SHORT ARTICLE

Whither voluntary communities of co-located patients in Vietnam? Empirical evidence from a 2016 medical survey dataset

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Abstract

Background: Empirical evidence on quality of life of poor patients falls short for policy-making in Vietnam. Financial burdens and isolation give rise to Vietnamese voluntary co-location clusters where patients seek to rely on each other. These communities, although important, have been under-researched. Increasingly, there are questions about their sustainability. Aim & Objectives: This study aims to identify factors that affect sustainability of such co-location clusters, seeking to measure the community prospect through critical determinants as seen by member patients. An in-depth analysis is expected to yield insights that help shape future policies contributing to improvement of healthcare systems. Material & Method: A dataset containing responses from 336 patients living in four clusters in Hanoi was obtained from a survey during 2015Q4-2016Q1. The processing of data is performed using R 3.2.3, employing baseline category logit models (BCL). Coefficients are estimated to compute empirical probabilities. **Results:** 1) There is a 50% probability that a patient seeing his/her benefits as unsatisfactory views the community prospect as dim; 2) The more a patient contributes time/effort, the less he/she believes in future growth; 3) There is a 80.8% probability that a patient who makes a significant financial contribution and receives back in-kind benefits predicts no growth. Conclusion: Patients predict community growth when receiving what they need/expect. There exists a kind of "liquidity preference". Only 14% and 32% make significant financial and labor contributions, respectively. There exists a "risk aversion" attitude, viewing contribution as certain while future benefits to be uncertain.

Keywords

Health behavior; co-located patients; voluntary community; healthcare cost; social life; medical poverty trap

Introduction

Socioeconomic issues associated with patients have received an increasing attention in the recent research literature. Major concerns have concentrated on the patient's quality of life, their needs and coping with – or, isolation from – the community, as well as their hardships. Nonetheless, empirical studies in and results from emerging economies, e.g. Vietnam, remain insufficient as far as policy implications are concerned.

Life is even harder for poor patients. Patients in poverty must regularly cope with asymmetric information and lack of networking, hence becoming

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more vulnerable to unofficial healthcare costs and related socioeconomic burdens. The cost issue is particularly acute for those who have lived far away from locations of healthcare stations and treatment facilities. 2014 official data show that in 2014, >92% of Vietnamese poor households are based in such poor regions (1), having access only to a severely underdeveloped healthcare system. Moreover, the increasing burdens on poor patients, due to costly long-term treatment, travel and accommodation, among others, have been well documented (2). While in a research published in 2001, 20% of poor households in northern Vietnam's rural areas reported being in debt due to healthcare cost (2), recent estimates provide a range of higher probabilities for poor and non-resident patients to become destitute (3).

Real-life stories of poor patients undergoing expensive treatments have been featured on numerous articles, giving the public a general idea of their hardships (4-5). 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. Voluntary communities of co-located (also "colocation clusters") patients have emerged to be a social phenomenon in large urban areas in Vietnam, such as Hanoi and Ho Chi Minh City. Such communities help their members improve their access to community-provided benefits from reducing living costs, to sharing medical information, to receiving temporary jobs for generated badly needed incomes. Since there is an increasing number of people who have to rely on these communities, their scale, and future prospect, has become a great concern for not only patients but also policy-makers. arise the questions concerning Here the community's development as judged by patients, the impacts of community's growth on its members, and their sustainability.

Theoretical background: The extant literature on colocated 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. For patients living in rural/remote areas and often in hardships, 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 hospitalizations than others of higher socioeconomic status (6). Therefore, it is not uncommon that early discharge or outpatient treatments are remedial measures to reduce financial hardships (7). These are more likely to happen when patients gather up in a community outside of the hospital, making colocation cluster an affordable option for the poor. There has been evidence suggesting that patients living in communities reported more comfort, cohesion and satisfaction in their living conditions than hospitalized patients in all life areas (8). But from another view, (9) provide evidence that there needs to be better understanding about some "QOL index" involving such aspects as treatment bottomline and rehabilitation success.

We also learn that the financial impact of treatment as well as anxiety involving their financial status in the future are of great concern, affecting almost onethird of care-givers and one-quarter of patients (7). According one study, medical costs only make up 32% of the average expenditure while 68% is spent on travel, food and basic commodities (10). Many patients finance their treatments by selling assets or borrowings (3). Another basic need that has given rise to co-location clusters: information (11). Most patients consider valuable information one of key factors influencing outcomes of their treatment, and improving their chance of surviving the tough life (11-13). Therefore, it is logical that in general societal reactions to the phenomenon has been in general favorable, with high social acceptance, 79% (14). Still, sustainable development of patient communities is a matter of concern. Unfortunately, the issue has somehow gone unnoticed as little evidence has been reported.

Aims & Objectives

This study aims to identify factors that affect sustainability/development of such co-location clusters based on a survey of member patients. Its questions seek to measure the community's development through critical determinants such as the benefits patients receive, contributions they make towards the community, and the extent to which their expectations are met by the clusters. An in-depth analysis is expected to yield insights that help shape future policies contributing to improvement of healthcare systems. The above general aim leads to specific objectives that the following would address.

Research questions: The study approaches the issues surrounding patient's perception of future growth of their communities. It seeks to explore possible relationships between key factors that are determining the future of such communities. Specific questions follow.

RQ1: Do financial benefits and in-kind benefits provided by the community really impact patients' perception about their community's future development?

RQ2: Is it true that the more patients expect from and contribute to their community, the more likely it is for patients to believe in their community's future? **RQ3**: In relation to patient contribution to the community – or the lack thereof – how do in-kind benefits influence patients' perception of its future? In addition, possible influences of monetary/material versus time/effort contributions by patients need to be compared.

Material & Methods

The survey was conducted through a series of meetings, during 2015Q4-2016Q1, with patients residing in four Hanoi-based patient communities, namely: a) chronic kidney disease (CKD) community; b) outpatient residency community; c) pediatric community; and, d) Ngoc Hoi community. The dataset has 336 qualified observations from respondents whose data were collected through authorized research personnel at the four clusters. The sampling aimed to acquire the most data thanks to the concentration of patients in those clusters. The process did not discriminate against any specific criteria for inclusion/exclusion, following ethical standards being maintained by Hanoi-based research firm Vuong & Associates through institutional regulation and decision, numbered V&A/15#01 (October 19, 2015), and with written approvals by survey participants being obtained by its surveying team.

Statistical Analysis: Raw data are first entered and processed by MS Excel. The processing and structuring of categorical data are performed using R statistical package (3.2.3); structured data tables for statistical analysis are in CSV format. The estimations employ baseline category logit (BCL) procedures as provided in (15). Coefficients are estimated by

multinomial logistic regression models; with empirical probabilities being computed using those coefficients; consult with (3, 13) for practical implementations.

Dataset: Data for RQ1: To evaluate the factors affecting patient's perception on community scale development, "Scalefut" serves as the dependent (response) variable in all models with two categorical values: "expansion" (growing) and "contraction" (unchanged/shrinking). RQ1 dataset is used to estimate impacts of financial benefits ("Ben.fin") and in-kind benefits ("Ben.ikd") on patient's perception about the community future; and is given in Table 1. "Ben.fin" has two different values: i) "met.fin" (when financial benefits meet patient's need); and, ii) "Ben.ikd" "unmet.fin" (the opposite). takes categorical values of "met.ikd" (in-kind benefits meeting their need) and "unmet.ikd" (the opposite). It can be seen that there is an equal portion of patients predicting expansion and contraction (169/167), but the structures are different due to conditions of opinions. Among patients whose needs were unmet by both financial and in-kind benefits from the community, only 29% predicts community expansion.

Data for RQ2: This set is given in <u>Table 2</u>, where factor "Expectation" (the community's response to patient expectations) takes two categorical values of "met.exp" (expectations met) and "unmet.exp" (issues remained); factor "Contr.eff" (voluntary caregiving that patients contribute to their community) takes two values of "sig.eff" (significant contribution) and "insig.eff" (insignificant).

Table 2 shows that nearly 93% (312/336) patients show satisfaction towards what they received from their community. 136 patients without significant time/effort contribution and with their expectations met believe in a brighter prospect for their community.

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 ("Contr.mm") versus time/effort contributions ("Contr.eff") by patients. "Contr.mm" has two values: "sig.mm" (significant contribution) and "insig.mm" (insignificant). The first estimation model for RQ3 uses two independent variables, factor "Contr.mm" and "Ben.ikd" for data given in <u>Table 3</u>. Only 1% patients who have made monetary/material contributions without getting in-kind benefits back see prospect of expansion.

<u>Table 4</u> is for the second estimation of RQ, with "Contr.eff" predictor replacing "Contr.mm", following which 125 patients – with neither significant contribution of time/effort nor in-kind benefits from the community – believe in community growth.

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 form $g(\mu_i) = X_i \beta$, where: $\mu_i = E(Y_i)$ corresponding to $y_i = (y_{i1}, y_{i2}, ...)^T$; row h of the model matrix **X**_i for observation i contains values of predictor variables for yih. Following this method, as $\pi_i(\mathbf{x}) = P(Y=i|\mathbf{x})$ represent a fixed setting for predictor variables, with $\sum_{i} \pi_i(\mathbf{x}) = 1$, categorical data are distributed over J categories of Y as binomial / multinomial with corresponding probabilities $\{\pi_1(\mathbf{x}), ..., \pi_i(\mathbf{x})\}$. Thus, the BCL model aligns each dependent (response) variable with a baseline category (BC): $\ln[\pi_i(\mathbf{x})/\pi_j(\mathbf{x})]$, for j=1,...,J-1. As $\ln[\pi_a(\mathbf{x})/\pi_b(\mathbf{x})] = \ln[\pi_a(\mathbf{x})/\pi_J(\mathbf{x})] \ln[\pi_{\rm b}(\mathbf{x})/\pi_{\rm J}(\mathbf{x})]$, the set of empirical probabilities from binomial / multinomial logits $\{\pi_i(\mathbf{x})\}$ can be computed, following practical evaluations and computations, as provided in (3,13).

Results

Result 1: The first result dealing with RQ1 is reported in <u>Table 5</u>, with all coefficients being statistically significant; all p<0.0001

Result from Table 5 suggests joint effects of "Ben.fin" and "Ben.ikd" on how the patient perceives community development. Value "met.fin" exhibits the single largest effect, with β_1 =1.337 (p<0.0001), representing a stronger influence than "unmet.ikd". For a deeper understanding, Eq. (RQ1) is constructed from Table 5 coefficients with associated conditions as stated by the BCL model given in RQ1.

$$\label{eq:linear} \begin{split} & ln(\pi_{expansion}/\pi_{contraction}) = -1.111 + 1.337 \times MetFin + \\ & 1.109 \times UnmetIkd \qquad (RQ1) \end{split}$$

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

There is a 55.6% probability a patient with financial and in-kind benefits met will predict the growth of co-location community, and a 50% probability that a patient seeing his/her financial and in-kind benefits as unsatisfactory would predict the community prospect to be dim.

Result 2: To learn about how meeting patient's expectation and their time/effort contribution affect their views about community future, the estimation in <u>Table 7</u> uses predictor variables: "Expectation" and "Contr.eff".

All coefficients show statistical significance at 1%. The largest coefficient observed that of "met.exp", which indicates the importance of "expectation met", with β_1 =1.97 (*p*<0.001). The empirical relationship is constructed from Table 7.

 $ln(\pi_{expansion}/\pi_{contraction}) = -1.458 + 1.971 \times MetExp - 1.273 \times SigEff$ (RQ2)

Empirical probabilities of community growth predictions are shown in <u>Table 8</u>.

Table 9 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 a patient contributes time/effort, the less he/she believes in future widening of the community.

Result 3: The estimation works with predictor variables "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. Both estimates are statistically significant and negative, with p<0.01.

In RQ3 estimations, both "met.ikd" and "sig.mm" play negative roles in determining "Scalefut", with equal impacts (β_2 =-0.912, *p*<0.0001; and β_3 =-0.913, *p*<0.001).

 $ln(\pi_{expansion}/\pi_{contraction}) = + 0.390 - 0.912 \times Metlkd - 0.913 \times SigMm$ (RQ3.1)

Equation (RQ3.1) helps to compute numerical probabilities reported in <u>Table 10</u>.

There is a 80.8% probability that a patient who makes a significant money/material contribution to the community and receives back in-kind benefits would predict no growth for the community in the future.

Discussion

Regarding RQ1: "Scalefut" shows stark contrasts in changes when "Ben.ikd" switches its value. It appears that patients view in-kind benefits as harmful to community's growth, and only financial benefits help. Figure 1 shows the shifting of views.

To measure the differences in patient's perception of future community growth in the cases of "met.ikd" and "unmet.ikd", <u>Figure 1</u> 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.

Both "expansion" lines decline when "expectation" changes from "met.exp" to "unmet.exp". In opposite, subjective probability of "contraction" shows a positive relationship. Therefore, subjective probabilities of growth improve if patient expectations are met. In addition, in case patients see their labor contribution to the community as significant ("sig.eff"), the probability of "expansion" is always lower than "contraction" (Figure 2; left). Meanwhile, if patients deem their time/effort contribution as less significant ("insig.eff"), the probability of "expansion" increases when their needs are met. 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.

Regarding RQ3: The effect of patient contribution and satisfactory in-kind benefits on community prospect is shown in <u>Figure 3</u>. The negative influence of "Ben.ikd" is once again confirmed by the positions of "met.ikd" and "unmet.ikd" lines.

Also, the two lines ("met.ikd" and "unmet.ikd") always move in the same direction when the situation changes from "insig.mm" to "sig.mm". But they swap positions when switching between two states of "Scalefut". Numerical values are given in Appendix C. Also we have Figure 4, exploring another aspect of RQ3, suggesting that "Contr.mm" and "Contr.eff" have equal impacts on "Scalefut".

Conclusion

Clearly, the patient's perception on future community expansion will steer them through taking specific actions in improving and developing the community. First of all, empirical results suggest that patients will show positive predictions on the broadening of their community when they receive what they need/expect. In fact, when financial needs are met (by income, loans or charity), patients tend to feel assured, even if the received benefits are small. An explanation is that perhaps when moving to entirely unfamiliar areas, patients and care-givers face surmounting hardships due to unexpected costs of different kinds. Financial benefits are thus the most practical, similar to the concept of "liquidity preference" in economics (16).

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 aversion" seems to greatly concern in-kind benefits, the type of value that is unlikely to match, hence 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 (16,17).

Everyone needs money, sick people in treatment even more so (17). 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 being unable to respond to this expectation, how will long-term commitment be formed within these groups of people? How will patients be glued to a voluntary community while

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struggling with their sickness and facing hugely uncertain financial positions?

Recommendation

The study results suggest serious efforts by scholarly and policy circles to more deeply look into these neglected desperate patients for a better society.

Limitation of the study

The dataset is confined to four clusters in Hanoi, and the present study is not able to compare other clusters in different urban areas to evaluate socioeconomic and cultural differences.

Authors Contribution

As the sole author, QHV designed the study, led the data collecting efforts, performed statistical analysis, wrote and aproved the manuscript.

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Tables

TABLE 1 (DATA FOR RQ1). DISTRIBUTION OF "SCALEFUT" FOLLOWING "BEN.FIN" AND "BEN.IKD"				
"Ben.fin"	"Ben.ikd"	"expansion"	"contraction"	
"met.fin"	"met.ikd"	5	20	
	"unmet.ikd"	58	4	
"unmet.fin"	"met.ikd"	27	46	
	"unmet.ikd"	79	97	

TABLE 2 (DATA FOR RQ2). DISTRIBUTION OF "SCALEFUT" AGAINST "EXPECTATION" AND "CONTR.EFF"

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

TABLE 3 (DATA FOR RQ3). DISTRIBUTION OF "SCALEFUT" FOLLOWING "CONTR.MM" AND "BEN.IKD"

"Ben.ikd"	"Contr.mm"	"expansion"	"contraction"
"met.ikd"	"sig.mm"	9	16
	"insig.mm"	23	50
"unmet.ikd"	"sig.mm"	4	18
	"insig.mm"	133	83

TABLE 4 (DATA FOR RQ3). DISTRIBUTION OF "SCALEFUT" FOLLOWING "CONTR.EFF" AND "BEN.IKD"

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

TABLE 5 ESTIMATIONS RESULT FOR RQ1

	Intercept	"Ben.fin"	"Ben.ikd"
		"met.fin"	"unmet.ikd"
	β_0	β_1	β_2
logit(expansion contraction)	-1.111***	1.337***	1.109***
	[-4.598]	[4.736]	[4.183]
	(-1.60,-0.65)	(0.80,1.91)	(0.60,1.64)
p-value	4.26×10-6	2.18×10-6	2.88×10-6

Significance: 0 '***'; z-value in square brackets; 95% CI in round brackets; Reference group is level 2 of the response; baseline category (BC) for "Ben.fin"="unmet.fin"; and, for "Ben.ikd"="met.ikd". Residual deviance (RD)=30.49 on 1 degree of freedom (d.f).

TABLE 6 PROBABILITIES OF GROWTH PROSPECTS UPON FINANCIAL BENEFITS AND IN-KIND BENEFITS

"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 7 ESTIMATED IMPACTS OF "EXPECTATION" AND "CONTR.EFF" ON "SCALEFUT"

Intercept	"Expectation"	"Contr.eff"
	"met.exp"	"sig.eff"
β_0	β_1	β_2
-1.458*	1.971**	-1.273***
[-2.303]	[3.079]	[-4.959]
(-2.92,-0.35)	(0.85,3.45)	(-1.79,-0.78)
0.021	0.002	7.07×10-7
	β ₀ -1.458* [-2.303] (-2.92,-0.35)	$\begin{tabular}{lllllllllllllllllllllllllllllllllll$

Significance: 0 '***' 0.001 '**' 0.01 '*'; z-value in square brackets; 95% Cl in round brackets; Reference group is level 2 of the response; BC for "Expectation" = "unmet.exp"; and, "Contr.eff"="insig.eff". RD=0.14 on 1 d.f.

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TABLE 8 DISTRIBUTION OF PROBABILITIES OF "SCALEFUT" FOR RQ2

"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 9 ESTIMATION FOR RQ3

	Intercept	"Ben.ikd"	"Contr.mm"
		"met.ikd"	"sig.mm"
	β_0	β_1	β_2
logit(expansion contraction)	0.390**	-0.912***	-0.913**
	[2.867]	[-3.539]	[-2.556]
	(0.13,0.66)	(-1.42,-0.41)	(-1.64,-0.23)
p-value	0.004	0.0004	0.011

Significance: 0 '***' 0.001 '**'; z-value in square brackets; 95% CI in round brackets; Reference group is level 2 of the response; BC for "Ben.ikd"="unmet.ikd"; and, for "Contr.mm"="insig.mm". RD=9.03 on 1 d.f.

TABLE 10 PROBABILITIES OF "SCALEFUT" UPON IN-KIND BENEFITS AND MONEY/MATERIAL CONTRIBUTIONS

"Scalefut"	"expansion"		"contraction"	
"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

Figures

FIGURE 1 CHANGING PROBABILITIES OF "SCALEFUT" AS "BEN.FIN"/"BEN.IKD" CHANGE (APPENDIX A)

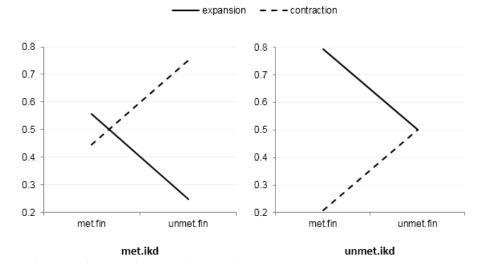


FIGURE 2 THE LIKELIHOOD OF EXPANSION AS EXPECTATION IS (UN)MET, CONTROLLING FOR "SIG.EFF"/"INSIG.EFF"

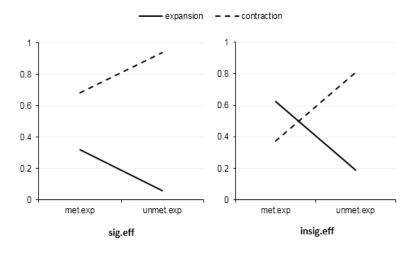


FIGURE 3 CHANGING ASSESSMENT PROBABILITIES UPON "BEN.IKD" AND "CONTR.MM"

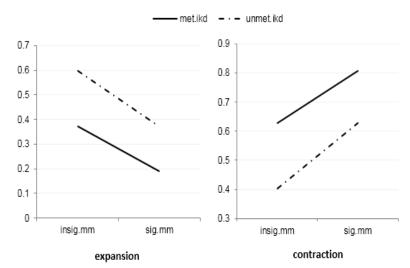


FIGURE 4 IMPACTS OF MONEY/MATERIAL AND TIME/EFFORT CONTRIBUTIONS ON COMMUNITY FUTURE (USING APPENDIX D COMPUTATIONS)

