizing an employee's performance. Analyzing a job is done to (1) define the necessary tasks for accomplishing each job-related duty, (2) identify the KSAs and (3) identify resources needed to perform the tasks.⁶ A functional job analysis being performed on an active position is completed to accurately identify all aspects of a job and the time needed to successfully perform each task. Human resources professionals often conduct job analyses in conjunction with the employee so that the KSAs required can be captured as well. The employee describes the tasks they perform and what KSA's and resources they perceive as needed for the job. The human resource professional analyzes this information across multiple job incumbents and fills in the gaps based on standards and employer expectations.⁶

Typically, a job analysis is performed for a job that an employee has been hired for; these employees, more or less, *choose* to do these jobs. Patients, on the other hand, are not hired for the job of managing a chronic illness. There is no 'at-will' statement that allows them to decide to quit (although if they do, the consequences could be dire). Moreover, for most chronic illnesses, the job of its management will last a lifetime, with no possibility of retirement. Since these unwilling 'employees' are not working for an organization that is required to provide employee support structures, they often must fend for themselves in the recognition and ownership of their role—as health and health care manager—and to obtain the necessary KSAs and resources to accomplish the tasks involved in managing their illness. Although most health care providers and organizations genuinely seek to provide supportive guidance to their patients, the support provided is often fractured, incomplete, not person-centred, confusing, ill-timed and/or contradictory.⁷

1.2 | Patient work—managing chronic illness

The patient work concept has been investigated by health care providers and sociologists, as well as by human factors and informatics/technology researchers.^{8,9} The terms self-management and self-care tend to be used interchangeably in chronic illness literature and refer to symptom recognition, monitoring, maintenance and management. Self-management focuses on lifestyle changes, medications and treatments that are needed to reduce symptoms. Although symptom-based self-management is a strongly recommended intervention, it is difficult for many people and typically has a poor success rate.¹⁰ Self-management is typically defined from the providers'—and not the patients'—perspective and does not fully reconcile the breadth of the work involved in managing and navigating a chronic illness. In this study, we sought to delineate

the activities most prevalent for chronic illness self-management from the perspectives of patients.

The concept of patient work was first identified in a study by Corbin and Strauss⁹ in which they developed a theory focused on the social costs and human suffering involved in the work of managing a chronic illness. They defined this work as 'a set of tasks performed by an individual or couple, alone or in conjunction with others, to carry out a plan of action designed to manage one or more aspects of the illness and the lives of ill people and their partners',^{9, p.9} and described three main components of patient work as (1) illness management work, (2) biographical work and (3) everyday life work. Later, Willems et al.¹¹ expanded Corbin and Strauss's three components of work by including a fourth component: (4) arrangement work, which consisted of organizing devices and making home modifications to improve the efficiency of daily/regular self-management tasks. Corbin and Strauss⁹ also discussed time as it relates to patient work, including chronic illness onset and diagnosis, followed by the illness trajectory. Four phases in the illness trajectory (i.e., the comeback, stable, unstable and downward phases) were identified, with the work of each phase varying as well as ebbing and flowing across these stages. Human factors scholars Holden et al.,¹² investigated the barriers to accomplishing patient work within the physical, social and organizational domains, and explored person-centred and design-driven innovations which may assist with chronic illness management. Viewing patient work through this lens depicts a series of duties and tasks associated with the person, task, tool and/or context. Shorrock¹³ discusses human work as a proxy for 'work-as-done'. He proposes that when we measure or analyze work, we are only considering proxies of that work. He also suggests that much of the work we do is variable, done in different ways by different people, and is unknowable as it takes place internally or in one's head and is therefore invisible.¹³⁻¹⁵ Indeed, informaticists recognize that patient facing informatics interventions can create extra patient work that is often invisible⁸ and thus add further breadth and complexity to chronic illness management.

Visible or invisible, patients have moved from the historical 'sick role' to a consumer role in which more work is being shifted from provider and organization to the already overloaded patient.¹⁶ Although providers may perceive this shift as empowering to their patients, researchers argue that more work does not necessarily mean more empowerment.^{17,18} To be fair, providers probably neither grasp the full scope of work managed by their chronically-ill patients, nor the education patients truly require to be able to do this work. Their picture is probably made even more incomplete to the extent the patient is working with providers in different offices and within different specialties. Providers also may not realize that patient work includes tasks associated with recognizing and preventing errors in their health care.¹⁹ Indeed, much patient work is invisible (as it is never articulated or recognized by providers), ever-evolving and requires an excessive investment of the patient's finite physical and emotional, tangible and intangible resources.²⁰ Sinding et al.²¹ began to touch on the tangible resources that are necessary to accomplish patient work, arguing that such patient work without the proper resources can lead to health disparities and burnout.

2 | METHODS

We used a qualitative research design employing focus group methodology and thematic analysis to investigate the scope and nature of patient work involved in the management of chronic illnesses.²² Despite evidence from prior research indicating that the overall nature and scope of the self-management role are fairly consistent regardless of the patient's diagnosis^{9,12-16} we sought a pool of participants for the focus group discussions with varied chronic illness types and phases to increase our chances of identifying the complete scope of the job.

We conducted three focus groups from November 2019 to April 2020. Due to the COVID-19 pandemic, we were only able to hold one in person focus-group; the other two were held via a video conferencing platform. To mitigate the potential for disengagement and/or withholding of information due to the virtual nature of discussion in these latter two focus groups, we used best practices for virtual team building and discussion. These included an opportunity for free discussion, the use of the chat function, and icebreakers at the beginning of each session as well as ensuring an equal opportunity to contribute to the discussion via calling on participants both systematically as well as randomly using nominal group technique (NGT).

2.1 | Participants

The sample was purposive in nature and inclusion criteria included having been (1) diagnosed with a chronic illness, (2) currently under the care of a provider for that chronic illness and (3) actively working with providers or the health care system (at least two visits in the last year) as a result of the illness.²³ Participants for the first focus group were recruited from the faculty and staff of the investigators' university. For focus groups 2 and 3, participants were recruited through a combination of the investigators' personal networks as well as advertisements posted at the local libraries and local support groups for the chronically ill. All participants were guaranteed confidentiality. Participants for the in-person focus group were compensated for their time (approximately 2.5 h) with a meal and a \$50 Amazon gift certificate. Participants for the virtual focus groups were compensated for their time (approximately 2 h) with a \$50 Amazon gift certificate. The difference in time duration between the in-person and virtual focus groups was a function of when the participants completed the demographic surveys (either during the event while eating or before the event via a Qualtrics²⁴ survey).

2.2 | Confidentiality

To ensure confidentiality, all participants selected identifiers of their choice to be used in lieu of their name during focus group discussion. The in-person focus group chose identifiers according to different colours (e.g., Ms. Pink, Mr. Purple, Ms. Green, etc.). The first Zoom



group chose identifiers associated with different types of fruits (e.g., Mr. Orange, Ms. Kiwifruit, Mr. Blackberry, etc.) and the second Zoom group chose identifiers associated with different types of animals (e.g., Mr. Black Lab, Ms. Cockatiel, etc.). The different identifier categories were chosen to help the researchers recall which of the three focus groups the participant attended, and all notes were taken using these identifiers.

2.3 | Procedure

In all groups, we communicated our data protection/confidentiality procedures as well as administrative matters. Each session was recorded using only the voice of the participants and not the video. Further, participants only used their pseudonyms when communicating. NGT was used to facilitate equal group interaction. NGT is a structured method using a round robin approach to capture individual ideas around a particular subject.²⁵ After each participant shares their ideas with the group a more unstructured discussion can occur to build on the shared ideas. NGT can be used when there is a specific goal of the interaction and discrete data points are desired.

Next, we asked participants to 'take a moment to think about the activities you undertake to manage your chronic illness. Imagine these activities are divided into 'buckets' or major groups of tasks. There are likely 5–7 major buckets/activities involved in this role. Silently brainstorm for a moment about what these major buckets might be.' Following the silent brainstorming phase, the facilitator (one of the investigators who was well-versed in leading such structured discussions) led a discussion using a NGT approach wherein all participants shared their unique ideas and duplication of idea generation was minimized.²⁶ The facilitator sought to gear the discussion towards identifying the reason behind each bucket and how critical each was to the patients' chronic illness management.

The next task was to ask participants to 'take a few moments to generate a list of specific tasks you must do within each bucket/duty'. Using the same NGT approach, the facilitator led a discussion uncovering an exhaustive list of the tasks associated with each of the duties/buckets. The facilitator then led a group discussion on how (1) critical, (2) frequent and (3) difficult each task was in relation to the other tasks in that bucket. Questions like—'How critical are each of these duties and their associated tasks? What happens if you make a mistake? What happens if you don't do the task? How frequently do you perform each of these tasks/duties? How difficult is each task/duty? How hard was it to learn?'—were used to guide the discussion. Then, the facilitator asked the participants, 'What prevents you from being able to accomplish these tasks?' The participants were prompted to consider all forms of constraints, from knowledge, behaviour, personality, time, assistance/support, technologies/materials, finances and so forth.

Finally, participants brainstormed the necessary KSAs needed to accomplish each task/duty, as well as the required materials/supplies/technologies/support. Questions like, 'what do you wish you knew?', 'what did you need to learn to do those things?' and

'what things do you wish you were better at?', were asked to help guide the discussion.

All investigators were present for each focus group, and each took notes using only pseudonyms and other un-identifying information about each participant. These notes were condensed and integrated to create the complete list of patient work tasks and duties as well as KSAs which were ultimately consolidated into a job description. One participant from each focus group reviewed the completed job description. Changes were editorial in nature and were incorporated into the final version of the job description.

Procedural integrity increased trustworthiness of this study. Trustworthiness was also strengthened by ascertaining credibility, transferability, dependability and confirmability. Study credibility was enhanced through member checking the draft job description and having all researchers review data independently then as a group to compare interpretations. Including a variety of chronic illnesses, reporting participant descriptive information and describing study procedures can increase the transferability of results. This study used focus group methodology with NGT (to structure group interaction) and thematic analysis, including coding and memo taking, to provide study dependability and confirmability.²⁷

3 | RESULTS

In this study, we used inductive processes such as collecting data to create the framework of a job description and we used deductive processes by using HRM techniques for job/work analysis to understand the scope of work involved with managing a chronic illness. A total of 30 people with at least one chronic illness participated. See Table 1 for demographic characteristics. The data are compiled for all three focus groups. Verbatim recordings and notes were used to categorize the data provided in the focus groups. A total of five coders began by analyzing the data independently, and then jointly met to discuss the themes identified. Five common themes were identified including self-care, managing relationships, managing resources, coordination and research/education. These themes (or duties in HRM terms) and their descriptions were created by the researchers and the participants together using an inductive approach, based on how participants described the tasks and the 'bucket' the participants agreed would represent a certain set of tasks. Self-care consisted of the actions taken to effectively manage physical and psychological symptoms of chronic illness. Relationship management is used to effectively manage relationships with employers, family, friends and providers to ensure the best outcomes. Resource management involved understanding and managing finances, health and prescription medication insurance. Coordinating resources related to visits to providers, and research/education involved gathering information and conducting research relative to all aspects of managing one's illness. Table 2 includes the themes and example comments made by participants. Each of these themes (aka 'job duties') is comprised of complex tasks that are tackled by people managing a chronic illness and which require specific KSAs, and other

TABLE 1 Participant demographics

	Total (n = 30)	Focus group 1 (in-person) n = 8	Focus group 2 (online) n = 12	Focus group 3 (online) n = 10
Age range in years		31–69	40–69	38–66
Mean age		56	55	51
Gender		6 female, 2 male	10 female, 2 male	9 female, 1 male
Race				
Caucasian	29	8	11	10
African American	1		1	
Education				
Doctorate	7	1	2	4
Master's/professional	10	4	3	3
2–4 years college	11	2	7	2
Some college	2	1	0	1
Years with illness				
Range		4–40	3–30	3–36
Mean		20.5	12.25	17.50
Employment status				
Full time	19	6	7	6
Part time	8	1	3	4
Both	3	1	2	0
Annual income (\$000's [United States])				
15–49	5	3	1	1
50–74	4	1	1	2
75–99	8	2	4	2
100–150	9	1	5	3
150+	3	1	1	1
Not reported	1	0	0	1
Insurance ^a				
Public	8	2	4	2
Private	24	6	8	10
Both	4	0	1	2

^aSome participants reported have both public and private insurance.

resources and characteristics. We report the five duties and their associated tasks in the job description in Table 3 and the corresponding required skills, abilities, and resources in Table 4.

Self-care refers to symptom management and involves adhering to the advice/prescriptions/treatments from providers. When providers and payers discuss patient adherence, self-care is the duty most often referenced. According to participants there are other duties that should be recognized. Relationship management refers not only to personal relationships with family and friends but also employer, coworker and provider relationships. Resource management is primarily concerned with financial management and

managing other resources such as childcare, transportation, and access to supplies. Organizing paperwork, scheduling appointments, procuring medications and referrals are examples of coordination. Research and education are required to self-educate about all aspects related to chronic illness and treatment. For each of these duties there are associated multifaceted tasks with commensurate KSAs, and resources that are needed to perform the corresponding tasks see Table 3. Duties and related tasks are not performed in silos and can therefore interact with each other in an integrated way that is, performing one task may contribute to successfully performing other tasks.

**TABLE 2** Categories and example participant comments

Theme	Participant comments
Self-care	'Listening to my body and doing what I need. Asking for help when I need it' (G. F.) 'Getting the sleep I need every night' (L. L.)
Managing resources	'Knowing your insurance takes a law degree' (J. M.) 'Managing the cost of everything in general and trying to find affordable insurance' (O. E.)
Manage relationships	'Providing explanations to others for why I can't do what I used to be able to do' (T. G.) 'Explain side effects' (T. G.) 'Making people believe migraines are a real thing and not just a simple headache' (K. B.) 'Didn't want to share everything' (B. L.)
Coordination	'Keep track of treatments for all doctors... they don't have the same information' (K. B.) 'Track symptoms (app not available) on spreadsheet' (L. Z.)
Research and education	'...Google everything, causes of illness, doctors to treat, medications, treatments, side effects for other medical procedures, multiple sites.' (T. G.) '... Stopped reading everything, getting some crazy advice and conflicting advice' (B. L.) 'Not all doctors agree with each other about what meds I should be taking, I like to ensure nothing is contraindicated' (C. T.)

While knowledge for each task may differ, there are core groups of skills, abilities and resources that are needed across all tasks. Core skills to effectively and efficiently manage a chronic illness are communication, complex problem solving, critical thinking, decision-making, emotional literacy, executive function, health literacy, literacy, multi-tasking, planning, organizing and prioritizing. Abilities needed are directly related to each skill, for example, when communication skills are being used the abilities of oral and written comprehension and expression, speech recognition, speech clarity and interpersonal acumen are being accessed. The abilities for each skill were identified using O*Net Online which is a US Department of Labour tool for functional job analysis.²⁸ See Table 4 for a list of core abilities.

Core resources include transportation, phone, computer and internet, information, support people, finances, medication, monitoring tools, time, energy/stamina, safe environment, healthy food, a place to rest, trustworthy referrals and the public library. The public library was included because for many it is the only place where they can access the internet. Time, energy and stamina are included as resources for the job of managing a chronic illness, though these would not appear in a typical (paying or volunteer) job since there is an assumption that the job incumbent would possess these characteristics.

There was one focused skill that is needed to be successful in managing a chronic illness that is not needed to perform every task and was therefore not included in the core list of skills. Financial literacy is a focused skill predominantly used in the managing resources duty. At this juncture it is important to convey that if patients themselves do not have the KSAs or resources (e.g., financial literacy), they may rely on others or organizations to provide them or go without.

The required KSAs (see Table 4) to effectively perform each of the major tasks of being a 'patient' were inferred from the list of duties and tasks. For example, adequately performing self-care

requires patients have knowledge of their medications and side effects, and be health literate. The skills required for self-care include critical thinking, decision-making and communication and planning skills. Patients must also have the abilities including literacy, working memory and mental flexibility. Patients should also possess a work style in which they are able to advocate for themselves, pay attention to detail, and perform rigorously. The job of 'patient' also requires using certain tools such as phone, internet, time, energy and monitoring tools (e.g., glucose monitor).

4 | DISCUSSION

Being diagnosed with a chronic illness is often life changing for a patient as its management involves complex, convoluted and time-consuming work that is seldom appreciated by others. Unlike most jobs where an opportunity to quit exists if it becomes too hard or unmanageable, a chronically ill patient cannot simply walk away from the 'job' of managing their illness without often significant repercussions. The results of three structured focus group discussions with chronically ill patients provide an initial understanding of (1) the breadth of work involved in chronic illness management, and (2) the nature of the KSAs, and resources needed to effectively perform this work. In this study, we apply methodologies from the HRM literature for job/work analysis to explore the scope and nature of the work associated with managing a chronic illness.

Self-care tends to be the duty in which providers are focused. The Stanford Chronic Disease Self-Management Programme (CDSMP),²⁹ one of the most popular CDSMP for numerous chronic illnesses, includes information on symptom recognition; lifestyle activities; communicating with family, friends and providers; sex and intimacy and finding resources. There are tasks not included in the



TABLE 3 Abbreviated job description

Duties/tasks	Knowledge	Skills	Abilities	Resources or tools
<i>Self-care—Take actions to effectively manage physical and psychological symptoms of chronic illness</i>				
Monitor and attend to the signs and symptoms of chronic illness by tracking symptoms, attending to bodily or environmental symptoms of flares/triggers, monitoring lab/test results. Communicate changes with provider.	Knowledge of illness-related information that is, symptoms, symptom tracking Knowledge of medications, administration, side effects, interactions Knowledge of treatments, procedures and testing	a. through m.	a. through m.	a. through j.
Monitor and attend to medication and treatments, including understanding, tracking and responding to potential side effects and contraindications and determining most effective dose/treatment. Monitor the safety of care/medications provided by others. Communicate changes with the provider.	Knowledge of what to ask provider Knowledge of illness-related information that is, symptoms, symptom tracking Knowledge of medications, administration, side effects, interactions Knowledge of treatments, procedures and testing	a. through m.	a. through m.	a. through j.
Manage and attend to accurate and timely self-administration of medications/treatments by ensuring continuous availability, monitoring expiration dates, understanding correct dosages and protocols and recording administrations/doses/protocols. Communicate changes with provider.	Knowledge of what to ask Know what is expected during and after treatment/therapy Knowledge of illness-related information that is, symptoms, symptom tracking	a. through m.	a. through m.	a. through j.
Adopt necessary dietary and lifestyle changes, including coordinating with others' needs, maintaining consistent food/sleep/exercise schedules, carrying food for emergencies, monitor and adapt diet as needed.	Knowledge of medications, administration, side effects, interactions Knowledge of treatments, procedures and testing Appropriate lifestyle changes that is, exercise, diet, sleep hygiene Knowledge of illness-related information that is, symptoms, symptom tracking	a. through m.	a. through m.	a. through j. k. Safe environment l. Good/healthy food m. Place to rest
	Knowledge of medications, administration, side effects, interactions Knowledge of treatments, procedures and testing			



TABLE 3 (Continued)

Duties/tasks	Knowledge	Skills	Abilities	Resources or tools
Monitor and attend to mental-health related issues (including depression, anxiety, fear, isolation, acceptance of diagnosis and implications for lifestyle, anger, disappointment, worry). Communicate changes with provider.	Appropriate lifestyle changes that is, exercise, diet, sleep hygiene Warning signs related to changing mental health	a. through m.	a. through m.	a. through j.
	Knowledge of illness-related information that is, symptoms, symptom tracking			
	Knowledge of medications, administration, side effects, interactions			
	Knowledge of treatments, procedures and testing			
Manage stress and seek support/therapy when needed.	Knowledge of stress and emotion management techniques—that is, meditation, yoga, exercise, CBT	a. through m.	a. through m.	a. through k.
<i>Relationship management—Effectively manage relationships with employers, family, friends and providers to ensure the best outcomes</i>				
Maintain open communication with supervisor and colleagues to facilitate task-related and time-off-related accommodations.	Knowledge of potential work and lifestyle accommodations relevant to CI management	a. through m.	a. through m.	a. through j.
Develop/maintain a support network for tangible and emotional support from family/friends/coworkers, maintain open communication with family/friends/coworkers to facilitate support, lifestyle accommodations and empathy.	Know the commitment/capacity of the people in the social network to provide support Knowledge of what should be communicated with others	a. through m.	a. through m.	a. through j.
	Knowledge of when to ask for professional help			
Develop/implement a communication plan for what, when, and how much detail to share about the nature of the illness as well as its implications, complications and needed accommodations, plan for how to appropriately respond to others' advice.	Knowledge of illness-related information that is, symptoms, symptom tracking Know the commitment/capacity of the people in the social network to provide support	a. through m.	a. through m.	a. through j.
	Knowledge of what should be communicated with others			
Create lifestyle accommodations that facilitate relationship maintenance and social life/interactions and to mitigate negative self-perceptions.	Knowledge and awareness of the needs of others Self-awareness	a. through m.	a. through m.	a. through j.

(Continues)



TABLE 3 (Continued)

Duties/tasks	Knowledge	Skills	Abilities	Resources or tools
Identify qualified providers with compatible communication styles, willingness to listen to ideas/concerns without dismissing or undermining patient concerns, facilitate management of chronic illness; develop and maintain quality relationships.	Knowledge of potential work and lifestyle accommodations relevant to CI management Knowledge of own communication style Where and what to know to a find provider	a. through m.	a. through m.	a. through j. and n. Trustworthy referrals
Develop relationships and open and honest communication with providers by adapting interpersonal communication style.	Knowledge of personal preference for provider skills/behaviours Knowing the skills you want the provider to have, having them be compatible with what is desired Know personal communication style	a. through m.	a. through m.	a. through j.
<i>Resource management—Understand and manage finances, health and prescription medication insurance, and coordinate resources related to visits to providers.</i>				
Budget and pay for treatments, medications, procedures, deductibles, copays and medical bills; ensure correct billing, develop payment plans, save and track receipts for taxes and maximum out of pocket. Negotiate payment plans if needed. Seek financial support (disability, etc.) if needed.	Personal finances, income, future expenses and so forth How to read and understand insurance policies, EOBs, FSA	a. through m. n. Financial health literacy	a. through m. and n. Locate, evaluate and use information, resources, and services and to make informed decisions about financial obligations, budgeting, credit, debt and planning for the future	a. through j.
Manage insurance—file claims with primary and secondary insurance if needed, request preauthorizations and physician requests for coverage; review EOBs, ensuring insurance has paid their part in full before paying out of pocket, appeal denials of claims	Personal finances How to read and understand insurance policies, EOBs, FSA Insurance process How to access resources	a. through n.	a. through n.	a. through j.
Compare & locate in-network providers, 'approved lists' of tests and covered supplies, medicines, visits, specialists, changing providers or PCPs, diagnostic tests, programmes that offer financial assistance for treatments/medications. Arrange second opinions when necessary	Personal finances How to read and understand insurance policies, EOBs, FSA Insurance process How to access resources	a. through n.	a. through n.	a. through j.
Determine best primary and secondary plans considering premiums and deductibles (whether private, Medicare, Medicaid), drug plans and HSAs, copays for different providers; determine annual deduction for FSA, project when deductible will be met	Personal finances How to read and understand insurance policies, EOBs, FSA Insurance process How to access resources	a. through n.	a. through n.	a. through j.



TABLE 3 (Continued)

Duties/tasks	Knowledge	Skills	Abilities	Resources or tools
Prepare for legal aspects of illness-management (HIPAA, power of attorneys, etc.), share account information and passwords with trusted family/friends only. Identify medical power of attorney and so forth.	How to read and understand medical forms and medical/legal terminology Know how to use technology	a. through n.	a. through n.	a. through j.
Manage timely delivery of medications, continuous access to equipment and supplies, transportation/logistics (hotel, family) to providers/specialists, childcare	Personal finances Insurance process How to access resources How to read and understand medical forms and medical terminology How to access social support if needed	a. through n.	a. through n.	a. through j.
<i>Coordination—Organize and schedule all appointments; paperwork and medical history</i>				
Schedule, coordinate, prepare for, and attend appointments with providers, lab, diagnostic tests, therapies; make phone calls, manage time, organize travel logistics	Policies of provider/organization office Best way to access and use the needed services	a. through m.	a. through m.	a. through j.
Coordinate time off from work for illness-related absences by understanding and leveraging employer policies for time-off and disability-related absences.	Knowledge of time-off policies and restrictions Knowledge of disability programmes, laws, benefits	a. through m.	a. through m.	a. through j.
Communicate and advocate for self by asking questions, relaying medical history with providers, office staff and others (friends, family and employers), asking for help when needed.	Knowledge of illness-related information that is, symptoms, symptom tracking Personal medical history-including meds Who to ask for illness- related help How to access social support if needed	a. through m.	a. through m.	a. through j.
Prepare for appointments with providers so all questions, concerns and research are addressed	What questions to ask, need to know what they don't know	a. through m.	a. through m.	a. through j.
Organize and maintain updated paperwork, passwords, phone numbers, health care portals	How to use technology How to organize paperwork (or digital documents) so it is available for appointments	a. through m.	a. through m.	a. through j.
Identify and procure necessary equipment, medications, treatments, qualified providers, facilities, referrals, second opinions	Knowledgeable about community resources Knowledge about health care system, what you can ask for	a. through m.	a. through m.	a. through j.

(Continues)



TABLE 3 (Continued)

Duties/tasks	Knowledge	Skills	Abilities	Resources or tools
	How to use technology How to access the support system Know your preferences for provider			
<i>Research/education—Self-educate about all aspects related to chronic illness and treatments</i>				
Gather reputable information/resources related to diagnoses, medications (including efficacy, side-effects, contraindications, new releases), treatments, diagnostic testing, alternative treatments, lifestyle changes, equipment, providers	Know terminology and alternate terms, quality sources of information, how to differentiate quality sources Self-aware (know self) to know what they are willing and able to do and what to spend their time learning about Need to know what the options are for sources of reliable information	a. through m.	a. through m.	a. through j. and o.
Research and make decisions regarding provider recommendations, reconcile conflicting advice, comparing potential treatments	Know terminology and alternate terms, quality sources of information, how to differentiate quality sources Self-aware (know self) to know what they are willing and able to do and what to spend their time learning about Need to know what the options are for sources of reliable information Know the rationale of the provider's advice Knowing what successful outcomes would be for yourself. Know what insurance provider will pay for Understand costs related to each alternative Sources of alternative funding	a. through m.	a. through m.	a. through j. and o.
Research and make decisions regarding diagnostic facilities, medications, treatments	Know terminology and alternate terms, quality sources of information, how to differentiate quality sources Self-aware (know self) to know what they are willing and able to do and what to spend their time learning about	a. through n.	a. through n.	a. through j. and o.



TABLE 3 (Continued)

Duties/tasks	Knowledge	Skills	Abilities	Resources or tools
	Need to know what the options are for sources of reliable information			
	Know the rationale of the provider's advice			
	Knowing what successful outcomes would be for yourself.			
	Know what insurance provider will pay for			
	Side effects, contraindications for medications/treatments			
	Know allergies			
	Know terminology and alternate terms,	a. through m.	a. through m.	a. through j. and o.
Investigate quality/reputability of information sources to assess its utility and applicability	Know quality sources of information and how to differentiate quality sources			
	Need to know what the options are for sources of reliable/quality information			
	Know how to access sources of information.	a. through m	a. through m.	a. through j. and o.
Navigate, utilize and reconcile across variety of informational resources (including Internet browsers, WebMD, MayoClinic, CDC, NIH, subscription services - Epocrates, diagnosis-specific support groups, libraries, social media, message boards, fundraising and research-related events, newsletters, family/friends/other, unsolicited advice)	Knowing how to assess quality and reliability of sources			
	Know terminology and alternate terms, quality sources of information, how to differentiate quality sources			
	Need to know what the options are for sources of reliable information			
	Know how to deflect unhelpful observations or comments			
Assess and compare new and current providers/organizations	Know what criteria you should assess to evaluate a provider or organization	a. through n.	a. through n.	a. through j. and o.
	Know who approved providers/organizations are in insurance plan			

Abbreviations: CI, chronic illness; EOB; explanation of benefits; FSA, flexible spending account; HSA; health savings account.

TABLE 4 Core skills, abilities and resources

Skills	Abilities	Resources
a. Communication skills	a. Oral and written comprehension and expression, speech recognition, speech clarity, interpersonal acumen	a. Transportation
b. Complex problem solving— including patient-based clinical reasoning	b. Problem sensitivity, inductive and deductive thinking, information ordering, implement decisions, protect from error	b. Phone
c. Critical thinking	c. Engage in reflective and independent thinking, problem sensitivity, inductive and deductive thinking, information ordering	c. Computer/Internet
d. Decision-making skills	d. Problem sensitivity, inductive and deductive thinking, information ordering	d. Information
e. Emotional literacy	e. Understand self and others and adapt behaviour accordingly: self-awareness, sensitivity, social skills, self-regulation, motivation, empathy	e. Support people
f. Executive function skills	f. Selective attention, memorization, perceptual speed	f. Finances-appropriate insurance coverage, optimizing any discounts, available cash for expenses and copays, HSA and FSA
g. Health literacy	g. Obtain, process and understand basic health information	g. Medications and/or therapeutic equipment
h. Literacy	h. Vision, read and comprehend, category flexibility, information ordering	h. Monitoring tools
i. Multitasking	i. Time sharing, manage multiple responsibilities at once	i. Time
j. Planning, organizational, prioritizing skills	j. Category flexibility, information ordering-prioritizing, organizing and accomplishing activity	j. Energy/stamina
k. Physical: endurance, stamina, strength, flexibility, agility & balance	k. Physical: arm-hand steadiness, manual dexterity, trunk strength, vision	k. Safe environment
l. Self-advocacy	l. Assertiveness, oral expression, persistence	l. Good/healthy food
m. Technological literacy	m. Access and use computers and or smart technology. That is, smart phone, ipad/tablet	m. Place to rest
		n. Trustworthy referrals
		o. Public library

Abbreviations: FSA, flexible spending account; HSA; health savings account.

CDSMP, such as communicating with employers and coworkers; resource management; coordinating appointments, paperwork and medical history. Educating and researching one's illness, medications and other treatments is minimally covered by the programme. Understanding that not all patient work may be covered in one programme, there are results from this study that flag areas that may be added or expanded in the current CDSMP.

Storey et al.³⁰ have described a cycle of HRM practices that include: (a) organizational design, (b) job design & team design, (c) recruitment & selection, (d) onboarding & induction, (e) assessment & appraisal, (f) training & development, (g) engagement & reward, (h) performance management and (i) career management. If we look at the job of being a patient in these HRM terms, we would consider how the design of the health care delivery system affects patient work performance. Is the current 'acute care system' working for patients managing chronic illnesses? Does the job design/description reflect the work that is being done and needs to be done? What is the level of skills, knowledge, abilities and resources available to each patient? Does the patient have the capacity to perform the work?⁷ Is the patient experiencing burnout from a difficult workload?²⁶ Who are members of the team helping the patient perform the work and do they know their roles and expectations?

Patients are not recruited or selected for the job of managing a chronic illness but to consider job selection and recruitment makes one think of preventive measures that can help people avoid or lessen their chances of acquiring a chronic illness and therefore not qualifying for the job. What, if any, are the onboarding and induction needs of those beginning the work of managing a chronic illness? Now that a job description has been created, we can begin to assess and appraise patient work in a unique, systems-based manner. This will help us identify what training and development might be needed to help patients develop the skills to perform the work. Patient engagement is currently measured and appraised.³¹ Are there any rewards for doing the work? How would patients describe those rewards? Performance management is a process in which setting clear goals and objectives, formal monitoring of performance and the use of outcome reviews to attempt to shape future behaviour.³⁰ Do patients have routine 'performance management' reviews with providers? Would that be helpful to their work performance? Career management in patient work terms could be described as the illness trajectory and how patients are prepared for it. This study begins to answer the question of whether the job design/description reflects the work that is being done. The job description created in this study is an innovative first step in answering the above questions and could help patients perform their work, help the system



determine what assistance is needed for patient work, and help patients and providers meet the desired outcomes of the work.

4.1 | Practical implications

Creating a job description is a crucial step in understanding the work a particular job requires. Knowing the duties and their associated tasks, as well as the KSAs, and resources required to perform those tasks can help identify training interventions and other supportive solutions for maximizing patient success. Stakeholders of all types (i.e., patient, patient advocate, provider, payor, health care organization) benefit not only from the clarity provided by having a complete picture of patient work, but also from understanding what is required for successful patient performance. Further, it provides all of those involved in the care a way to appreciate the patient's successes as well as anticipating and preventing future roadblocks.

Although our results can be considered more of a general job description for chronic illness management and not specific to any particular chronic illness, research suggests illness management involves substantially consistent tasks across illness types. Regardless, the content of this job description should be considered more of a base than a boundary as individual patients may emphasize or incorporate different tasks based on diagnosis, priority, preference or time frame. By understanding the scope/nature of work involved in chronic illness management as well as the competencies/resources required for their effective performance, patients and their providers and advocates are better able to identify ways to assist, relieve and encourage these patients. Training and other supports can be created and workload feasibility analyses can be conducted. Finally, providers are in a better position to recognize instances of patient burnout and identify ways to support the patient's flagging motivation.

4.2 | Limitations and future research directions

One limitation of this study is that we did not distinguish between individual time periods within the management of chronic illnesses (diagnosis, maintenance, acute flare-up) or the phases of the illness trajectory (comeback, stable, unstable and downward). This study provides a base of knowledge that can be used to standardize or individualize a plan of care that considers the KSA's and resources needed to carry out that plan. Future research is needed to further investigate the nature of patient work across diagnoses, type, phases/periods and caregiver involvement so differentiated supports can be created. Future research is also needed to validate the results of our job analysis and the resulting job description. It is possible some tasks with related KSAs, and resource requirements were not well-captured in this study as a result of where in time our focus group participants were in their illness trajectory. Future research should investigate the work of hospitalized patients with chronic illness. Although there was variation in the types of chronic illnesses represented in this study, participant diversity could be further

improved to capture different socioeconomic status, working status, race and gender. It would be interesting for future research to pilot this job description resulting from the current study as a framework to investigate other such populations' descriptions of chronic illness management to establish any similarities or differences.

5 | CONCLUSION

If providers want to help patients self-manage their chronic illness through education and interventions, they must have a more holistic understanding of the scope and nature of this work, as well as an appreciation of the complexities and roadblocks faced by their patients. We cannot only shine a flashlight on the problems faced by the struggling, overworked patient. Instead, we must use a floodlight to also uncover work occurring in the upstream and downstream. For better or worse, the health care system is motivated by reimbursement, and sometimes the patient outcomes and criteria that encourage a flashlight approach wherein insufficient attention is paid to the management of illness. If the health care system were to embrace more of a public health (floodlight) approach, we would see the bigger picture of chronic illness management as well as better identify potential roadblocks.

AUTHOR CONTRIBUTIONS

Carolyn Kleman conceived the idea of analyzing patient work through an HRM lens. All five authors (Carolyn Kleman, Jessica Mesmer Magnus, Martha Andrews, Kori Meyer, and Barbara J. Lutz) were involved in the design of the study, data collection, data analysis and interpretation, drafting the article, critical revision of the article and final approval of the version to be published.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

Research data are not shared.

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REFERENCES

1. National Center for Chronic Disease Prevention and Health Promotion. Chronic diseases in America. Centers for Disease Control and Prevention (CDC) Published January 24, 2022. Accessed February 23, 2022. <https://www.cdc.gov/chronicdisease/resources/infographic/chronic-diseases.htm>
2. World Bank. Life expectancy at birth, total (years). Published 2019. Accessed December 10, 2021. <https://data.worldbank.org/indicator/SP.DYN.LE00.IN>

3. National Health Council. About chronic illness. Published July 29, 2014. Accessed December 10, 2021. <https://nationalhealthcouncil.org/wp-content/uploads/2019/12/AboutChronicDisease.pdf>.
4. Barber C. The problem of 'Long Haul' COVID. *Scientific American* 2020. Published December 29, 2020. Accessed January 15, 2022. <https://www.scientificamerican.com/article/the-problem-of-long-haul-covid/>.
5. Andersen L. Managing RA (or any chronic illness) is a full-time job. Published June 4, 2020. Accessed January 15, 2022. <https://www.healthcentral.com/article/chronic-illness-full-time-job>.
6. Oliver P. Why conduct a job task analysis? History and Government Faculty Publications. 2020. 322.
7. Lutz BJ, Young ME, Creasy KR, et al. Improving stroke caregiver readiness for transition from inpatient rehabilitation to home. *Gerontologist*. 2017;57(5):880-889. doi:10.1093/geront/gnw135
8. Yin K, Harms T, Ho K, et al. Patient work from a context and time use perspective: a mixed-methods study protocol. *BMJ Open*. 2018;8(12):e022163. doi:10.1136/bmjopen-2018-022163
9. Corbin JM, Strauss A. *Unending Work and Care: Managing Chronic Illness at Home*. Josey-Bass; 1988.
10. Yancy CW, Jessup M, Bozkurt B, et al. 2013 ACCF/AHA guideline for the management of heart failure: a report of the American College of Cardiology Foundation/American Heart Association Task Force on practice guidelines. *J Am Coll Cardiol*. 2013;62(16):e147-e239. doi:10.1161/CIR.0b013e31829e8776
11. Willems DL, Hak A, Visser FC, Cornel J, van der Wal G. Patient work in end-stage heart failure: a prospective longitudinal multiple case study. *Palliat Med*. 2006;20(1):25-33.
12. Holden RJ, Schubert CC, Mickelson RS. The patient work system: an analysis of self-care performance barriers among elderly heart failure patients and their informal caregivers. *Appl Ergon*. 2015;47:133-150. doi:10.1016/j.apergo.2014.09.009
13. Shorrock S. Proxies for work-as-done. *Humanistic systems*. Published October 28, 2020. Accessed June 30, 2022. <https://humanisticsystems.com/2020/10/28/proxies-for-work-as-done-1-work-as-imagined/>
14. Gorman RK, Wellbeloved-Stone CA, Valdez RS. Uncovering the invisible patient work system through a case study of breast cancer self-management. *Ergonomics*. 2018;61(12):1575-1590. doi:10.1080/00140139.2018.1503339
15. Unruh KT, Pratt W. The invisible work of being a patient and implications for health care: '[the doctor is] my business partner in the most important business in my life, staying alive'. *Conf Proc Ethnogr Prax Ind Conf*. 2008;2008(1):40-50.
16. Burnham JC. The death of the sick role. *Soc Hist Med*. 2012;25(4):761-766. doi:10.1093/shm/hks018
17. Byholm A, Bertelsen P. Patient at work-in the era of PRO. *Stud Health Technol Inform*. 2017;241:115-121.
18. Rogers A, Kirk S, Gately C, May CR, Finch T. Established users and the making of telecare work in long term condition management: implications for health policy. *Soc Sci Med*. 2011;72(7):1077-1084. doi:10.1016/j.socscimed.2011.01.031
19. Unruh KT, Pratt W. Patients as actors: the patient's role in detecting, preventing, and recovering from medical errors. *Int J Med Inform*. 2007;76(suppl 1):S236-S244. doi:10.1016/j.ijmedinf.2006.05.021
20. van Wissen K, Blanchard D. The 'work' of self-care for people with cardiovascular disease and prediabetes: an interpretive description. *Int J Nurs Stud*. 2021;116:103548.
21. Sinding C, Miller P, Hudak P, Keller-Olaman S, Sussman J. Of time and troubles: patient involvement and the production of health care disparities. *Health*. 2012;16(4):400-417. doi:10.1016/j.ijnurstu.2020.103548
22. Maguire M, Delahunt B. Doing a thematic analysis: a practical, step-by-step guide for learning and teaching scholars. *AISHE-J*. 2017;3:3351-33514. <http://ojs.aishe.org/index.php/aishe-j/article/view/335>
23. Etikan I, Musa SA, Alkassim RS. Comparison of convenience sampling and purposive sampling. *Am J theor and Appl Stat*. 2016;5(1):1-4. doi:10.11648/j.ajtas.20160501.11
24. Qualtrics. Provo, UT, USA. <https://www.qualtrics.com>
25. Olsen J, The Nominal Group. Technique (NGT) as a tool for facilitating pan-disability focus groups and a s anew method for quantifying changes in qualitative data. *Int J Qual Met*. 2019;18:1-10. doi:10.1177/1609406919866049
26. Pena A, Estrada CA, Soniat D, Taylor B, Burton M. Nominal group technique: a brainstorming tool for identifying areas to improve pain management in hospitalized patients. *J Hosp Med*. 2012;7(5):416-420. doi:10.1002/jhm.1900
27. Korstjens I, Moser A. Series: practical guidance to qualitative research. part 4: trustworthiness and publishing. *Eur J Gen Pract*. 2018;24(1):120-124. doi:10.1080/13814788.2017.1375092
28. O*Net. Updated February 22, 2022. Accessed February 23, 2022. <https://www.onetonline.org/>
29. Lorig K, Laurent D, Gonzalez V. *Living a Healthy Life with Chronic Conditions*. Bull Publishing Company; 2020.
30. Storey J, Wright PM, Ulrich D. *Strategic Human Resource Management: A Research Overview*. Routledge; 2019.
31. Abdoli S, Hessler D, Smither B, Miller-Bains K, Burr EM, Stuckey HL. New insights into diabetes burnout and its distinction from diabetes distress and depressive symptoms: a qualitative study. *Diabetes Res Clin Pract*. 2020;169:108446. doi:10.1016/j.diabres.2020.108446

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