

Whither voluntary communities? A study of co-located patients in Vietnam

Quan Hoang Vuong, Trong-Khang Nguyen, Thuy-Dzung Do and Thu-Trang Vuong

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This study of a 336-patient data set examines how a patient community's benefits and how meeting patients' imperative needs impact their perception of the future of a voluntary community.

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Keywords: Health behavior, co-located patients community, healthcare cost

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Abstract: While much research has focused on issues related to patients' quality of life and access to health care in developing countries, the life of ill people in poverty still hasn't been approached in numerous facets, and is especially embryonic in many emerging economies. This study of a 336-patient data set examines how a patient community's benefits and how meeting patients' imperative needs impact their perception of the future of a voluntary community.

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1. Introduction

Health-related quality of life is a rapidly spreading out field of research. Issues associated with the patient's life have received more attention recently in research literature. Almost all concerns have concentrated on the patient's quality of life, their needs, their level of integration in - or, in some cases, isolation from - the community, and, of course, their hardships. Nonetheless, empirical studies on patient's life in an emerging economy such as Vietnam remain insufficient as far as facts reflected.

For poor patients, long-term treatments seem to be the highest barriers. In fact, patients in poverty must regularly cope with asymmetric information and lack of networking, making them vulnerable to unofficial health care costs as well as socioeconomic burdens. Furthermore, most of them live in poor or remote areas, usually far from the location of treatment facilities, resulting from frequent travels that would significantly disrupt their family life. And there are not few of them; in fact, in 2014, 92,29% poor households throughout the country are found in such areas (VGP 2015), which have a severely underdeveloped health care system. Moreover, the increasing burdens on poor patients, such as financial difficulties, long-term treatments, travel requirements and accommodation needs, as well as their growing despair, are all well documented. For instance, in a previous research, on the problem of patients risking destitution for medical treatment, Whitehead et al. (2001) report that in northern Vietnam's rural areas, 20% of poor households were in debt due to the burden of health care costs.

Real-life stories of poor patients undergoing expensive treatments have been featured on numerous articles, giving the public a general idea of their hardship. In particular, an article on VTC online newspaper reports about the struggling lives of chronic kidney disease patients who have gathered up to live in the same area in a close-knit group, which we shall hereon refer to as "voluntarily co-located patients community" or "community" for short. The story told was that of patient Mai Van Ma, in Co Do commune, Ba Vi district (Northwest of Hanoi). His entire family of three was diagnosed with kidney disease; moreover, he had been exposed to Agent Orange during the war. At the time being, financial situations were tough: his salary of VND1.2 million could not cover the total VND1.3 million cost of travel and hospitalization fees. All living expenses and treatment costs weighed on his wife, who was a street vendor. Fortunate enough, his family found this CKD patient community as a resolution and has resided there for 16 years for his regular kidney dialysis (VTC Online 2011). Another similar story but in a different patient community: the couple Sung A Chau and Mua Thi Sa in Son La (a northwestern province of Vietnam) has a 5-month-old child born without anus. Their difficult economic conditions could barely support long-term treatment (Viet-Ha 2015); they thus had to join the Pediatric community for support so as to overcome difficulties. There have been many impoverished, indebted families with a member suffering from some disease. Financial burdens and isolation pushed them into forming patient communities, where they could feel more at ease knowing that they had each other to rely on.

For many rural and remote dwellers, patient community provides benefits in diminishing cost of living as well as sharing information by putting them into a network – something they previously lacked. Since there are a great number of people who rely on these communities, as mentioned above, the scale of patient communities has become a great concern for not only patients and their family, but also policy-makers. Here arise the questions concerning the community's development as judged by patients, the impacts of community's growth on its members, and the sustainability of patient communities.

This paper aims to identify factors that may affect a patient community's development based on a survey of member patients with poor socioeconomic status. Many of the questions seek to measure the community's development through critical determinants such as the benefits patients receive as community member, contributions that patients make towards the community, and the extent to which the community meets the patient's expectations.

The article has four main parts. It begins with a brief literature review examining issues associated with patient's life. Next, it moves on to presenting the research method of baseline category logit model, which is employed to model conditional probabilities of community expansion when certain specific events occur. The third section represents the data set and analysis, together with computed probabilities, which address the research questions. The paper closes with a discussion on key insights and suggestions for future research.

2. Research questions

2.1. A brief literature review

The extant literature on co-located patients is inadequate, and focuses mainly on issues related to patients' quality of life (QOL) outside the hospital, their satisfaction in life, the influence of socioeconomic status on patient's treatment as well as the needs of the ill and their families. In addition, researchers also shed light on aspects of approach to health care, especially for the poor. This section aims to briefly discuss issues in regard to member patients of communities which have given rise to the research questions.

For patients living in rural, remote areas and often in difficulties, it is a challenge to access both patient communities and hospital-based services for generalist and specialist medical care. Yet, poor patients with lower income and less education often require more resources and entail longer hospital stays than others of higher socioeconomic status (Epstein et al. 1990). Hence, major concerns that could increase burdens on ill people and their families include a lack of specialized local care as well as additional costs related to travel and accommodation, particularly in the case of long-term treatment. It has also been pointed out that early discharge or outpatient treatments are remedial measures to reduce financial hardships (Clavarino et al. 2002), all of which are more likely to happen when patients gather up in a community outside of the hospital. In essence, living in a patient community is considered an effective option for the poor.

However, there is controversy about whether inhabiting communities is more convenient. Ever since deinstitutionalization began more than two decades ago, the dramatic decline of patients living in the hospital has posed concerns about their quality of life outside the hospital. Their living conditions, financial constraints and the degree of their isolation from the communities have been examined. Lehman et al. provide some useful results: patients living in communities reported more comfort, cohesion and satisfaction in their living conditions than hospitalized patients in all life areas (Lehman et al. 1986).

In the same vein, other researchers have also touched upon this problem. Distinguished statements have been made on the benefits of patient communities via comparing QOL among groups of patients differing in terms of living/housing conditions. Therein lies the interest in assessing patient's QOL as an index representing the bottom line of treatment and rehabilitation success. On one hand, Nilsson et al. highlight that there were no dissimilarity in the subjective ratings of OOL among four surveyed groups: inpatients, patient communities, home treatment and outpatients (Nilsson et al. 1998). On the other hand, Lehman et al. (1986) show their opposite view that the patient community provides a more favorable environment as well as supports for their patients, financial assistance in particular (Lehman et al. 1986). In addition, finance is one of the most consistent sources of dissatisfaction among all patient groups. Unsurprisingly, the financial impact of treatment as well as anxiety involving their financial status in the future were of high concern, affecting almost one-third of carers and one-quarter of patients (Clavarino et al. 2002). According to Hardeman et al., for a hospitalized patient, medical cost only make up 32% of the average total expenditure while 68% is spent on travel, food and basic commodities. Most patients financed their treatment by selling assets or taking out loans before going to the hospital (Hardeman et al. 2004). In addition, travel requirements and accommodation burdens are their most important constraints (Vuong, Q. H. 2015).

In short, it is evident that people living in poor and remote areas – with the lowest hospital utilization rates – always receive outdated information, face difficulties accessing the hospital and bear financial burdens (Hardeman et al. 2004). Yet, Delva et al. point out that the need of information and of assurance are two of the most important necessities for an ill person, with the need for support and comfort following suit. The need for information is estimated highly by most, probably due to the fact that being informed improves the patient's perception of their situation, thereby increasing carers' and relatives' ability to cope with the situation (Delva et al. 2002). Therefore, poor patients tend to be deprived of the right to have their very human needs fulfilled.

And even if patient communities can provide members with information and assurance from mutual support, member patients are still in need of external help. In fact, the society still has an enormous influence on patients. However, society's attitude towards the existence of patient communities is questionable. Lubin et al consider society's reactions to establishment residential programs and conclude that social acceptance is relatively high – 79%. Nevertheless, patient communities are still opposed by nearly 2% surveyed people. There are a number of reasons expressed for this opposition, such as lowering real estate values, affecting the neighborhood's image and bringing in undesirable individuals (Lubin et al. 1982).

By this fact, sustainable development of patient communities is a matter of concern. The issue is either new or goes unnoticed somehow, as it seems to have had little evidence or discussion about this particular problem / phenomenon so far. An in-depth analysis on the problems of these vulnerable patients and the solution that they have come up with – patient communities – will significantly contribute to the improvement of health care systems. This suggests the need of empirical investigations to examine patient's evaluations on scale development of community, which is what this paper seeks to explore.

2.2. Research questions

This study will approach issues surrounding patient's perception of the scale and future growth of their community, explore relationships between the benefits provide by patient community in response to patient's expectations and measure patient's contribution to their community. These considerations are reflected in the following research questions:

<u>RQ1</u>: Do financial/income benefits and in-kind benefits received from the patient community really impact patients' evaluations of their community's future development?

<u>RQ2</u>: Is it true that the more patients expect from and contribute to their community, the likelier it is for patients to believe in their community's future growth?

<u>RQ3</u>: In relation to patients' contribution – or the lack thereof – to the community, how do in-kind benefits from the community influence patients' perception on community scale development in the future? In addition, the influence of patient-made monetary/material contributions versus that of time/effort contributions shall be compared.

3. Research method

The BCL framework that is used to examine the survey data of this study will estimate a multivariate generalized linear model (GLM) in the following form:

$$\mathbf{g}(\mathbf{\mu}_i) = \mathbf{X}_i \mathbf{\beta},$$

where, $\mu_i = E(\mathbf{Y}_i)$, corresponding to $\mathbf{y}_i = (y_{i1}, y_{i2}, ...)'$; row *h* of the model matrix \mathbf{X}_i for observation *i* contains values of independent (also, predictor) variables for y_{ih} .

Following this method, as $\pi_j(\mathbf{x}) = P(Y = j | \mathbf{x})$ represent a fixed setting for independent variables, with $\sum_j \pi_j(\mathbf{x}) = 1$, categorical data are distributed over *J* categories of *Y* as either binomial or multinomial with corresponding probabilities { $\pi_1(\mathbf{x}), ..., \pi_j(\mathbf{x})$ }. Thus, the BCL model aligns each dependent (response) variable with a baseline category: $\ln[\pi_j(\mathbf{x})/\pi_J(\mathbf{x})]$, with j = 1, ..., J - 1.

As $\ln[\pi_a(\mathbf{x})/\pi_b(\mathbf{x})] = \ln[\pi_a(\mathbf{x})/\pi_J(\mathbf{x})] - \ln[\pi_b(\mathbf{x})/\pi_J(\mathbf{x})]$, the set of empirical probabilities from binomial and/or multinomial logits $\{\pi_i(\mathbf{x})\}$ can be computed using the formula:

$$\mathbf{\pi}_j(\mathbf{x}) = \frac{\exp\left(\alpha_j + \beta_j^{\mathrm{T}} \mathbf{x}\right)}{1 + \sum_h^{J-1} \exp\left(\alpha_h + \beta_h^{\mathrm{T}} \mathbf{x}\right)}.$$

The categorical variables used in our models are both dichotomous (e.g., the variate "Scalefut" takes value of "expansion" or "contraction"). Their coded names and values are described in the corresponding data set in the data section. A relevant example of real-world analysis employing actual survey data is given in Vuong (2015).

4. Data, estimations and results

4.1. Data

The survey was conducted through a series of meetings, during 2015Q4-2016Q1, with patients residing in four Hanoi-based patient communities, namely CKD (chronic kidney disease) community, outpatient residency community, pediatric community and Ngoc Hoi community. The data set has 336 qualified observations.

Data for RQ1

With the aim to evaluate the factors affecting patient's perception on community scale development, "Scalefut" will be used as the dependent variable in all models with two categorical values: "expansion" (broadening or growing) and "contraction" (stabilizing or shrinking).

Data subset for RQ1 can be used to estimate the impacts of financial benefits ("Ben.fin") and in-kind benefits ("Ben.ikd") on patient's evaluation/perception about future scale development of community. This data set is provided in Table 1. The first factor "Ben.fin" is defined as taking two different values of distinct states. Value "met.fin" represents when financial benefits from community meet patient's need and "unmet.fin" as the opposed state. The second factor "Ben.ikd" takes categorical values of "met.ikd" (in-kind benefits meeting patient's need) and "unmet.ikd" (in-kind benefits not meeting patient's need) to show the community's responsiveness to patient's material needs. Empirical modeling employs data given in Table 1 as follows:

"Ben.fin"	"Ben.ikd"	"expansion"	"contraction"
"met.fin"	"met.ikd"	5	20
IIIct.IIII	"unmet.ikd"	58	4
"unmet.fin"	"met.ikd"	27	46
unmet.m	"unmet.ikd"	79	97

Table 1 (Data for RQ1). Empirical distribution of "Scalefut" following "Ben.fin" and "Ben.ikd"

Tab.1 represents the distribution of patient's evaluations of community future development following two variables, "Ben.fin" and "Ben.ikd". It can be seen that there is an equal portion of patients predicting expansion and contraction. Among patients whose needs were unmet by both financial and in-kind benefits from the community, only 29% predicts community expansion.

Data for RQ2

Likewise, "Scalefut" (mentioned above) serves as response variable in our next model. In Table 2, factor "Expectation" (the community's response to patient's expectations, as judged by the patient) takes two

categorical values of "met.exp" (meet expectations) and "unmet.exp" (many issues remaining); factor "Contr.eff" (the level of voluntary care-giving - as contribution - that patients made to their community, evaluated by the patient themselves) takes two values of "sig.eff" (significant contribution) and "insig.eff" (insignificant). Table 2 presents the structured data table for RQ2.

"Expectation"	"Contr.eff"	"expansion"	"contraction"
"mat avn"	"sig.eff"	30	65
"met.exp"	"insig.eff"	136	81
"	"sig.eff"	1	11
"unmet.exp"	"insig.eff"	2	10

Table 2 (Data for RQ2). Empirical distribution of "Scalefut" following "Expectation" and "Contr.eff"

Tab.2 shows the fact that nearly 93% (312 out of 336 responses) patients show satisfaction towards what they received from their community. 136 patients without significant time/effort contribution and with their expectations met suppose that the community's scale will expand in the future.

Data for RQ3

The main objective of RQ3 is to consider the impact of financial/in-kind contribution on how patients evaluate community development in the future, and then compare the effects of monetary/material contributions versus time/effort contributions.

Monetary/material contributions of patients for their co-located area are assessed through factor "Contr.mm", taking two values: "sig.mm" (significant contribution) and "insig.mm" (insignificant). The first empirical model for RQ3 uses two independent variables, factor "Contr.mm" and "Ben.ikd" (mentioned above). Distribution of patients following "Contr.mm" and "Ben.ikd" is presented in the Table 3 below.

<u><u> </u></u>			0
"Ben.ikd"	"Contr.mm"	"expansion"	"contraction"
"met.ikd"	"sig.mm"	9	16
met.iku	"insig.mm"	23	50
"unmet.ikd"	"sig.mm"	4	18
unmet.ika	"insig.mm"	133	83

Table 3 (Data for RQ3). Empirical distribution of "Scalefut" following "Contr.mm" and "Ben.ikd"

Only about 1% patients (corresponding to 4 responses) who have made monetary/material contributions without getting in-kind benefits from co-located area assesses expansion on community scale. Likewise, in Table 4, distribution of patients by time/effort contributions and in-kind benefits is reported.

"Ben.ikd"	"Contr.eff"	"expansion"	"contraction"
"met.ikd"	"sig.eff"	19	37
met.iku	"insig.eff"	13	29
"unmet.ikd"	"sig.eff"	12	39
unmet.ikd	"insig.eff"	125	62

Table 4 indicates that 125 patients – with neither significant contribution of time/effort nor fulfilled needs concerning in-kind benefits from the community – believe their community will grow.

4.2. Estimations and results

The results reported for investigation of RQ1-RQ3 are estimated using software R. All relevant statistics are provided in corresponding result tables. Subsequent empirical results then help establish relationships between polytomous response variables and discrete explanatory variables. Then we move on to compute specific probabilities upon specific "events" of hypothetical influence.

The first estimation and results:

The first set of result considering the problems stated in RQ1 is reported in Table 5, with all coefficients being statistically significant, mostly at a conventional level (p < 0.0001).

	Intercept	"Ben.fin"	"Ben.ikd"		
		"met.fin"	"unmet.ikd"		
	β_0	β_1	β_2		
logit(orpansion contraction)	-1.111****	1.337***	1.109***		
logit(expansion contraction)	[-4.598]	[4.736]	[4.183]		
Signif. codes: 0 '***' 0.001 '**' 0.01 '*' 0.05 '.' 0.1 ' ' 1, z-value in square					
brackets; baseline category for: "Ben.fin": "unmet.fin"; and, "Ben.ikd":					
"met.ikd". Residual deviance: 30.49 on 1 degrees of freedom.					

Table 5. Estimated coefficients for RQ1 with associated statistics

Table 5 gives us an outlook on joint effects of "Ben.fin" and "Ben.ikd" on how the patient perceives community development. The equation indicates that financial benefits and in-kind benefits received are related to patient's evaluation. Value "met.fin" exhibits the single largest effect, with β_1 =1.337 (p-value<0.0001), representing a much higher development evaluation than "unmet.ikd". To have a deeper understanding of this result, the following fact is constructed from coefficients with associated conditions as stated by the BCL model given in RQ1.

$$\ln\left(\frac{\pi_{\text{expansion}}}{\pi_{\text{contraction}}}\right) = -1.111 + 1.337 \times \text{MetFin} + 1.109 \times \text{UnmetIkd}$$
Eq. (RQ1)

Probability distributions of development assessment upon financial benefits and in-kind benefits based on Eq. (RQ1) is reported in Table 6.

Table 6. Probability distributions of develo	pment assessment upon financial	benefits and in-kind benefits
	1 1	

"Scalefut"	"expansion" (a)		"contraction" (b)	
"Ben.fin" "Ben.ikd"	"met.ikd"	"unmet.ikd"	"met.ikd"	"unmet.ikd"
"met.fin"	0.556	0.792	0.444	0.208
"unmet.fin"	0.248	0.500	0.752	0.500

Table 6 suggests that a patient who receives income/financial and in-kind benefits meeting their needs tends to predict community growth, corresponding to approximately 55.6% of those observed.

In particular, "Scalefut" shows starkly contrasting changes when different values of "Ben.ikd" are considered. The probability that a patient would judge the community as likely to expand is higher when

the patient's condition is "unmet.ikd", while "contraction" drops. In other word, in-kind benefits enhance patient's negative perception on community's growth. All above results are illustrated in Fig.1.

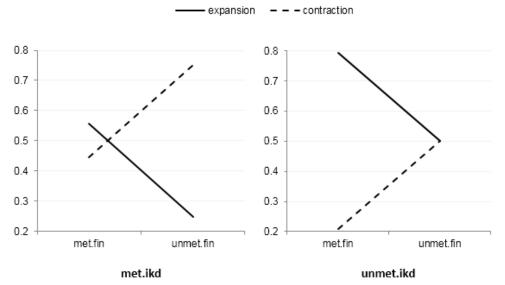


Figure 1. Changing probabilities of "Scalefut" depending on "Ben.fin" and "Ben.ikd" (constructed from Appendix A)

To measure the differences in patient's perception of future community growth in the cases of "met.ikd" and "unmet.ikd", Fig.1 is likely to provide us further insight. In both graphs, the two lines move in opposite directions. It is easy to realize that "contraction" line always goes down and in contrary, "expansion" jumps when changing from "met.fin" to "unmet.fin". This result tells us that whether or not receiving in-kind benefits, getting financial benefits will help improve positively patient's assessment on community expanding scales in the future.

The second estimation and results

To quantify the impact of degree of meet patient's expectation and time/effort contribution on the patient's assessment of community scale in the future, the following estimation has "Scalefut" as response variable and two group predictor variables: "Expectation" and "Contr.eff" as seen in Table 7.

rable 7. Estimated impacts of Expectation and Contrient on Sealerut					
	Intercept	"Expectation"	"Contr.eff"		
		"met.exp"	"sig.eff"		
	β_0	β_1	β_2		
logit(expansion contraction)	-1.458*	1.971**	-1.273***		
logn(expansion contraction)	[-2.303]	[3.079]	[-4.959]		
Signif. codes: 0 '***' 0.001 '**' 0.01 '*' 0.05 '.' 0.1 ' ' 1, z-value in square					
brackets; baseline category for: "Expectation": "unmet.exp"; and,					
"Contr.eff": "insig.eff". Residual deviance: 0.14 on 1 d.f.					

Table 7. Estimated impacts of "Expectation" and "Contr.eff" on "Scalefut"

All coefficients in Table 7 have shown statistical significance at the conventional level of 10%. The largest coefficient observed in Table 7 is that of "met.exp", which indicates the importance of "Expectation", with β_1 =1.97 (p-value<0.01). An empirical relationship is constructed from Table 7.

$$\ln\left(\frac{\pi_{\text{expansion}}}{\pi_{\text{contraction}}}\right) = -1.458 + 1.971 \times \text{MetExp} - 1.273 \times \text{SigEff}$$
Eq. (RQ2)

This relationship leads to empirical distributions of probabilities of community growth predictions, as shown in Table 8:

"Scalefut"	"expansion" (a)		"contraction" (b)	
"Expectation" "Contr.eff"	"sig.eff"	"insig.eff"	"sig.eff"	"insig.eff"
"met.exp"	0.319	0.626	0.681	0.374
"unmet.exp"	0.061	0.189	0.939	0.811

Table 8. Distribution of probabilities of "Scalefut" for RQ2

Table 8 reveals an interesting result. A patient who has contributed time and/or effort to their community and whose expectation exceeds community' response, is 93.9% likely to judge the community as contracting.

Furthermore, the increase in probability of "expansion" when moving from "sig.eff" to "insig.eff" (from 31.9% to 62.6% in case of "met.exp", for instance) and the respective decline of "contraction" show a noteworthy fact: The more time/effort a patient contributes, the less said patient believe in future widening of the community.

Generally speaking, the tendency shown in Table 8 is represented perspicuously in Fig.2 (drawn using computed data in Appendix B) :

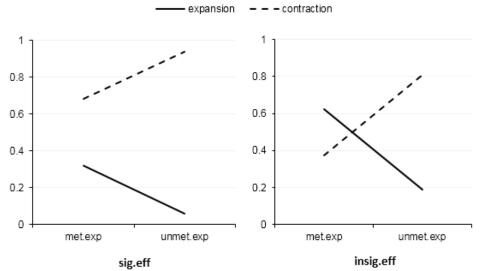


Figure 2. Evaluating likelihood of expansion in case of "sig.eff" and "insig.eff"

In both graphs, the "expansion" line moves in the same direction of decline when turning from "met.exp" to "unmet.exp". In opposite, subjective probability of "contraction" expresses a positive relationship. Considering Fig.2 tells us the truth that probabilities' assessment on growing scale will soar if community satisfies the patient's expectations.

In addition, in Fig.2 (left), the line representing "contraction" is above that of "expansion", while two lines intersect in Fig.2 (right). This shows that in the case of "sig.eff" (patients evaluating their own time/effort

contribution to the community as significant), the probability of "expansion" is always lower than "contraction". Meanwhile, if patients deem their time/effort contribution as less significant ("insig.eff"), the probability of "expansion" increases when their needs are met in the community. Generally, patients who contribute little to none to the community while still having their expectations met by the community's benefits are more likely to predict that the community will expand in the future.

The third estimation and results

The last set of estimation works with the response variable "Scalefut" and predictor variables of group "Ben.ikd" and "Contr.mm" to determine the subjective probabilities of patient's evaluations based on patient's money/material contribution and in-kind benefits from their community. All estimates are statistically significant and negative, with p-value<0.1.

	Table 9. Estimation for KQ5				
	Intercept	"Ben.ikd"	"Contr.mm"		
		"met.ikd"	"sig.mm"		
	β_0	β_1	β_2		
logit(oversion)	0.390**	-0.912***	-0.913**		
logit(expansion contraction)	[2.867]	[-3.539]	[-2.556]		
Signif. codes: 0 '***' 0.001 '**' 0.0	Signif. codes: 0 '***' 0.001 '**' 0.01 '*' 0.05 '.' 0.1 ' ' 1, z-value in square				
brackets; baseline category for: "E	brackets; baseline category for: "Ben.ikd": "unmet.ikd"; and, "Contr.mm":				
"insig.mm". Residual deviance: 9.	"insig.mm". Residual deviance: 9.03 on 1 degrees of freedom.				

Table 9. 1	Estimation	for	RQ3
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In RQ3 estimations, factors such as "met.ikd" and "sig.mm" all play negative roles in determining the "Scalefut". Both above factors have equal impacts on the independent variable, with corresponding estimated coefficients of β_2 =-0.913 (p<0.001) and β_3 =-0.913 (p<0.1). Furthermore, the negative sign proves that these two factors reminish the probability of community growth prediction. From Table 9's results, Equation RQ3.1 is constructed as:

$$\ln\left(\frac{\pi_{\text{expansion}}}{\pi_{\text{contraction}}}\right) = 0.390 - 0.912 \times \text{MetIkd} - 0.913 \times \text{SigMm} \qquad \text{Eq. (RQ3.1)}$$

Next, empirical relationship enables the computing of conditional probabilities in Table 10 as follow:

"Scalefut"	"expansion"	"expansion"		"
"Ben.ikd" "Contr.mm"	"insig.mm"	"sig.mm"	"insig.mm"	"sig.mm"
"met.ikd"	0.372	0.192	0.628	0.808
"unmet.ikd"	0.596	0.372	0.404	0.628

Table 10. Probabilities of "Scalefut" divided by in-kind benefits and money/material contributions

The largest probability observed in Table 10 is 80.8%, showing that a patient who contributes a significant amount of money/material to the community, despite receiving sufficient in-kind benefits, tends to believe that the community will not grow in the future. Evidences in Tab.10 evoke a rather high likelihood of "contraction" in the case of "met.ikd" and "sig.mm".

To visualize the effect of the patient's contributions as well as the extent to which in-kind community benefits meet their expectations on community scale evaluation, Fig.3 may be useful. The negative influence of factor "Ben.ikd" on the patient's prediction of the community's future scale is once again confirmed by the positions of the "met.ikd" line and the "unmet.ikd" line in the two graphs. Additionally, "Contr.mm" is added into Fig.3 to provide a deeper understanding of the patient's evaluation.

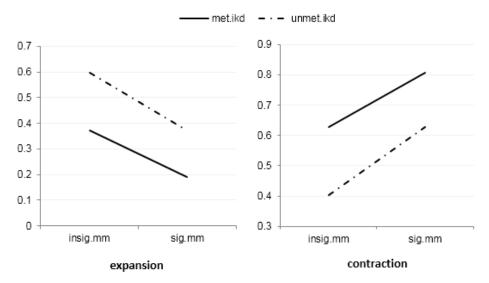


Figure 3. Changing assessment probabilities upon "Ben.ikd" and "Contr.mm"

Observing Fig.3, it is remarked that the two lines representing "met.ikd" and "unmet.ikd" in each graph move in the same direction when the situation changes from "insig.mm" to "sig.mm". When a patient has a considerable money/material contribution for their community, the probability of them supposing community "expansion" tends to decrease, and in opposition, the likelihood of "contraction" increases. In all circumstances, receiving in-kind benefits does not alter this tendency.

The impacts of "Contr.mm" and "Contr.eff" on "Scalefut" are measured and compared, then visualized in the following figure. All estimated results and the probability distributions are presented in Appendix C

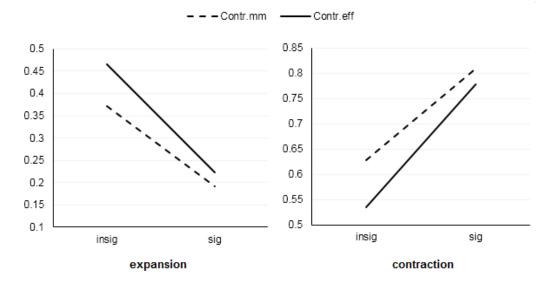


Figure 4. Assessment of co-located area scale with degree of contribution of money/material and time/effort (constructed from Appendix D)

Fig.4 (left) visualizes an empirical result that both two lines representing the level of contribution of money/material and time/effort show tendencies of going down when changing from "insig" to "sig". In

contrary, Fig.4 (right) expresses the reversed trend. These results confirm that "Contr.mm" and "Contr.eff" have equal impacts on "Scalefut".

However there is still a noteworthy difference: the slope of "Contr.eff" line is steeper than that of "Contr.mm". This indicates that the patient's time/effort contribution has a bigger impact than that of money/effort contribution on their evaluation of community scale.

5. Final remarks

The attempt to model patient's evaluation of community scale suggests that the choice of variables is crucial. The following section discusses those relationships, provides explanations, and concludes with key remarks.

Clearly, the patient's perception on the possibility of community expansion in the future will steer them through taking specific actions in improving and developing the community. First of all, empirical results have proven that patients will show positive predictions on the broadening of their community when they receive what they need or expect. Following a general observation on the personal evaluations of patients, it is remarked that, in addition to emotional support, information and personal experiences concerning treatments, communities also provide financial benefits (earnings from work, mutual support...) as well as in-kind benefits to sick people. Out of these aids, patients tend to appreciate financial help the most. In fact, when their financial needs are met (obtained in the form of generated income, loans or charity), patients tend to feel assured, even if the received benefits are small. This is due to the fact that, upon moving to entirely unfamiliar areas, patients and their carers always face hardships or, in more drastic cases, destitution, due to unexpected costs such as travel and accommodation fees as well as an increase in treatment costs. Financial benefits from the community are thus the most practical and foremost concern to patients; this fact helps explain a higher confidence in the community's sustained future among patients.

In contrast, in-kind benefit plays from the community a less significant role in influencing the patient's evaluation. Another related point worth remarking is that patients tend to be much more modest in contributing to their communities. Out of those surveyed, only 14% and 32% make significant money/material contributions and time/effort contributions respectively; the rest find their own contribution negligible, adding little to no values to the community's development. The cause to both of these occurrences roots perhaps in the patient's mindset, believing that any contribution is certain and counts as their immediate loss, while future benefits are uncertain and might not meet their needs. In other words, they are reluctant to risk contributing more than what they might receive back – a deficit of benefits. Here, this "risk" seems to greatly concern in-kind benefits, the kind of benefit that is more likely to not match what they truly need and thus, more likely to cause them the aforementioned "deficit". Essentially, this evidence further agrees with previous studies in pointing out that financial burdens are not only patients' main source of distress, but also their primary reason to gather up and stick together as a community.

Everyone needs money, diseased people in treatment even more so. Yet, only less than one out of four patients receive sufficient financial assistance from the community according to their own needs. With patients putting direct emphasis on financial benefits and the community unable to fully respond to this expectation, how shall long-term commitment be formed within these groups of people? How will patient communities hold together?

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Appendix

Appendix A. Probabilities of "Scalefut" depending on "met.ikd" and "unmet.ikd"

"Ben.ikd"	"met.ikd"		"unmet.ikd"	
"Ben.fin"	"met.fin"	"unmet.fin"	"met.fin"	"unmet.fin"
"expansion"	0.556	0.248	0.792	0.500
"contraction"	0.444	0.752	0.208	0.500

Appendix B.	Probabilities	of "Scalefi	it" upon	"sig eff"	and "insid	reff"
Appendix D.	1 IOUdulinities	of Scalen	n upon	sig.cm	and more	2.011

"Contr.eff"	"sig.eff"		"insig.eff"	
"Expectation"	"met.exp"	"unmet.exp"	"met.exp"	"unmet.exp"
"expansion"	0.319	0.061	0.626	0.189
"contraction"	0.681	0.939	0.374	0.811

Appendix C. Estimated impacts of "Ben.ikd" and "Contr.eff" on "Scalefut"

	Intercept	"Ben.ikd"	"Contr.eff"	
		"met.ikd"	"sig.eff"	
	β_0	β_1	β_2	
la cit(over an cion la centre ction)	0.548^{***}	-0.688^{*}	-1.109***	
logit(expansion contraction)	[3.751]	[-2.551]	[-4.194]	
Signif. codes: 0 '***' 0.001 '**' 0.01 '*' 0.05 '.' 0.1 ' ' 1, z-value in				
square brackets; baseline category for: "Ben.ikd": "unmet.ikd"; and,				
"Contr.eff": "insig.eff". Residual deviance: 13.03 on 1 d.f.				

Estimated model:

$$\ln\left(\frac{\pi_{\text{expansion}}}{\pi_{\text{contraction}}}\right) = 0.548 - 0.688 \times \text{MetIkd} - 1.109 \times \text{SigEff}$$

Eq. (RQ3.2)

Distribution of probabilities of "Scalefut" following by "Ben.ikd" and "Contr.eff"

"Scalefut"	"expansion"		"contraction	n''
"Ben.ikd" "Contr.eff"	"insig.eff"	"sig.eff"	"insig.eff"	"sig.eff"
"met.ikd"	0.465	0.223	0.535	0.777
"unmet.ikd"	0.634	0.363	0.366	0.637

Appendix D. Assessment of co-located area scale with degree of contribution of money/material and time/effort

"Scalefut"	"expansion"		"contraction"	
	"Contr.mm"	"Contr.eff"	"Contr.mm"	"Contr.eff"
"insig"	0.192	0.223	0.628	0.535
"sig"	0.372	0.465	0.808	0.777

Appendix D. The spreadsheet represents a conditional probability of the probabilistic tables

-			
	Name	Position	The formula for calculating probabilities
(a)	Table	1 st row,	e ^(-1.111+1337+1.109)
	6(a)	2^{nd}	$\pi_{\text{dev}} = \frac{1}{1 + e^{(-1.111 + 1337 + 1.109)}} = 0.792$
		column	
(b)	Table	2^{nd} row,	$e^{(-1.458-1.273)}$
	8(a)	1 st	$\pi_{\text{dev}} = \frac{e^{(-1.458 - 1.273)}}{1 + e^{(-1.458 - 1.273)}} = 0.061$
		column	
(c)	Table	1 st row,	$e^{(0.390-0.912-0.913)}$
	10(b)	2 nd	$\pi_{\text{undev}} = 1 - \frac{e^{(0.390 - 0.912 - 0.913)}}{1 + e^{(0.390 - 0.912 - 0.913)}} = 0.808$
		column	
Note:	The order	of rows ar	nd columns in the table only sees numerical part

Appendix E. Some R codes performed regressions

RQ1	<pre>> RQ1=read.csv("D://Data336/tab31.34.82.csv",header=T)</pre>
	> attach(RQ1)
	> contrasts(RQ1\$Ben.fin)=contr.treatment(levels(RQ1\$Ben.fin),base=2)
	<pre>> contrasts(RQ1\$Ben.ikd)=contr.treatment(levels(RQ1\$Ben.ikd),base=1)</pre>
	> fit.RQ1=glm(cbind(expansion,contraction)~Ben.fin+Ben.ikd,data=RQ1,family=binomial)
	> summary(fit.RQ1)
RQ2	> RQ2=read.csv("D://Data336/tab6.52.82.csv",header=T)
	> attach(RQ2)
	<pre>> contrasts(RQ2\$Contr.eff)=contr.treatment(levels(RQ2\$Contr.eff),base=1)</pre>
	> contrasts (RQ2\$Expectation) =contr.treatment(levels(RQ2\$Expectation),base=2)
	> fit.RQ2=glm(cbind(expansion,contraction)~Expectation+Contr.eff,data=RQ2,family=binomial)
	> summary(fit.RQ2)
	> RQ3.1=read.csv("D://Data336/tab34.51.82.csv",header=T)
RQ3	> attach(RQ3.1)
	<pre>> contrasts(RQ3.1\$Ben.ikd)=contr.treatment(levels(RQ3.1\$Ben.ikd),base=2)</pre>
	<pre>> contrasts(RQ3.1\$XContr.mm)=contr.treatment(levels(RQ3.1\$Contr.mm),base=1)</pre>
	> fit.RQ3.1=glm(cbind(expansion,contraction)~Ben.ikd+Contr.mm,data=RQ3.1,family=binomial)
	<pre>> summary(fit.RQ3.1)</pre>
	> RQ3.2=read.csv("D://Data336/tab34.52.82.csv",header=T)
	> attach(RQ3.2)
	<pre>> contrasts(RQ3.2\$Ben.ikd)=contr.treatment(levels(RQ3.2\$Ben.ikd),base=2)</pre>
	<pre>> contrasts(RQ3.2\$Contr.eff)=contr.treatment(levels(RQ3.2\$Contr.eff),base=1)</pre>
	> fit.RQ3.2=q1m(cbind(expansion,contraction)~Ben.ikd+Contr.eff,data=RQ3.2,family=binomial)
	> summary(fit.RQ3.2)