

Value-Based Health Care for Chronic Care: Aligning Outcomes Measurement with the Patient Perspective

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Background: Value-based health care is increasingly used for developing health care services by relating patient outcomes to costs. A hierarchical value scorecard for creating outcome measurements has been suggested: the 3-tier model. The objective of this study was to test the model against the patient's view of value in a chronic care setting. **Methods:** Semistructured interviews with 22 persons with rheumatoid arthritis were conducted, transcribed, and analyzed using qualitative content analysis. Themes were extracted, and the model was critically applied and revised. **Results:** The study validates existing dimensions in the model but suggests adding information, social health, predictability, and continuity to make it more useful and representative of patients' preferences. **Conclusion:** Although the model aims to focus on outcomes relevant to patients, it lacks dimensions important to individuals with rheumatoid arthritis. The data illustrate difficulties in finding patients' preferred outcomes and imply tactics for arriving at meaningful measurements.

Key words: content analysis, patient outcome assessment, quality of health care, rheumatoid arthritis, value-based care

Quality in health care is increasingly understood as defined by patient outcomes.¹ The shift in health care toward outcome measurements rather than a process focus is expected to significantly improve the health status of patients.² Value-based health care^{3,4} and its 3-tier model⁵ have emerged as a popular framework for selecting and structuring outcomes influential in diverse areas such as surgery,⁵ emergency

medicine,⁶ prisoner health,⁷ and physical therapy.⁸ However, previous research has not clearly elucidated how to operationalize the framework or demonstrated empirical support for the model.⁹ In particular, there is a lack of studies investigating the model's applicability⁹ and overall assumptions to focus strongly on outcomes rather than processes. The literature has explicitly criticized the model for its lack of patient-centeredness¹⁰ and its failure to cover chronic and palliative care¹¹ and raised questions of how to define outcomes in chronic care settings, such as the care of rheumatoid arthritis (RA).¹² However, empirical data have not substantiated this criticism, the model itself, or scientific applications of the model.

This lack of critical application of the model is problematic because value-based health care is being implemented at hospital management (eg, the Mayo Clinic in the United States and Karolinska University Hospital in Sweden), as well as global levels (eg, the International Consortium for Health Outcomes Measurement). In parallel, patient participation is gaining interest as a civil rights issue¹³ while the development of value-based health care is happening largely disconnected of patient preferences. Therefore, this study aimed to test the 3-tier model against patients' views of value in a chronic care setting.

METHODS

Analytical framework

The 3-tier model,⁴ and its adaptation to a chronic care setting,³ states that outcome measurements should be multidimensional and take place in 3 tiers. The model assumes that the tiers represent all outcomes of value to patients and that outcomes and the relative

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The study was funded by Stockholm County Council and Forte (The Swedish Research Council for Health, Work Life and Welfare, grant no. 2014-4238). The authors thank participants for open-heartedly sharing their views and experience; the Rheumatology Clinic at Karolinska Hospital and the Swedish Rheumatism Association for help with recruitment and providing interview locations; and, finally, Professor Staffan Lindblad for enthusiastic support and feedback.

The authors hereby declare no financial support or benefits from commercial sources for the work reported on in the article, or any other financial interests that could create a potential conflict of interest or the appearance of a conflict of interests with regard to the work.

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Q Manage Health Care
Vol. 25, No. 4, pp. 203–212

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DOI: 10.1097/QMH.000000000000115

importance of each tier differ with the diagnoses. This assumption suggests a need to adjust the model to the context. The model explicitly excludes many process measures such as patient satisfaction.

In the model, tier 1 concerns *survival* (ie, mortality) and *degree of recovery or health* (eg, physical and mental functional status or control of chronic disease complications). Tier 2 concerns *time to recovery or return to normal activities* (ie, time to treatment or definitive diagnosis, time to access specialist treatment of more complicated or urgent issues, time spent accessing treatment, and workdays missed) and *disutility of care or treatment process* (ie, pain and anxiety before and during treatment, care complications, and need for emergency department visits or hospitalizations). Tier 3 concerns *sustainability of recovery or health over time* (ie, maintained functional level, frequency of urgent care issues, and acuity of chronic conditions and complications) and *long-term consequences of therapy* (ie, long-term side effects). Subcategories in the aforementioned parentheses are suggestions from the original publications.^{3(pp521, E1, E2)} Some measurements are assumed the same in all adults with chronic illnesses, whereas others are specific to the diagnosis.

Methodological approach

Because the purpose of the 3-tier model is to influence care in an external reality, this study was conducted from a postpositivistic paradigm¹⁴ in which results should be seen as hypotheses. An ethical subjectivist definition of the value was used. That is, the value was defined as the opinions expressed by the individual.¹⁵

Setting

Rheumatoid arthritis was chosen because it is a prevalent (0.15%-1.07%) chronic disease¹⁶ with a largely unpredictable pattern that requires many different actors, technologies, and treatments. Thus, it exhibits a typical chronic disease pattern. In Stockholm, Sweden, interdisciplinary teams at specialized rheumatology outpatient clinics manage RA and all related care. An appointment is guaranteed within 30 days of referral. The teams first monitor patients closely and then follow up annually. Inpatient care is unusual. Patients contact the clinic in case of swollen or painful joints for a cortisone injection within a week. Patient fees and medications are partially subsidized for all patients and completely subsidized after the patients reach a set threshold.

Data collection

Written informed consent was given by all participants, and the study was approved by the local ethics committee in Stockholm (registration nos. 2009/895-31/5 and 2012/1911-31/5). The participants, who lived in Stockholm, Sweden, were purposefully selected for age, sex, time since disease onset, and satisfaction with care (Table 1).

In-depth interviews (N = 22) were conducted by the first author from 2011 to 2013 using a semistructured interview guide to gather rich and nuanced data.¹⁷ The

first draft of the interview guide was constructed on the basis of service literature¹⁸⁻²³ to include issues that influence consumer-perceived service quality, as well as 10 interviews conducted earlier for a separate research project with persons with RA. The interview guide was revised iteratively as participants introduced new concepts. The iterations continued until reaching data saturation and no new themes emerged.²⁴ To increase the richness of the responses, a diverse set of questions covering process and outcomes was used.¹⁷ For example:

- When you evaluate the effect of treatment, what do you take into account?
- Tell me about how your illness affects your life.
- What do you consider valuable in health? In your illness?
- Do you ever receive unnecessary care?
- How does information technology affect care?
- In the rare case that participants did not spontaneously cover all tiers in the 3-tier model, they were then asked specifically about those dimensions.

The participant chose the interview location. The interviews lasted from 1 hour 4 minutes to 1 hour 55 minutes ($M = 1$ hour 34 minutes). The interviews were audio recorded and transcribed verbatim by a professional transcriber and reviewed by the interviewer.

Analysis procedure

The interviews were analyzed using qualitative content analysis²⁵ in parallel with data collection. The interviews were read several times to increase congruence of analysis and the interview as a whole. The data were openly coded and grouped to form themes using the computer program QSR NVivo v.10.0. The themes were matched with subcategories in the 3-tier model most fitting the theme using abductive analysis.²⁶ Themes that did not fit the model formed new subcategories. Participants were available during analysis for narrative accuracy checks.²⁷ An experienced qualitative researcher analyzed a random sample of 3 interviews nonblinded to first analysis to ensure analytical saturation. Presenting the results was challenging due to the rich and complex data that forced us to make choices. The results in the study constitute a condensed narrative to adhere to the word limit. Furthermore, some data instances could be categorized both as degree of recovery or health and as disutility of care or treatment process. Such instances were categorized as degree of recovery or health if the issue affected the participant in the long term, whereas the issue was categorized as disutility if it was limited to the care process. Finally, the results section in the study reflects an attempt to illustrate the variability in participants' perceptions of value, although it has not been possible to fully convey the various differences in their views and experiences.

RESULTS

The data confirmed that the subcategories of the 3-tier model³ mattered to at least some individuals, but

Table 1. Participant Profiles

Participant ID	Age, y	Debut (Years Ago)	Sex	Satisfaction With Care	Disease Activity	Recruiter
P1	41	11	Female	Not satisfied	Low	Clinician
P2	69	11	Female	Not satisfied	Low	Clinician
P3	30	5	Female	Satisfied	Low	Clinician
P4	52	16	Female	Satisfied	Low	Clinician
P5	48	10	Male	Not satisfied	Low	Clinician
P6	37	4	Male	Not satisfied	Low	Clinician
P7	46	28-27	Female	Satisfied	High	Clinician
P8	66	48	Female	Satisfied	Low	Patient network
P9	33	7	Female	Satisfied	Low	Clinician
P10	55	6	Female	Satisfied	Low	Clinician
P11	59	19	Male	Satisfied	Low	Clinician
P12	49	29	Female	Not satisfied	Low	Patient network
P13	51	10	Female	Satisfied	Low	Clinician
P14	61	19	Female	Satisfied	Low	Patient network
P15	82	2	Female	Not satisfied	Low	Clinician
P16	56	32	Female	Satisfied	Low	Patient network
P17	41	19	Female	Satisfied	Moderate	Patient network
P18	59	22	Female	Satisfied	High	Clinician
P19	57	2	Female	Not satisfied	High	Clinician
P20	70	5	Female	Satisfied	Low	Clinician
P21	65	3	Male	Satisfied	Low	Clinician
P22	46	10	Male	Satisfied	Low	Clinician

participants expressed different views on how and when the subcategories mattered. Importantly, the data indicated that participants perceived issues other than those included in the 3-tier model as relevant. Data in support of the original model are presented briefly with quotes in Table 2, whereas the new subcategories have been given more space to illustrate their meaning and distinctiveness.

Support for the original model

Survival

Mortality. Before diagnosis, fear of death was common among participants. With established diagnosis, some participants valued survival because they had families. Others did not think survival was important because, for example, they perceived survival as insignificant compared with quality of life.

Degree of recovery or health

In general, valuable outcomes were the same whether recovering from initial onset of disease or recovering from flares. Being cured was the ultimate goal for some participants. *Physical and mental functional status* is split into the first 3 subcategories due to the richness of the data.

Avoiding physical symptoms. Preference for specific symptoms differed. Aspects that participants mentioned as important to avoid were shaking, pain, fatigue, stiffness, range of motion, hair loss, decreased grip function, and swollen joints. For some participants, pain relief was the most important outcome, whereas others cared more if pain affected functions such as work or activities of daily living (ADL). Participants who experienced fatigue said handling it was more important than handling pain or decreased motion.

Avoiding aesthetic symptoms. Aesthetic problems participants perceived as important were joint malformations, effects on walking style, inability to wear certain shoes, and weight gain or loss. Some participants did not want their RA to be visible because they did not want to be treated differently in social situations beyond health care. Others perceived having a visible disease as valuable because then people would not question their health status.

Ability to perform ADL and exercise. Most participants saw carrying out ADL and leisure and physical activities—carrying groceries, horseback riding, bicycle riding, walking, performing yoga, or even lifting a cup of coffee—as very important.

Table 2. Supporting Quotes^a

Category	Quote
Survival	<p><i>Mortality:</i> "I have thought about death every day. But not as something scary, but, more . . . that I must live first until [my first grandchild] finishes ninth grade, and then until the other finishes." (Participant 8)</p> <p>"You know, if you are 66 like I am, if I live to 75, I do not care, I do not care, I do not have that . . . I'm not afraid of death or anything." (Participant 21)</p>
Degree of recovery or health	<p><i>Avoiding physical symptoms:</i> "Think to wake up one day and not be in pain anymore. There, oh what a dream. But, although I am quite optimistic, I do not believe it actually." (Participant 11)</p> <p><i>Avoiding aesthetic symptoms:</i> "I don't want the questions, 'What have you done with your feet?' or 'What have you done with the legs?' or 'Why are you walking so strange?' So it has been a struggle with that, to make sure you are not pigeonholed." (Participant 6)</p> <p><i>Ability to perform ADL and exercise:</i> "That is the hardest, the absolute hardest. Someone else is supposed to cut my food, my meat on the plate that I want to have cut in my way. I don't want it mixed with the sauce . . . Somehow, integrity in those aspects is still difficult after being in need of so much help. My husband still cannot cut it the way I want." (Participant 4)</p> <p><i>Control of chronic disease complications:</i> "Of course, if health care can see an unfortunate, that it is connected, that [the disease] could lead to some other unfortunate consequences [other than a return of the symptoms I'm seeking care for], then you might want to know about it, and if it is possible to ensure that it does not happen either." (Participant 5)</p>
Time to recovery or return to normal activities	<p><i>Time to treatment/remission:</i> "The time from . . . the first symptoms to treatment, it's important, it is clear that it must have to take half a year at least before one can be sure . . . to have a clinical diagnosis. However, that is important to receive quickly." (Participant 16)</p> <p>"I can put acupuncture after you have bathed,' [the physiotherapist] says . . . Then I don't have to wait two days . . . and it feels really, really great." (Participant 18)</p> <p><i>Time to definitive diagnosis:</i> "I think it's really important to get a diagnosis. I do not really know why but it . . . [Laughs] it feels like, it is easier to explain why you . . . cannot do some stuff, perhaps." (Participant 3)</p> <p>"So, I was also like: nice, you get as a diagnosis. Yes, well, crap that I've got this, but still, you know why you feel this way. I know why I feel like this, it wasn't all in my head." (Participant 19)</p> <p><i>Time to access specialist treatment:</i> "You must get the aid when you have pain, you cannot say to a rheumatic person, we [only] do injections Tuesdays and Fridays . . . It is not a rheumatic person that has come up with that, it's a health person." (Participant 1)</p> <p><i>Time spent accessing treatment:</i> "I'm not here for health care. So, I want them to sync it. Then, if I have a number of visits, you should be able to do it the same day." (Participant 16)</p> <p><i>Workdays missed:</i> "The care must, of course, be good enough to enable me to continue with my original profession . . . You lose your profession, you lose your life." (Participant 10)</p>
Disutility of care or treatment process	<p><i>Pain and anxiety before and during treatment:</i> "The existential—that's the big platform that health care and we all somehow have to consider. Maybe it is done in different ways, but I'm thinking of the anxiety. How will it end up for me? Will I be able to walk in the future? Will I get worse? Or, is it the case that professor [name of physician] was mistaken, and this is an unusual form of systemic sclerosis?" (Participant 5)</p> <p><i>Care complications:</i> "So, I called and said, '[Chloroquine Phosphate] doesn't work, I cannot be outside.' 'Yes, but you must try it for three months.' And I was like, 'But I have not gotten a damn better.'" (Participant 17)</p>
Health over time	<p><i>Sustainability:</i> "Didn't I get more time? It became only like this? And then I have a real difficult slowing myself down when I feel that the medication [effect] begins to decrease." (Participant 4)</p> <p>"When I am not able to [get around] . . . But, I know I will have to live with that and it doesn't grieve me. I have so damn good kids and daughters-in-law and shit, so I do not care about it. If I want to go somewhere, I can call [them]." (Participant 21)</p>
Long-term consequences of care	<p><i>Avoiding long-term side effects:</i> "[The anti-inflammatory pain medicine], it is my opium. And it is not good for heart and arteries. I try to decrease the dosage, but then I get more pain. So . . . I don't like that, that heart and arteries are affected." (Participant 8)</p> <p>"The important thing is that I get the medicine that makes me feel good in my illness. I mean, the [medicine] I have today, I do not know about its side effects, for it is not many who have it and there has not been more than 10 or 11 years." (Participant 14)</p>

^aParticipant # refers to a participant in Table 1.

Control of chronic disease complications. Some participants spontaneously stated avoiding secondary diseases such as coronary disease was important to them. Other participants had been unaware of the risk of secondary disease but wanted to avoid it once they were informed about it. In addition, avoiding surgery due to destroyed joints was important to some participants.

Time to recovery or return to normal activities

Time to treatment/remission. Some participants expressed the importance of minimizing the time until perceived investigation or treatment and the time to information about the disease. However, time to improved outcome—mainly time to pain relief and also time to mobility achieved—was instead more important to most participants.

Time to definitive diagnosis. Diagnosis had an existential value as an end point beyond being the basis for treatment, for example, by removing doubts that the symptoms were an illusion. In addition, having a diagnosis provided emotional comfort and made it easier for participants to explain why they were unable to take part in activities.

Time to access specialist treatment of more complicated or urgent issues/flare. Most participants felt it important to get quick relief from acute symptoms regardless of whether the acute symptoms came from the disease onset or a flare of an established disease.

Time spent accessing treatment. To most participants, it was important to minimize time spent planning and accessing treatment and health care, including time traveling to the hospital or laboratory, waiting in waiting rooms or on the telephone, and spent with the doctor—especially if the visits had no health outcome consequences (eg, routine checkups). Other participants, however, perceived short health care visits as disappointing.

Workdays missed. Work was important to provide participants feelings of purpose and of being needed, and keeping their same jobs was important for their feelings of identity. For some participants, it was important that health care motivated them to work whenever possible while receiving sick leave when necessary.

Disutility of care or treatment process

Pain and anxiety before and during treatment. Pain inflicted during and due to the care processes was of no importance to participants, but they valued their feelings of safety, including continuity of care and not being alone with their feelings. Some participants said that health care personnel motivating them to fight for recovery was very important. Some expressed the economical disadvantages of having RA, such as being on sick leave, paying for medications, or having to travel by cab.

Care complications. Short-term side effects decreased the participants' perceived value of the medication. Par-

ticipants gave examples of their inability to drink alcoholic beverages or sunbathe, headaches, and the psychogenic effects of corticosteroids and opioids.

Need for emergency department visits or hospitalizations. Not found in the data.

Health over time

Sustainability. Participants mentioned the importance of stability in aspects conforming to the 3-tier model: maintaining functional levels, frequency of urgent care issues, and acuity of chronic conditions and complications. They saw value in feeling sustainably good, at least until the next checkup. For some participants, it was important to have as few flares as possible; for some, the number of flares was not important if quickly treated; and others were not at all concerned about sustainability.

Long-term consequences of care

Avoiding long-term side effects. Although some participants expressed value in avoiding cancer caused by biological drugs or a change in their appearance caused by corticosteroids, reducing long-term side effects was never more important than treatment outcomes.

New subcategories

Degree of recovery or health

Feeling sufficiently informed. The majority of participants expressed that knowledge of the disease and treatment was an important end point for them. Such knowledge increased their acceptance of disease progression and flares and their willingness to fight and enabled them to discuss the disease and treatment with their doctors. Some participants stated that when they did not understand something in the health care process, they thought about it long afterward, which affected their everyday life. For other participants, lack of information would be better described as a disutility. As demonstrated in the following quotes, some participants felt it important to possess knowledge to adjust medication and gain greater control of their health:

When I had the onset, you received so much information, so I'm not sure what stayed in the head at that time. Most of it became clear later, when I found it out by myself, discussed, and went to meetings or courses or something like that. . . . Then, I have knowledge of my medication, my disease, and what the physician allows me to do. (Participant 14)

You feel that you could get answers to all the questions that you had. And that is very important. I didn't have to Google that much. But I like Googling, [it is a] good way to answer things, and then you can check with a doctor if it is true or not. (Participant 20)

Social support from family and health care. Feeling that family, friends, and health care personnel understood and cared about the situation was also important to most participants. They made no distinction between the characteristics of their relationships with health care personnel and those with family and friends.

[My doctor] is successful 90 times out of 100. But then those ten times that she does not succeed But since you have met a doctor who will listen to you as a person, as an individual, you will not mind those ten times. (Participant 1)

I have a wife who tells me that “now you have to . . . give in,” and knows; she sees when I’m feeling bad even if I’m not saying anything. And that makes it possible for me to slow down in life. (Participant 6)

I asked him for a referral, and there was no problem. On the contrary, he is delighted to help me It is important for me, of course, to have the right doctor, because I still have a chronic illness and I need to have people around me who support and see me. (Participant 7)

Health over time

Predictability. Many participants perceived having predictable disease activity as more important than feeling as well as possible, because having a predictable disease made it possible for them to plan activities such as traveling. Although the importance of removing chronic pain decreased as the disease progressed, removing acute pain remained important.

For me, it’s been an incredible reward in the medication. I feel smooth in disease activity. Then, what’s happening inside and what the blood tests show, [I don’t know]. But for me to feel smooth in [the disease], that I’m evenly strong (Participant 6)

Then, it’s so hard that this disease is tricky also because one day maybe I’m quite rested, the next day I’m really bad. I do not know myself. And that, I think is tough. (Participant 12)

One wants to know the prognosis [of the disease] as well, but I mean it’s not so easy. But then, I want [the doctor] to tell me that. (Participant 16)

Continuity. Having the same nurse, doctor, or physiotherapist when discussing chronic symptoms was important to all participants. When seeking help for acute symptoms, the outcome of their care was more relevant than continuity to most of the participants, whereas in diagnostic examinations, such as blood tests, continuity had no importance.

If I go to the health center with tonsillitis . . . I do not care whether I have met the doctor before. But when it is a chronic disease and it is medicine and medicine and hospital treatment, it is so wonderful to have the same. (Participant 4)

Now when I see my rheumatologist, it’s more fun seeing her than ever, because she knows me, and she will say, “It feels so good. Now it feels much, much better. You are not at all as swollen, and I can see that you are walking much better.” (Participant 6)

DISCUSSION

This study lends support to understanding health care quality in terms of outcomes. Specifically, persons with RA care primarily about outcomes and the 3-tier model can be a relevant way to separate those outcomes. However, this study shows limitations of the model, given that its intended purpose is to redirect attention, delivery, and planning efforts in care toward patient value. For one, the data indicate that patients have different perceptions of how and when each category is valuable than that is captured by the model. Furthermore, the data identified subcategories not originally present in the model.

Refining the 3-tier model

On the basis of the data, the 3-tier model can be modified to better suit a chronic care setting, and the Figure displays this refined model. The data suggest 3 primary adjustments. For one, “time to treatment” should be extended to include “remission.” Furthermore, the provider-centric vocabulary of the original model excludes the use of self-care seen in this and earlier studies.^{28,29} Hence, the refined model replaces “time to access specialist treatment for more complicated or urgent issues” with “time to treatment in case of flares,” where the subcategory title does not necessarily assume health care involvement. Finally, with the exception of “time to diagnosis,” outcome measures suitable for the onset of RA are equally important in acute flares. Therefore, the 3-tier model is better illustrated as a cycle rather than a hierarchy. This also makes more sense from the patient’s perspective because the tiers are measured at different periods in the individual patient care cycle.

Earlier studies

Table 3 compares the subcategories of the refined model (Figure) with earlier studies of qualitative literature. In this comparison, a few interesting disparities are notable. First, although the value of avoiding comorbidity as an end point could not be found in the literature, comorbidity was described as a mechanism for decreased physical function and quality of life.⁵²

Second, although several studies mentioned the importance of diagnosis,^{41,43,47} none characterized it as having an existential value of its own, as suggested in the present study. That is, the previous studies

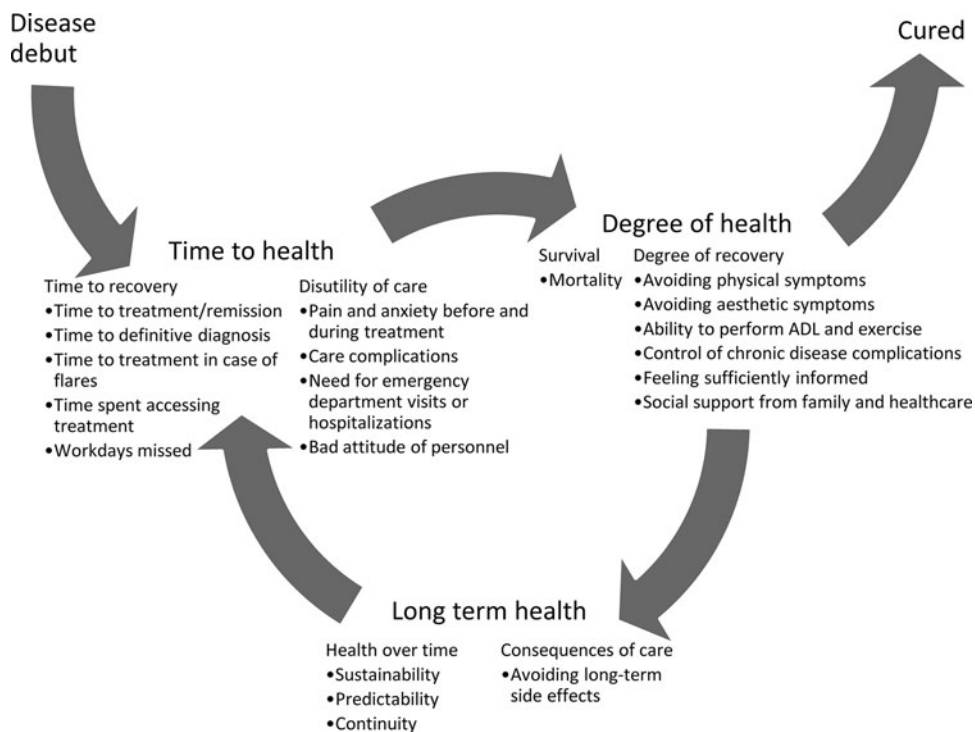


Figure. The 3-tier model adjusted to the acute and chronic care settings with the risk of flares and recurrence of disease. ADL indicates activities of daily living.

either did not state the reason for the importance of diagnosis⁴⁷ or saw diagnosis only as a tool for improving health.^{41,43} Furthermore, another study³⁶ explicitly stated that diagnosis was not important. That discrepancy could be due to the limited sample size in these qualitative studies.

Third, the need for emergency department visits or hospitalizations was not found in the present study. This is not surprising, given that rheumatology care in Sweden is rarely managed via the emergency department or with hospitalizations. A study with data from United States, however, illustrated how emergency visits result from having a flare.²⁸ Hence, even if this subcategory may be less relevant in the Swedish setting, this study cannot support a general exclusion of this subcategory, especially not for other chronic diseases.

Methodological considerations and limitations

This study has several limitations, including the risk of bias in the sample selection. For example, all participants were from the Stockholm area and persons from the countryside might present different views. However, this limitation was countered by using a thorough set of earlier studies to back the findings. Furthermore, the participants’ statements were assumed to represent their views, but there can be many reasons for this not being the case. Only one researcher performed the major part of the analysis, which could affect the validity of the results. In addition, a survey or systematic literature review would have provided greater generalizability of the findings; however, this study’s objective required a deep understanding of

the patient experience not retrievable in the literature and, as demonstrated, the study found subcategories not already present in the qualitative literature. Finally, some results presented concerning economy (eg, patient fees and sick leave), continuity, and time spent in health care and emergency department visits describe situations typical of the Swedish setting and may not be transferable to other countries. However, the strong agreement of this study’s findings with earlier studies from different contexts suggests a high generalizability of the findings.

Practical implications to redirect attention to patient value in chronic care

The findings illustrate areas important to patients with RA. Many of these outcomes are not given attention in contemporary quality assessments of health care, and most are certainly not measured in today’s health care systems. Rather, those systems focus on mortality as an outcome measure in aggregate comparisons and clinical composite measures⁵³ in clinical care. To reduce these discrepancies, measurements must align with patients’ preferred outcomes. Validated measurements for all areas of importance to patients may not exist; they need to be developed. This study’s findings underscore the complexity of designing such measurements. Although the present study could identify aspects perceived as important by all patients—aspects thus relevant to measure—patients had different views regarding what would constitute the desired state of each aspect. That is, in some cases (eg, pain relief), all patients preferred more to less. In other cases (eg,

Table 3. Refined 3-Tier Model Comparison With Original Model and the Literature

Category	Subcategory	Refined: Present Study	Original: Porter et al ³ (2013)	Other Literature
Survival	Mortality	X	X	Mortality secondary to other outcomes ^{28,33}
Degree of recovery or health	Avoiding physical symptoms	X	X	Avoiding pain, ²⁹⁻³² fatigue ³¹⁻³⁴
	Avoiding aesthetic symptoms	X	X	Aesthetic symptoms ^{30,35,36}
	Ability to perform ADL and exercise	X	X	Maintaining habits of everyday life, ^{31,33,34,36,37} exercise ³⁸
	Control of chronic disease complications	X	X	Avoiding surgery ³⁵
	Feeling sufficiently informed	X		Feeling sufficiently informed ^{29,30,38-41}
	Social support from family and health care	X		Receiving social support from family ^{34,42-44} and health care, ^{31,41,45} avoiding bad attitude of personnel ^{31,41,46}
Time to recovery or return to normal activities	Time to treatment/remission	X	X	Time to improved health functional status ^{30,35,43} and pain relief ²⁸
	Time to definitive diagnosis	X	X	Time to diagnosis ^{41,43,47}
	Time to treatment in case of flares	X	X	Not found
	Time spent accessing treatment	X	X	Minimizing time spent in health care ^{35,47}
	Workdays missed	X	X	Workdays missed ^{31,32,34,37,42,46-48}
Disutility of care or treatment process	Pain and anxiety before and during treatment	X	X	Anxiety ^{40,47,49} and poor economy ⁵⁰
	Care complications	X	X	Short-term side effects ^{32,49}
	Need for emergency department visits or hospitalizations		X	²⁸
Health over time	Sustainability	X	X	Sustainability, ^{33,35,50} acuity of chronic conditions and complications ^{35,51}
	Predictability	X		³⁷
	Continuity	X		31,41
Long-term consequences of care	Avoiding long-term side effects	X	X	33,39,49

aesthetics), some patients preferred visible symptoms whereas other patients preferred the opposite. Even in terms of mortality, often accepted as the most important outcome, some participants explicitly said it was unimportant. Their preferences differed over time, especially concerning trade-offs among aspects. This diversity could potentially be circumvented by one of the following 4 approaches:

1. General measurements (eg, "To what extent does RA limit you from doing what is important to you?");

2. Specific questions open to the patient's own interpretation (eg, "To what extent is your disease predictable?");
3. Individualized, self-stated patient goals and measurement of achievements; or
4. Flexibility in what to measure or possibly patient-preferred prioritizations among a fixed set of measurements.

Furthermore, the discrepancy between the original model and patient preferences is a reminder to test theoretical frameworks against empirical data before using

the framework in health care management or system design decisions. Initiatives that create outcome measurements using the framework of value-based health care,^{3,4} such as the International Consortium for Health Outcomes Measurement, need to critically assess the framework in light of the patient perspective.

Theoretical implications

The findings have implications for how to view and assess outcomes in health care, illustrating that the view of the patient may differ from the traditional view of the researcher. This concerns if specific aspects are considered processes or outcomes and how categories of social support are formed. More specifically, continuity and attitude of health care personnel have been traditionally considered process measures,^{19,20} but in this setting, they are outcomes. In addition, earlier studies discussing social support from family and social support from health care^{31,41} divide those aspects. However, in the data of this study and to persons with RA, this division does not make sense since social support from health care fills the same function as social support from family. It remains to be discovered whether this holds quantitatively and for other chronic diseases.

CONCLUSION

The 3-tier model³ with modifications may be applied to RA as a framework for research, outcome development, and clinical management. The findings highlight that process-oriented measurements cannot represent quality in clinical practice; rather, focusing on outcomes better captures areas important to persons with chronic disease. This, however, requires further efforts to align the outcomes with patient preferences.

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